National Gynae-Oncology Registry

NGOR
NATIONAL GYNAE-ONCOLOGY REGISTRY

MONASH University

OVARIAN CANCER AUSTRALIA

2022 Annual Report

Ovarian, Tubal & Peritoneal Cancer (OTP)

Rare Ovarian Tumours

OTP Cancer Module: January 2022 – December 2022

Rare Ovarian Tumour Module: April 2017 – December 2022

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Suggested citation
Perera S, Whitely A, Lloyd M, Knights T, Nguyen T, Sandhu S, Rome R, Zalcberg J on behalf of the National Gynae-Oncology Registry. National Gynae-Oncology Registry 2022 Annual Report. Monash University, School of Public Health and Preventive Medicine, Report No 2

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Abbreviations

ACSQHC	Australian Commission on Safety and Quality in Health Care
AHPEQ	Australian Hospital Patient Experience Question Set
ASA	American Society of Anesthesiologists
BMI	Body Mass Index
BRCA	Breast Cancer gene 1 and 2 (BRCA1, BRCA2)
BSO	Bilateral salpingo–oophorectomy
CAP CT	CT scan of the chest, abdomen and pelvis
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
EORTC QLQ–30–OV–28	European Organization for the Research and Treatment of Cancer Quality of Life Questionnaire, combined with the Ovarian Cancer module
FIGO	International Federation of Gynecology and Obstetrics
ICCR	International Collaboration on Cancer Reporting
MDM	Multi–disciplinary team meeting
MRFF	Medical Research Future Fund
MRI	Magnetic resonance imaging
NGOR	National Gynae–Oncology Registry
NMA	National Mutual Acceptance
OTP	Ovarian, tubal and peritoneal
PARPi	Poly (ADP–ribose) polymerase inhibitor
PBS	Pharmaceutical Benefits Scheme
PET	Positron emission tomography
PREMs	Patient–reported experience measures
PROMs	Patient–reported outcome measures
QoL	Quality of life
RCPA	Royal College of Pathologists of Australasia
TAH	Total abdominal hysterectomy

Foreword

By Associate Professor Robert Rome, NGOR Clinical Lead

Another year has passed, and 2022 has been a busy one for the National Gynae-Oncology Registry. In 2022 six hundred and fourteen women with ovarian, tubal, peritoneal (OTP) cancer were registered in the Ovarian Cancer Module. The outcomes and performance against the fifteen OTP cancer Clinical Quality Indicators (CQIs) are presented in our Second Annual Report. A further 219 women with Rare Ovarian Tumours had been registered in 2017 to 2022 and their details are also presented in this report.

Overall, 1248 women with endometrial cancer had been screened by the end of 2022. We hope to present the outcomes and performance against the relevant CQIs for these women, especially those with recurrent endometrial cancer, in the next Annual Report.

The CQIs for cervical cancer and vulvar cancer have been defined and agreed upon and accrual will commence once funding has been secured.

A steadily increasing number of public and private hospitals were contributing to the NGOR. By the end of 2022, thirty-three hospitals across all the states were contributing, which was an increase of 11 during the year.

Patient reported outcome/experience measures (PROM/PREMs) were examined in a pilot study during the year. Presentations of the NGOR work have been made at several scientific meetings in 2022 including ANZGOG (Melbourne, March), ASGO (Melbourne, April), and COSA (Brisbane, November). These are listed in the Appendix B.

I would like to thank the participating clinicians, especially those on the overarching Steering Committee and the various disease-specific Working Groups, for their input and expert advice on clinical matters. As the NGOR matures it is becoming apparent that the CQIs need to be reviewed and revised from time to time.

The NGOR is managed by the Monash University School of Public Health and Preventive Medicine. I am most grateful to the registry staff for their support and hard work in the driving the NGOR and to the data managers and collectors. In conclusion I convey my thanks to the many patients who have consented to participate in the Registry.

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 present the second annual report of the National Gynae-Oncology Registry (NGOR). The NGOR is Australia's first and only clinical quality registry for gynaecological cancers. I am proud to introduce the Report which documents the accomplishments achieved by our team in 2022, and the collaborative efforts that continue to emphasise the importance of documenting whether evidence-based, best practice care is received by all patients with gynaecological cancers in Australia.

This Annual Report presents the data collected by NGOR throughout 2022 from patients diagnosed with ovarian cancer (formally ovarian, tubal and peritoneal (OTP) cancer). It also presents, for the first time, findings from NGOR's Rare Ovarian Tumours module, comprising data for patients diagnosed with non-epithelial ovarian tumours (about 10% of all ovarian cancer cases). These two modules provide insight into the standard of care for patients diagnosed with OTP cancer or a rare ovarian tumour in Australia, and the ability to understand any variation from best-practice recommendations. This is the long-term goal of the NGOR.

We present the outcomes from 28 public and private hospitals around Australia for 15 clinical quality indicators (CQIs) for OTP cancer that reflect optimal, evidence-based care. The data presented for each indicator reflect patients diagnosed from January 2022 to December 2022. For the Rare Ovarian Tumours module, descriptive data is presented, reflecting patients diagnosed from 2017-2022. A separate set of CQIs have been developed to reflect best practice care for this latter module, and these will be presented in subsequent reports.

This year also saw the commencement of the NGOR's work to better understand the outcomes and experiences of patients with OTP cancer, from the patients themselves. A pilot study into patient-reported outcomes and experiences will hopefully allow greater understanding of patient priorities and perspectives, and how these can inform best practice care for OTP cancer. We hope to present the outcomes of this work in upcoming reports.

The NGOR's continuing successes and our ability to achieve our milestones are largely due to the support of patients involved in this registry, our valued collaborations with Ovarian Cancer Australia, the continued support from the Australian Society of Gynaecologic Oncologists and the Australia New Zealand Gynaecological Oncology Group, the NGOR Steering Committee, the Ovarian Cancer Working Group, the Rare Ovarian Tumours Working Group, the NGOR Operational Team, and the many clinicians and data collectors at each collaborating health service. I would like to express my appreciation and gratitude to all involved for your hard work, commitment and enthusiasm for this registry and the work we've accomplished together so far.

Work on the remaining modules of the NGOR are ongoing; we hope to start data collection for women diagnosed with cervical cancer in 2024 alongside data for those diagnosed with vulvar cancer, pending funding outcomes.

I remain excited to see the NGOR grow and progress from its formative years to become an important resource for clinicians, scientists and the community to measure the extent and impact of any variations in care for patients diagnosed with several important gynaecological cancers.

Professor John Zalcberg, AO

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

Foreword

By Sue Hegarty, Chief, National Ovarian Cancer Advocacy and Support

At Ovarian Cancer Australia, we are on a heartfelt mission to provide care and support for those affected by ovarian cancer and represent them by leading change.

Ensuring that all women have timely access to effective and affordable treatments is among our top priorities. It is a privilege for us to stand by the NGOR, an incredible team of expert clinicians and researchers working tirelessly toward this goal.

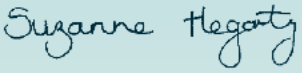
Ovarian cancer is Australia's deadliest female cancer, with a survival rate of just 49%. Sadly, there is no early detection test, and the symptoms are often vague and easily confused with other health issues. By the time symptoms appear, many people are already in the advanced stages of the disease. This is why it is crucial to ensure that all women have access to the best possible care.

Despite significant progress in the sector, many gaps remain in the knowledge of ovarian cancer care and treatment in Australia. The NGOR gathers data to empower doctors and researchers, highlights effective treatments, and identifies areas for improvement. It not only sheds light on the most effective treatments and treating centres but serves as an early warning system to improve patient outcomes and quality of care.

Our deepest gratitude goes to the courageous women who participate in the NGOR. Your contribution is vital to our mission to improve the quality of life for those diagnosed and living with ovarian cancer, now and in the future. Ovarian cancer can be an incredibly frightening disease, and it is heart-warming to see the sector united to improve outcomes for women.

As one of the initial supporters of this program, we are immensely proud of continuing our contribution to the NGOR by assisting with the steering committee and Patient Reported Outcome Measures (PROMs).

We look forward to our ongoing partnership, and together, we will continue to advocate to save lives and ensure that no one affected walks alone.



Suzanne Hegarty

Chief, National Ovarian Cancer Advocacy and Support

Executive Summary

Established in 2017, the National Gynae-Oncology Registry (NGOR) is a clinical quality registry (CQR) capturing clinical data on newly diagnosed cancers of the uterus, ovary, fallopian tube, peritoneum, cervix, vulva and vagina in Australia. This report presents data from the NGOR's Ovarian, Tubal and Peritoneal (OTP) Cancer Module and Rare Ovarian Tumour Module. Key findings from the OTP Cancer Module are presented for patients diagnosed with primary epithelial OTP cancer between 1st January 2022 and 31st December 2022 (Section I of this report). Pilot data are presented for the first time for patients diagnosed with a rare ovarian tumour between 28th April 2017 and 31st December 2022 (Section II of this report).

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. For the OTP Cancer Module, each CQI has been risk-adjusted according to relevant variables such as comorbidities, age, FIGO stage, etc. Data available for some CQIs were limited and therefore must be interpreted with caution. As the Rare Ovarian Tumour Module remains in its pilot phase, only descriptive data are presented in this report.

Key Findings: Section I - OTP Cancer Module

Patients

614
Eligible patients diagnosed between 1 Jan 2022 and 31 Dec 2022

64.1 years
Average participant age at diagnosis

At Diagnosis

Most common tumour grade:
Grade III

Most common morphology:
Serous adenocarcinoma

Most common FIGO stage at diagnosis:
IIIC

Most common method of diagnosis:
Histopathology

Surgical Adverse Events

6.1 %
of patients experienced an intraoperative event

4.2 %
of patients experienced a serious postoperative event

Treatment & Management

96.7 %
of patients were presented at a multidisciplinary meeting (MDM)

47.7 %
of patients had primary surgery

34.5 %
of patients had interval surgery

87.5 %
of patients had first-line chemotherapy with a platinum-taxane doublet

42.9 %
of patients who were sub-optimally debulked received first-line chemotherapy (platinum-taxane doublet) and bevacizumab

Targeted Therapy

84.7 %
of eligible patients underwent genetic testing

66.7 %
of patients with germline or somatic mutations commenced maintenance PARPi therapy within eight weeks of ceasing chemotherapy

Key Findings: Section II - Rare Ovarian Tumour Module

Patients

219
Eligible patients diagnosed between 28 Apr 2017 and 31 Dec 2022

47.2 years
Average participant age at diagnosis

At Diagnosis

Most common morphology:
Adult granulosa cell tumour

Most common FIGO stage at diagnosis:
IA

Most common method of diagnosis:
Histopathology

Treatment & Management

97.7 %
of patients were presented at a multidisciplinary meeting (MDM)

99.5 %
of patients had first–line surgery

62.5 %
of patients with ≥ Stage II disease had first–line chemotherapy

10.4 %
of patients with ≥ Stage II disease had first–line hormonal therapy

6.3%
of patients with ≥ Stage II disease had first–line radiation therapy

Surgical Adverse Events

6.1 %
of patients experienced an intraoperative event

1.9%
of patients experienced a serious postoperative event

"We are all too well aware of how deadly ovarian cancer is, and the survival rate remains stubbornly low. The work the registry does is therefore vital in working towards lifting treatment for patients across Australia to optimal level. One hopes that in the not too distant future patients will be assured of the highest quality treatment, regardless of where they live and which hospital they attend.

I was first diagnosed with Ovarian Cancer Stage III in 2008 and it returned in 2010, 2012 and 2013. And yes, obviously I am still here, but do realise how extremely blessed I am, having lost much loved friends along the way.

Sadly, I am a rarity. However, one of the reasons I survived is no doubt because of my amazing medical team, who were so supportive both medically and emotionally during my treatment. It is because of this that I am delighted to be a small part of this team as I would like to dream that every woman diagnosed with a gynae cancer can receive the standard of care I did.

We have set up a sub-committee to initiate a pilot study assessing patient-reported outcomes, which I see as an essential part of quality of care. In all aspects of my treatment I felt I was listened to and treated with respect. Decisions made were discussed and my input was valued, which made me feel part of the treatment and healing process. Knowledge is power in this situation and I am convinced that the more patients are involved, the better the outcomes. In my view as a patient this would be a very valuable addition to the registry."

Janice Antony

Patient Advocate (Ovarian Cancer)
NGOR Consumer Representative

About the National Gynae-Oncology Registry (NGOR)

The NGOR is a multi-modular clinical quality registry (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 the quality of care and outcomes for patients diagnosed with gynaecological cancer by capturing data pertaining to their diagnosis, treatment, and disease outcomes. Data are reported against agreed measures of best practice in risk-adjusted and benchmarked reports. Figure 1 shows the NGOR's feedback loop.

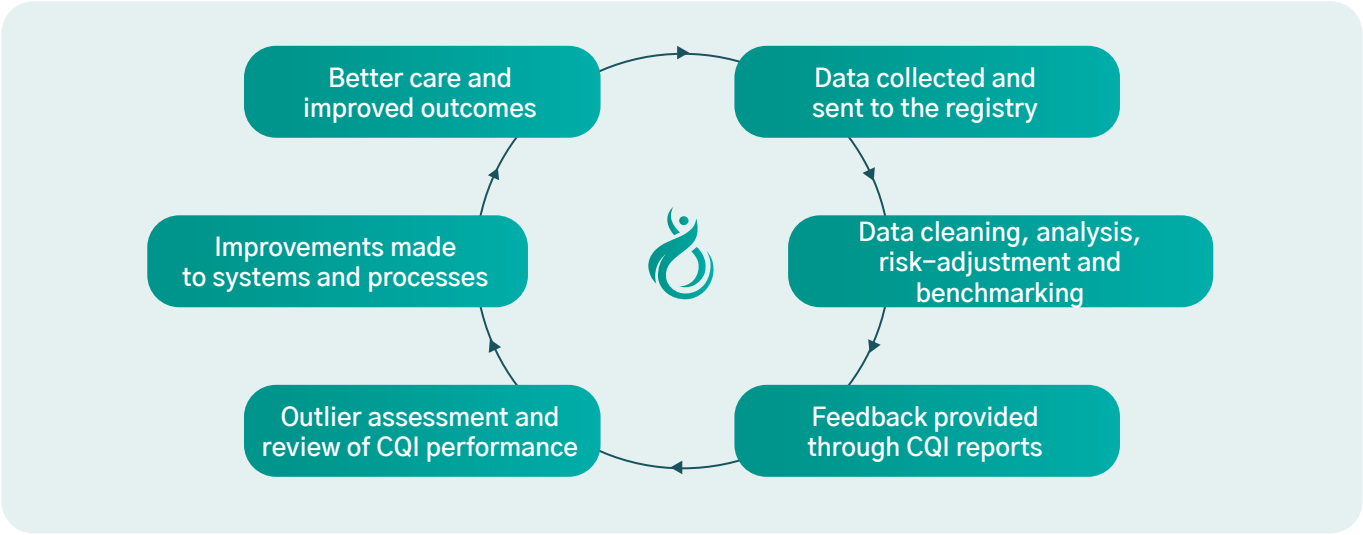


Figure 1: The NGOR's feedback loop. Adapted from the Australian Commission on Safety and Quality in Health Care[1].

There are currently five modules within the NGOR, each addressing a different type of gynaecological cancer: (1) ovarian, tubal and peritoneal (OTP), (2) rare ovarian tumours, (3) endometrial, (4) cervical, and (5) vulvar. Each module has a unique set of clinical quality indicators (CQIs) that have been tailored to monitor patterns of care according to national guidelines and published empirical research. These CQIs have been further refined through collaboration with clinical and academic experts, as well as consumers. Additional modules for uterine sarcomas and vaginal cancer are also being considered.

The NGOR partners with 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.

Section I of this report presents the key findings from the OTP Cancer Module for patients diagnosed between 1st January 2022 to 31st December 2022. Section II presents the pilot data from the Rare Ovarian Tumour Module for patients diagnosed between 28th April 2017 to 31st December 2022.

Acknowledgements & Funding Statement

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

We would like to thank everyone who has agreed to be a part of the NGOR, as well as each participating hospital, their clinical staff, data collectors, and other hospital personnel, whose collaboration has significantly contributed towards the registry's progress.

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.

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 OTP Cancer Module 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

Ovarian cancer is one of the 10 leading causes of premature death in Australian women[2]. In Australia and New Zealand, ovarian cancer diagnoses account for 6.4% of the global incidence, and more than 70% of women diagnosed do not survive[3]. Low survival is largely due to most women (around 75%) being diagnosed at an advanced stage, likely due to experiencing non-specific symptoms beforehand. 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, genetic predisposition, obesity, and nicotine use[8]. There is currently no screening test for the early detection of ovarian cancer.

Due to ovarian cancer's high mortality rate, it is important that care is guided by evidence-based clinical guidelines[9]. These guidelines can improve the quality of care and outcomes for patients with ovarian cancer, for example, by recommending optimal cytoreductive surgery which 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 New South Wales found 55% of patients did not receive their first treatment in a specialist gynae-oncology hospital[9].

Overview of Data Collection in the Ovarian, Tubal and Peritoneal (OTP) Cancer Module and the Rare Ovarian Tumour Module

The primary purpose of the OTP Cancer Module 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 Rare Ovarian Tumour Module captures data on diagnoses and outcomes for patients with rare non-epithelial ovarian tumours. This module will be discussed in greater detail in Section II of this report. Pilot data collection for the Rare Ovarian Tumour Module commenced in 2021 and included some retrospective recruitment. These data established patterns of care and enabled appropriate CQIs for these tumour types to be defined. Data for the OTP Cancer and Rare Ovarian Tumour Modules are obtained from patient medical records by trained data collectors at 28 participating hospitals around Australia.

Within the reporting period, 614 eligible participants were recruited into the OTP Cancer Module. All 2022 data for the OTP Cancer Module, including risk-adjusted data for each CQI, are included in this report. For the Rare Ovarian Tumour Module, 219 eligible participants were recruited during the pilot phase. Preliminary descriptive statistics for the pilot phase are also presented in this report.

Limitations and Considerations when Interpreting OTP Cancer Module 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 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 are most useful. It is possible however, that through registries, medical records may be revised to include more pertinent and structured information in the long-term.

For the data presented in this report, explanations, as well as a summary of potential limitations where applicable, are included alongside each data point to aid interpretation.

Patient-Reported Outcome/Experiences Measures (PROMs/PREMs)

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 data collection is currently being piloted in the OTP Cancer Module. Following clinical and consumer consultation in 2021, 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] were 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. The pilot is expected to conclude in early 2024, with preliminary data anticipated to be included in the 2023 NGOR Annual Report.

Statement of Ethics and Governance Approval

The NGOR operates within a National Mutual Acceptance (NMA) ethics approved Operating and Governance Framework (HREC/17/MonH/198). 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 commenced after relevant approvals were obtained.

NGOR History

September 2017:

Funding received from The Australian Society of Gynaecologic Oncologists (ASGO), and the Contributing to Australian Scholarship and Science (CASS) Foundation for the OTP Cancer Module pilot.

2017 – April 2020:

OTP Cancer Module pilot begins. First CQI report is released.

August 2019:

Awarded the Audrey Voss Gynaecological Cancer Research Grant from the Epworth Medical Foundation to establish endometrial, cervical, and vulvar cancer modules.

May 2020:

Awarded a Medical Research Future Fund grant to create the OTP Cancer Module.

October 2020:

OTP Cancer Module PROMs/PREMs qualitative project begins.

December 2020:

Endometrial cancer module CQIs finalised.

March 2021:

1,000 patients in the NGOR across five Australian states.

Endometrial Cancer Module pilot begins.

October 2021:

Rare Ovarian Tumour Module pilot begins.

December 2021:

2,000 eligible patients in NGOR across five Australian states.

February 2022:

OTP Cancer Module PROMs/PREMs qualitative project finishes.

April 2022:

Cervical cancer CQIs finalised.

August 2022:

Approval obtained for data collection to commence in Queensland. The NGOR is now established in all six Australian states.

September 2022:

Vulvar cancer CQIs finalised.

November 2022:

The NGOR's first OTP Cancer Module Quality Indicator Reports are distributed to all collaborating sites.

PROMs/PREMs qualitative data are presented at the Clinical Oncology Society of Australia Annual Scientific Meeting.

3,000 eligible patients in the NGOR across all six Australian states.

December 2022:

PROMs/PREMs feasibility and acceptability pilot begins in the OTP Cancer Module.

Collaborations with a further 11 hospitals, bringing the total number of collaborating hospitals to 33.

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 2). 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.
- Patients aged 18 years or older at the time of their diagnosis.

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, medical record number, date of diagnosis, and primary treatment hospital are retained unless deletion of all data is requested by the patient. Retention of these basic details ensures that patients are not re-recruited in the event of 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/PREMs data collection), but permits the inclusion of their personal and health data in the registry.

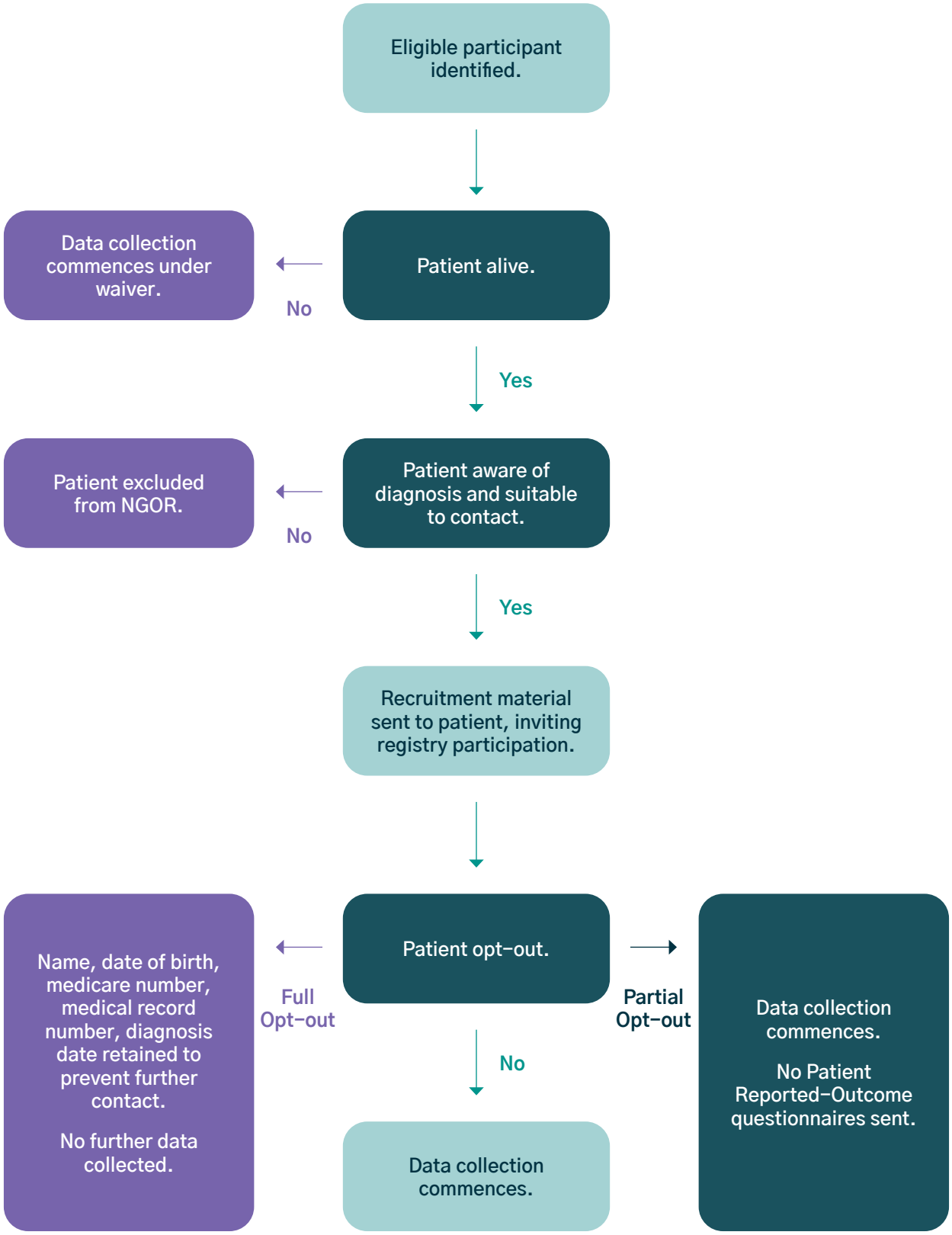


Figure 2: The NGOR workflow

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 five clinical Working Groups for: (1) OTP cancer, (2) rare ovarian tumours, (3) cervical cancer, (4) endometrial cancer, and (5) vulvar cancer. The OTP Cancer Executive Committee and associated reference groups have oversight of the MRFF grant and registry milestones (see Figure 3).

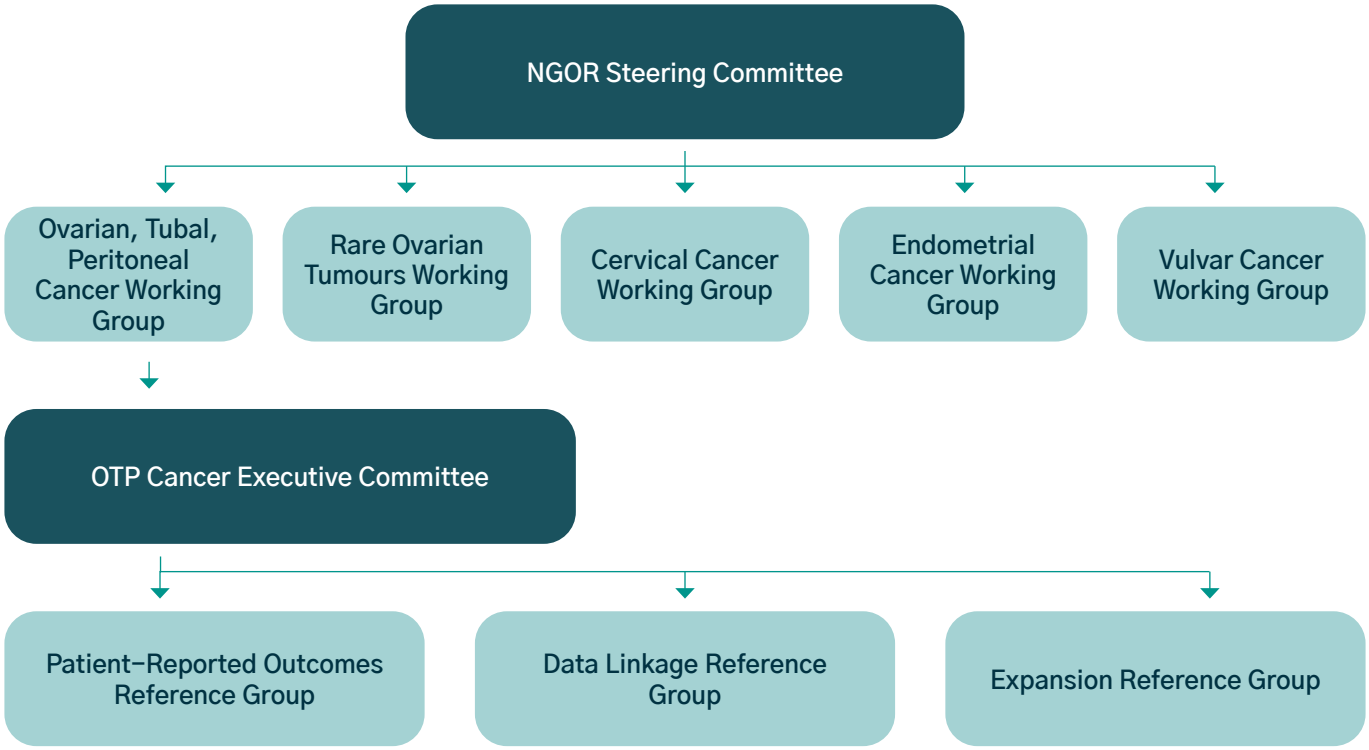


Figure 3: The NGOR governance structure.

Registry Engagement

By the end of 2022, the NGOR had established connections with 33 public and private hospitals across Australia (Figure 4), with ongoing plans for expansion. A list of all partnering hospitals is provided in Table 1.

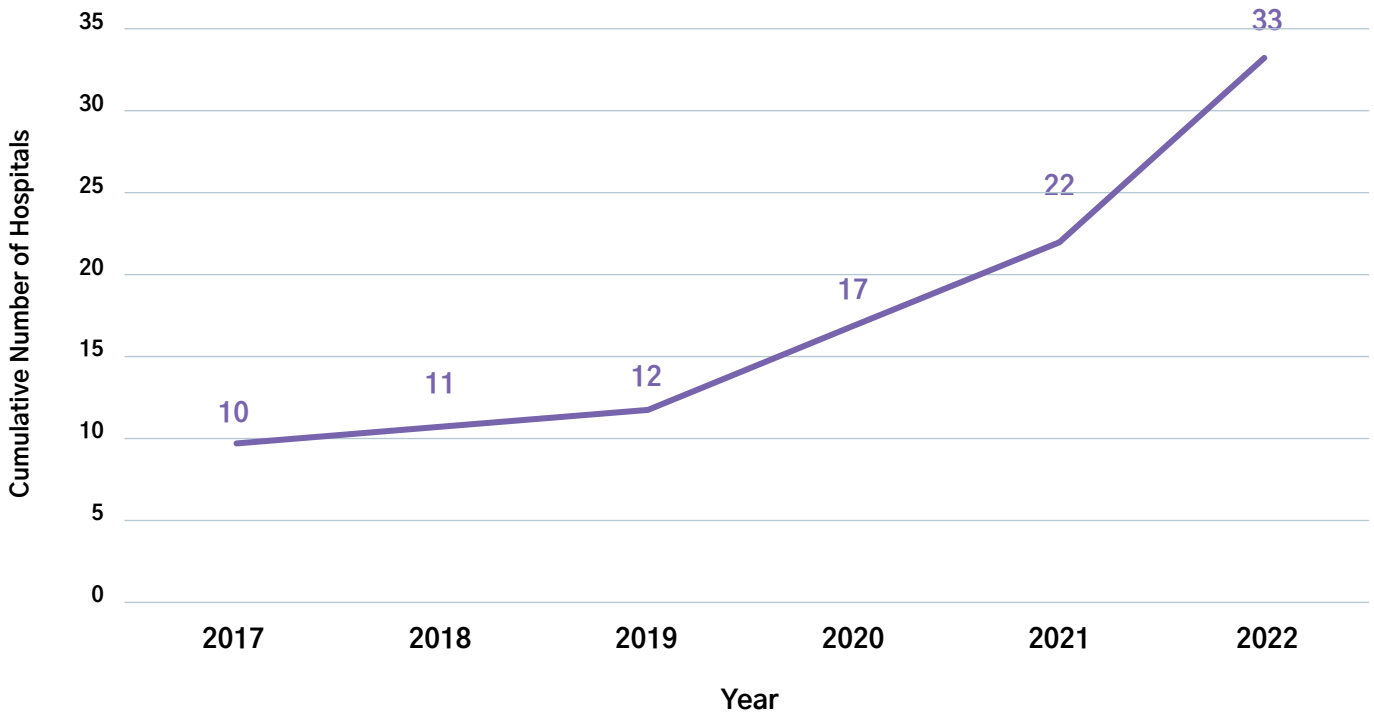


Figure 4: Cumulative number of hospitals partnering with the NGOR (N=33) between December 2017 and December 2022.

