MONASH University

# AUSTRALIAN & NEW ZEALAND THYROID CANCER REGISTRY

## 2021 ANNUAL REPORT

AUSTRALIAN & NEW ZEALAND
THYROID CANCER
REGISTRY

# CONTENTS




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This report was produced with the support of the Australian and New Zealand Endocrine Surgeons (ANZES) and the Australian Thyroid Foundation.

**Suggested citation:**
Ioannou L, Serpell J, Brown B, Hansen J, Bavor C, Earnest A, Miller J, Bendinelli C, Cope D, Glover A, Gough J, Harper S, Lee J, Lisewski D, Meyer-Rochow W, Sidhu S, Sywak M, Topliss D, Walters D, Zalcberg J, Allnutt M, Bhatt C, Aniss A, Ahern S, Millar J. The Australian and New Zealand Thyroid Cancer Registry Annual Report, 2021. Public Health and Preventive Medicine, Monash University, July 2022, Report No. 04.


## Data Period

The data contained in this document was extracted from the Australian and New Zealand Thyroid Cancer Registry (ANZTCR) on 05 April 2022 and pertains to data that relates to patient events from 25 September 2017 to 31 December 2021. As the registry does not capture data in real time, there may be a lag period between the occurrence of an event and its capture in the registry's database, ANZTCR REDCap Database (ANZTCR-RCD).

AUSTRALIAN & NEW ZEALAND THYROID CANCER REGISTRY

MONASH University

AUSTRALIAN & NEW ZEALAND ENDOCRINE SURGEONS

THE AUSTRALIAN THYROID FOUNDATION LTD

# FOREWORD

## FROM THE CLINICAL LEAD OF THE ANZTCR

It gives me great pleasure to introduce the fourth annual report of the ANZTCR for 2021. Firstly, it goes without saying the past 30 months have been enormously challenging for all of us during the COVID-19 pandemic. However, the ANZTCR Coordinating Centre, Management Committee and Steering Committees have continued to work hard and this year we have seen the onboarding of sites in New Zealand and the commencement of electronic patient-patient reported outcome and experience measures.

We continue to enjoy the strong support of Australian and New Zealand Endocrine Surgeons (ANZES), Endocrinologists, ENT/Head and Neck Surgeons, Nuclear Medicine Physicians, and Data Managers. The registry continues to grow exponentially and demonstrates in this annual report its primary purpose of improving outcomes for thyroid cancer patients. The results contained in this report indicate a high-quality outcome for our patients.

I particularly would like to thank all our contributors for keeping the data in the registry so up to date, which has enabled this important analysis. I wish to thank Professor John Zalcberg, Professor Jeremy Millar, Dr Liane Ioannou, Claire Bavor, Benjamin Brown and Jessy Hansen, from the Cancer Research Program at Monash University. Further, our strong and committed Steering Committee remain integral to the success of the ANZTCR.

This registry is now well established and is an important achievement as a key quality initiative for thyroid cancer patients. Finally, I would like to express my appreciation to our contributing patients, the Australian Thyroid Foundation, and our funders.

**Professor Jonathan Serpell**
Clinical Lead, ANZTCR
Director, Department of General Surgery, Alfred Health
Director, Breast, Endocrine and General Surgery Unit, Alfred Health

## FROM THE PRESIDENT OF ANZES

I am pleased to present the ANZTCR 2021 Annual Report. Despite the challenges presented during the COVID-19 pandemic, the ANZTCR has achieved some wonderful milestones this including the collection of quality of life data directly from patients.

The ANZTCR is a multi-centre, binational clinical quality registry aiming to improve outcomes for newly diagnosed thyroid cancer patients in Australia and New Zealand. This report presents the aggregate clinical quality indicator outcomes for the early management of thyroid cancer in Australia and New Zealand using 4-years of data from the ANZTCR.

I would like to offer thanks and recognition to all the ANZES members and participating clinicians who have taken the time to contribute their data and time to the registry. By doing so, they are demonstrating their commitment to excellence in thyroid cancer care. As clinician engagement increases, the registry becomes an increasingly valuable tool for reducing unwarranted variation in care as well as a platform for research.

Finally, I would like to thank all those involved in managing the registry, especially Professor Jonathan Serpell for his continued vision and leadership.
I would also like to encourage all ANZES members to contribute, if not doing so already. I am excited to watch the registry continue to evolve in 2022 and beyond.