Table 1: Participating hospitals as at the end of 2022*

Location	Name of Hospital*
New South Wales	Chris O'Brien Lifehouse
	John Hunter Hospital
	Liverpool Hospital
	Prince of Wales Private Hospital
	Royal Hospital for Women
	Royal North Shore Hospital
	St George Hospital
	St George Private Hospital
	Sydney Adventist Hospital
	Westmead Hospital
	Westmead Private Hospital
South Australia	Calvary North Adelaide Hospital
	Flinders Medical Centre
	Flinders Private Hospital
	Royal Adelaide Hospital
Tasmania	Hobart Private Hospital
	Royal Hobart Hospital
Victoria	Cabrini Health
	Epworth Healthcare
	Frances Perry House
	Mercy Hospital for Women
	Monash Health
	Peninsula Health
	Peter MacCallum Cancer Centre
	Royal Women's Hospital
	Warringal Private Hospital
	Werribee Mercy Hospital
	Western Health
Western Australia	Hollywood Private Hospital
	King Edward Memorial Hospital
	St John of God, Murdoch Hospital
	St John of God, Subiaco Hospital
Queensland	Royal Brisbane and Women's Hospital

*28 out of the 33 hospitals contributed data during the reporting period.

Section I: Outcomes from the OTP Cancer Module

Participant Recruitment

A total of 2,450 patients were recruited to the OTP Cancer Module between the registry commencement in 2017 and the end of 2022 (Figure 5).

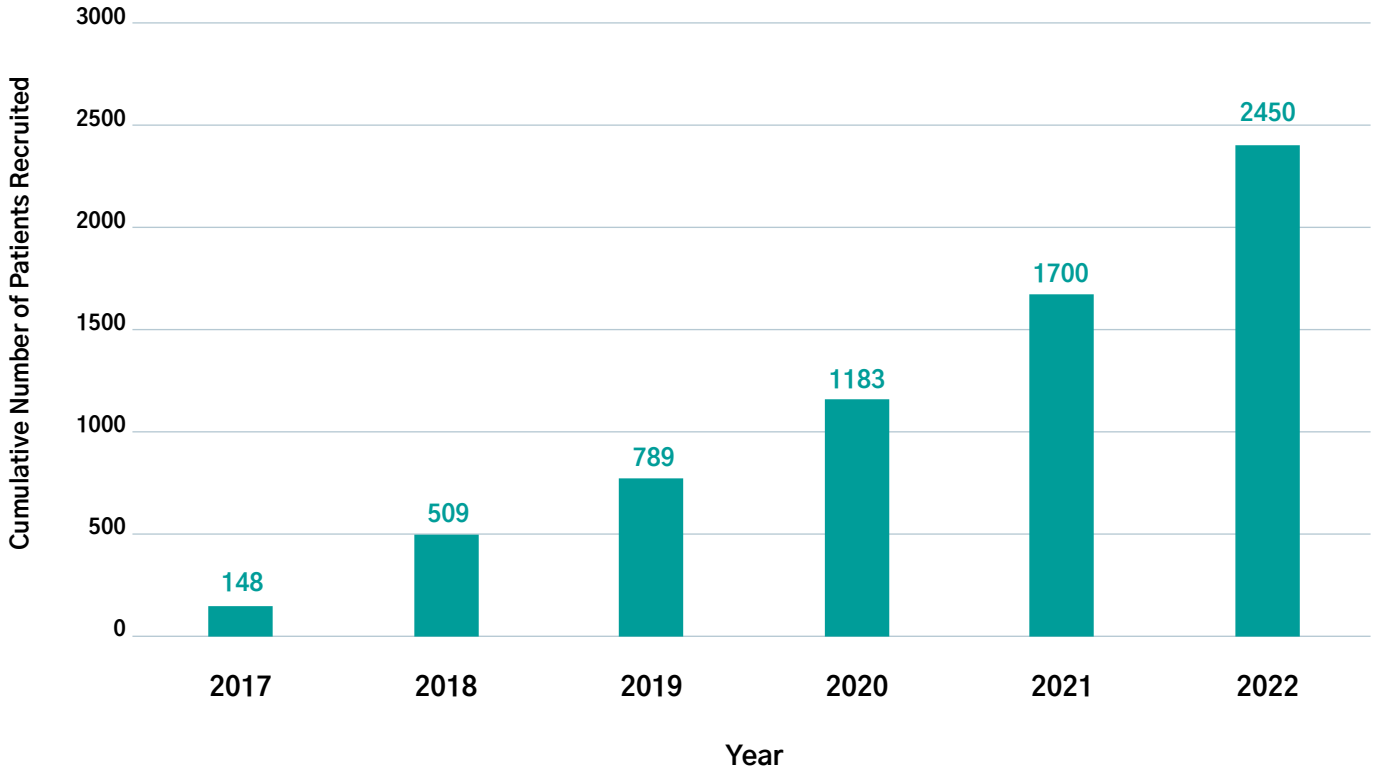


Figure 5: Cumulative number of patients recruited (N = 2,450) into the OTP Cancer Module between December 2017 and December 2022.

Of those believed to have been diagnosed with OTP cancer within the reporting period, 750 participants were recruited into the NGOR. Of these, 31 fully opted out of the module, 31 were treated at a site not included in this report, 30 were excluded due to no data collection having occurred at the time of reporting, 20 had their initial diagnosis later confirmed as having occurred outside the reporting period, 11 were reallocated to a different module (e.g. endometrial cancer), nine were later determined ineligible and four were uncontactable. Overall, 614 participants were included in the OTP Cancer Module who were diagnosed within the reporting period (Figure 6).

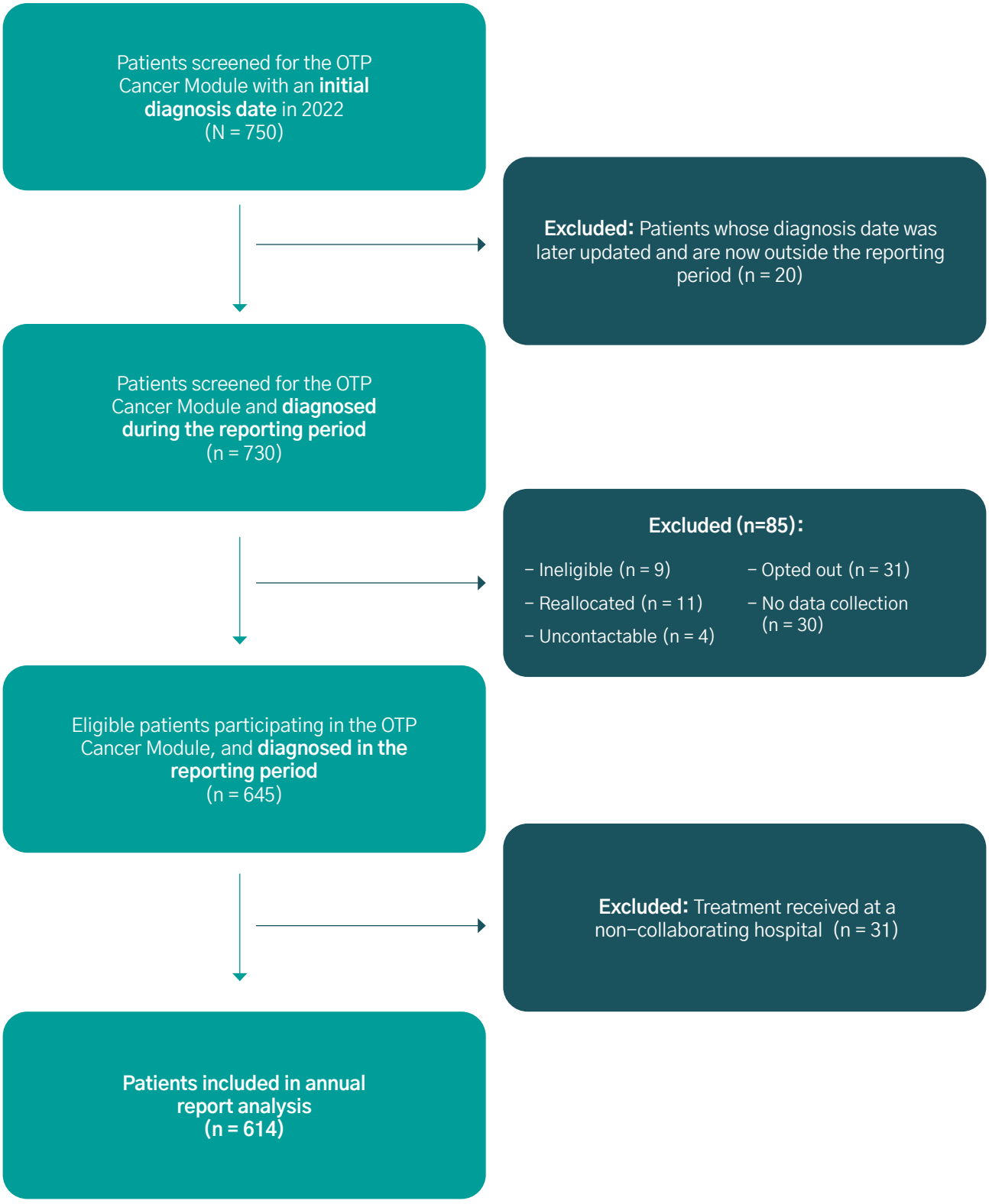


Figure 6: NGOR patient recruitment flowchart for the OTP Cancer Module.

All patients were given two weeks to either fully or partially opt-out of the OTP Cancer Module, prior to data collection commencing. Between 2017–2022, an average of 4.15% of patients per year elected to fully opt-out and 2.81% of participants elected to partially opt-out. Figure 7 shows the participant opt-out statistics for 2017–2022.

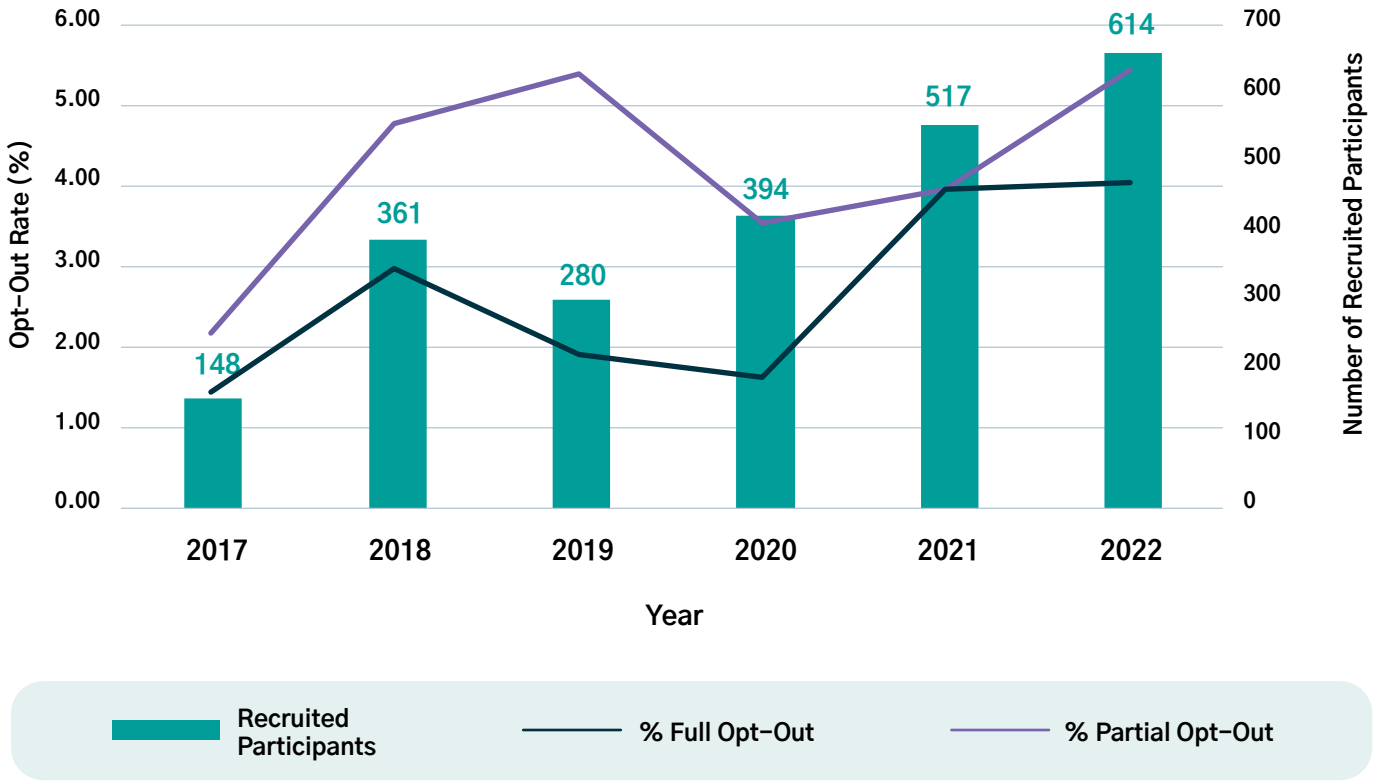


Figure 7: Participant yearly opt-out rates displayed as a percentage of the number of recruited participants each year, from 2017-2022.

As a consumer on the NGOR Project, I have been both a witness to and a participant in its growth and development to the fully functioning program that it is now. I have a feeling of pride looking at the mature Registry and knowing that I have been a part of that. And satisfaction that, perhaps, in a small way, I have been able to represent the perspectives of other women living with ovarian cancer and going through the uncertainty and upheaval of the initial diagnosis and treatment phase.

The team of researchers and clinicians driving the Registry impresses me as they are just as interested in, and committed to, the wellbeing of women living with this cancer as they were at the beginning, and I feel they are truly motivated by a sense of service to the community. When I see the information that the Registry is collecting, it is validating and reassuring about my own experience and makes me wish that, when I was first diagnosed, there was such a coordinated body of knowledge available for researchers and clinicians to share and pass on to women in the form of good care.

Most of us women have a fair idea what we're up against with ovarian cancer and we know it is difficult. But reducing uncertainty and deepening knowledge creates a safety net around us. This can give us confidence that "someone's got this" and the best that can be done will be done. I am grateful for the opportunity to participate in the Registry program as a consumer and I look forward to further insights and refinements as it continues to mature.

Kristin Young
Patient Advocate (Ovarian Cancer)
NGOR Consumer Representative

Descriptive Statistics

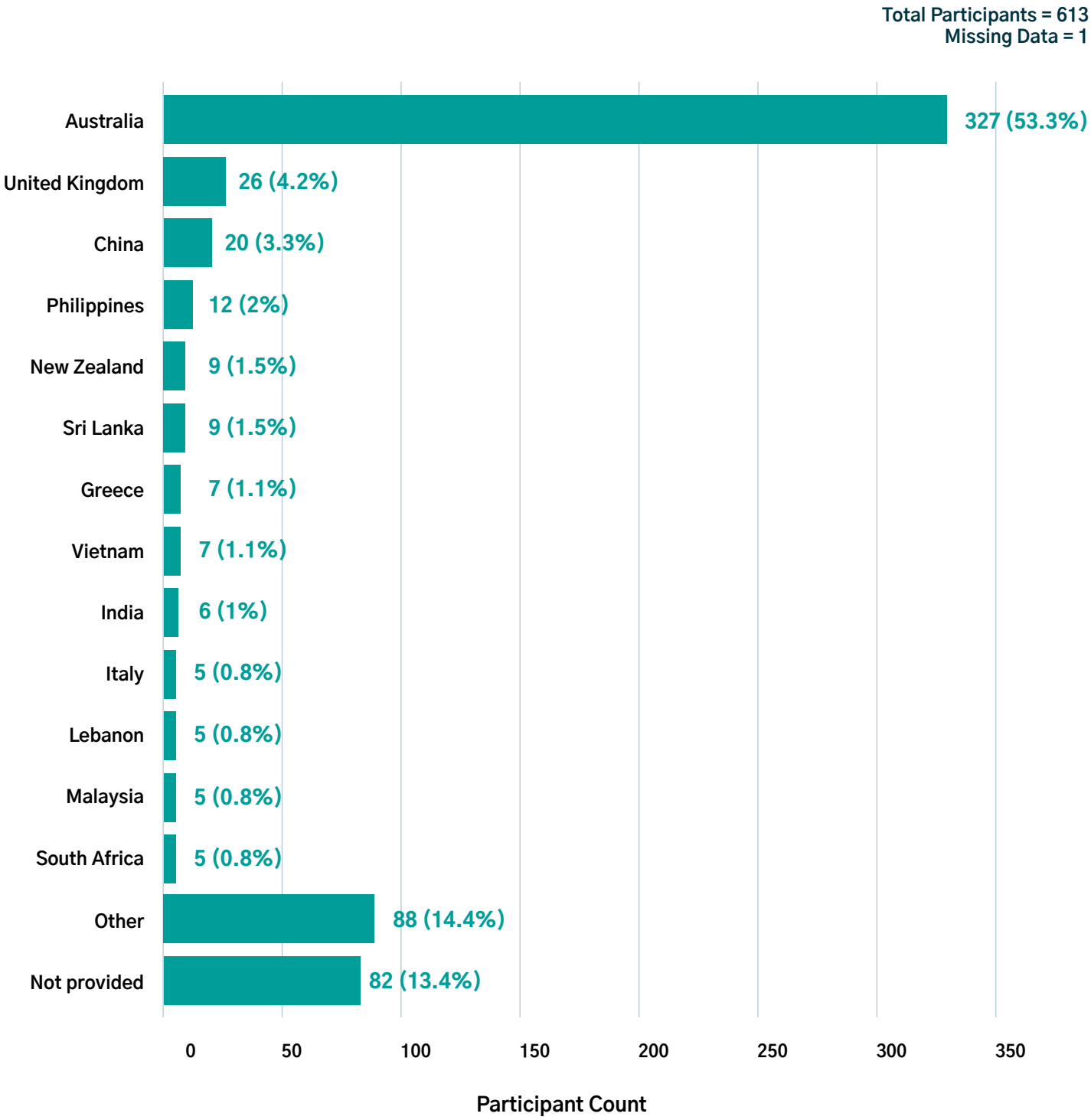


Figure 8: Country of birth.

Distribution of country of birth for patients diagnosed in 2022. Countries with fewer than five patients are grouped into the 'Other' category.

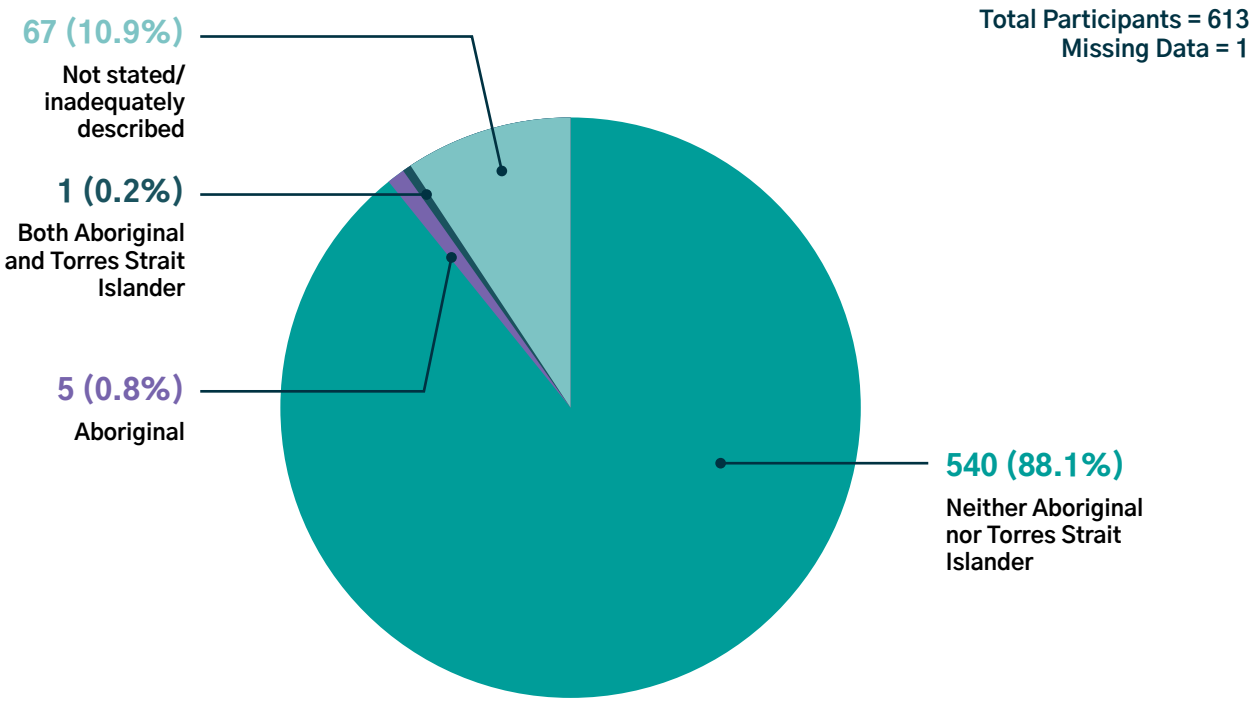


Figure 9: Aboriginal or Torres Strait Islander Status.

Distribution of Aboriginal or Torres Strait Islander status for patients diagnosed in 2022. During the reporting period, no patients were identified as Torres Strait Islander only, in their hospital medical record.

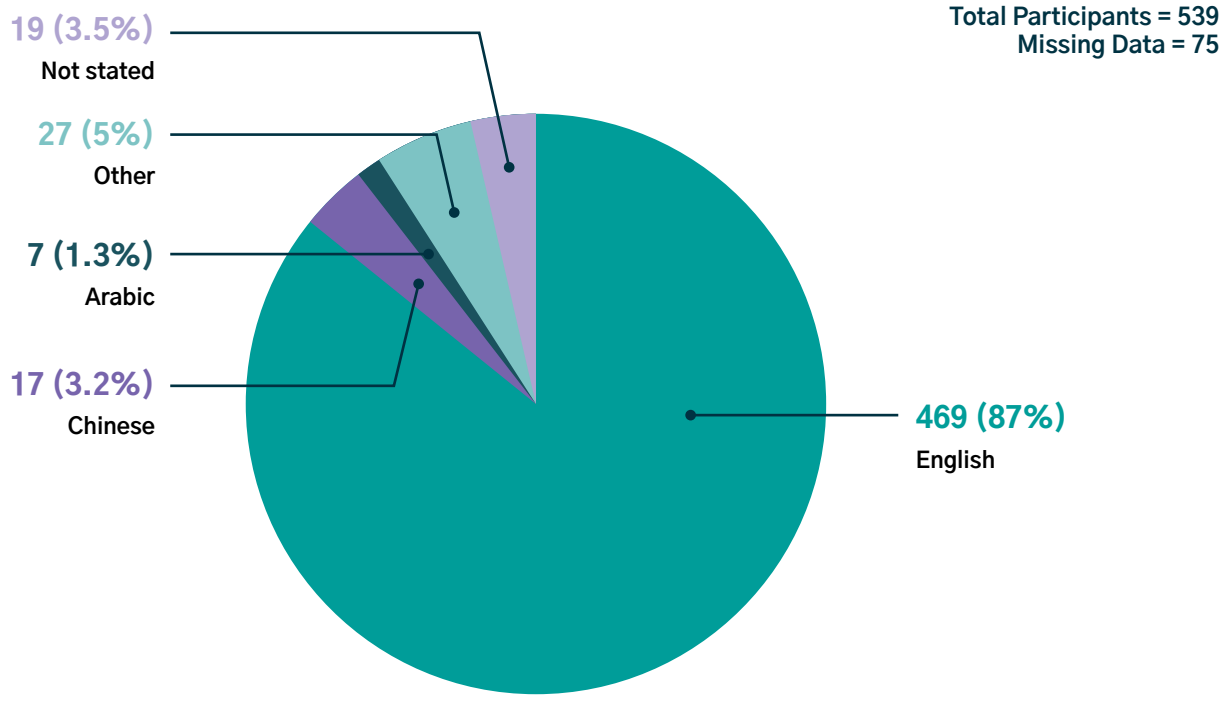


Figure 10: Preferred language

Distribution of preferred language for patients diagnosed in 2022. Languages with fewer than five patients are grouped together into 'Other' category. 'Not stated' refers to the information not recorded or easily accessible in the patient's medical record.

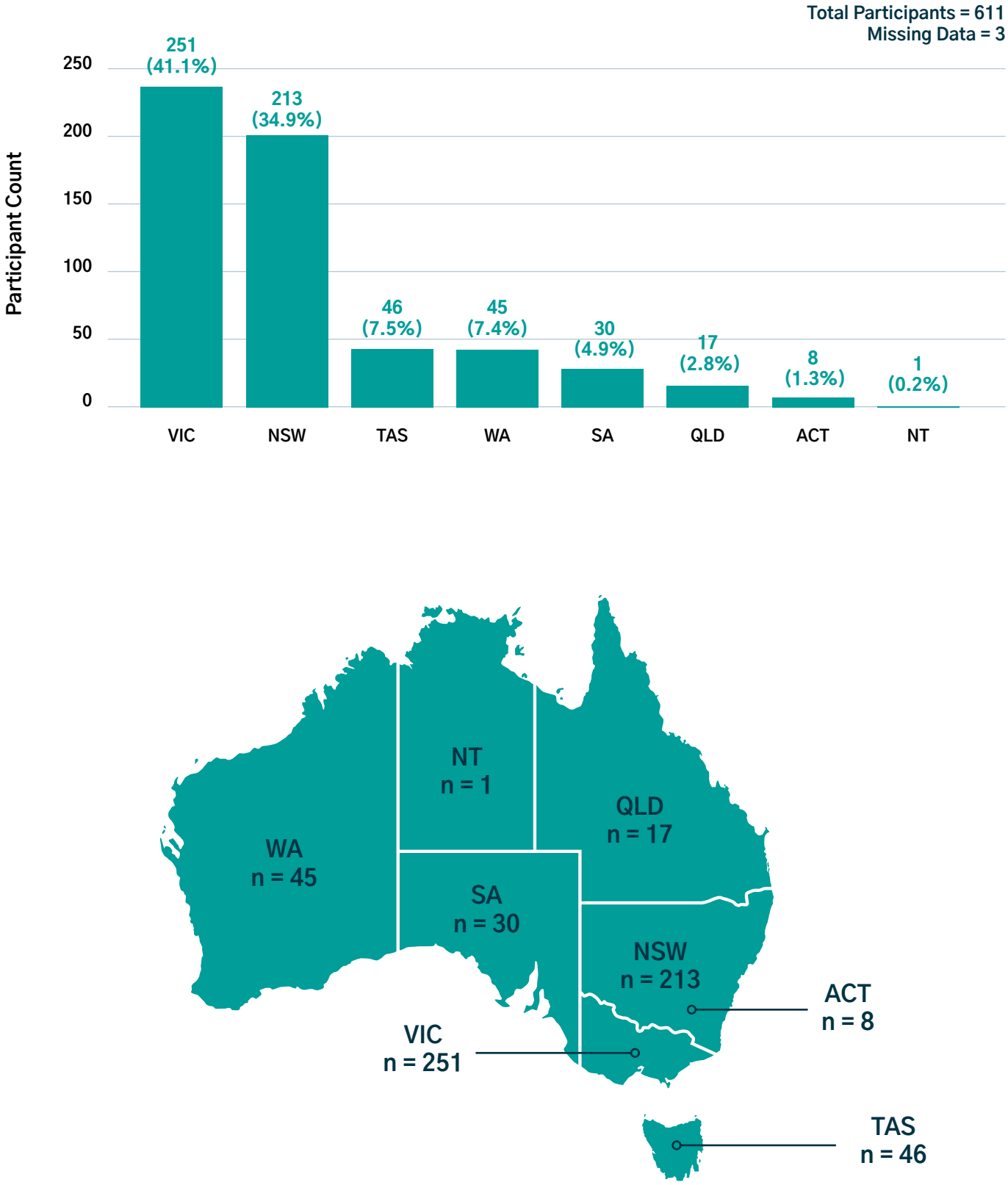


Figure 11: Residential distribution

Distribution of participant residential location at the time of diagnosis for patients diagnosed in 2022. Whilst some participants were residing in the Northern Territory (NT) or the Australian Capital Territory (ACT), the NGOR did not have any participating hospitals within these territories during the reporting period. This means that some participants were living in NT or ACT but received their treatment at a participating hospital in either Victoria (VIC), New South Wales (NSW), Queensland (QLD), South Australia (SA), Western Australia (WA) or Tasmania (TAS).

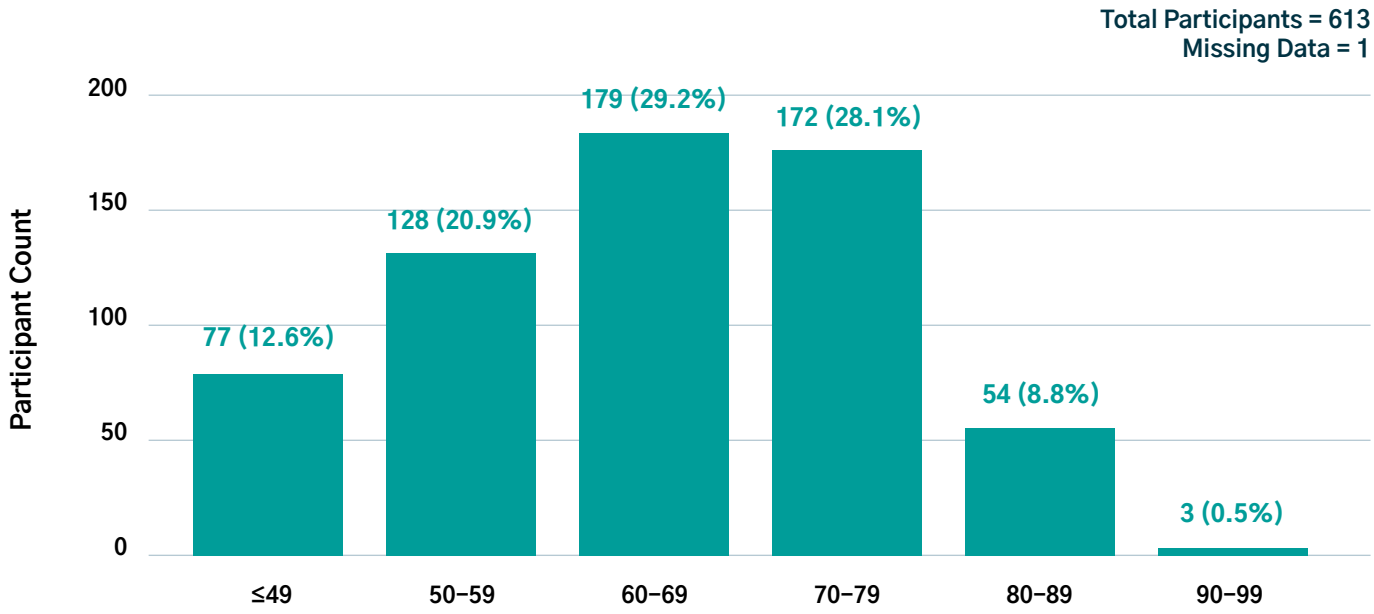


Figure 12: Participant age at diagnosis.

Distribution of age at diagnosis for patients diagnosed in 2022. Average participant age was 64.1 years.

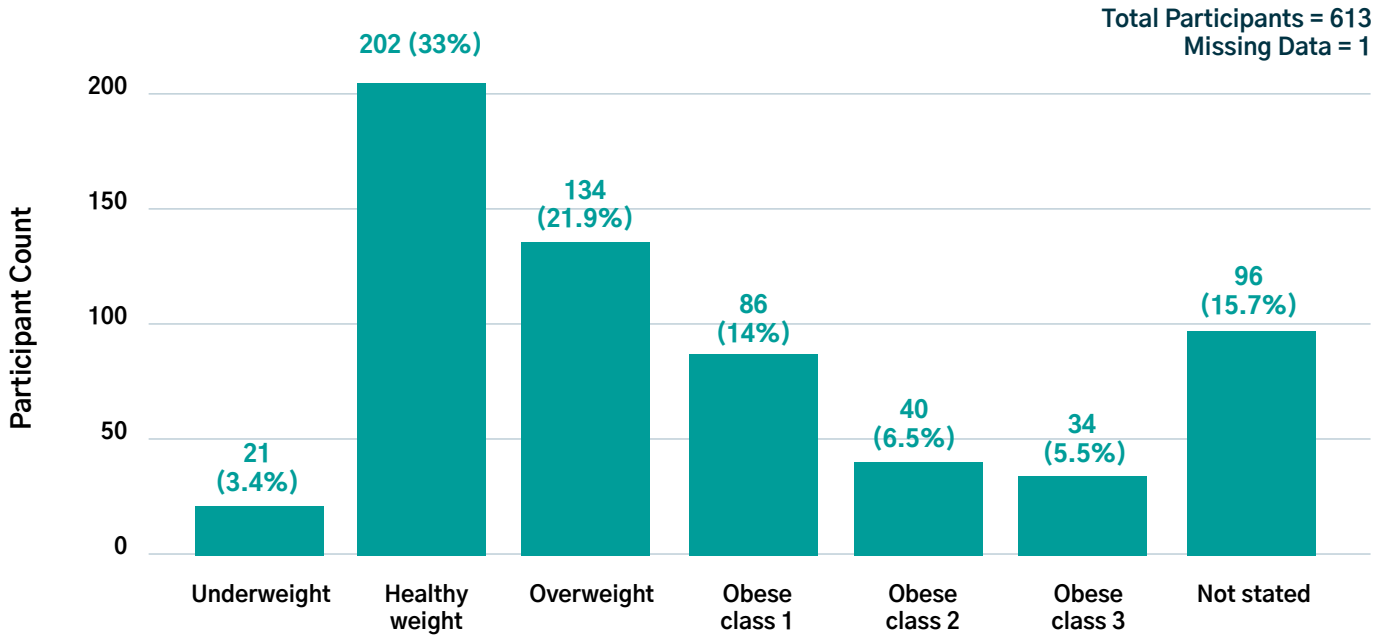


Figure 13: Participant Body Mass Index (BMI).

Distribution of BMI scores at the time of diagnosis for patients diagnosed in 2022. The classification of 'not stated' indicates that there was no information on the patient's weight or BMI score in their medical record. BMI scores <18.5 = underweight; 18.5–24.99 = healthy weight; 25–29.99 = overweight; 30–34.99 = obese class 1; 35–39.99 = obese class 2; ≥40 = obese class 3.

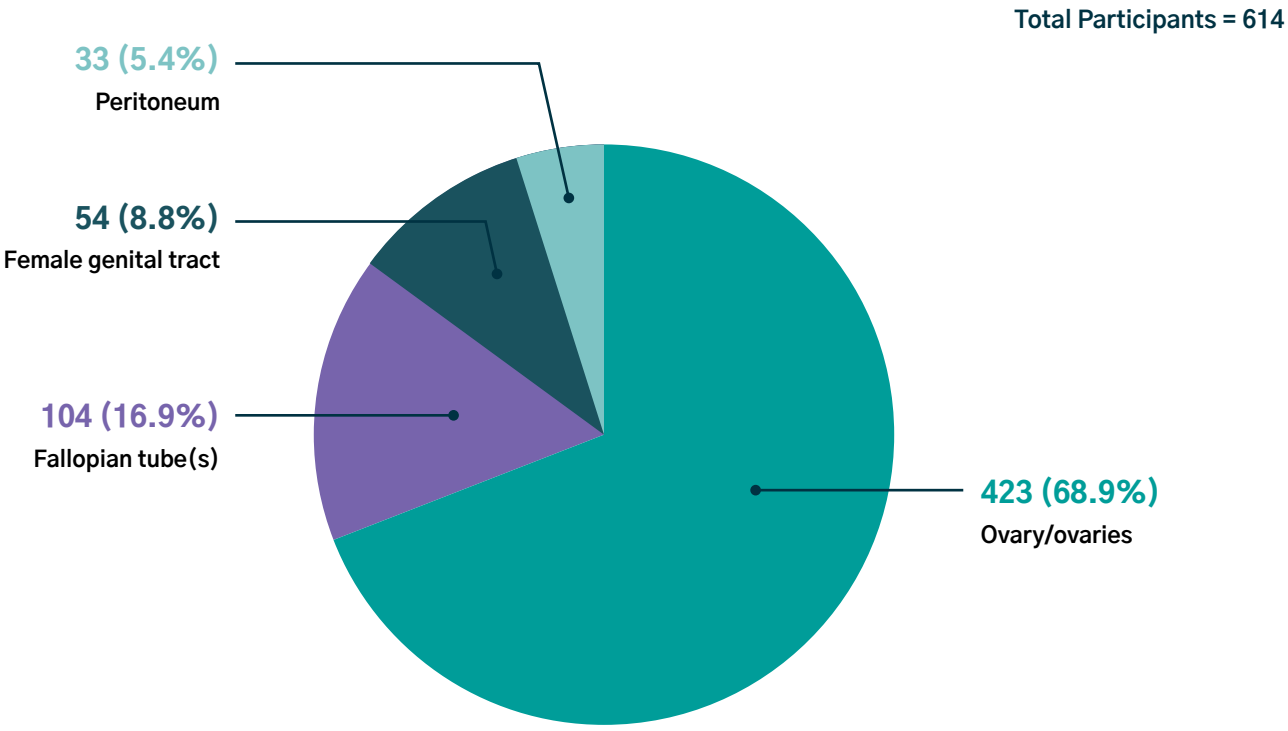


Figure 14: Primary tumour site.

Distribution for primary tumour site for patients diagnosed in 2022. 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 a specific primary site due to tumour complexities, or it may be too early to determine (i.e. determination may occur after surgery).

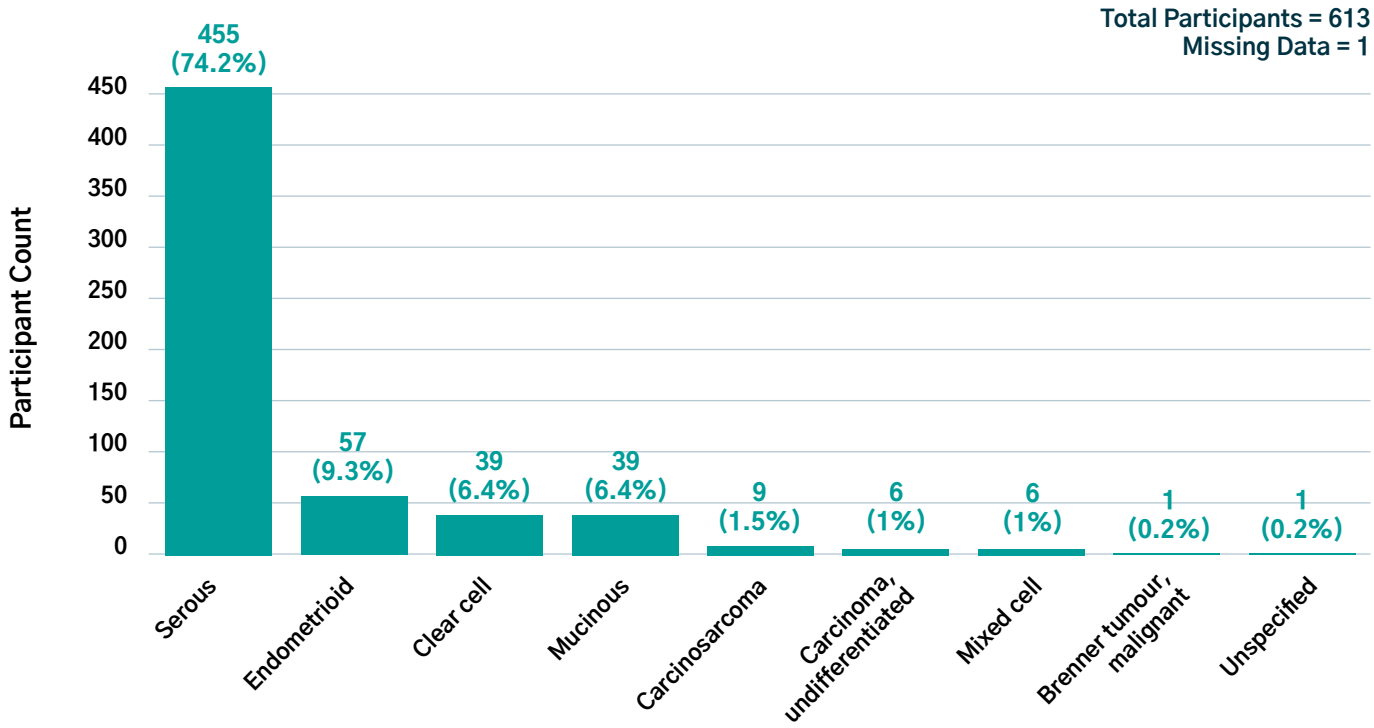


Figure 15: Cancer morphology.

Distribution of cancer tissue histopathological type or classification for patients diagnosed in 2022. All cancer types shown are malignant, epithelial tumours.

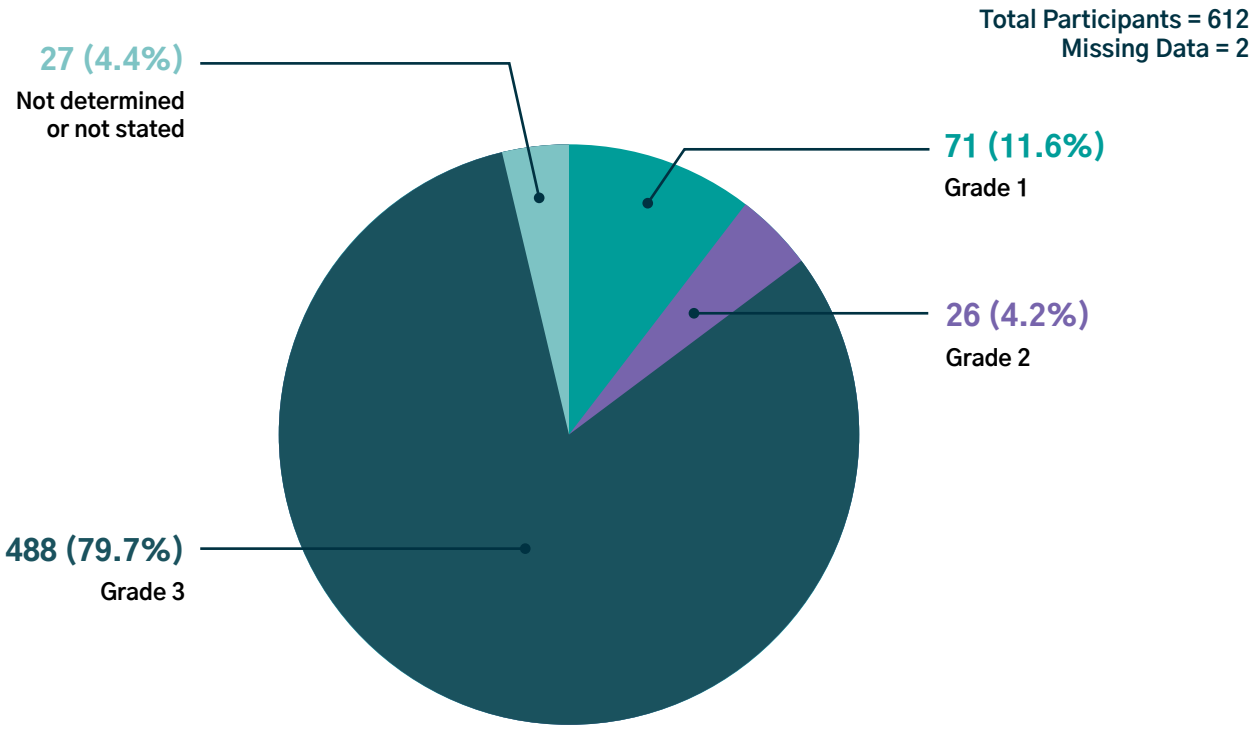


Figure 16: Tumour grade.

Distribution of tumour grades at the time of diagnosis, for patients diagnosed in 2022. Tumour grade refers to the level of abnormality of the cells, where higher grades indicate greater abnormality. Tumour grades marked as 'not determined or not stated' indicate that available information relating to the tumour grade was either missing or difficult to determine from the patient's medical record.

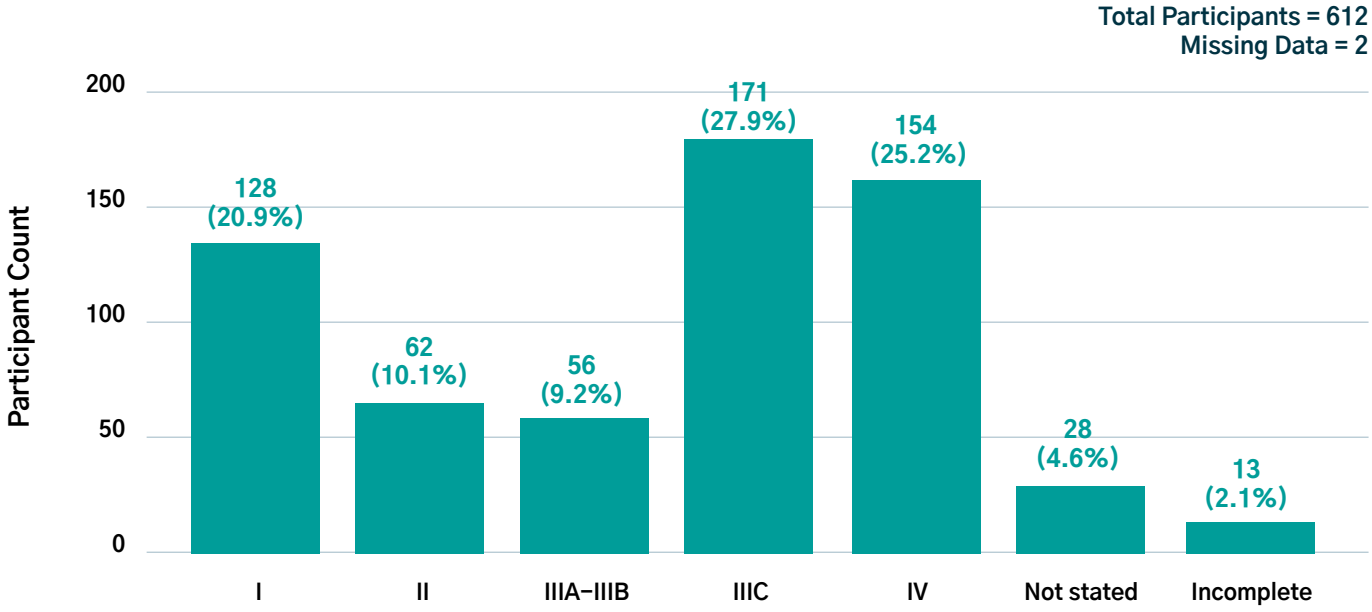


Figure 17: FIGO stage at diagnosis.

Distribution of staging according to the International Federation of Gynecology and Obstetrics (FIGO), which is the most widely adopted approach to staging gynaecological cancers. Data are shown for patients diagnosed in 2022. All staging information was obtained at the time of diagnosis. FIGO stage refers to the spread of the tumour, where higher FIGO stages indicate 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 staging was planned but incomplete at the time of diagnosis.

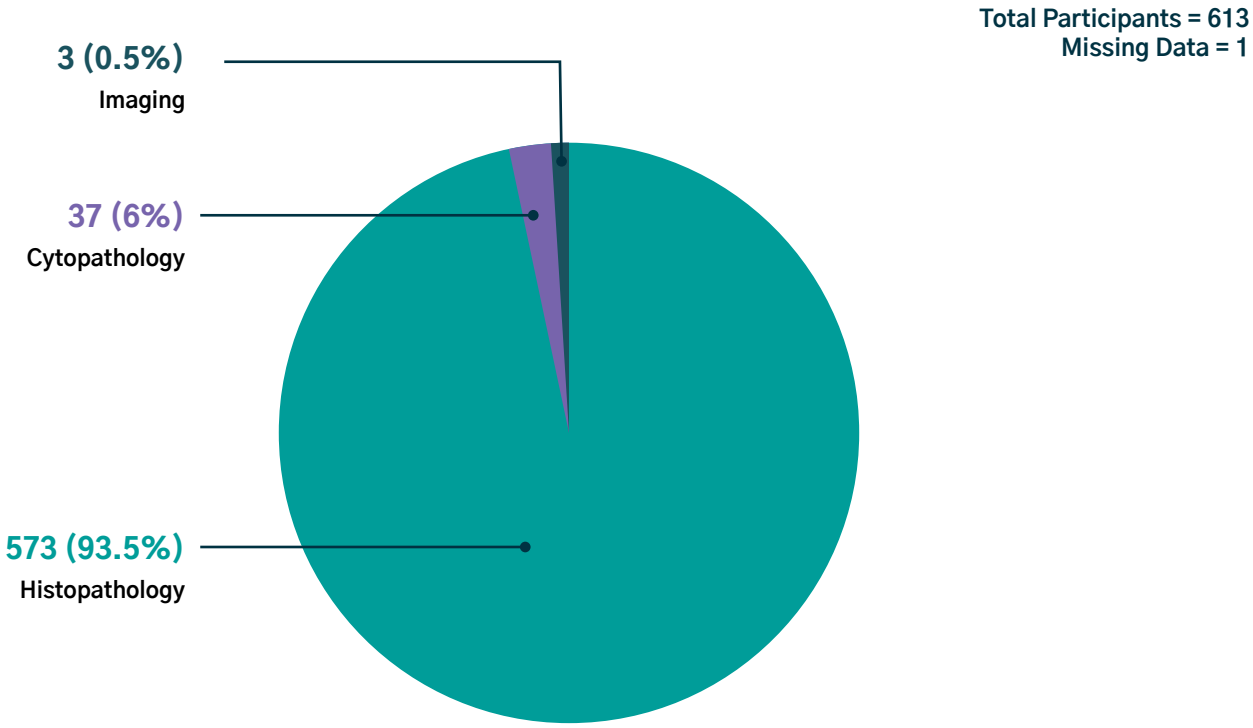


Figure 18: Level of diagnostic evidence.

Highest/most reliable diagnostic methods used within the OTP Cancer Module cohort. Data are shown for patients diagnosed in 2022. Histopathology is considered the highest level of evidence for diagnosis, followed by cytopathology, then imaging.

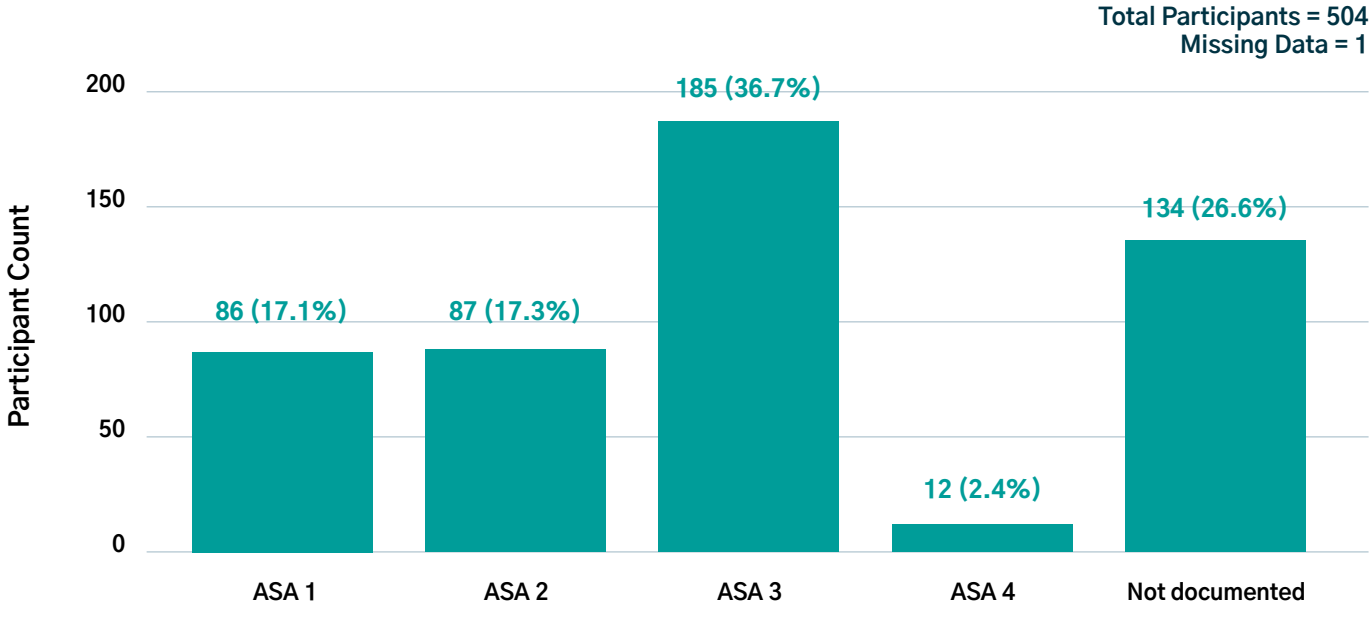


Figure 19: ASA score.

Distribution of American Society of Anesthesiologists (ASA) physical status scores. Data are shown for patients diagnosed in 2022, and scores range from 1–6. Lower scores indicate greater health. ASA scores are only captured for patients who undergo surgery. No patients in this cohort had an ASA score of 5 (moribund patients whom are not expected to survive) or 6 (declared brain dead). 'Not documented' indicates that data relating to ASA score were either missing or difficult to determine from the patient's medical record.

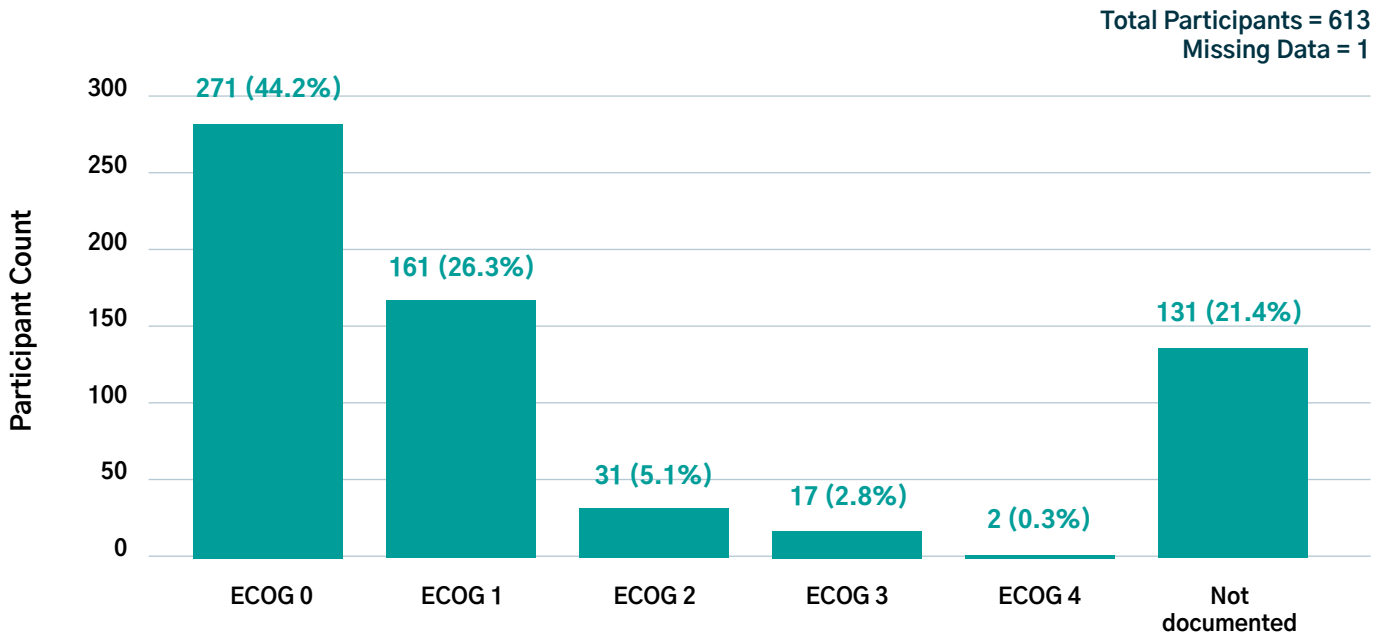


Figure 20: ECOG score.

Distribution of physical functioning at diagnosis, for patients diagnosed in 2022. Physical functioning is measured according to the Eastern Cooperative Oncology Group (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.

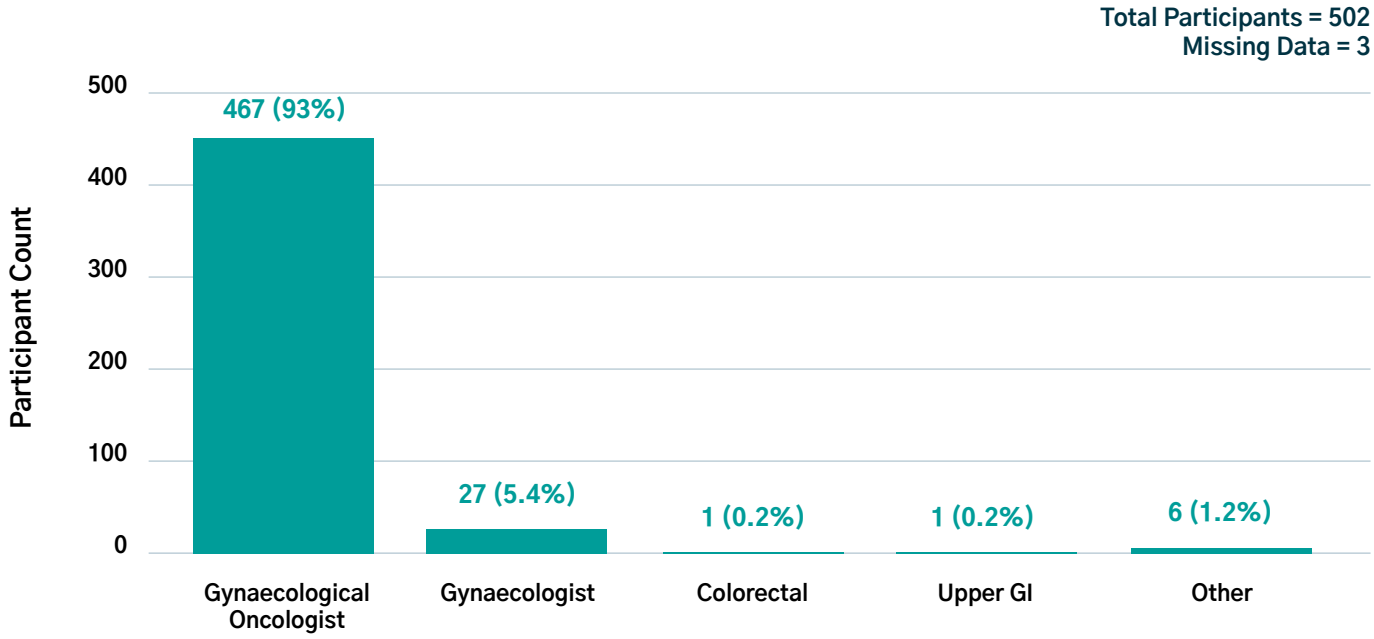


Figure 21: Speciality of supervising surgeon.

Distribution of supervising surgeon specialisation for patients diagnosed in 2022. 'Other' refers to surgeons of other specialties, e.g. general surgery.

Clinical Quality Indicators (CQIs)

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 either funnel plots (see Figure 24 for an example funnel plot) or a standard bar chart. Funnel plots are the recommended graphical representation when comparing institutional data19. This allows each hospital to be compared to each other for benchmarking purposes.

All participating hospitals receive annual CQI reports containing data (including funnel plots) for each of the 15 CQIs. This allows for visual comparison and benchmarking of their site's performance against other sites. Hospitals confirmed as an outlier on any of the CQIs are encouraged to review and confirm their data accuracy. The CQIs presented as funnel plots in this report have been risk-adjusted. This means that the data analyses accounts for any relevant risk factors such as Charlson comorbidity score, age, and/or FIGO stage. Information on risk-adjustment is provided for each funnel plot, including where risk-adjustment produced no significant effect. Missing data for any funnel plot may be due to difficulties in accessing the relevant information in the patient's medical record.

OTP Cancer Module CQIs

1. Proportion of patients with newly diagnosed OTP cancer who are discussed at a multi-disciplinary meeting (MDM).
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)** Patients who had CT imaging of their chest, abdomen and pelvis, or PET imaging.
   - **b)** Patients who had CT imaging of their abdomen and pelvis (but may not have had chest imaging), or PET imaging.
3. Proportion of patients with newly diagnosed OTP cancer who have their histological or cytological diagnosis confirmed prior to receiving first-line neoadjuvant chemotherapy.
4. Proportion of patients with clinically apparent early stage (Stage I or II) OTP cancer who undergo surgical staging procedures.
5. Proportion of patients with advanced (Stage IIB, III, or IV) OTP cancer who undergo primary cytoreductive surgery and have:
   - **a)** no residual cancer (0cm).
   - **b)** some residual cancer that is less than 1cm.
6. Proportion of patients with advanced (Stage IIB, III, or IV) OTP cancer who undergo interval cytoreductive surgery and have:
   - **a)** no residual cancer (0cm).
   - **b)** some residual cancer that is less than 1cm.
7. Proportion of patients who undergo surgery for OTP cancer and have at least one unplanned intraoperative event.
8. Proportion of patients with OTP cancer who experience one or more serious (Clavien-Dindo ≥ III) adverse events during the first 30 days after surgery for OTP cancer.
9. Proportion of patients with newly diagnosed OTP cancer whose histopathology report contains the minimum required elements.
10. Proportion of patients with OTP cancer who receive first-line chemotherapy with a platinum-taxane doublet.
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.
12. Proportion of patients with OTP cancer who commence:
    - **a)** First-line adjuvant chemotherapy within 28 days of surgery.
    - **b)** First-line neoadjuvant chemotherapy within 28 days of diagnosis.
13. Proportion of eligible patients who had germline or somatic genetic testing for BRCA1, BRCA2 and other relevant gene mutations.
14. Proportion of patients with pathogenic germline or somatic genetic mutations of BRCA1 or BRCA2 who commence maintenance PARPi therapy within 8 weeks of ceasing first-line chemotherapy.
15. 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

Funnel plots illustrate 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 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 on the funnel plot. Sites within the inner (darker shaded) funnel are sites whose performance against the CQI is within 95% (two standard deviations) of the overall mean. Sites within the outer (lighter shaded) funnel, are sites whose performance is within 99.8% (three standard deviations) of the mean. Any site that is outside of the outer funnel is considered an outlier, as their performance is greater than three standard deviations from the mean. In Figure 22, 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).