**Associate Professor Julie Miller** Immediate Past-President, ANZES
Head, Thyroid and Endocrine Tumour Group, The Royal Melbourne Hospital

# EXECUTIVE SUMMARY

The ANZTCR was established in 2017 as a clinical quality registry to collect the diagnosis, treatment and outcome data of individuals diagnosed with thyroid cancer, in both public and private health services. This report presents key findings from the ANZTCR's first four years of data collection.

In 2021, the ANZTCR implemented automated data extraction and import process to three additional surgical databases, paving the way for this process to be undertaken at other sites. The ANZTCR also commenced the collection of patient-reported outcome and experience measures to feedback to sites alongside clinical data.

- As of 31st December 2021, a total of 40 hospitals across four states were participating in the ANZTCR, with 59 contributing surgeons.
- As of 31st December 2021, there were 1687 participants in the ANZTCR, comprising 73% females and 27% males; at least some follow-up data was available for 99% of participants.
- The median age of participants was 52 years for females and 57 years for males (median overall age 53 years).
- Diagnosis of thyroid cancer was based on histology (62%), cytology (37%) and histology of metastasis (1%).
- At diagnosis, 42% of participants had at least one specified comorbidity, 3% had previously been exposed to upper body radiation and 4% had previous thyroid surgery.
- During diagnostic work-up, 92% of participants had an ultrasound and 89% had fine needle aspiration cytology (FNA); 24% underwent a computed tomography (CT) scan, 5% had a thyroid nuclear scan, 6% a positron emission tomography (PET) scan. Thirty two of 38 participants with evidence of voice abnormality prior to diagnosis underwent a laryngeal examination.
- The majority of participants underwent a total thyroidectomy (54%), or hemithyroidectomy (39%), with 7% undergoing a different procedure. Of those participants who had a subsequent procedure 83% had a completion thyroidectomy.
- More than half (52%) of participants had a lymph node dissection; where known, 23% with therapeutic intent and 68% with prophylactic intent.
- Pathology data was available for 1555 participants, and included 93% with differentiated, 3% with medullary and 1% with poorly differentiated thyroid cancer. Lymph node metastases were reported in 30% of participants at the time of initial procedure, with distant metastases reported in 1%.
- For 29% of participants, the finding of cancer was incidental.
- Nerve integrity monitoring was used during the initial procedure in 75% of participants. Seventeen participants had recurrent laryngeal nerves (RLN) damaged or sacrificed during their procedure (approximately 1%).
- Surgical complications reported in the registry included temporary RLN palsy (3%); with haemorrhage, infection and seroma reported in less than 1%.
- Postoperative treatment included medical supplementation with calcium (59%), vitamin D (12%) and thyroxine (62%).
- Eleven of twelve clinical quality indicators are reported using aggregate data.

## FUNDING PARTNERS

The ANZTCR relies on funding grants from a range of sources to support its operations.

The ANZTCR is very privileged to have a consistent industry supporter in Medtronic, which has supported the registry from its early days and has enabled it to increase its reach nationally, and now binationally.

The ANZES membership has also made a very significant contribution to the ANZTCR, both through their participation in the registry, and through their financial support of the registry. The registry sincerely thanks the membership for their ongoing commitment and support to this important craft group initiative.

In 2021, the ANZTCR was also fortunate enough to receive untied funding from a pharmaceutical company, Eisai Australia.

Without these important funders, the ANZTCR and this report would not be possible.