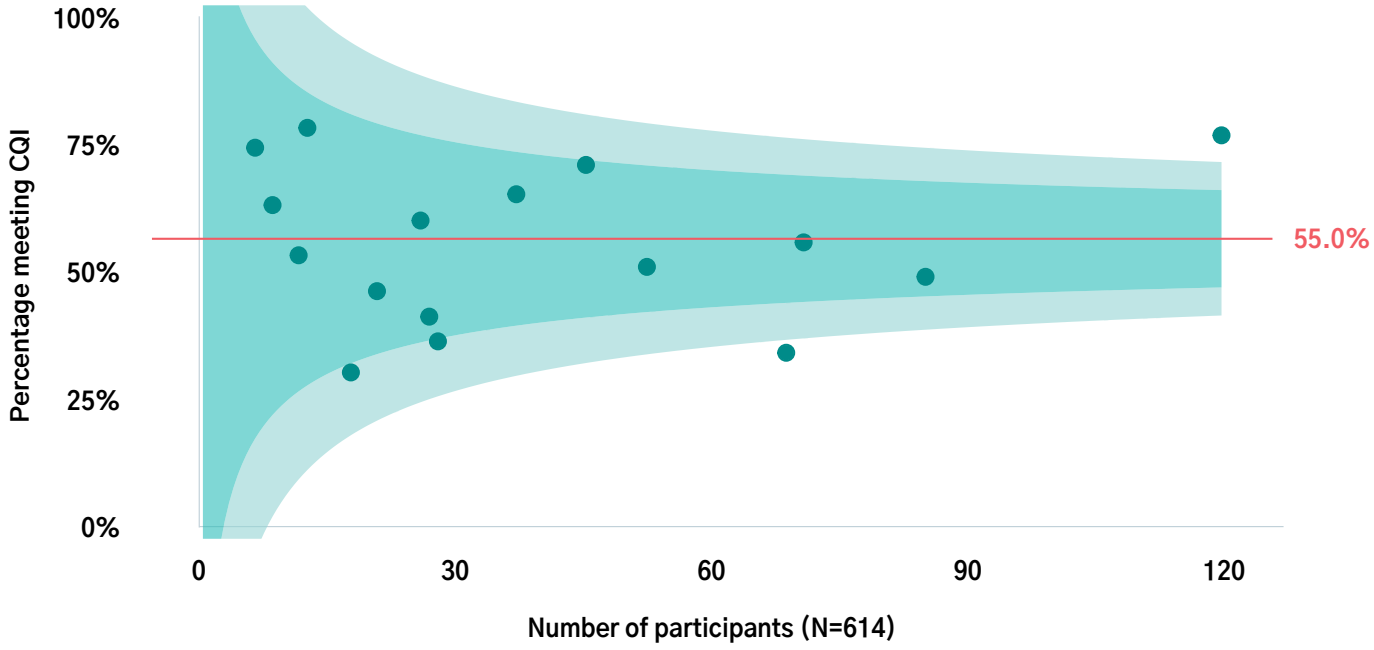


Figure 22: Example funnel plot.

The 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 Optimal Care for OTP Cancer

Diagnosis and Staging

Optimal diagnosis and staging practices for OTP cancer involve several interconnected processes. In the NGOR, these processes are defined by 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 23–27. Data for CQI 4 are presented as a bar chart.

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

Multi-disciplinary meetings (MDMs) provide an essential avenue through which clinicians and other health practitioners (e.g. allied health) 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, 96.7% of patients with newly diagnosed OTP cancer were discussed at an MDM (Figure 23). Outliers for this CQI may indicate sites where data collection occurred prior to a patient being discussed at an MDM, or where documentation was incomplete. As this CQI applies to all patients in the OTP Cancer Module, no risk-adjustment has been applied.

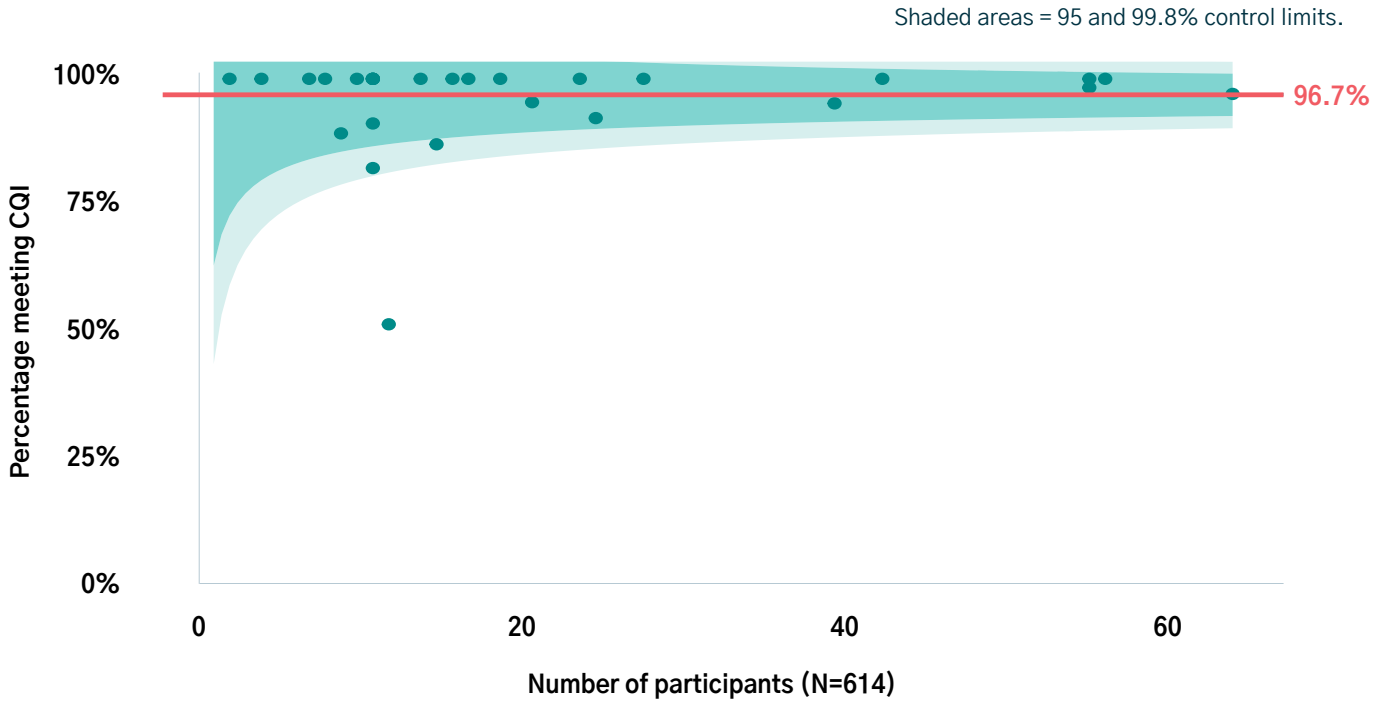


Figure 23: CQI #1.

Proportion of patients with newly diagnosed OTP cancer who were discussed at a multidisciplinary team meeting. No risk-adjustment was applied. There was missing data for 2 patients for this CQI.

CQI 2: Proportion of patients with newly diagnosed OTP cancer who had CT and/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, 62.5% of patients had a chest, abdomen and pelvic (CAP) CT or a PET scan to stage their cancer prior to commencing treatment (Figure 24; CQI 2a), while 82.1% of patients had a CT scan of only their abdomen and pelvis or a PET scan to stage their cancer prior to commencing treatment (Figure 25; 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. As this CQI applies to all patients in the OTP Cancer Module, no risk-adjustment has been applied.

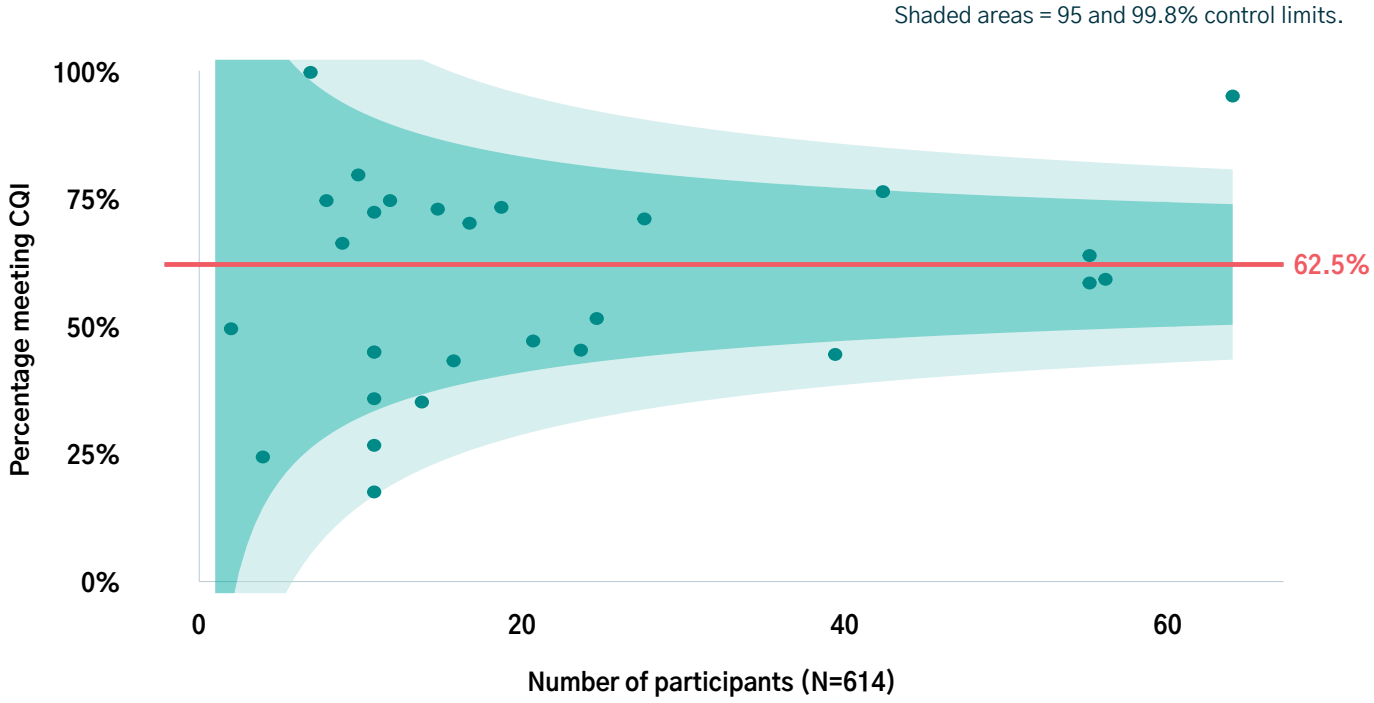


Figure 24: CQI #2a.

Proportion of patients who had a CAP CT scan or PET imaging to stage their cancer prior to commencing treatment. No risk-adjustment was applied. There was missing data for 2 patients for this CQI.

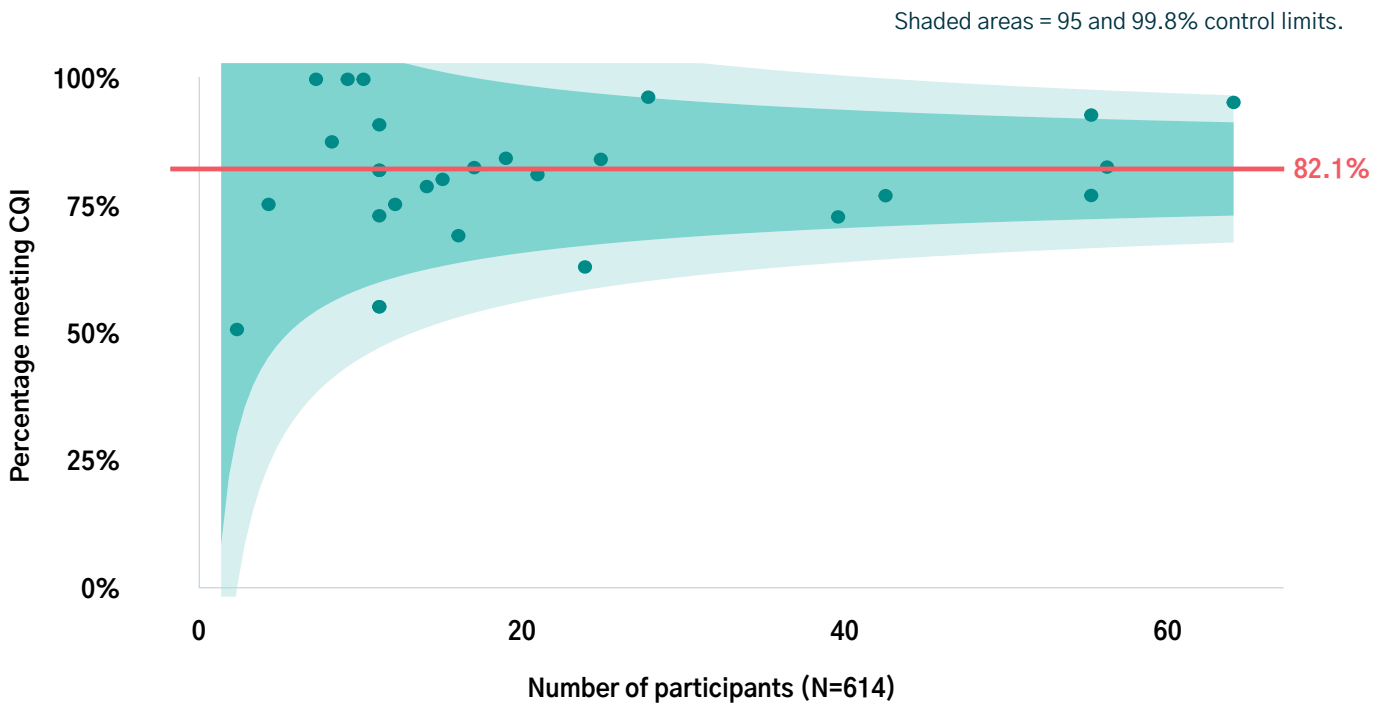


Figure 25: CQI #2b.

Proportion of patients who had a CT scan of the abdomen and pelvis or PET imaging to stage their cancer prior to commencing treatment. No risk–adjustment was applied. There was missing data for 2 patients for this CQI.

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

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, 95.8% of patients had their OTP cancer diagnosis confirmed via histology or cytology, prior to commencing first-line neoadjuvant chemotherapy (Figure 26). As this CQI applies to all patients in the OTP Cancer Module who receive neoadjuvant chemotherapy, no risk-adjustment has been applied.

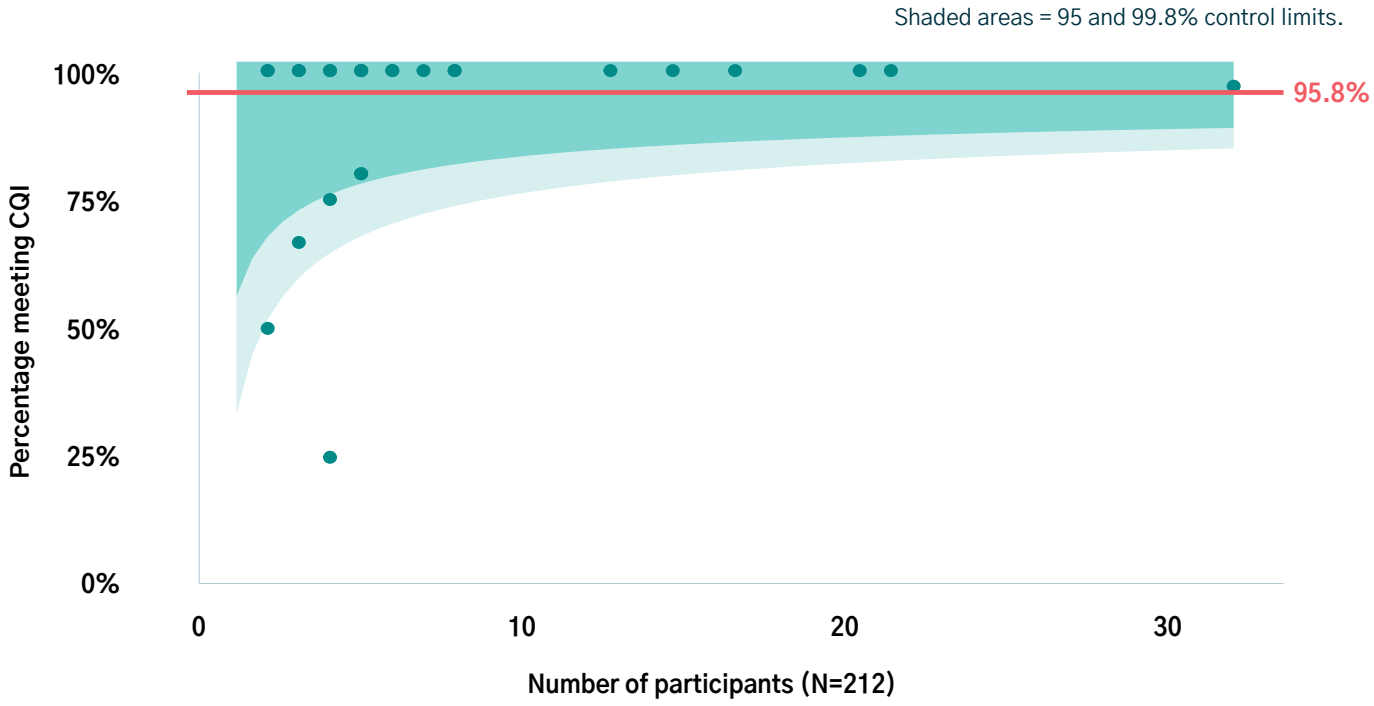


Figure 26: CQI #3.

Proportion of patients with newly diagnosed OTP cancer who had their diagnosis confirmed by histology and/or cytology prior to receiving first-line neoadjuvant chemotherapy. No risk-adjustment was applied. There was no missing data for this CQI.

CQI 4: Proportion of patients with clinically apparent early stage (Stage I or II) OTP cancer who undergo surgical staging procedures

Cancer staging provides information regarding the amount of cancer as well as the extent of cancer spread, which is useful in guiding treatment options. Surgical staging aims to detect small macroscopic or microscopic metastatic disease via laparotomy or laparoscopy. The OTP Cancer Module uses the staging convention outlined by the International Federation of Gynecology and Obstetrics (FIGO)[20]. Surgical staging includes any of the following procedures: peritoneal washings, omentectomy/omental biopsy, biopsy of any suspicious lesions/masses, and an appendicectomy (the latter only for mucinous tumours)[21]. 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[22,23]. Total abdominal hysterectomy (TAH) and bilateral salpingo-oophorectomy (BSO) is usually performed but is not always required for 'adequate' surgical staging.

For example, these procedures are not performed when surgical treatment is fertility sparing. The surgical staging procedures completed for patients diagnosed with clinically apparent early stage OTP cancer in 2022 are shown in Figure 27. In 2022, patients underwent omentectomy/omentum biopsy (92.1%), BSO (87.1%), peritoneal washings (86%), evaluation of all peritoneal surfaces (85.4%), TAH (83.7%), and biopsy of any suspicious lesions/masses (82.6%). The frequencies for pelvic and para-aortic lymph node sampling were comparatively lower, at 26.4% and 6.2%, respectively. As there remains a lack of consensus regarding which surgical staging procedures should be performed to classify a patient as 'adequately' surgically staged, we have not been prescriptive in defining or reporting this CQI. For this reason, we have chosen to present this CQI as a bar chart illustrating the frequency at which each procedure was performed. No risk-adjustment was applied for this CQI as it applies to all patients in the OTP Cancer Module with Stage I or II disease who underwent surgical staging.

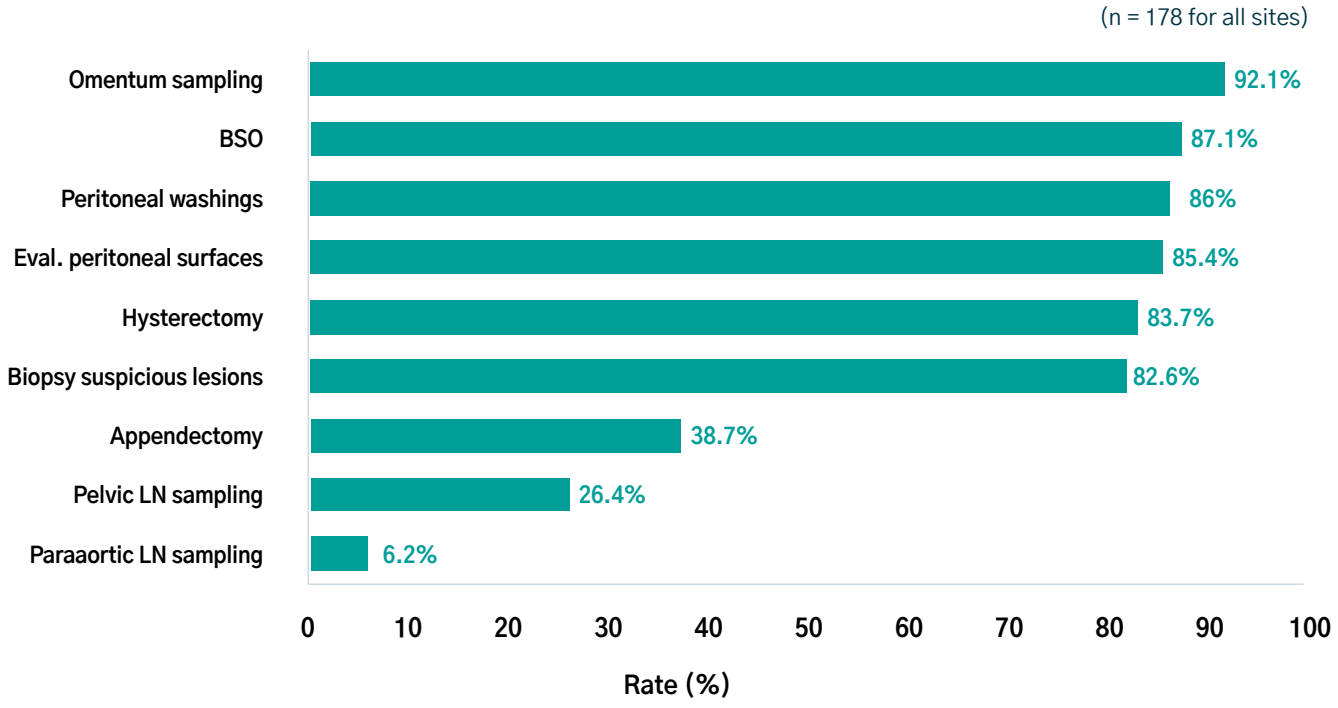


Figure 27: CQI #4.

Proportion of patients with clinically apparent early stage (Stage I or II) OTP cancer who underwent surgical staging procedures. No risk-adjustment was applied.

CQI 9: Proportion of patients with newly diagnosed OTP cancer whose histopathology 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)[23] and/or the International Collaboration on Cancer Reporting (ICCR)[24]. 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, 98% of patients with a new OTP diagnosis had a pathology report containing the minimum required elements (Figure 28). As this CQI applies to all patients in the OTP Cancer Module, no risk–adjustment has been applied.

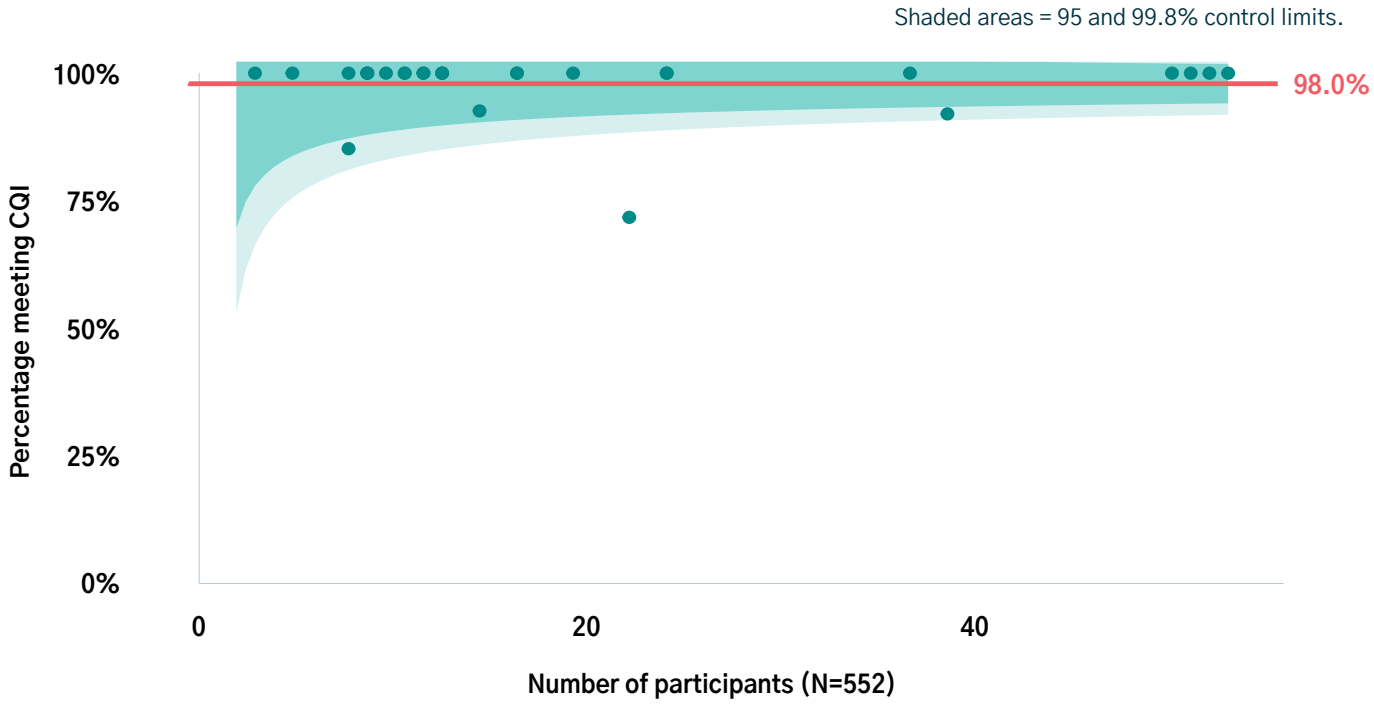


Figure 28: CQI #9.

Proportion of patients with newly diagnosed OTP cancer whose pathology report contained the minimum required elements. No risk–adjustment was applied. There was missing data for one patient for this CQI.

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 OTP Cancer Module, this has been defined by CQIs 5–8. The funnel plots illustrating the outcomes for each of these CQIs are shown below in Figures 29–35.

CQI 5: Proportion of patients with advanced (Stage IIB, III, or IV) OTP cancer who undergo primary cytoreductive surgery and have either no residual cancer, or less than 1cm of residual cancer

Primary surgery is defined in the OTP Cancer Module as surgery that is performed prior to commencing other treatments such as chemotherapy. In advanced (FIGO Stage IIB, III or IV) OTP cancer, cytoreductive (debulking) surgery which aims to remove all macroscopic cancer is appropriate. No macroscopic residual cancer or residual cancer less than 1cm is associated with better patient prognosis compared to sub-optimal debulking where tumours greater than/or equal to 1cm remain after surgery[25, 26]. In the current reporting period, 128 patients with advanced OTP cancer underwent primary cytoreductive surgery. Of these, 75 (58.6%) had no macroscopic residual cancer (Figure 29; CQI 5a) and 18 (14.1%) had macroscopic residual cancer which was less than 1cm in size (Figure 30; CQI 5b). A small number of patients who received only one cycle of induction chemotherapy 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. For both CQI 5a and 5b, the ability to achieve no residual cancer, or less than 1cm of residual cancer, may depend on the patients' age, cancer stage, and/or comorbidities. No specific risk-factor(s) had a statistically significant impact on the result for CQI 5a or 5b.

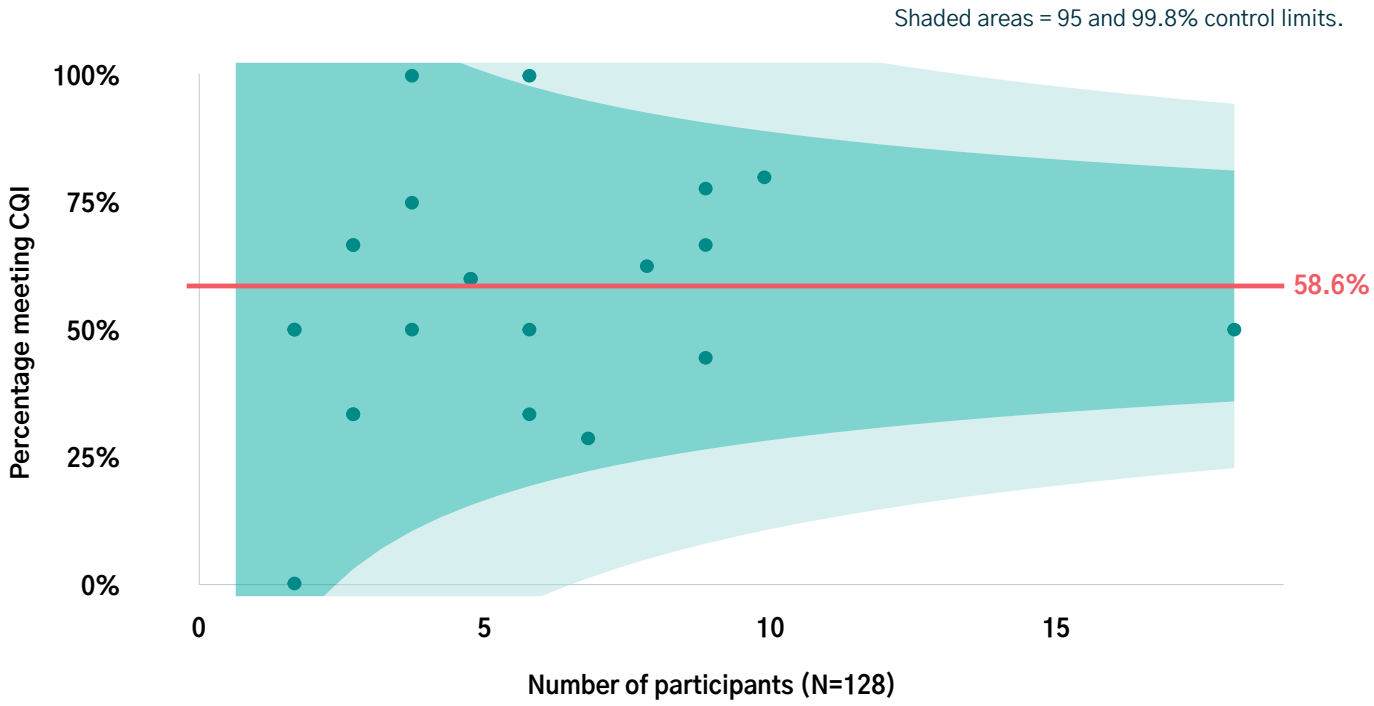


Figure 29: CQI #5a.

Proportion of patients with advanced OTP cancer who underwent primary cytoreductive surgery and had no macroscopic residual cancer. No specific risk-factors had a statistically significant impact on the outcome for CQI 5a. There was missing data for 14 patients for this CQI.