Medtronic

AUSTRALIAN & NEW ZEALAND ENDOCRINE SURGEONS

Eisai

# INTRODUCTION

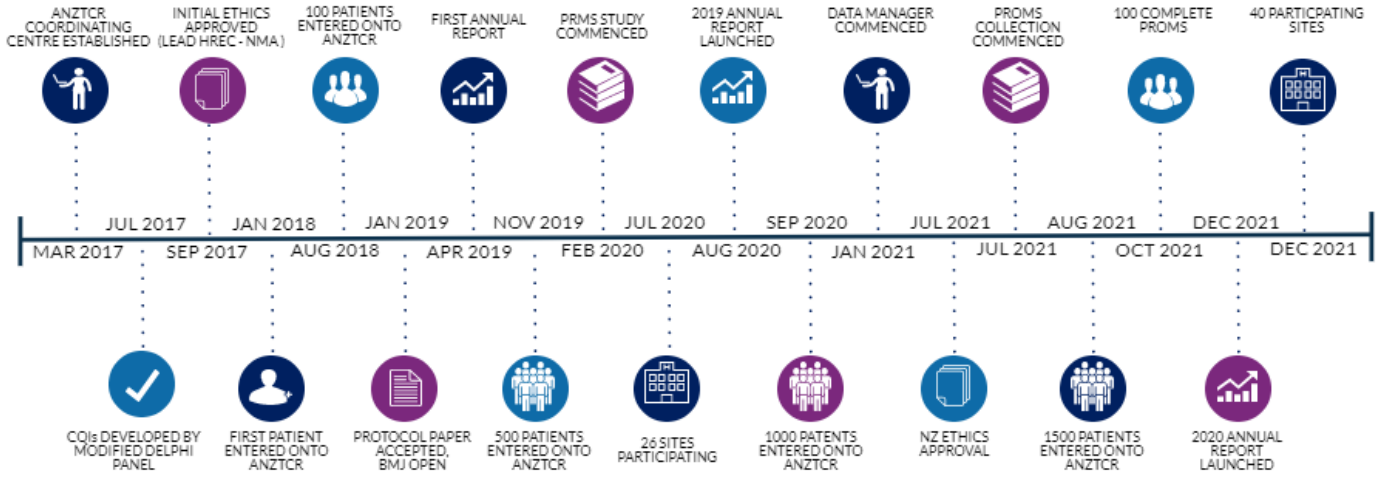
The ANZTCR is a clinical quality registry established in 2017 to monitor the quality of care provided to patients diagnosed with thyroid cancer. The ANZTCR collects the diagnosis, treatment and outcome data of individuals with thyroid cancer, in both public and private health services.

The ANZTCR conforms to the national operating principles for clinical quality registries as detailed in the 'Operating Principles and Technical Standards for Australian Clinical Quality Registries 2008'[1] and the 'Framework for Australian Clinical Registries 2014'[2] published by the Australian Commission for Safety and Quality in Healthcare (ACSQHC).

We report the first four years of data collection and aggregate ANZTCR clinical quality indicator (CQI) outcomes.

## MILESTONES

The ANZTCR milestones are highlighted in the diagram below:




## REGISTRY GOVERNANCE

### Steering Committee

The ANZTCR is led by a multidisciplinary steering committee which guides registry strategy and policy, monitors data collection and quality assurance, and produces data reports. Current membership includes representation from ANZES, the Australian Society of Otolaryngology Head and Neck Surgeons (ASOHNS), the Australian Thyroid Foundation, and Monash University.

The Steering Committee comprises representation from Australia and New Zealand, and includes representation of the following specialities and/or expertise:

- Surgery
- Endocrinology
- Radiation oncology
- Nuclear medicine
- Medical oncology
- Patient advocacy
- Data management
- Registry science

For a list of ANZTCR policies and procedures, please see Appendix G.

Monash University has custodianship of the data which includes accountability for the privacy, security and integrity of patient information held within the registry. Data is collected and managed using REDCap electronic data capture tools hosted and managed by Helix (Monash University). REDCap (Research Electronic Data Capture)[3] is a secure, web-based application designed to support data capture for research studies, providing 1) an intuitive interface for validated data entry; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for importing data from external sources.

### Management Committee

A Management Committee oversees the daily operations of the registry undertaken by the ANZTCR Coordinating Centre based at Monash University.

# REGISTRY METHODOLOGY

## PARTICIPANT RECRUITMENT

All patients newly diagnosed with thyroid cancer from a participating site are eligible to participate in the prospective registry.

**Inclusion criteria**

- All newly-diagnosed patients presenting to a participating hospital with a confirmed primary thyroid cancer.
- Patients who are ≥16 years of age at the time of diagnosis.

**Exclusion criteria**

- Patients diagnosed earlier than 1st September 2017.

The ANZTCR uses an *opt-out* recruitment process. Patients can opt-out of the registry at any time by emailing or calling the ANZTCR.

Recruitment can only begin after authorisation has been granted by the site's research ethics and governance office:

**Phase 1** All patients diagnosed with thyroid cancer, based on histological confirmation (provided approximately 1-2 weeks post-diagnosis) are eligible to participate. The treating surgeon (or designated staff member) enters minimal patient details into the ANZTCR REDCap Database (ANZTCR-RCD) including the thyroid cancer diagnosis and patient disclosure.

**Phase 2** The ANZTCR Coordinating Centre identifies new patients in the registry and provides information about the registry via a mail-out. The mail-out includes the ANZTCR Participant Introductory Letter and the ANZTCR Participant Explanatory Statement. Participation is assumed if the patient does not contact the ANZTCR within two weeks of the date of the mail-out.

**Phase 3** The surgeon then enters participant diagnosis, surgical, pathology and treatment data into the registry database at approximately 90 days post-surgery to coincide with postoperative follow-up.

**Recruitment of patients diagnosed with non-invasive follicular thyroid neoplasm with papillary-like nuclear features (NIFTP)**

Patients diagnosed with NIFTP are included in the registry via a waiver of consent due to the potential for the terminology used around this diagnosis to vary.

## DATA ELEMENTS

A consensus set of CQIs were developed for the early management of thyroid cancer using a modified-Delphi approach, informed by international thyroid cancer guidelines and relevant literature (Appendix H).

The ANZTCR minimum data set includes variables relating to the quality indicators, variables required for patient identification and contact, and other variables of particular relevance to early thyroid cancer management, based on the standard care provided (see Appendix C).

## DATA COLLECTION PROCESSES

Data is collected and entered in the ANZTCR-RCD using two methods:

1. Direct data entry into the ANZTCR-RCD by surgeons (or their staff e.g., data manager). The ANZTCR-RCD provides a secure online connection to the registry database (primary method of data collection).
2. Data extracts from unit, institution and multi-institution databases held by participating surgeons or electronic medical records where data mapping indicates high levels of data item matching.

### Data Importing

In 2020, the ANZTCR implemented the automated extraction and import of data from the Royal North Shore Hospital, Endocrine Surgical Unit's Database, and the Alfred Monash University Endocrine Surgery Database into the ANZTCR-RCD. This process can also be undertaken at other sites who have closely aligned datasets or existing thyroid cancer or endocrine surgery databases. The benefits of setting up a direct import include reduced time spent on data entry, increased ease of contributing to the ANZTCR and the establishment of a data source for in-house analysis.

There are three ways to set-up data importing at a site:

**1. Using a copy of the ANZTCR-RCD:** A copy of the ANZTCR-RCD may be used at the site and custom fields may be added, as long as the original fields remain unedited.

**2. Using a copy of a thyroid disease database:** A copy of a thyroid disease database, like that from the Royal North Shore Hospital Endocrine Surgical Unit's Database, or like the Alfred's, may be used at the site. The database contains all the fields required for the ANZTCR.

**3. Undertaking data mapping to use a site's current database:** A site's current database can be mapped to the ANZTCR-RCD to determine if the names of the fields need to be changed and/ or added to allow for importing. To do this the site database must be in REDCap.

## REPORTING

As the ANZTCR continues to expand its coverage and recruitment of patients it will be able to report CQI outcomes back to sites. A risk-adjustment process will be established to ensure that these benchmarked reports are adjusted for differences in casemix at different sites. Sufficient caseload is required before these reports can be generated, with a minimum patient volume per site to be determined.

### Annual Reports

Aggregate outcomes in relation to the CQIs have been included in this report.

### Site Benchmarked Reports

In 2022 the ANZTCR anticipates producing benchmarked reports of CQIs to sites for the first time. In the interim, participating sites can log onto the database and access their patient information and download data reports at any time.

## PATIENT-REPORTED MEASURES

In 2021, the ANZTCR commenced the electronic collection of patient-reported outcomes (PROs) and patient-reported experiences (PREs) as we are interested in knowing about the health and well-being of people diagnosed with thyroid cancer. The ANZTCR would like to understand what factors are important to their quality of life so they can help improve the care they receive from their surgeons and hospitals.

### Process of Collecting PRMs

Eligible registry participants will be invited to participate in patient-reported outcome and experience questionnaires (patient-reported measures – PRMs) via text message or email. An invitation to complete the PRMs questionnaire will be sent at predetermined intervals following diagnosis, 3-, 6-, 12-months and then annually for 5-years, or until the participant opts-out or passes away.