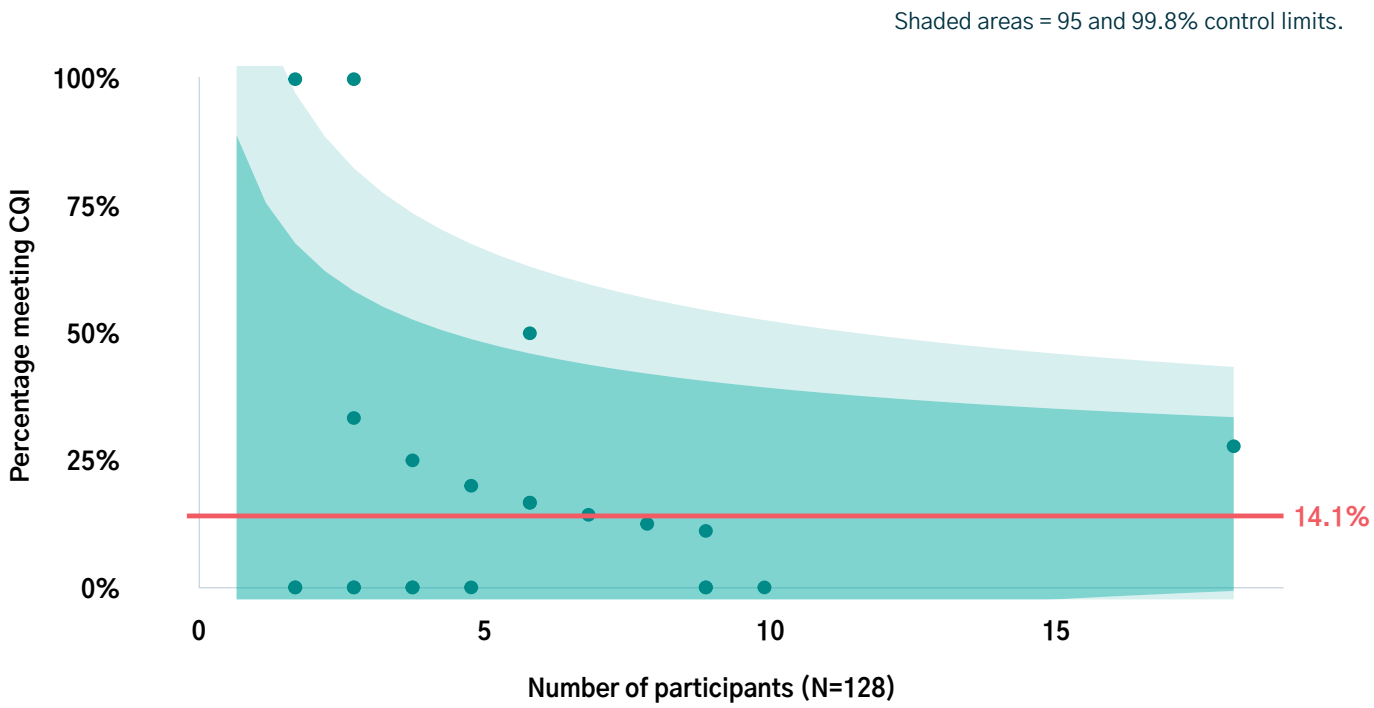


Figure 30: CQI #5b.

Proportion of patients with advanced OTP cancer who underwent primary cytoreductive surgery and had <1cm of macroscopic residual cancer. No specific risk-factors had a statistically significant impact on the outcome for CQI 5b. There was missing data for 14 patients for this CQI.

CQI 6: Proportion of patients with advanced (Stage IIB, III, or IV) OTP cancer who undergo interval cytoreductive surgery and have either no residual cancer, or less than 1cm residual cancer

Interval cytoreductive (debulking) surgery is defined in the OTP Cancer Module as surgery that is performed after 2–4 cycles of chemotherapy. In this reporting period, 182 patients with advanced (FIGO Stage IIB, III or IV) OTP cancer underwent interval cytoreductive surgery. Of these, 92 (50.5%) had no macroscopic residual cancer (Figure 31; CQI 6a), and 64 (35.2%) had macroscopic residual cancer which was less than 1cm in size (Figure 32; CQI 6b). Patients who underwent surgery for recurrent or progressive disease were excluded from this analysis, as well as patients who did not have surgery at a collaborating NGOR hospital. 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. For both CQI 6a and 6b, the ability to achieve no residual cancer, or less than 1cm of residual cancer, may depend on the patients' age, cancer stage, and/or comorbidities. No specific risk-factor(s) had a statistically significant impact on the result for CQI 6a or 6b.

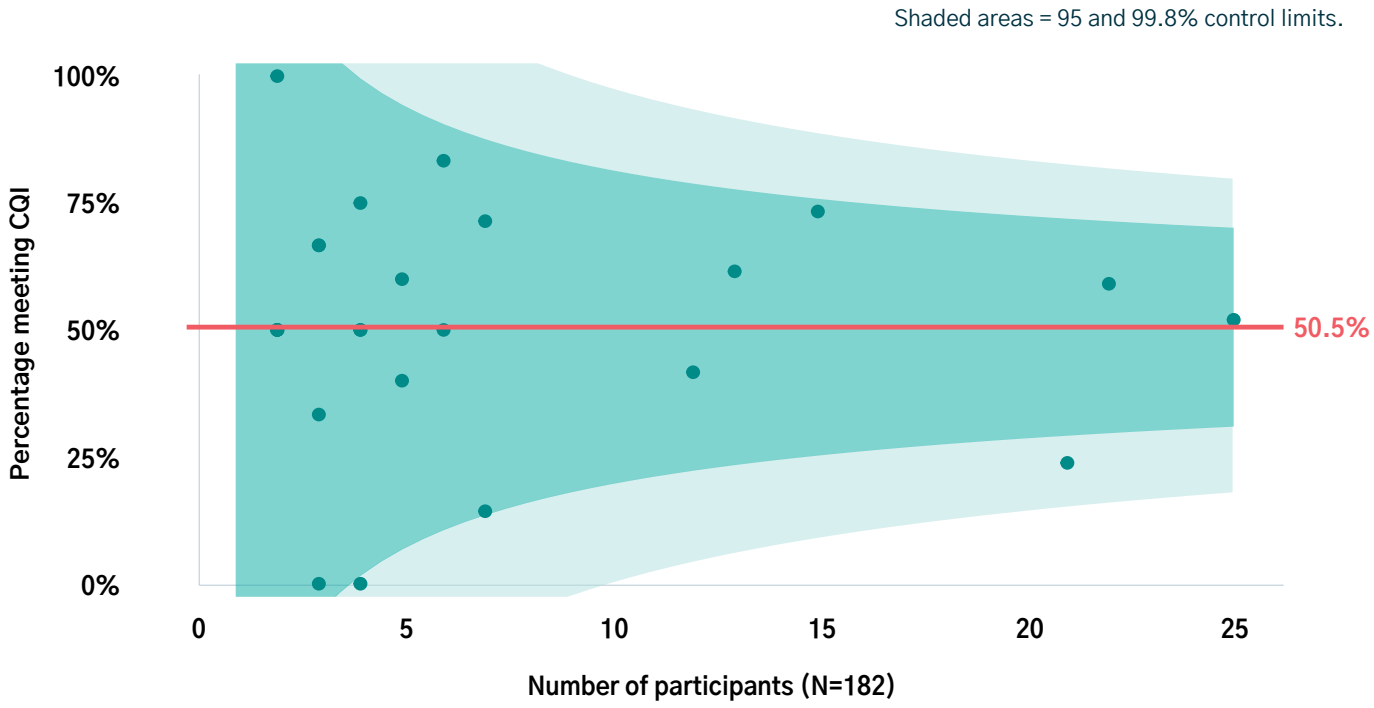


Figure 31: CQI #6a.

Proportion of patients with advanced OTP cancer who underwent interval cytoreductive surgery and had no macroscopic residual cancer. No specific risk-factors had a statistically significant impact on the outcome for CQI 6a. There was missing data for 8 patients for this CQI.

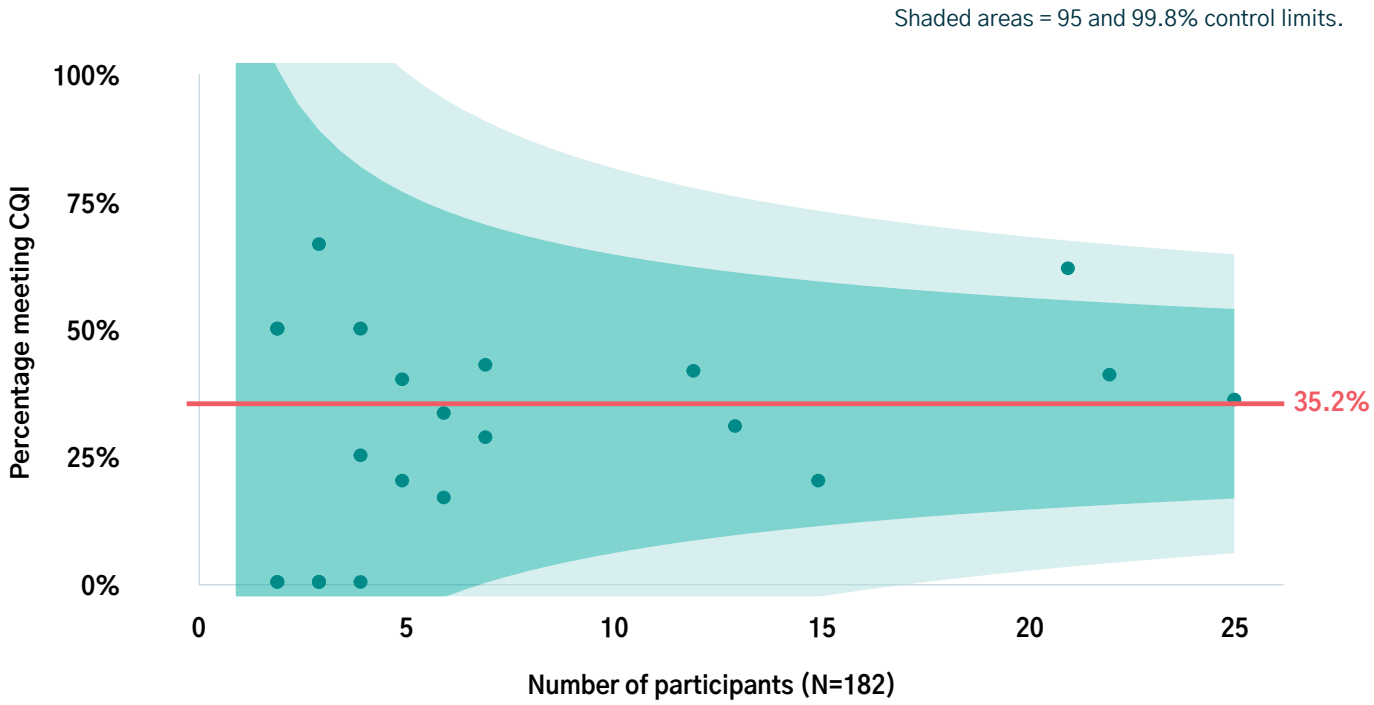


Figure 32: CQI #6b.

Proportion of patients with advanced OTP cancer who underwent interval cytoreductive surgery and had <1cm of macroscopic residual cancer. No specific risk–factors had a statistically significant impact on the outcome for CQI 6b. There was missing data for 8 patients for this CQI.

CQI 7: Proportion of patients who undergo surgery for OTP cancer and have at least one unplanned intraoperative event

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, 6.1% of patients undergoing surgery for OTP cancer experienced at least one unplanned intraoperative event (Figure 33). Patients who did not have surgery at a collaborating NGOR hospital are excluded from this analysis. For CQI 7, the occurrence of intraoperative events may depend on the patients' age, cancer stage, and/or comorbidities. No specific risk-factor(s) had a statistically significant impact on the result for CQI 7. Figure 34 shows the distribution for the type of unplanned intraoperative event recorded.

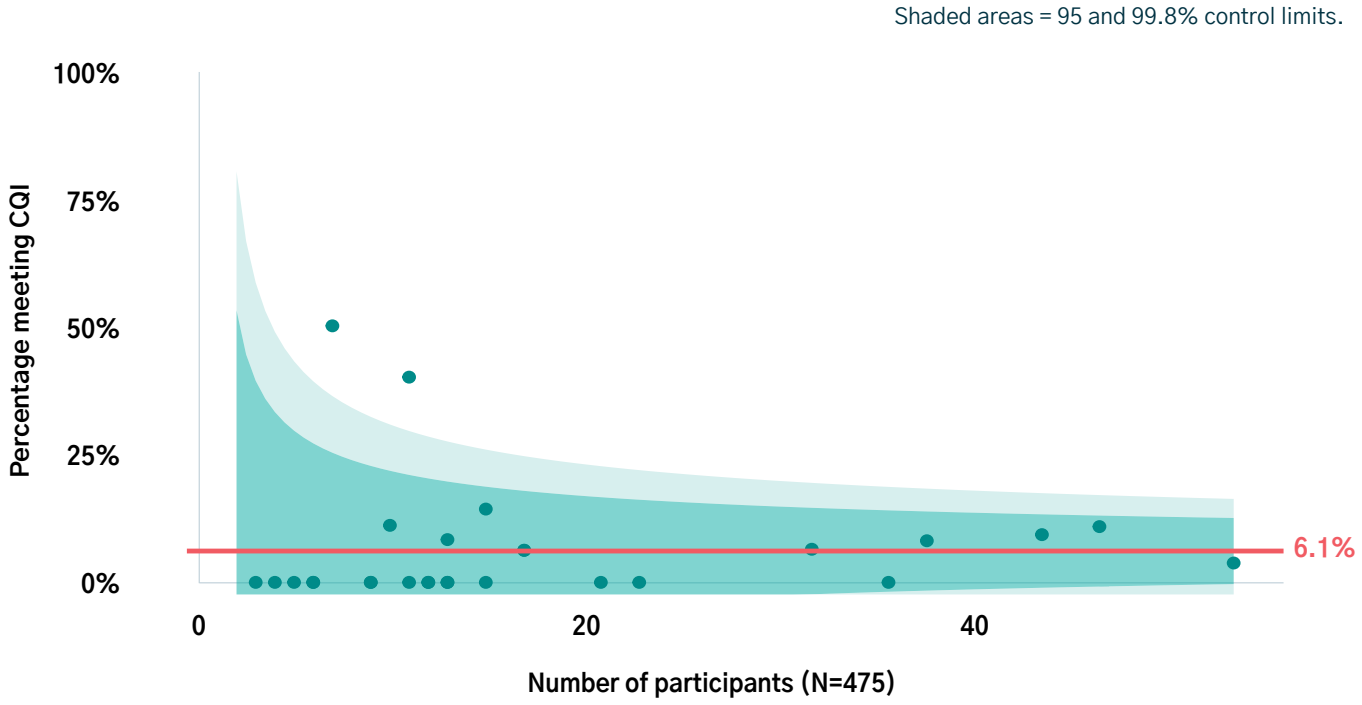


Figure 33: CQI #7.

Proportion of patients undergoing primary or interval surgery for OTP cancer who experienced one or more unplanned intraoperative events. No specific risk-factors had a statistically significant impact on the outcome for CQI 7. There was missing data for 4 patients for this CQI.

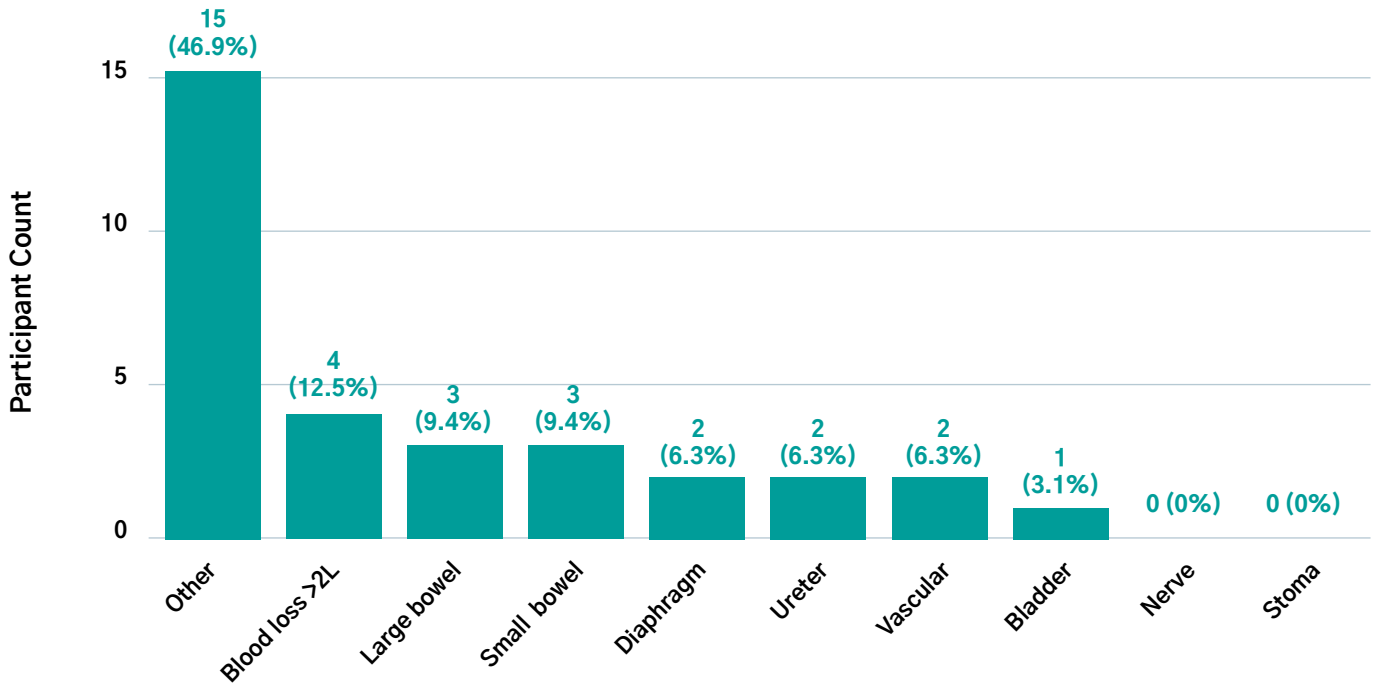


Figure 34: Intraoperative events.

Distribution for the type of unplanned intraoperative events experienced. 'Other' intraoperative events includes a ruptured mass/cyst, pericardial arrest, etc.

CQI 8: Proportion of patients with OTP cancer who experience one or more serious (Clavien–Dindo ≥ III) adverse events during the first 30 days after surgery for OTP cancer

The Clavien–Dindo Classification system[27] 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 postoperative adverse event that requires surgical, endoscopic or radiological intervention. During the reporting period, 4.2% of patients experienced one or more serious (Clavien–Dindo Grade III–V) adverse events during the first 30 days after primary or interval surgery for OTP cancer (Figure 35). Patients who did not have surgery at a collaborating NGOR hospital were excluded from this analysis. For this CQI, the occurrence of postoperative 30–day adverse events may depend on the patients' age, cancer stage, and/or comorbidities. However, no specific risk–factor(s) had a statistically significant impact on the result for CQI 8. Figure 36 shows the distribution for the type and severity of serious postoperative 30–day adverse events recorded.

Shaded areas = 95 and 99.8% control limits.

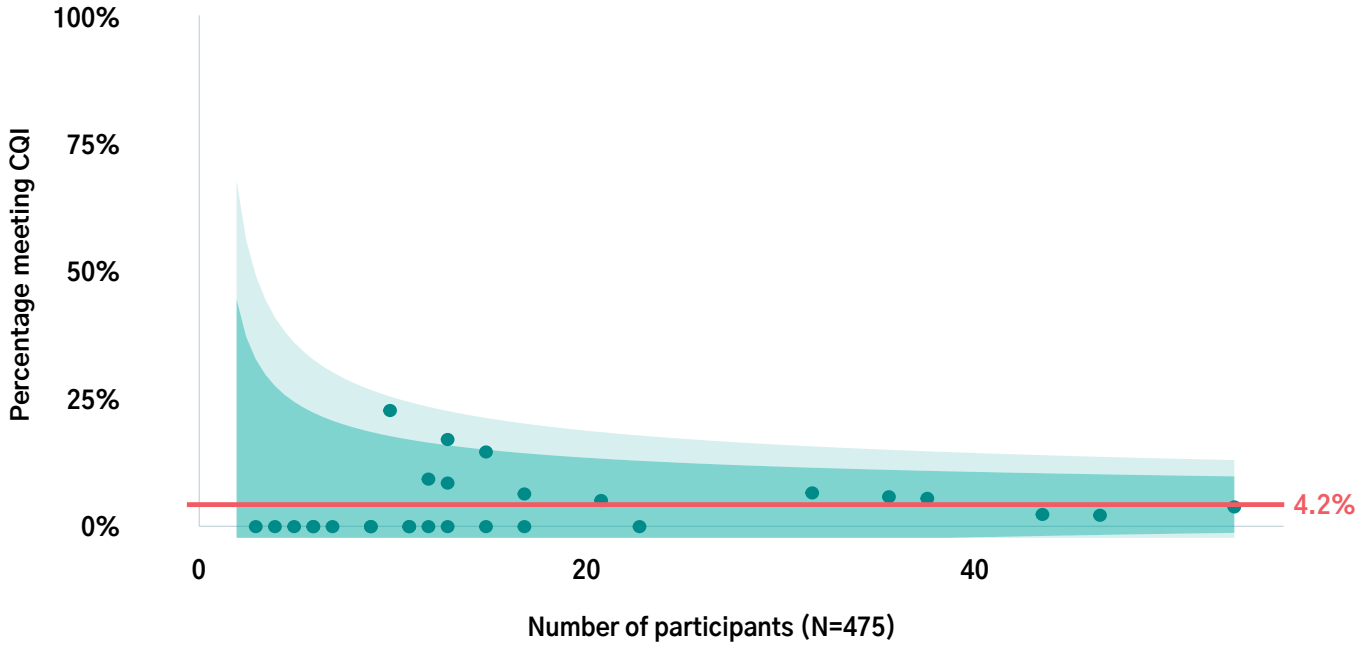


Figure 35: CQI #8.

Proportion of patients who experienced one or more serious adverse events which had Clavien–Dindo ≥ Grade III severity during the first 30 days after surgery for OTP cancer. No specific risk–factors had a statistically significant impact on the outcome for CQI 8. There was missing data for 29 patients for this CQI.

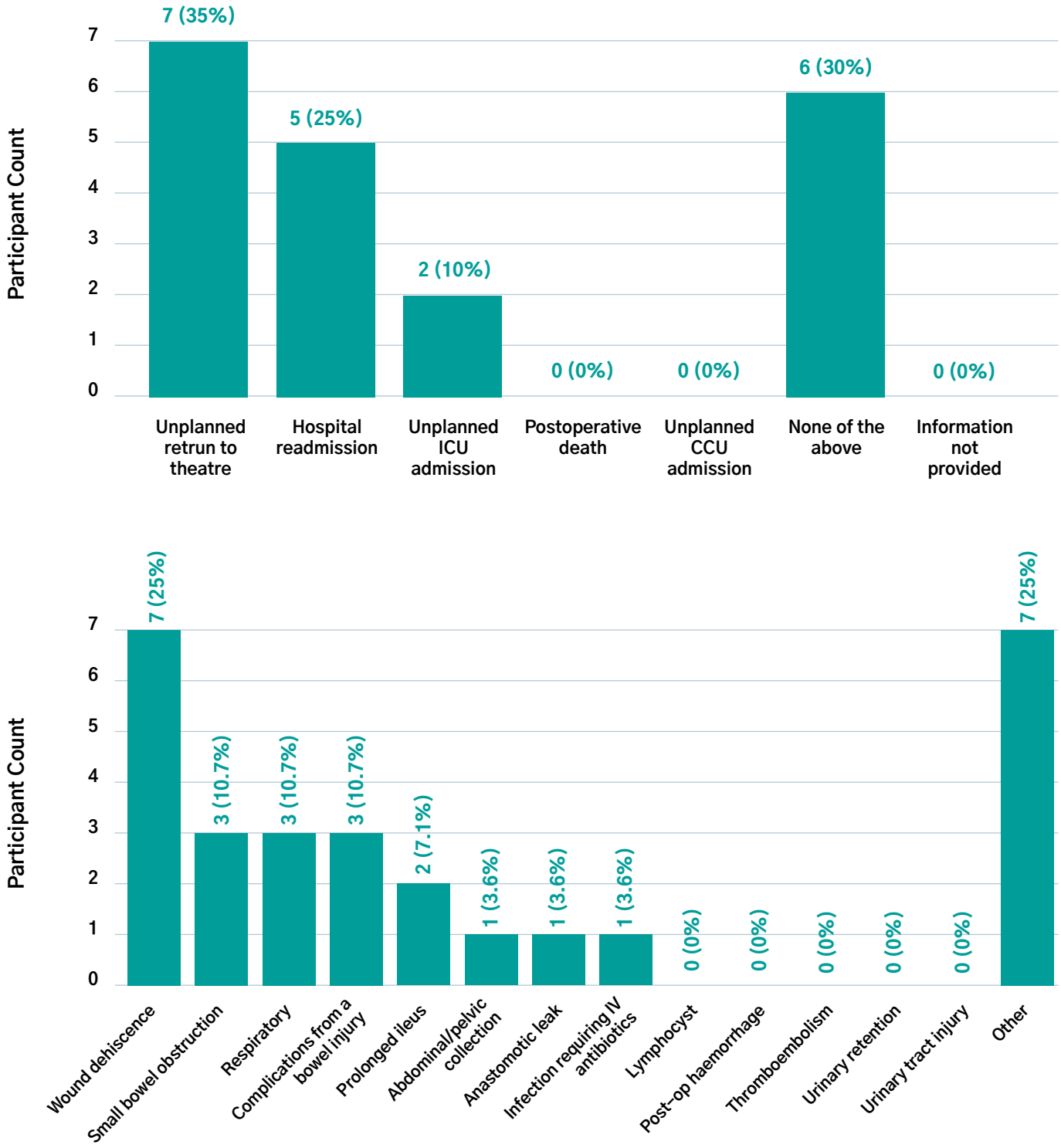


Figure 36: Postoperative 30-day adverse events.

Distribution for the type and severity of serious postoperative 30-day adverse events experienced. 'Other' postoperative events include pleural effusion, ureteric obstruction, etc.

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 subtype, the decision regarding which chemotherapy regimen to use often depends on patient factors, such as general health and disease progression. For epithelial ovarian cancer, chemotherapy often involves the administration of two different types of drugs as a 'doublet'; the platinum–taxane doublet being a key part of initial treatment[28]. Given the importance of chemotherapy in effective ovarian cancer treatment, patterns of 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 37–39.

Missing data for these CQIs may reflect patients who received chemotherapy at a hospital that is not a collaborating NGOR hospital. It is common for patients to receive chemotherapy at a different hospital, e.g. regional or rural patients may have their surgery performed at a metropolitan hospital, but receive chemotherapy at a hospital or other health service that is local to them.

CQI 10: Proportion of patients with OTP cancer who recieved first–line chemotherapy with a platinum–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[29], this should include a platinum compound, which can be in the form of a doublet with a taxane. During the reporting period, 87.5% of patients with OTP cancer received first–line chemotherapy with a platinum–taxane doublet (Figure 37). 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. For this CQI, older patients, or those with severe comorbidities may only be given single–agent chemotherapy due to side–effect burden. No specific risk–factor(s) had a statistically significant impact on this result for CQI 10.

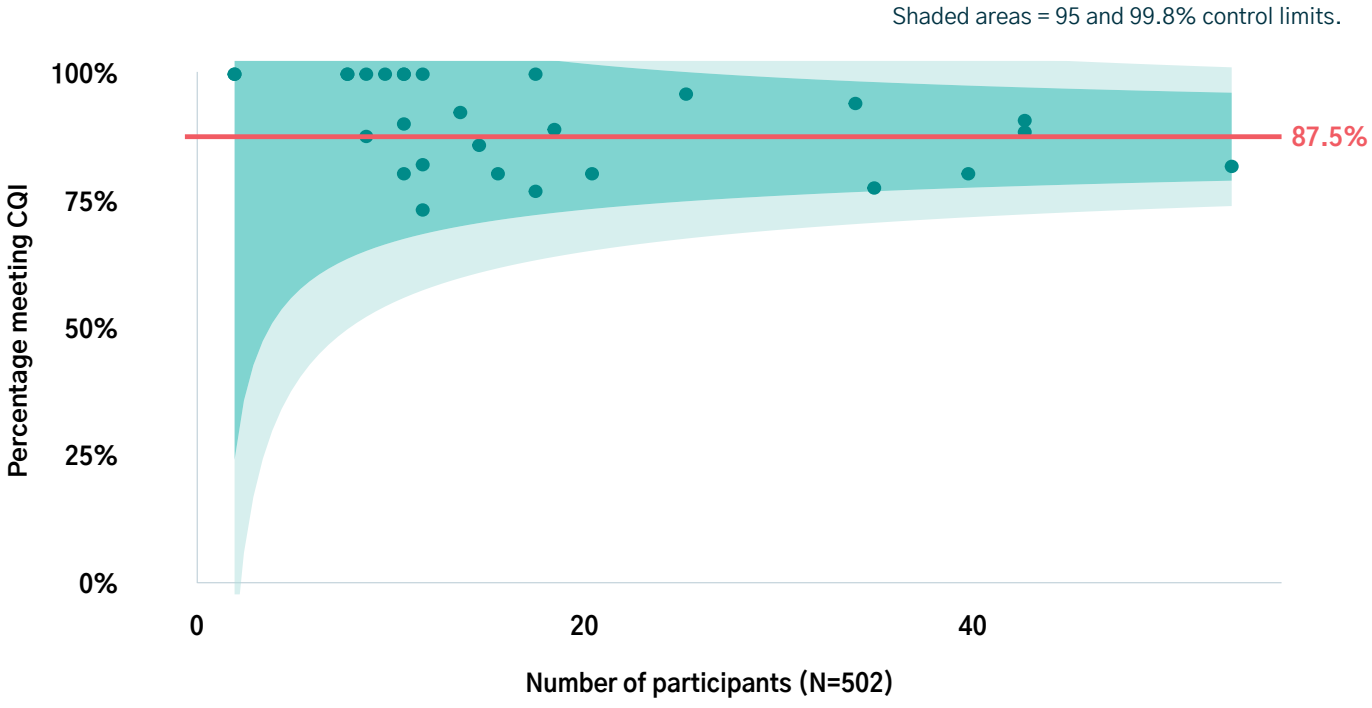


Figure 37: CQI #10.

Proportion of patients with OTP cancer who received first–line chemotherapy with a platinum–taxane doublet. No specific risk–factors had a statistically significant impact on the outcome for CQI 10. There was missing data for 15 patients for this CQI.

CQI 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

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 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-taxane doublet. It is associated with improved patient outcomes[30]. In the reporting period, 42.9% of patients with sub-optimally debulked OTP cancer or Stage IV cancer received first-line (platinum-taxane doublet) chemotherapy as well as bevacizumab (Figure 38). 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. For this CQI, first-line chemotherapy with a platinum-taxane doublet and bevacizumab may be impacted by the patients' age, and the presence of severe comorbidities or postoperative complications, particularly those with bowel involvement. No specific risk-factors had a statistically significant impact on the result for CQI 11.