**Inclusion Criteria**

- Patients participating in the ANZTCR

**Exclusion Criteria**

- Interpreter required (non-English speaking)
- Registry participants that have opted-out of PRMs

### PRMs Questionnaire Content

Patient-reported data that measures patient outcomes, including quality of life, and patient experiences will be collected by providing the validated European Organisation for Research and Treatment of Cancer (EORTC) general quality of life questionnaire (QLQ-C30) and the thyroid cancer-specific module (THY34) to eligible registry participants.

In addition to measuring patient outcomes and experiences, participants may be asked if they wish to provide feedback on the process of collecting patient-reported data and the content of the questionnaires. The reason for this will be to periodically gather feedback from participants about registry processes and content to ensure participant acceptability and feasibility. The instructions for this patient evaluation clearly indicate that it is optional, states how many additional questions are included and the expected length of time required to complete it.

### PRMs Reporting & Feedback

*Patient Feedback*

Upon completion of the questionnaire participants will receive links to patient advocacy and support websites, such as the Australian Thyroid Foundation, Cancer Australia and Cancer Council Australia. A ‘Thank you Postcard’ will be sent to all registry participants who are completing patient-reported data collection annually. This postcard will also contain the contact details for the Australia Thyroid Foundation, a consumer advocacy group.

*Clinician & Hospital Reports*

Patient-reported data collected from participants may be shared as aggregate data with ANZTCR participating clinicians and sites involved in their care via benchmarked reports. At this stage, no individual level, or identifiable data will be shared with any ANZTCR participating clinicians and sites. In the future, the ANZTCR will explore options for reporting these results to clinicians in real-time. Participants will be notified of this at the time of completing the questionnaire and can request that this does not occur.

# CLINICIAN ENGAGEMENT

Surgeons are informed about the registry through ANZES and other sources including the ANZTCR newsletter. Principal and associate investigators at each hospital are ambassadors for the registry and further promote participation at their site.

Contributing Clinician Agreement forms are distributed to surgeons to invite them to participate in the registry. This is a once-only process for clinicians and notes the intent of the surgeon to participate in the registry and enter data on all patients for whom they are listed as the diagnosing or treating clinician in participating hospitals and private practice.

## SURGEON INCENTIVES

The ANZTCR annually acknowledges surgeons who participate in the registry in a number of ways:

### CME Audit Points

The ANZTCR is recognised by the Royal Australasian College of Surgeons (RACS) as a Continuing Medical Education (CME) audit activity that aims to improve the quality of patient care. Contributing surgeons receive annual CME credit points in Surgical Audit and Australian and New Zealand Audits of Surgical Mortality.

### Valued Contributor Logo

A valued contributor logo is provided to contributing surgeons to recognise their valued contribution to the registry. Surgeons are able to use the logo at their own discretion i.e. on their email signature, important documents and letters, and website.

### Database Reports

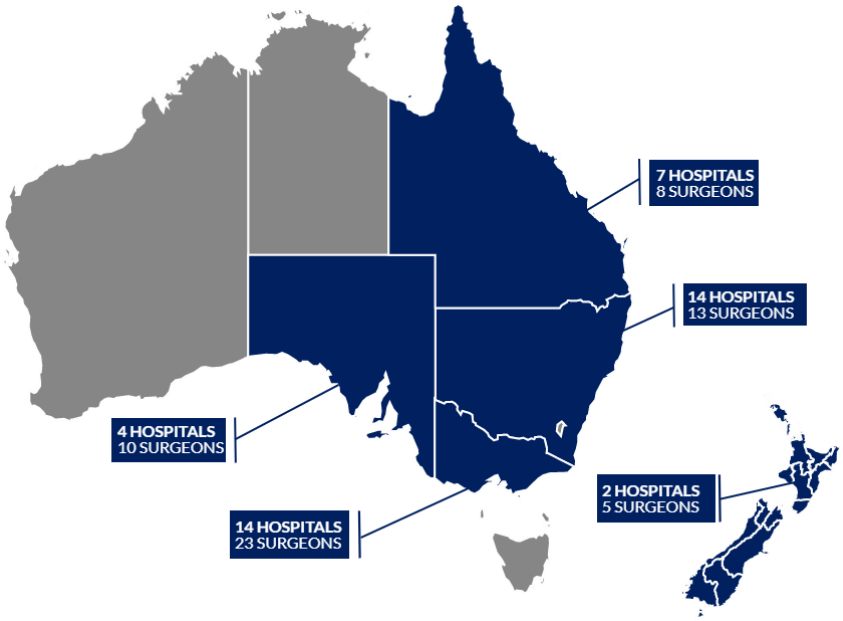
The ANZTCR-RCD allows surgeons to run patient-level and aggregate data reports in real-time. Resources are provided to contributing surgeons with instructions on how to run these reports.

# SUMMARY OF THE REGISTRY DATA

## SITE PARTICIPATION

As of December 31 2021, 40* sites had obtained governance approval. There were 22 public and 18 private health services/ hospital sites across Australia and New Zealand participating in the ANZTCR. Figure 1 illustrates the expansion of the registry across Australia since it commenced data collection in early 2018.

*FIGURE 1* NUMBER OF HOSPITAL SITES AND SURGEONS PER STATE CONTRIBUTING TO THE REGISTRY




*Victorian sites are counted at the health service level

## SURGEON PARTICIPATION

Surgery for thyroid cancer is performed by surgeons from different specialities including endocrine surgery, general surgery and Ear-Nose-Throat (ENT) surgery (otolaryngology). The registry aims to include all surgeons at a participating site that operate on patients with thyroid cancer. Figure 2 displays the speciality area of the 59 surgeons currently contributing to the ANZTCR.

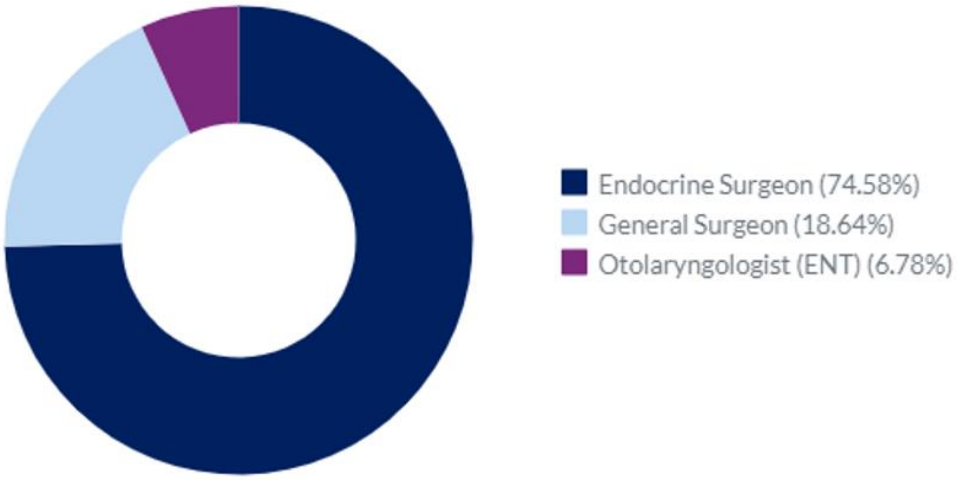



*FIGURE 2* AREA OF SURGEON EXPERTISE

## REGISTRY PARTICIPATION

The data presented in this report pertains to patient events from 25 September 2017 to 31 December 2021.The ANZTCR obtained ethics approval in September 2017, and the ANZTCR-RCD was launched late January 2018. There may be some delay between the patient being entered on the database and the patient receiving their invitation letter.

A total of 1777 patients have been invited to participate in the registry since January 2018. Of the 1777 patients invited, 90 (5.1%) have chosen to opt-out and 39 (2.1%) partially opted-out, where their clinical data will be collected but they will not be contacted for patient-reported measures or other research. As at 31 December 2021, the ANZTCR confirmed the participation of 1687 thyroid cancer patients and their data.

Table 1 demonstrates patient participation in the ANZTCR from 1 January 2018 to 31 December 2021. The registry has an opt-out rate of 5.1%.