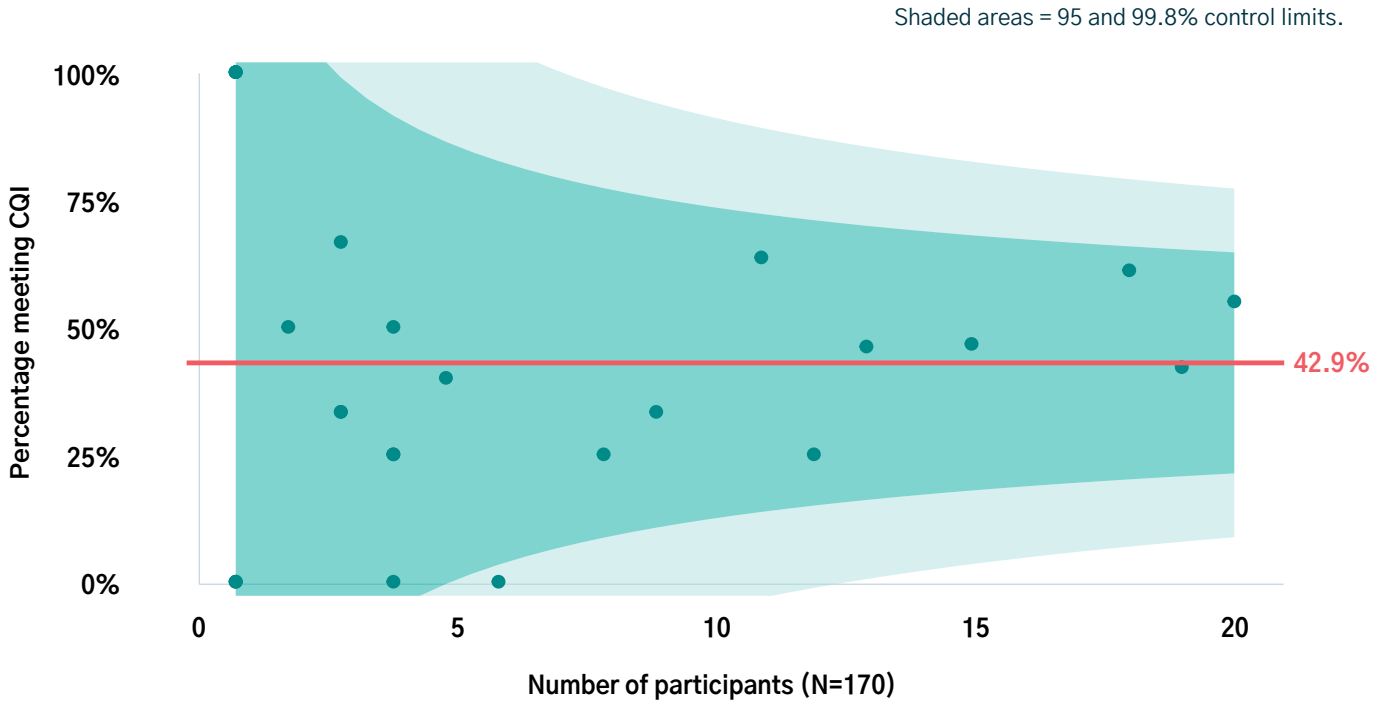


Figure 38: CQI #11.

Proportion of patients with sub-optimally debulked OTP cancer (residual cancer ≥1cm) or Stage IV OTP cancer who received first-line chemotherapy with a platinum-taxane doublet and bevacizumab. No specific risk-factors had a statistically significant impact on the outcome for CQI 11. There was missing data for 5 patients for this CQI.

CQI 12: Proportion of patients with OTP cancer who commence first-line adjuvant chemotherapy within 28 days of surgery, or commence first-line neoadjuvant chemotherapy within 28 days of 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[31–34]. Even in patients with no residual cancer following surgery, delayed initiation of chemotherapy can lead to earlier cancer recurrence[32]. 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[35]. 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[31]. For some Stage III or IV cancers, chemotherapy can be commenced prior to surgery (neoadjuvant chemotherapy), or chemotherapy can be commenced as the only treatment (i.e. no subsequent surgery if, for example, 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[35], as the aim of this approach is to try to shrink the tumour in order to improve surgical outcomes. In the current reporting period, 40.8% of patients with OTP cancer commenced adjuvant chemotherapy within 28 days of surgery (Figure 39; CQI 12a), and 76% of patients with OTP cancer commenced neoadjuvant chemotherapy within 28 days of diagnosis (Figure 40; CQI 12b). Lower averages may indicate the presence of post-surgery complications or slower recovery that results in the delay of adjuvant chemotherapy. For this CQI, the ability for patients to start chemotherapy within 28 days of surgery may depend on patients' age, cancer stage and/or comorbidities, as well as barriers to specialist healthcare access. No specific-risk factor(s) had a statistically significant impact on the result for either CQI 12a or 12b.

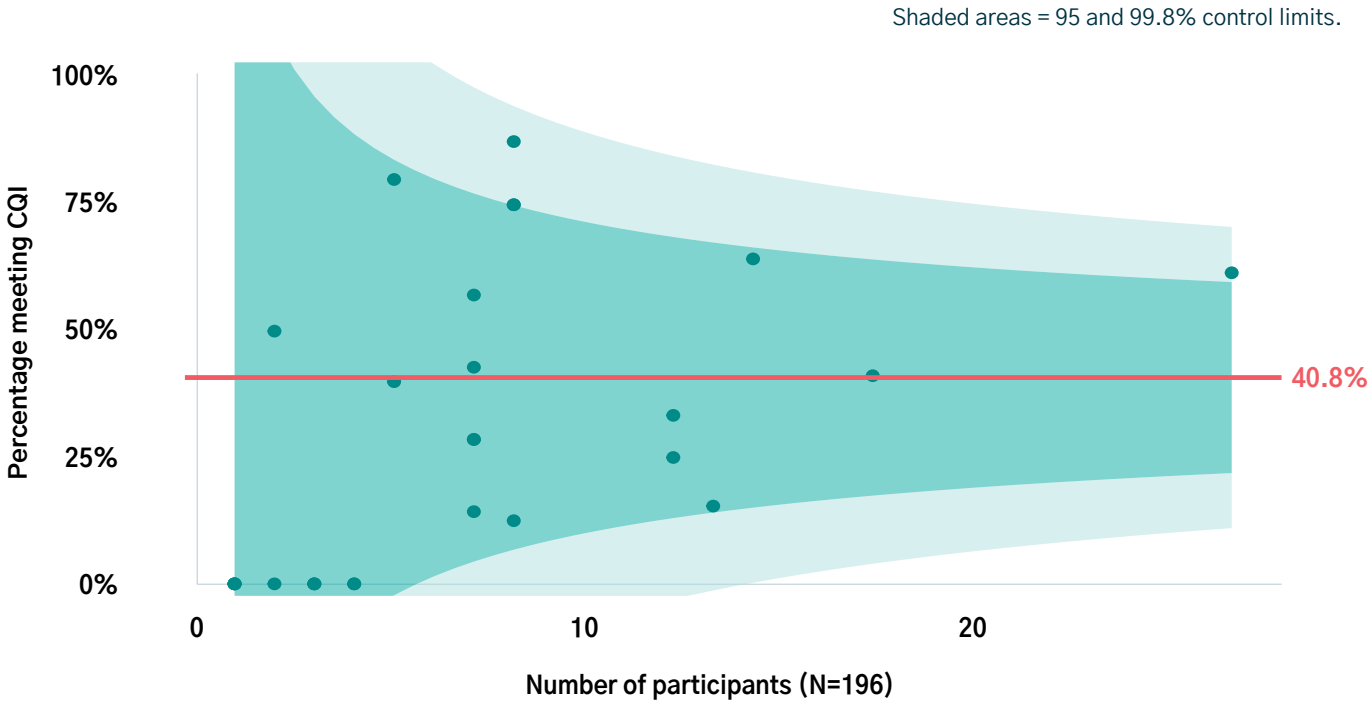


Figure 39: CQI #12a.

Proportion of patients with OTP cancer who commenced first-line adjuvant chemotherapy within 28 days of surgery. No specific risk-factors had a statistically significant impact on the outcome for CQI 12a. There was no missing data for this CQI.

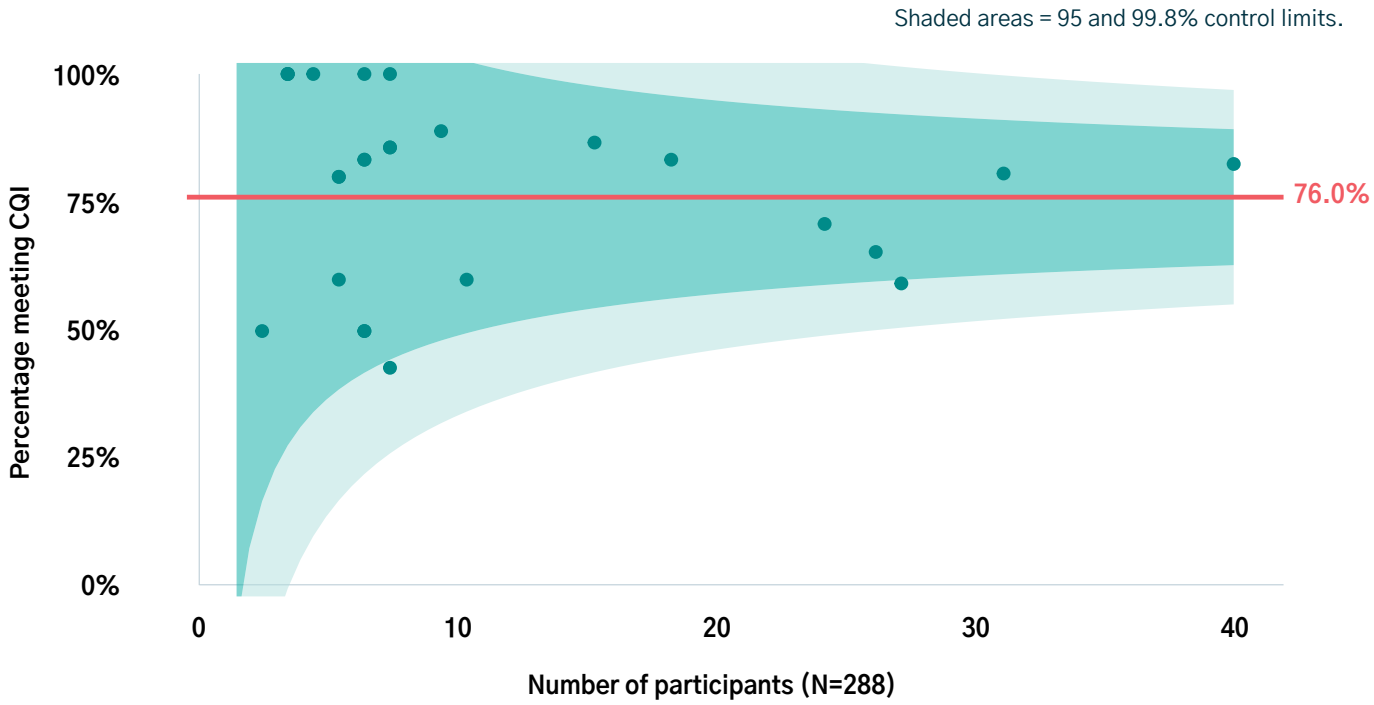


Figure 40: CQI #12b.

Proportion of patients with OTP cancer who commenced first-line neoadjuvant or sole chemotherapy within 28 days of diagnosis. No risk-adjustment was applied. There was no missing data for this CQI.

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[36]. 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 41 and 42.

CQI 13: Proportion of eligible patients who had germline or somatic genetic testing for BRCA1, BRCA2 and other relevant gene mutations

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 those originating from 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 that the risk of developing ovarian cancer is approximately 44% for patients with a BRCA1 mutation, and 17% for patients with a BRCA2 mutation up to the age of 80 years[37]. It is generally recommended that all patients with OTP cancer are offered genetic counselling and testing for BRCA1 and BRCA2 mutations, however, in Australia funding is only available for patients with high grade non–mucinous epithelial cancers[35, 38, 39]. In the current reporting period, 84.7% of eligible patients had germline or somatic testing for genetic mutations (including BRCA1 and BRCA2) prior to completing first–line chemotherapy (Figure 41). A lower average may reflect the inherent difficulty in capturing these data due to patient confidentiality, as genetic testing information is often difficult to obtain and this information is infrequently fed back to sites. 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. As this CQI applies to all patients in the OTP Cancer Module, no risk–adjustment has been applied.

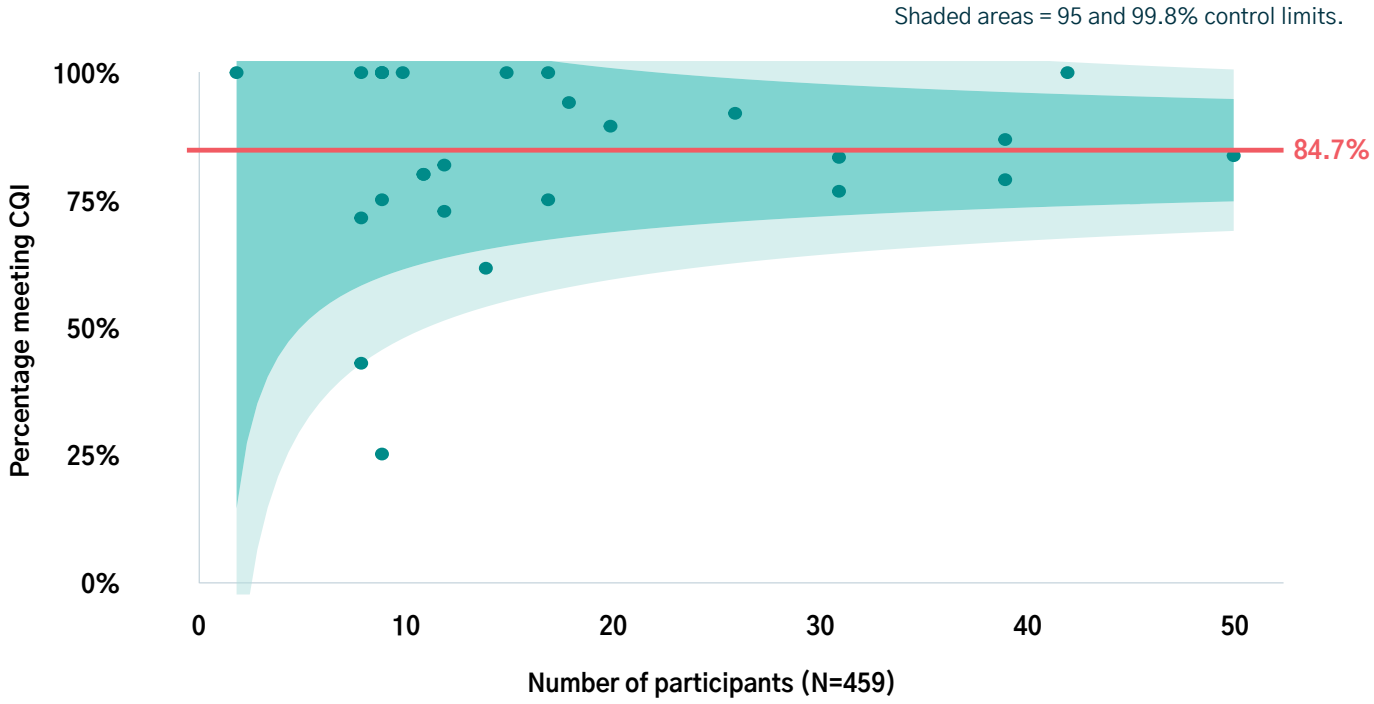


Figure 41: CQI #13.

Proportion of eligible patients who had germline or somatic testing for BRCA1, BRCA2 and other relevant mutations before completing first–line chemotherapy. No risk–adjustment was applied. There was missing data for 7 patients for this CQI.

CQI 14: Proportion of patients with pathogenic germline or somatic genetic mutations of BRCA1 or BRCA2 who commence maintenance PARPi therapy within 8 weeks of ceasing first-line chemotherapy

PARP inhibitors (PARPi) target gene mutations in BRCA1 and BRCA2. If tumour cells possess a mutated BRCA gene, PARPi therapy can further prevent or slow DNA repair within cells, which can ultimately lead to tumour cell death[40]. Therefore, PARPi are typically only prescribed to patients with a known BRCA mutation. 'Maintenance treatment' refers to the administration of PARPi once chemotherapy has finished; it has been recommended that the interval between cessation of chemotherapy and commencement of PARPi is no longer than eight weeks[41]. In the current reporting period, 66.7% of patients with BRCA1 or BRCA2 germline or somatic mutations commenced maintenance PARPi treatment within eight weeks of ceasing first-line chemotherapy (Figure 42). 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, or patients that received PARPi therapy after the 8-week timeframe. As this CQI applies to all patients in the OTP Cancer Module, no risk-adjustment has been applied.

Shaded areas = 95 and 99.8% control limits.

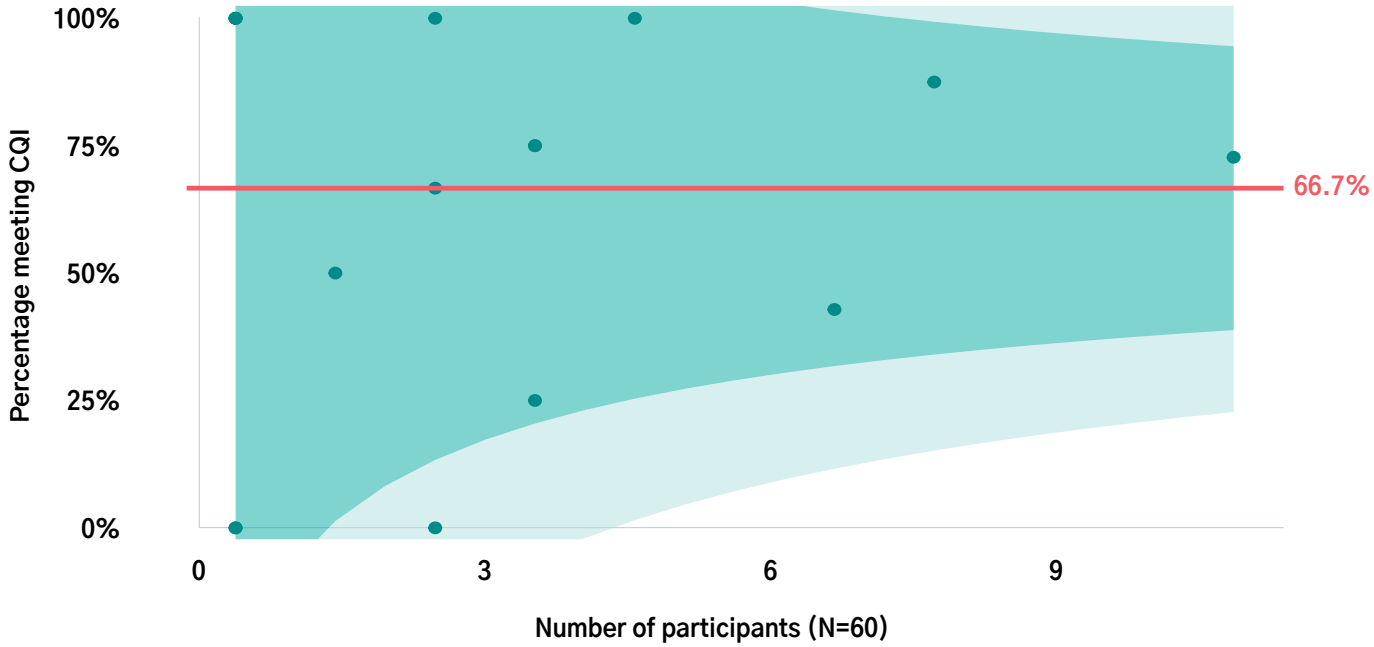


Figure 42: CQI #14.

Proportion of patients with germline or somatic mutations of BRCA1 or BRCA2 who commenced maintenance PARPi therapy within eight weeks of ceasing first-line chemotherapy. No risk-adjustment was applied. There was missing data for 7 patients for this CQI.

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.

CQI 15: Proportion of patients with OTP cancer who were 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 bridging the gap between clinical research and basic science. 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, 17.9% of patients with OTP cancer were enrolled in an interventional clinical trial or in translational research (Figure 43). 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 render them ineligible for a trial. Not all hospitals have capacity or resources to conduct research studies as this depends heavily on available funding. 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. There was missing data for 17 patients for this CQI.

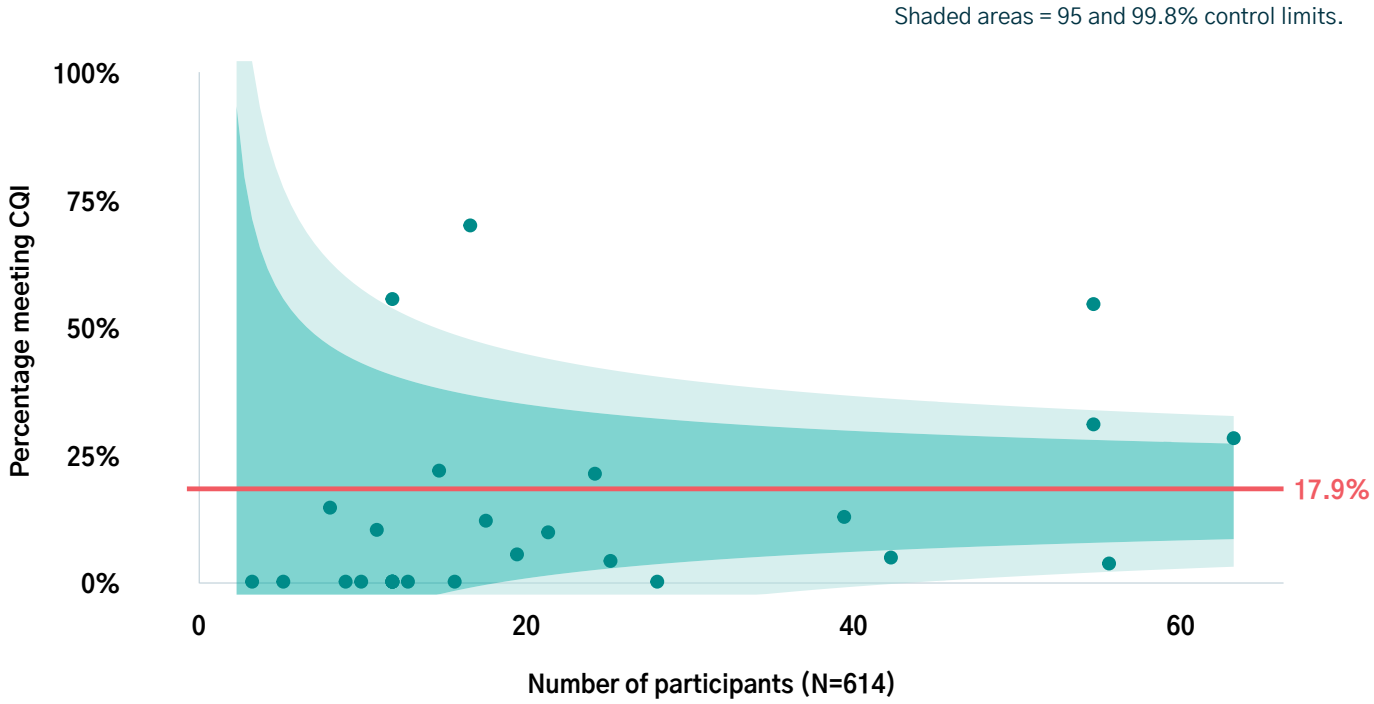


Figure 43: CQI #15.

Proportion of patients enrolled in an interventional clinical trial or translational research during the reporting period. No risk-adjustment was applied. There was missing data for 17 patients for this CQI.

Section II: Rare Ovarian Tumour Module

Overview of the Rare Ovarian Tumour Module

Development of a module for rare ovarian tumours not captured in the OTP Cancer Module occurred in 2017. The 'rare' ovarian tumours included in this module comprise primarily of non-epithelial ovarian tumours, as well as some extremely rare ovarian carcinomas (e.g. small cell), which have treatment patterns largely distinct from the more common epithelial subtypes. These tumours together comprise approximately 10% of ovarian malignancies43. The Rare Ovarian Tumour Module intends to capture cancerous cases; however, some rare tumours with suspected malignancy or uncertain malignant potential are also included.

Cases in the Rare Ovarian Tumour Module are broadly grouped into five histological classifications:

1. Ovarian sex cord-stromal tumours, which include adult granulosa cell tumours, juvenile granulosa cell tumours and Sertoli-Leydig cell tumours. Adult granulosa cell tumours comprise approximately half of the cancers included in this module, whilst the juvenile variant is much less common and usually diagnosed before the age of 18 years44. As a result, most patients diagnosed with the juvenile variant are excluded from the NGOR, due to eligibility criteria requiring participants to be aged at least 18 years at diagnosis.
2. Malignant ovarian germ cell tumours, which include dysgerminomas, yolk sac tumours and immature teratomas, and are usually diagnosed before the age of 3045.
3. Cancerised mature teratoma of the ovary, which occur when a benign cystic teratoma undergoes a malignant transformation. This is an uncommon occurrence and results in the development of a squamous cell carcinoma in most cases46.
4. Neuroendocrine tumours of the ovary, which can be further divided into poorly differentiated carcinomas and well-differentiated neuroendocrine tumours, also known as carcinoids47.
5. Miscellaneous malignant ovarian tumours that do not fit into any of the above categories. These include small cell carcinoma of the ovary hypercalcaemic type, ovarian sarcomas (excluding carcinosarcomas) and malignant Wolffian tumours of the ovary. Carcinosarcomas, clear cell carcinomas, mucinous carcinomas and malignant Brenner tumours are included in the OTP Cancer Module.

Due to the heterogeneity of tumour subtypes included in the Rare Ovarian Tumour Module, and the variation in treatment patterns between them, developing comprehensive and appropriate CQIs has been challenging, particularly given the absence of current data on patterns of care for these tumours in an Australian context. Because of this, a decision was made to collect pilot data for patients diagnosed from 2017 to 2022 for the Rare Ovarian Tumour Module using a 'minimum data set'. The pilot data collected was used to guide the development of four CQIs. Given these data are still preliminary, only descriptive data will be presented in this report, however future reports will provide data relevant to each CQI, similar to that reported for the OTP Cancer Module.

Participant Recruitment

Of the 33 partnering hospitals, 20 provided data for patients diagnosed with a rare ovarian tumour within the reporting period, with a total of 253 participants identified as potentially eligible for inclusion into the Rare Ovarian Tumour Module. Of these, 25 were later determined to be ineligible, five fully opted–out of the registry, three were reallocated to a different registry module (e.g. the OTP Cancer Module), and one was a duplicate of another patient already included in the registry. This resulted in an overall total of 219 eligible and included participants in the Rare Ovarian Tumour Module (Figures 44 and 45).

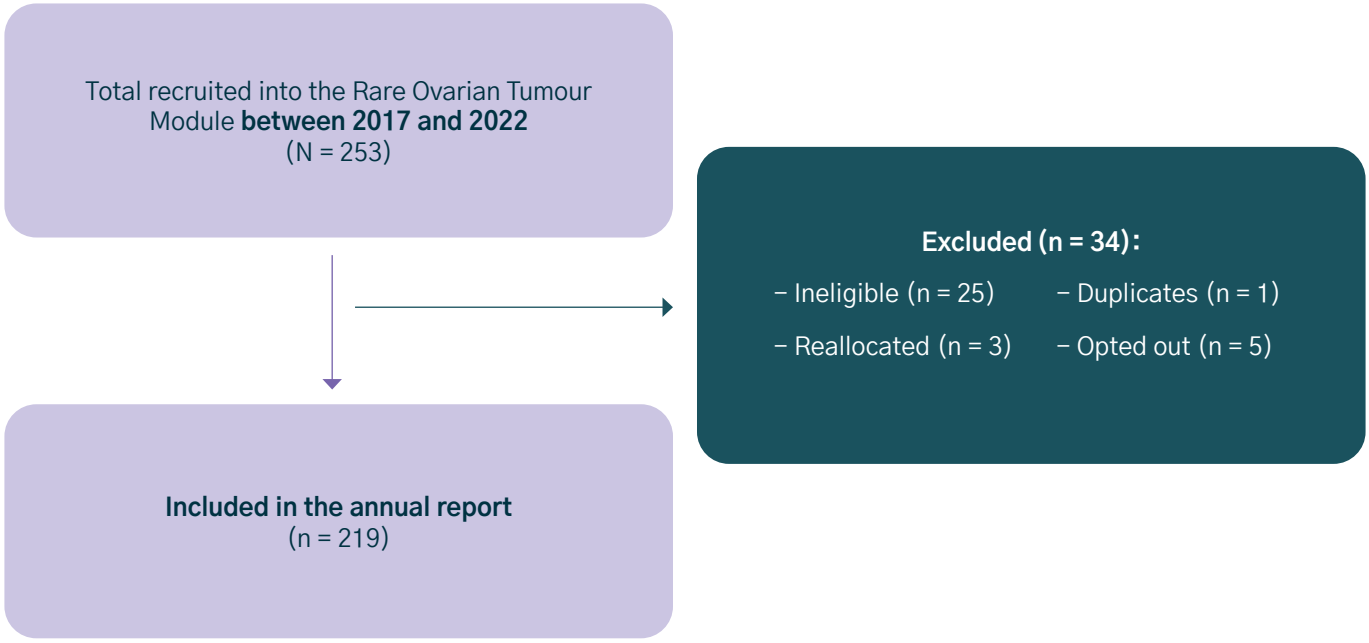


Figure 44: NGOR patient recruitment flowchart for the Rare Ovarian Tumour Module.

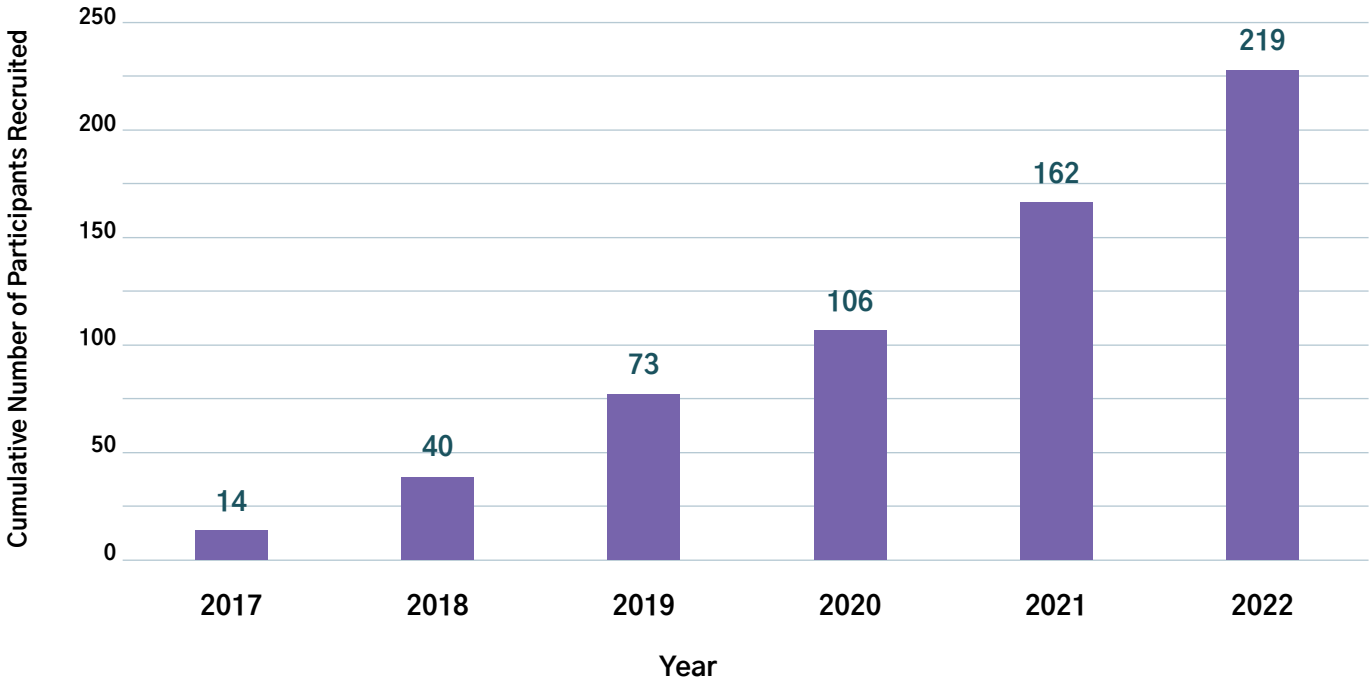


Figure 45: Cumulative number of patients included (N = 219) in the Rare Ovarian Tumour Module between April 2017 and December 2022

As with the OTP Cancer Module, all patients were given a period of two weeks to opt-out of the registry. On average, 1.82% (5 patients) elected to fully opt-out of the Rare Ovarian Tumour Module during 2017–2022, while 1.23% (3 patients) elected to partially opt-out during this same period. Figure 46 shows the participant opt-out statistics for 2017–2022.

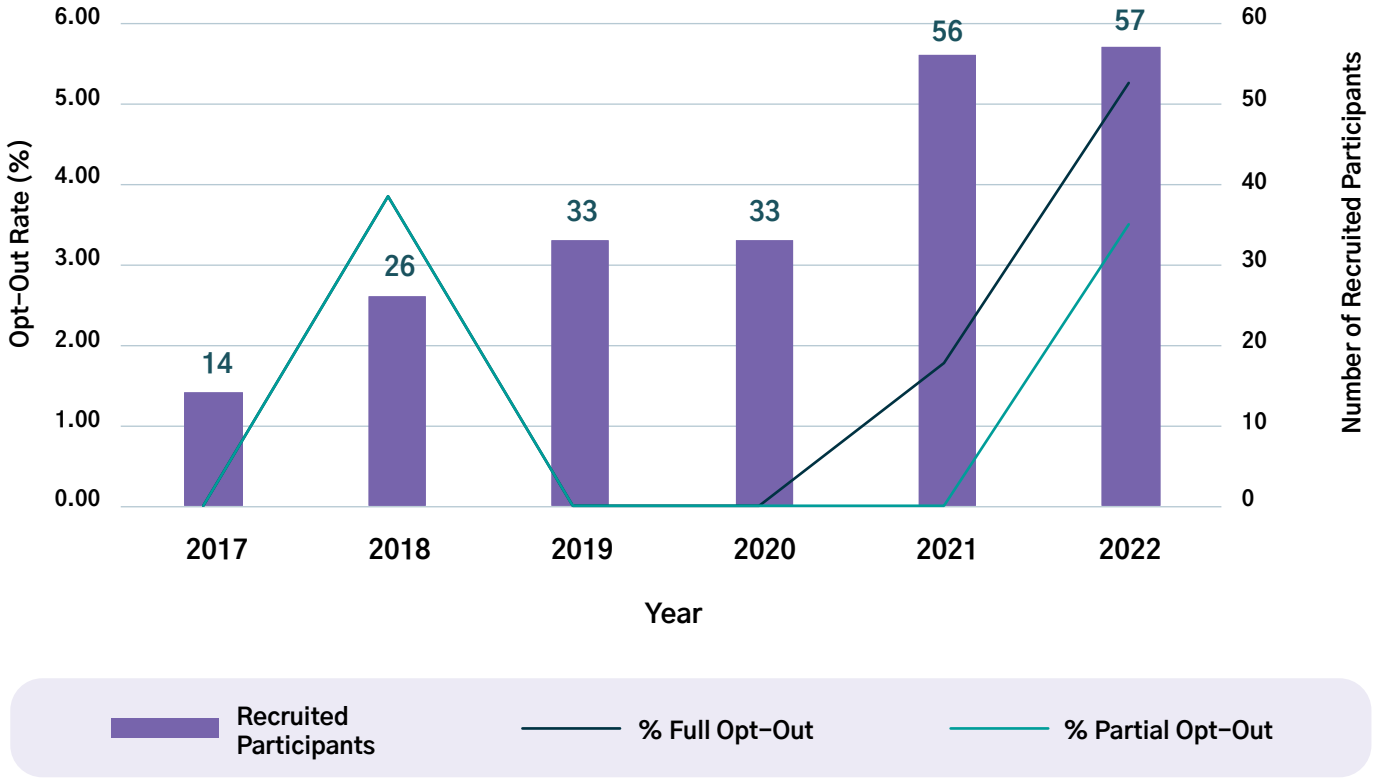


Figure 46: Participant yearly opt-out rates displayed as a percentage of the number of participants diagnosed in each year, from 2017–2022 for the Rare Ovarian Tumour Module.

Descriptive Statistics

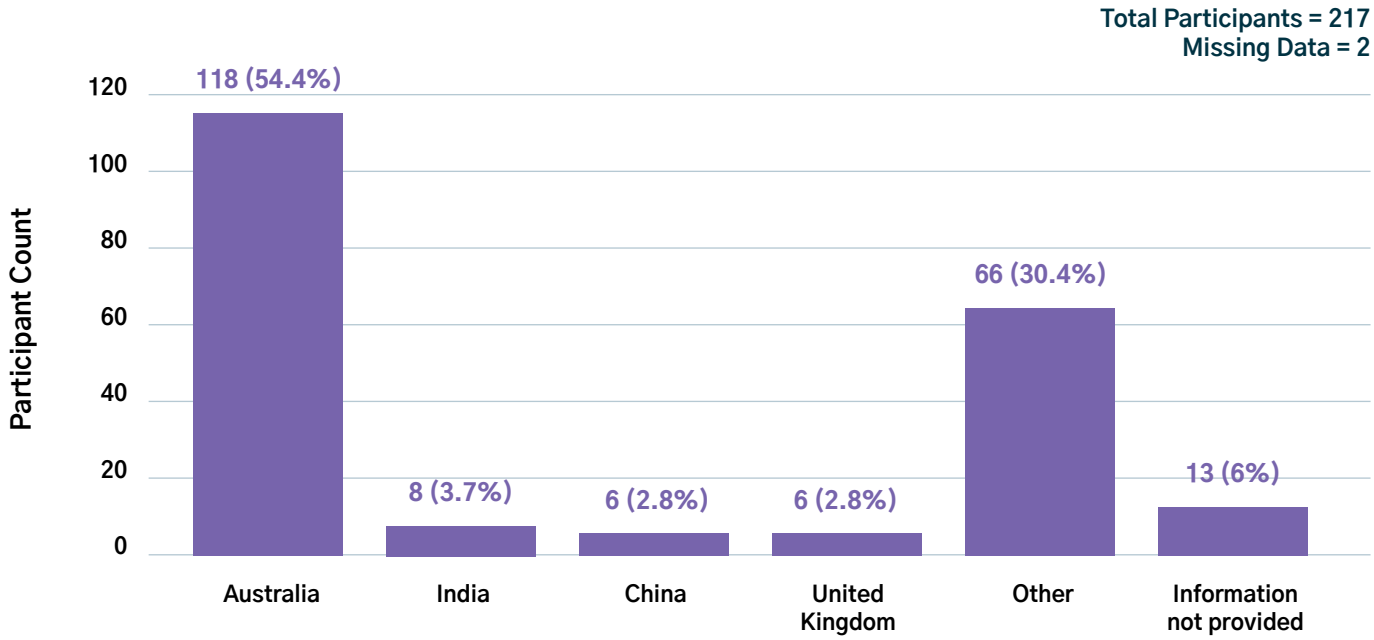


Figure 47: Country of birth.

Distribution of country of birth for patients diagnosed between 2017 and 2022. Countries with fewer than five patients represented are shown in the 'other' category.

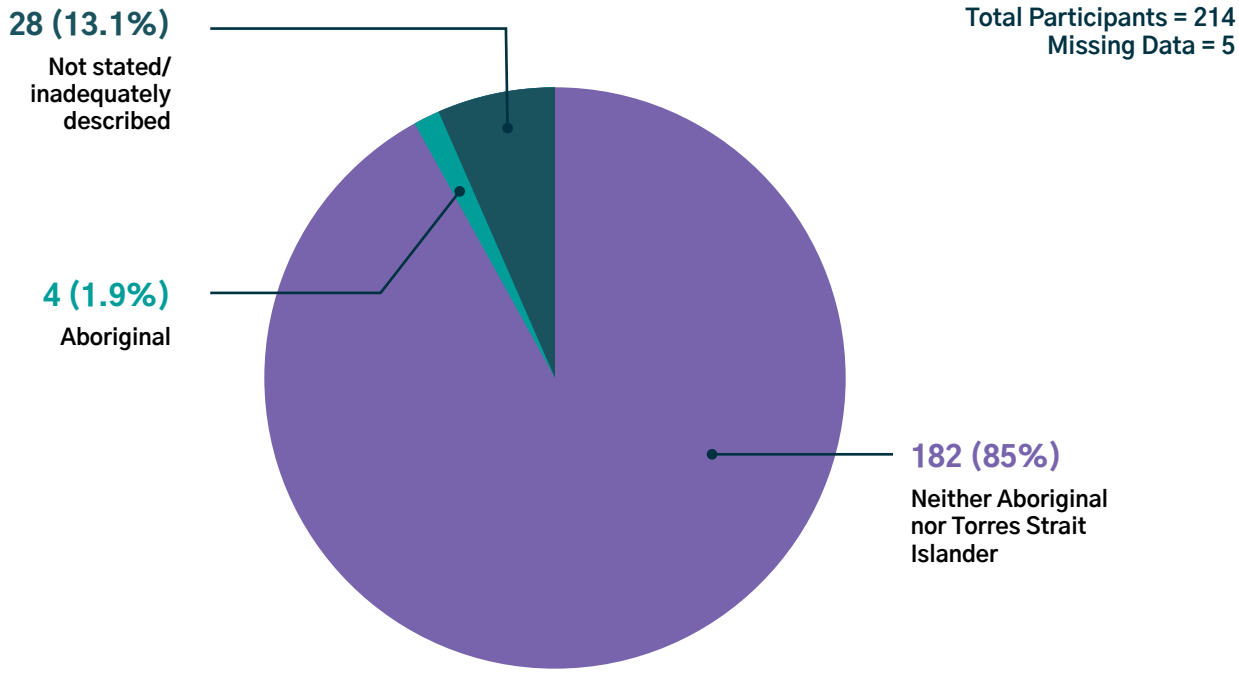


Figure 48: Aboriginal or Torres Strait Islander Status.

Distribution of Aboriginal or Torres Strait Islander status for patients diagnosed between 2017 and 2022. During the reporting period, no patients were identified as Torres Strait Islander only in their hospital medical record.

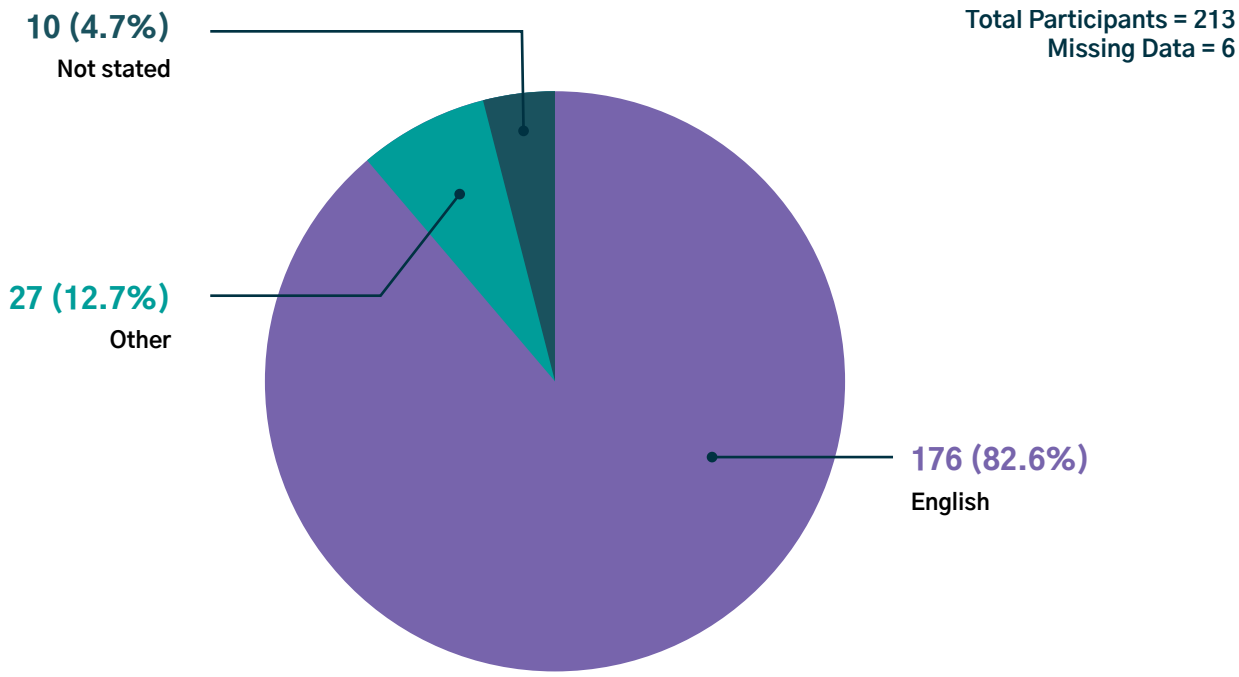


Figure 49: Preferred language.

Distribution of patient's preferred language for patients diagnosed between 2017 and 2022. Languages with fewer than five patients represented are shown in the 'other' category. 'Not stated' refers to the information not being recorded or easily accessible in the patient's medical record.

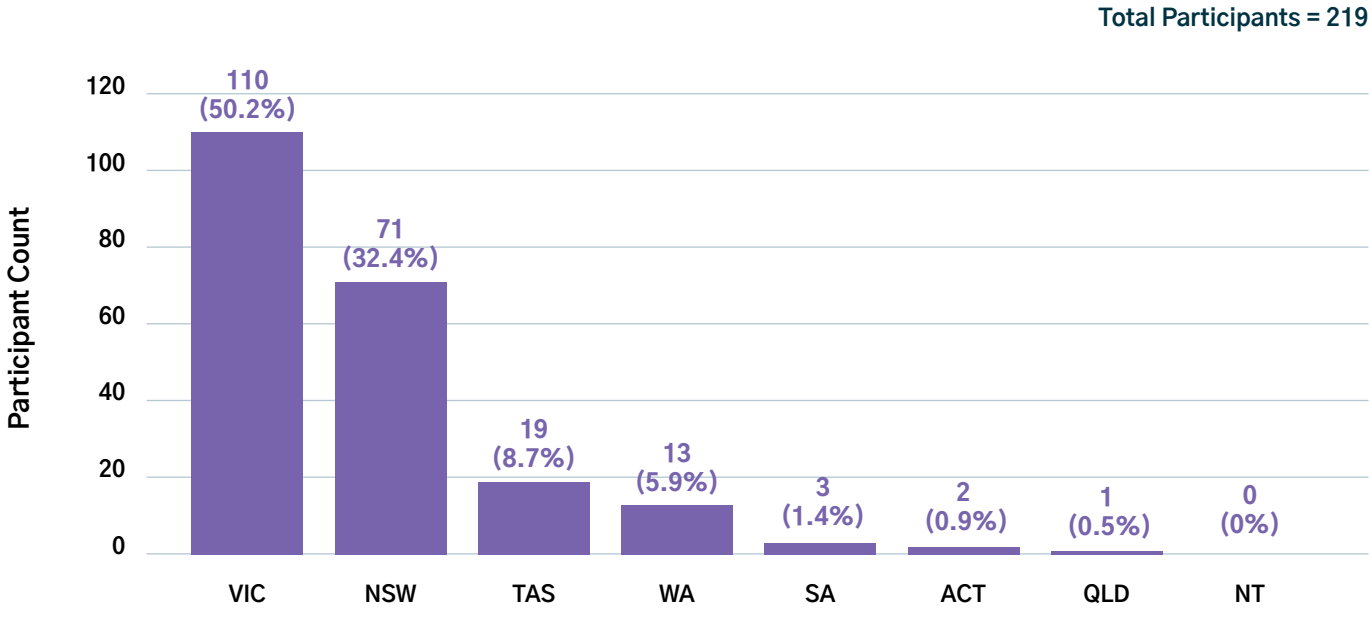


Figure 50: Residential distribution.

Distribution of participant residential location at the time of diagnosis, across Australia for patients recruited between 2017 and 2022.

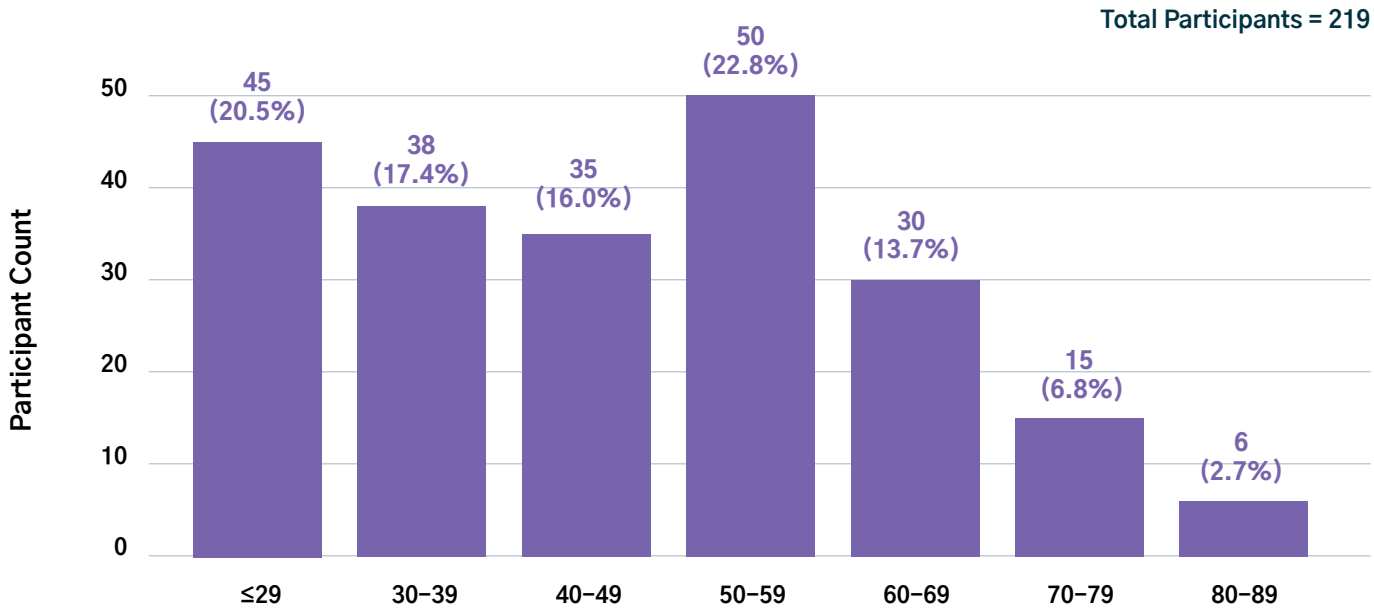


Figure 51: Participant age at diagnosis.

Distribution of the participants' age at diagnosis for patients diagnosed between 2017 and 2022.

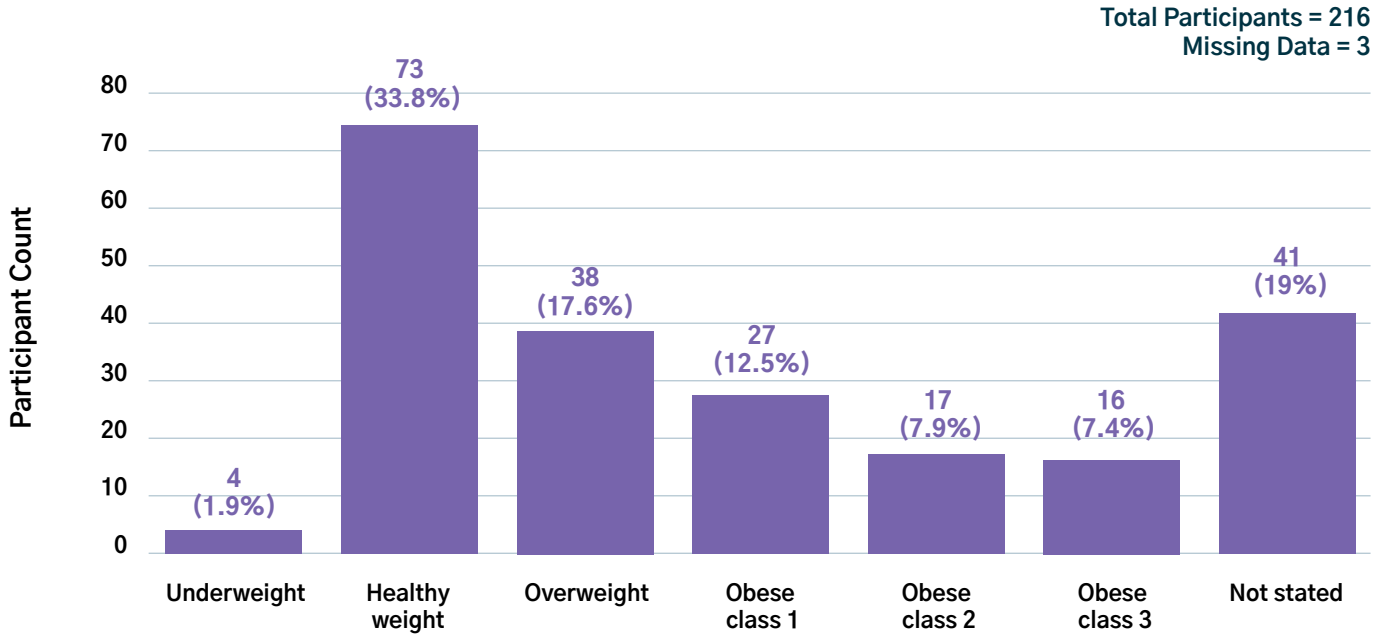


Figure 52: Participant body mass index (BMI).

Distribution of the participants' BMI at the time of diagnosis for patients diagnosed between 2017 and 2022. The classification of 'not stated' indicates that there was no information on the patient's weight or BMI score in their medical record. BMI scores of <18.5 = underweight; 18.5–24.99 = healthy weight; 25–29.99 = overweight; 30–34.99 = obese class 1; 35–39.99 = obese class 2; ≥40 = obese class 3.

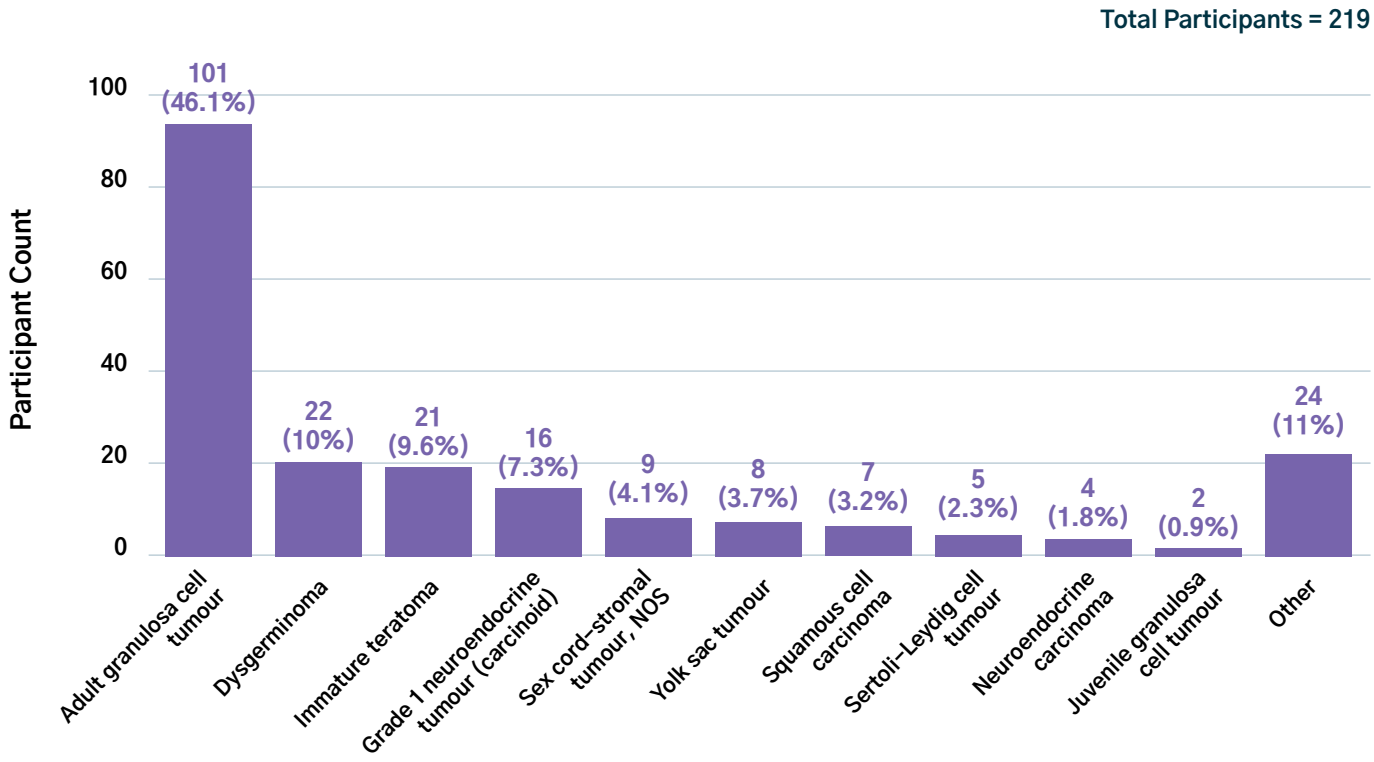


Figure 53: Cancer morphology.

The above graph shows the cancer tissue's histopathological type or classification, for patients diagnosed between 2017 and 2022. All cancer cases shown are known or suspected to be malignant. Histopathology reports are collected for all cases in this registry module for validation of the recorded diagnosis. Subtypes with fewer than five cases included in this cohort have been aggregated in the 'Other' category. These diagnoses include Wolffian tumour of the ovary, mixed germ cell tumour, ovarian sarcoma and small cell carcinoma, hypercalcaemic type.

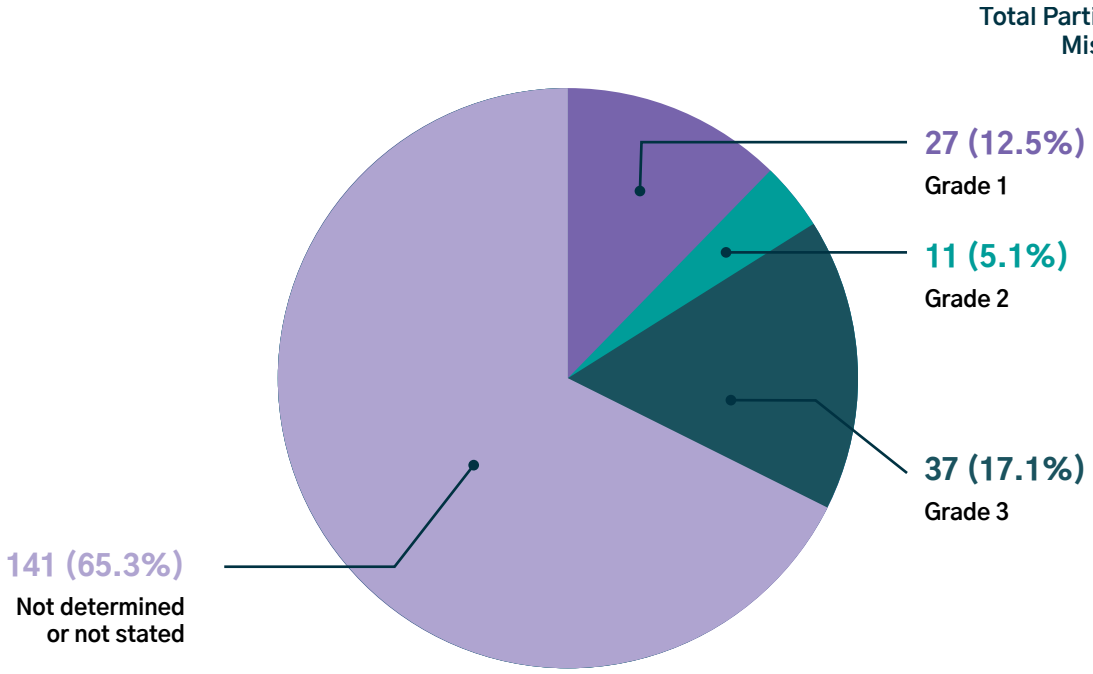


Figure 54: Tumour grade.

The above graph shows the distribution of tumour grades at the time of diagnosis, for patients diagnosed between 2017 and 2022. Tumour grade refers to the level of abnormality of the cells, where higher grades indicate greater abnormality. Many histological subtypes included in this registry module have no associated grading system, including adult granulosa cell tumours which comprise approximately half of the cohort. For this reason, majority of participants have 'Not determined or not stated' selected as their tumour grade.

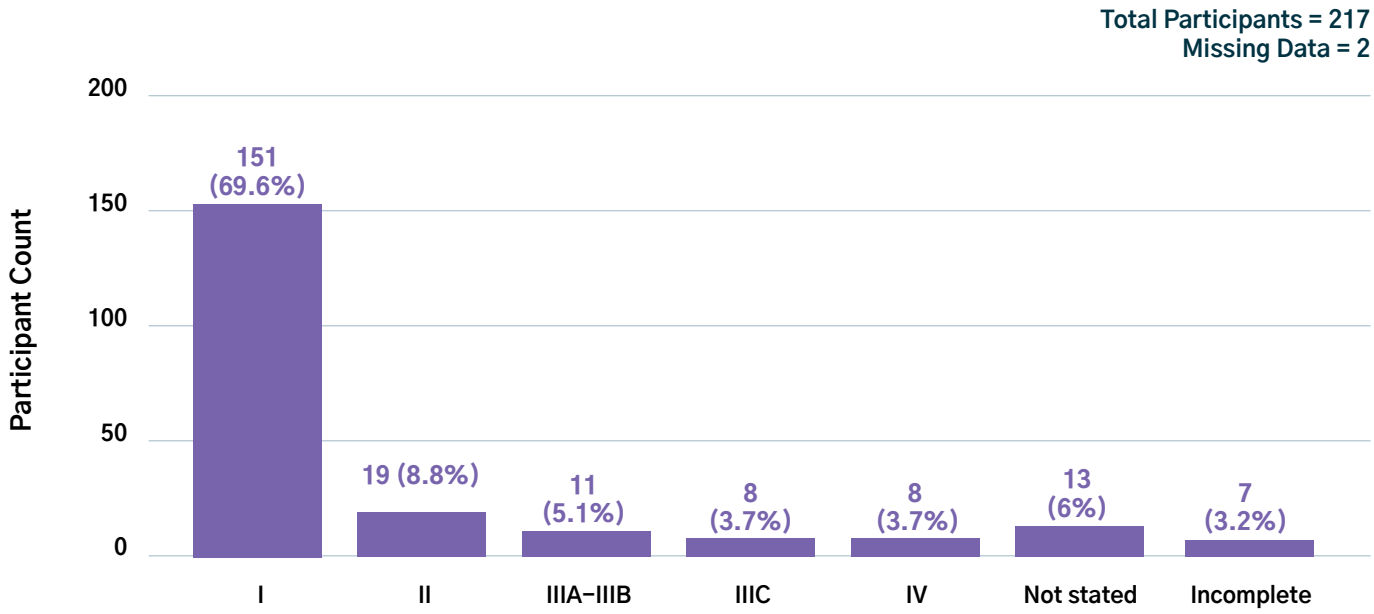


Figure 55: FIGO stage at diagnosis.

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. Data are shown for patients diagnosed between 2017 and 2022. All staging information was obtained at the time of diagnosis. FIGO stage refers to the spread of the tumour, where higher FIGO stages indicate greater tumour spread. The classification of 'incomplete' indicates that FIGO staging may not have been completed due to patients not undergoing staging surgery, or staging was incomplete at the time of diagnosis.

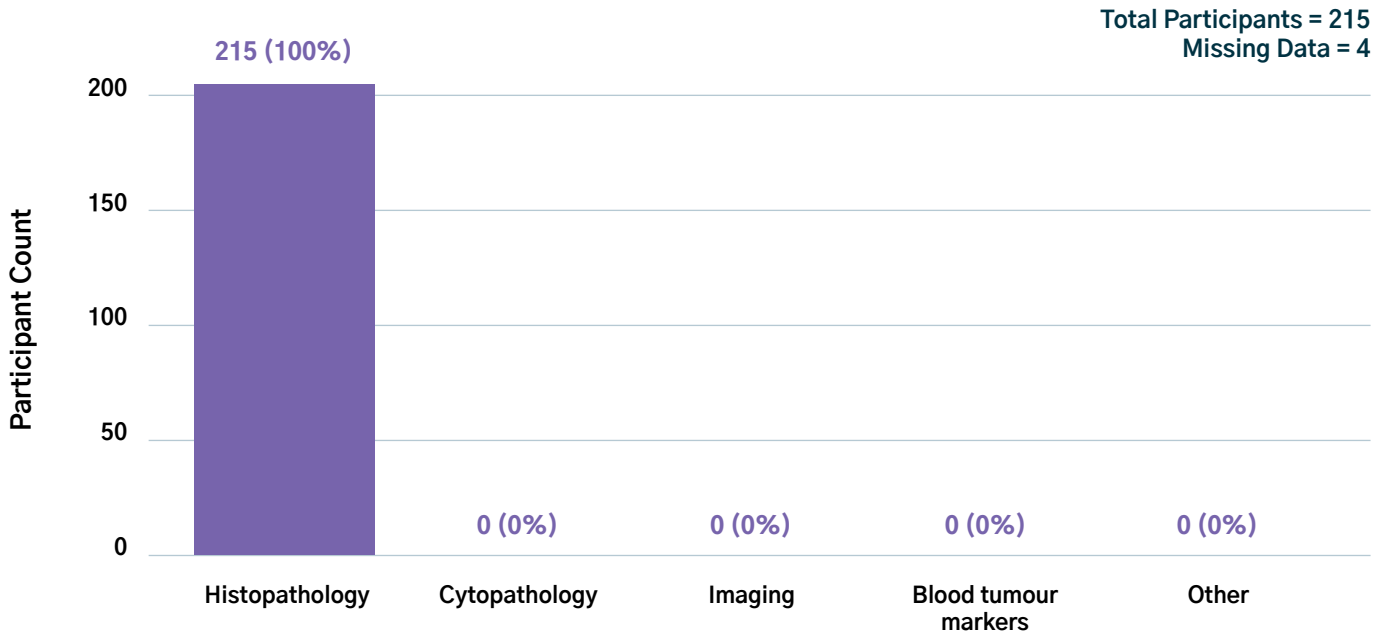


Figure 56: Level of diagnostic evidence.

Data shown indicates the highest level of evidence used to confirm a patient's cancer diagnosis, for those diagnosed between 2017 and 2022. 'Blood tumour markers' such as inhibin.

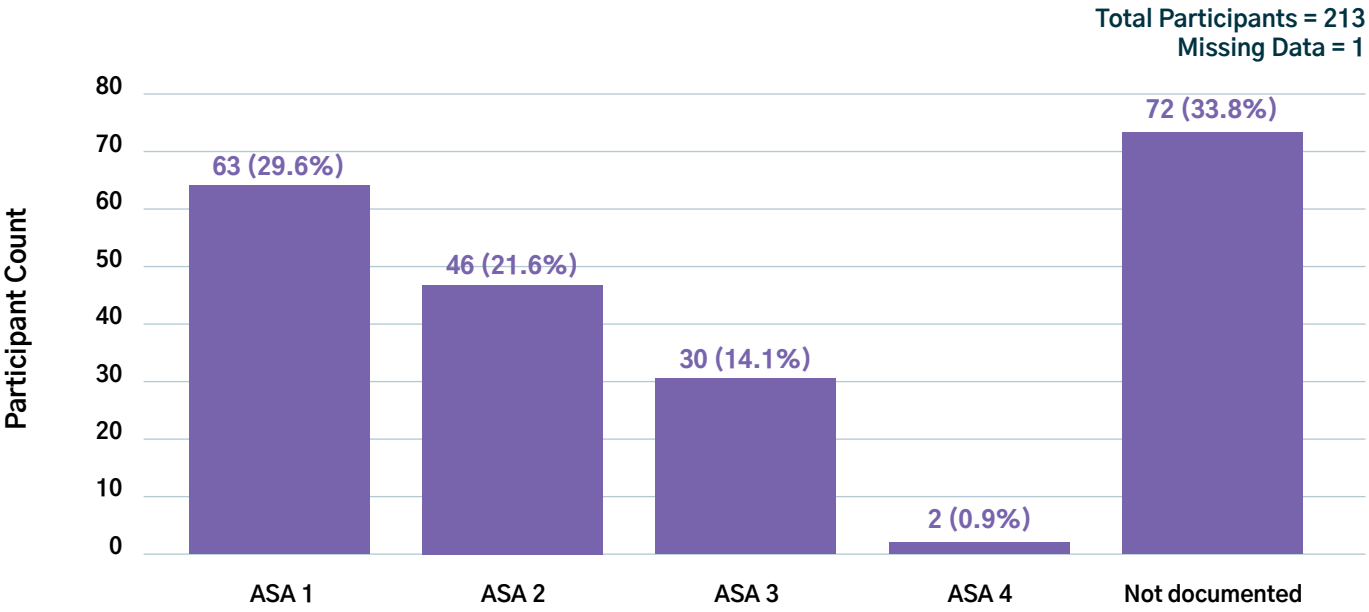


Figure 57: ASA score.

This graph shows the American Society of Anesthesiologists (ASA) method of determining physical status, with scores ranging from 1–6. Data are shown for patients diagnosed between 2017 and 2022. Lower scores indicate greater health. ASA scores are only captured for patients who have surgery. Scores not shown indicate that no patient within the OTP Cancer Module 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.

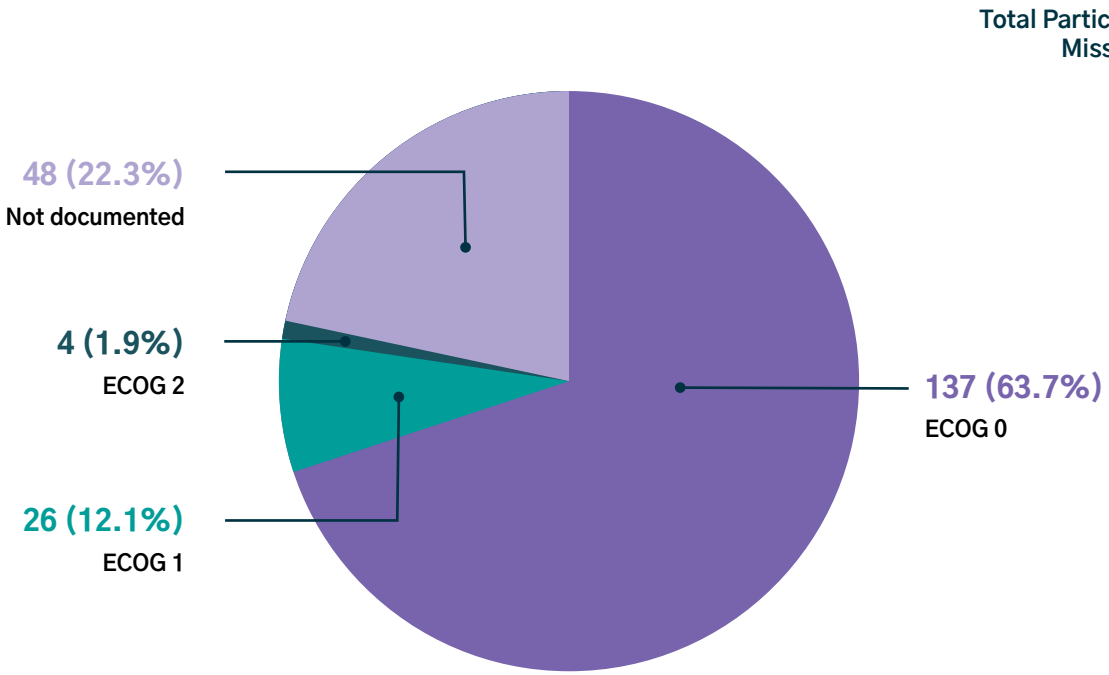


Figure 58: ECOG score.

Distribution of physical functioning at diagnosis, for patients diagnosed between 2017 and 2022. Physical functioning is measured according to the Eastern Cooperative Oncology Group (ECOG). ECOG scores ranging 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.

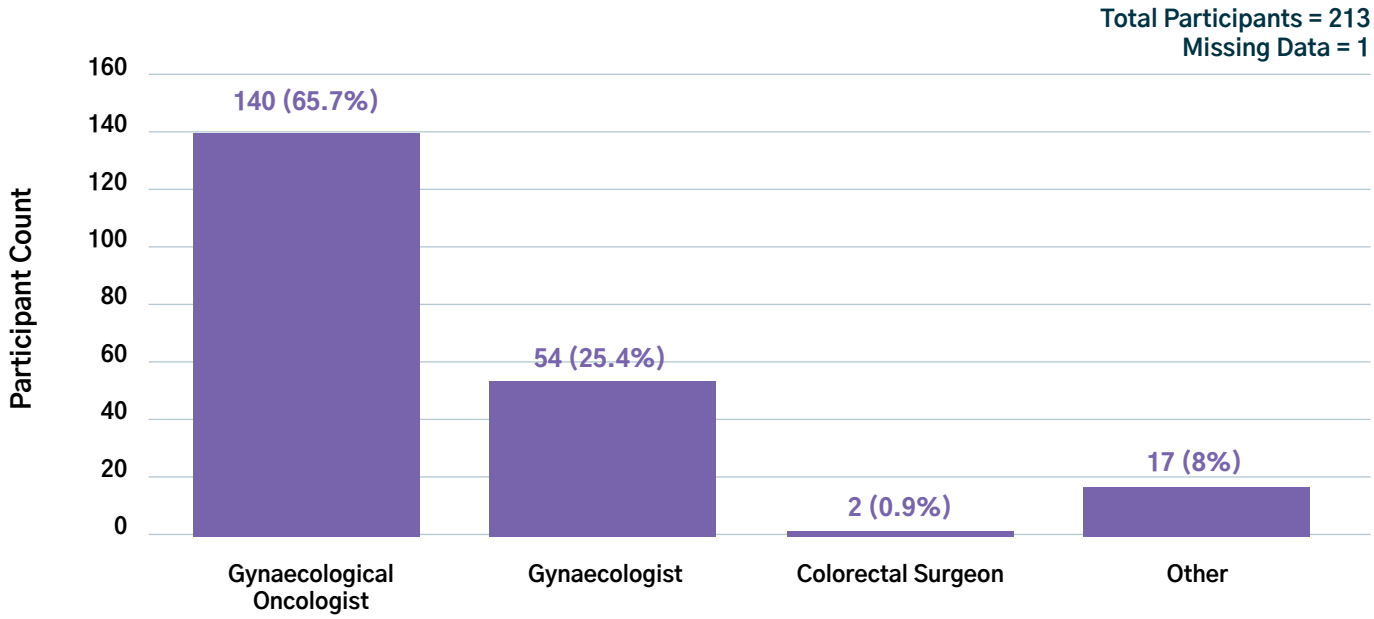


Figure 59: Speciality of supervising surgeon.

The above graph shows the distribution for the specialty of the supervising surgeon, for patients who were diagnosed and had their first surgical treatment between 2017 and 2022. Many patients, particularly those with early stage disease, will not initially present to a specialist gynaecological oncology unit. Ovarian cancer may not be suspected, and the tumour may be a surprise finding during surgery for another condition. Patients may therefore initially undergo surgical staging with a general gynaecologist. They may also be offered re-staging surgery upon referral to a gynaecological oncologist if the first staging surgery was deemed to be incomplete. 'Other' refers to surgeons of other specialties, e.g. general surgery.

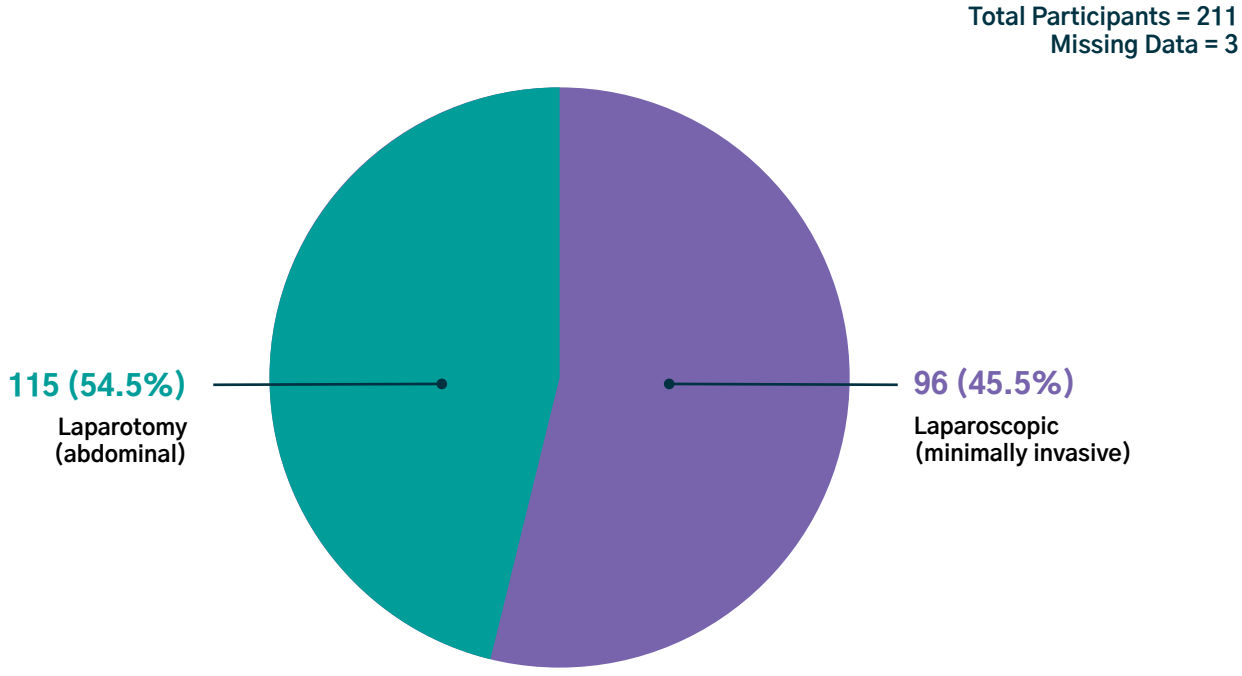


Figure 60: Surgical approach for first surgery.

The above graph depicts the rate of invasive vs. minimally-invasive surgery for patients diagnosed with a rare ovarian tumour during 2017–2022. Abdominal surgery is also known as 'open' surgery or a laparotomy, and involves a relatively large incision being made into the abdominal wall. Minimally invasive surgery via use of a laparoscope for the staging of ovarian cancer has become significantly more common in the last two decades. However, not all patients will be suitable candidates for minimally invasive surgery and appropriate patient selection is required to minimise the risk of adverse events and conversion to open surgery[48].

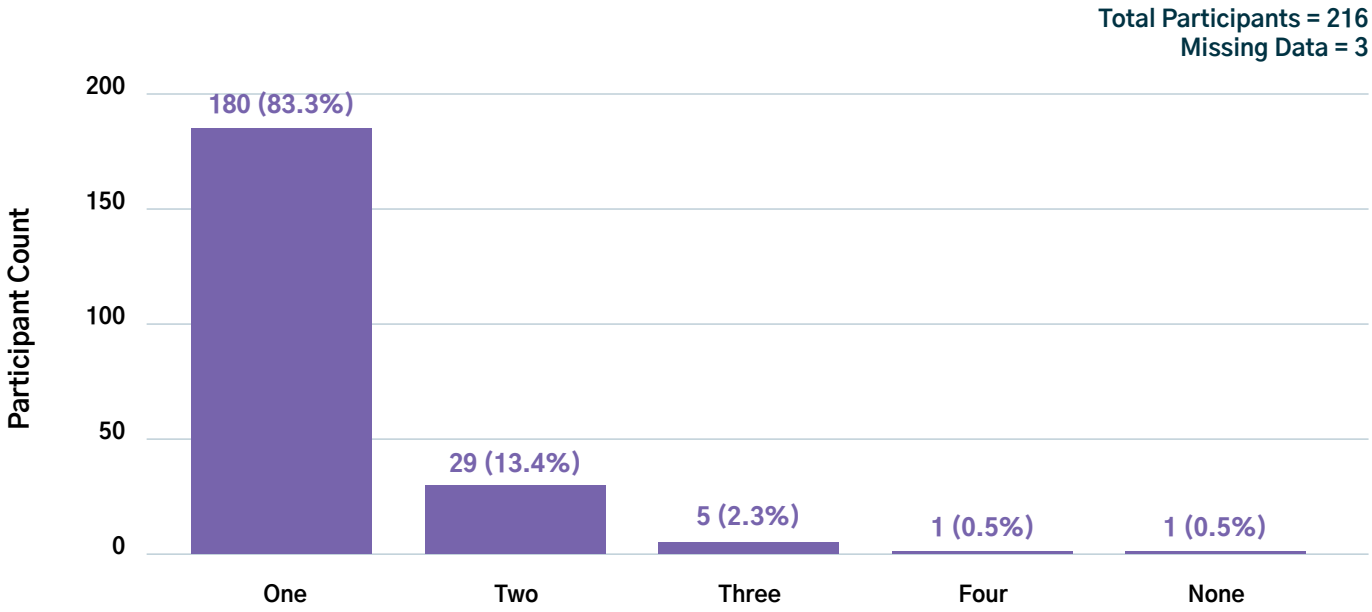


Figure 61: Number of surgeries.

Distribution of the number of surgeries performed as part of first-line treatment (i.e. excluding surgery for recurrence). Surgery is critical in the treatment of rare ovarian cancers and repeat surgery is often warranted, particularly in cases where surgical staging was determined to be incomplete.

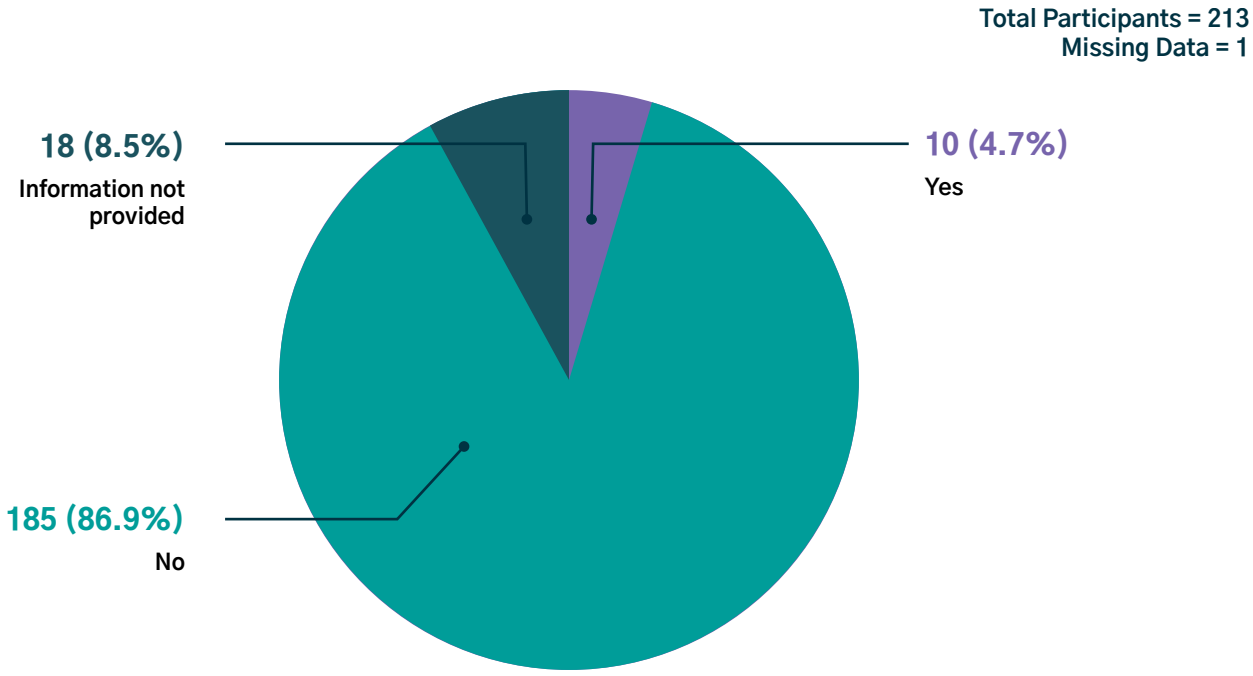


Figure 62: Intraoperative events.

The above graph illustrates the rate of intraoperative adverse events for initial surgery. This data relates to adverse events which occurred during surgery that could not have been anticipated prior to surgery, such as excessive bleeding or damage to an adjacent internal organ. A classification of 'Information not provided' indicates that information on whether an intraoperative event occurred or not, was not available through the medical record(s) from which data were collected.

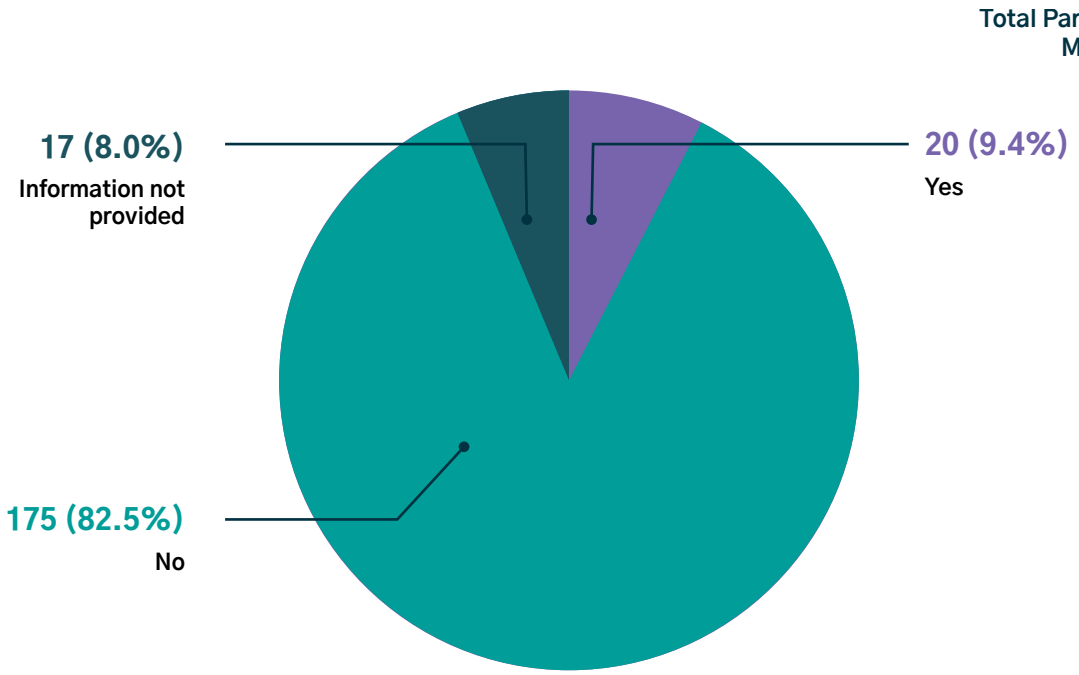


Figure 63: Postoperative events.

The above graph illustrates the rate of postoperative 30–day adverse events for initial surgery. Both patients with minor (Clavien–Dindo grade I–II) and severe (Clavien–Dindo grade ≥ III) postoperative events are included in the graph above. Only four of the 20 patients in this cohort who experienced a postoperative 30–day adverse event had this event classified as grade III or higher. This indicates a lower rate of serious postoperative 30–day adverse events for those in the Rare OTP Cancer Module compared to those in the OTP Cancer Module. A classification of 'Information not provided' indicates that information on whether a postoperative event occurred or not, was not available through the medical record(s) from which data were collected.

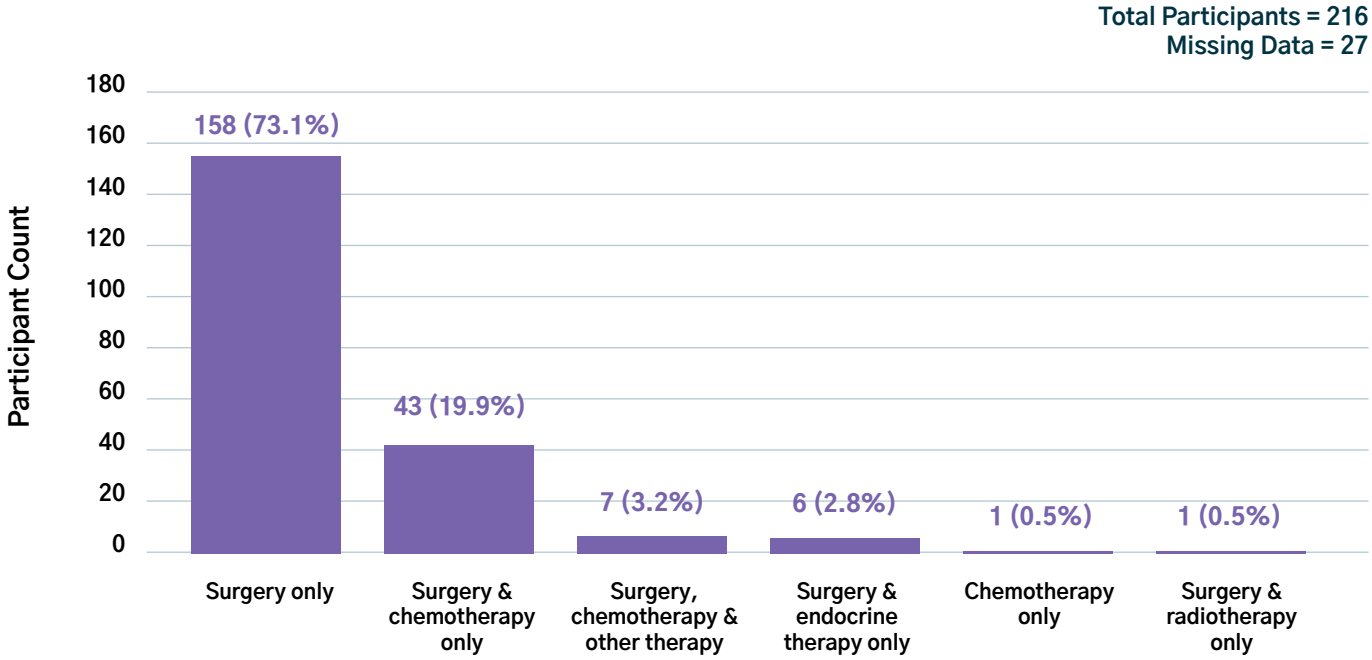


Figure 64: Therapies.

The above graph illustrates the proportion of patients with tumour spread who received each class of first–line adjuvant therapy. For patients with early stage disease and/or specific histological diagnoses, provision of adjuvant therapy may not have been indicated.

Future Directions

The OTP Cancer Module will focus on building connections with specialist gynae-oncologist hospitals in Queensland, Northern Territory and the Australian Capital Territory to ensure complete data capture across the country.

The NGOR will also be focusing on strong data collection within the Endometrial Cancer Module, as well as completing the OTP Cancer Module PROMs pilot study, which is expected to conclude in early 2024. From 2023 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 CQIs for both the Cervical and the Vulvar Modules have also been developed, with pilot data collection anticipated to begin once funding has been secured.

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, alongside greater academic outputs to highlight key findings.

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 the 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 the 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 or Debulking 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. 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.

Human Development Index (HDI): A summary measure reflecting long–term progress in three essential areas of human development: (1) good health and longevity, (2) access to knowledge and opportunities to learn, and (3) an acceptable standard of living. A country with a high HDI is considered to be succeeding in all three areas of human development.

Interval cytoreductive (debulking) surgery: Surgery that occurs after 2 to 4 cycles of neoadjuvant 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.

Neoadjuvant therapy: Treatment given prior to surgery. In OTP cancer this is usually chemotherapy, but may include radiation therapy or hormone therapy.

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

Residual tumour: 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: Determining the extent of tumour at laparotomy or laparoscopically. 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 multi-disciplinary 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)** Patients who had CT imaging of their chest, abdomen and pelvis, or PET imaging. **B)** Patients who had CT imaging of their abdomen and pelvis but may not have had chest imaging, or PET imaging.	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 their 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 early stage (Stage I or II) OTP cancer who undergo surgical staging procedures. Surgical staging procedures includes any of: ▪ Total abdominal hysterectomy ▪ Bilateral salpingo-oophorectomy ▪ Peritoneal washings ▪ Omentectomy/omental biopsy ▪ Biopsy of any suspicious lesions or masses ▪ Appendectomy (for mucinous tumours only)	Number of patients with stage I or II ovarian (or tubal) cancer who underwent any of the listed surgical 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 (Stage IIB, III, or IV) OTP cancer who undergo primary cytoreductive surgery and have: **A) no** residual cancer (0cm). **B) some** 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 residual cancer or (b) 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 (Stage IIB, III, or IV) OTP cancer who undergo interval cytoreductive surgery and have: **A) no** residual cancer (0cm). **B) some** 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 residual cancer or (b) 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 who undergo surgery for OTP cancer and have at least one unplanned intraoperative event.	Number of patients who suffer one or more unplanned intraoperative events.	All patients undergoing surgery for OTP cancer.	N/A
8	Proportion of patients with OTP cancer who experience one or more serious (Clavien–Dindo ≥ III) adverse events 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 histopathology 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 who receive first-line chemotherapy with a platinum 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 commence: **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 - 2022

Presentations:

The Australian Society of Gynaecologic Oncologists – 2022 Annual Scientific Meeting (Melbourne, Australia)

- "The National Gynae–Oncology Registry: An update" – Associate Professor Robert Rome

Clinical Oncology Society of Australia – 2022 Annual Scientific Meeting (Brisbane, Australia)

- "Interest in sexual activity following ovarian, tubal and peritoneal cancer treatment: A mixed–methods study" – Ms Alice Sporik
- "The EORTC QLQ–C30 and QLQ–OV28 for PROMs data collection in the National Gynae–Oncology Registry: A thematic analysis of the perspectives and content needs of women with ovarian cancer" – Dr Sharnel Perera

Students:

PhD

- "Real world outcomes for women with ovarian cancer: Measuring quality of care in Australian using a clinical quality registry" – Dr Mahendra Naidoo (in progress)

Honours

- "Evaluating concordance between registry and source data in the determination of comorbidity" – Ms Jessica Ravindran (completed)

Cabrini Scholarship (Medical)

- "Patient selection for interval debulking surgery in ovarian cancer: A review of current guidelines" – Dr YiJie Neo (completed)
- "Comparing Australian and international clinical quality indicators for cervical cancer" – Dr Amanda Nguyen (completed)

Scholarly Intensive Placement (Medical)

- "Associations between endometrial cancer stage at diagnosis and age, menopausal status, and body mass index, using data from the National Gynae–Oncology Registry" – Dr Georgia Kaloupis (completed)
- "Synoptic operative reporting in oncology" – Dr Mahima Jain (completed)

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OVARIAN CANCER AUSTRALIA

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