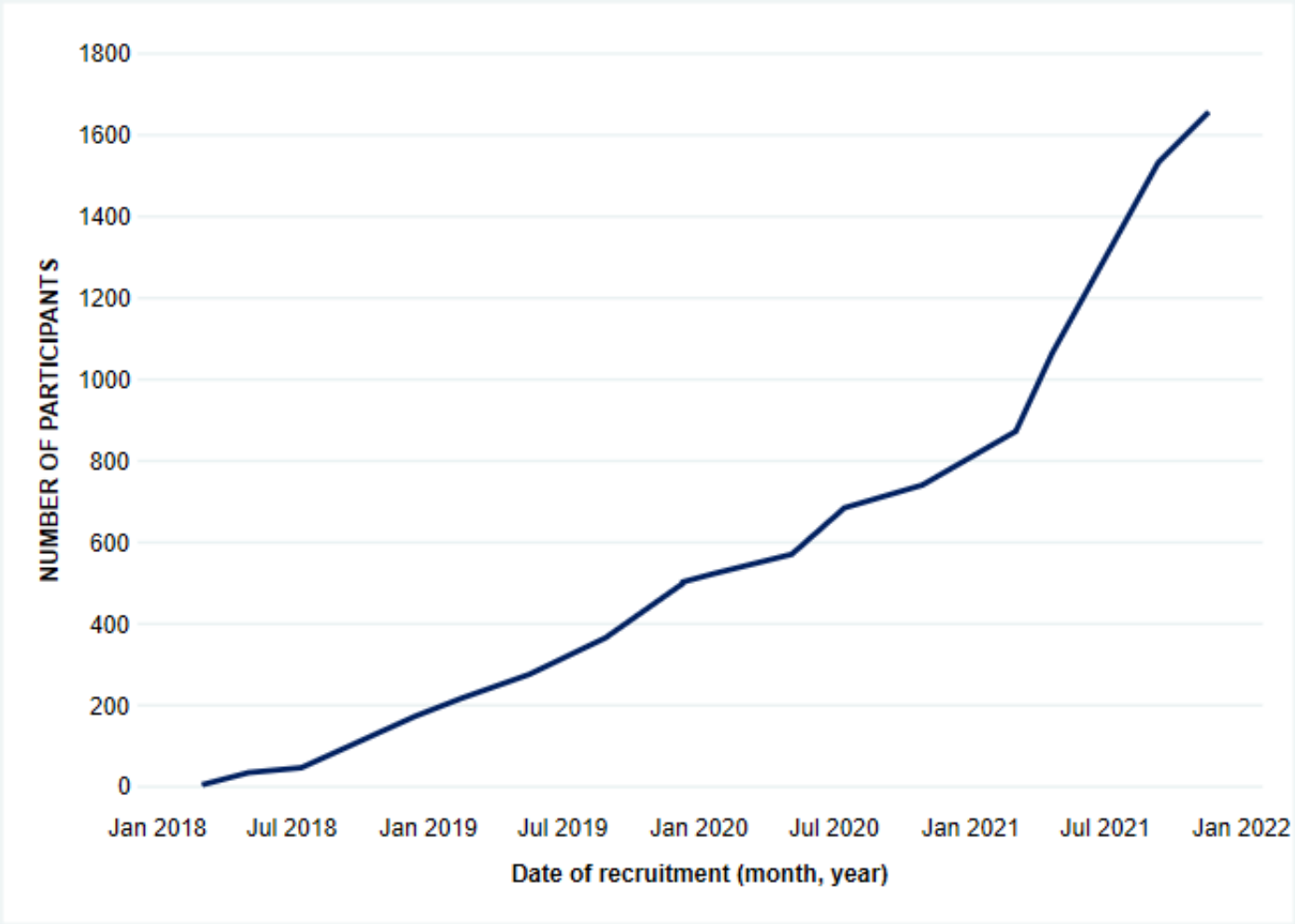
*TABLE 1* PATIENT PARTICIPATION IN THE REGISTRY FROM 1 JANUARY 2018 TO 31 DECEMBER 2021

| Participation Status | Frequency | % |
|---|---|---|
| Invited | 1777 | 100 |
| Complete Opt-Out | 90 | 5.1 |
| Participating* | 1687 | 94.9 |

*39 partial opt-outs.

Figure 3 illustrates the steady growth of registry participants from across Australia since its commencement in January 2018.

*FIGURE 3* ACCUMULATION RATES OF PARTICIPANTS IN THE REGISTRY FROM JANUARY 2018-2022 (n=1687)

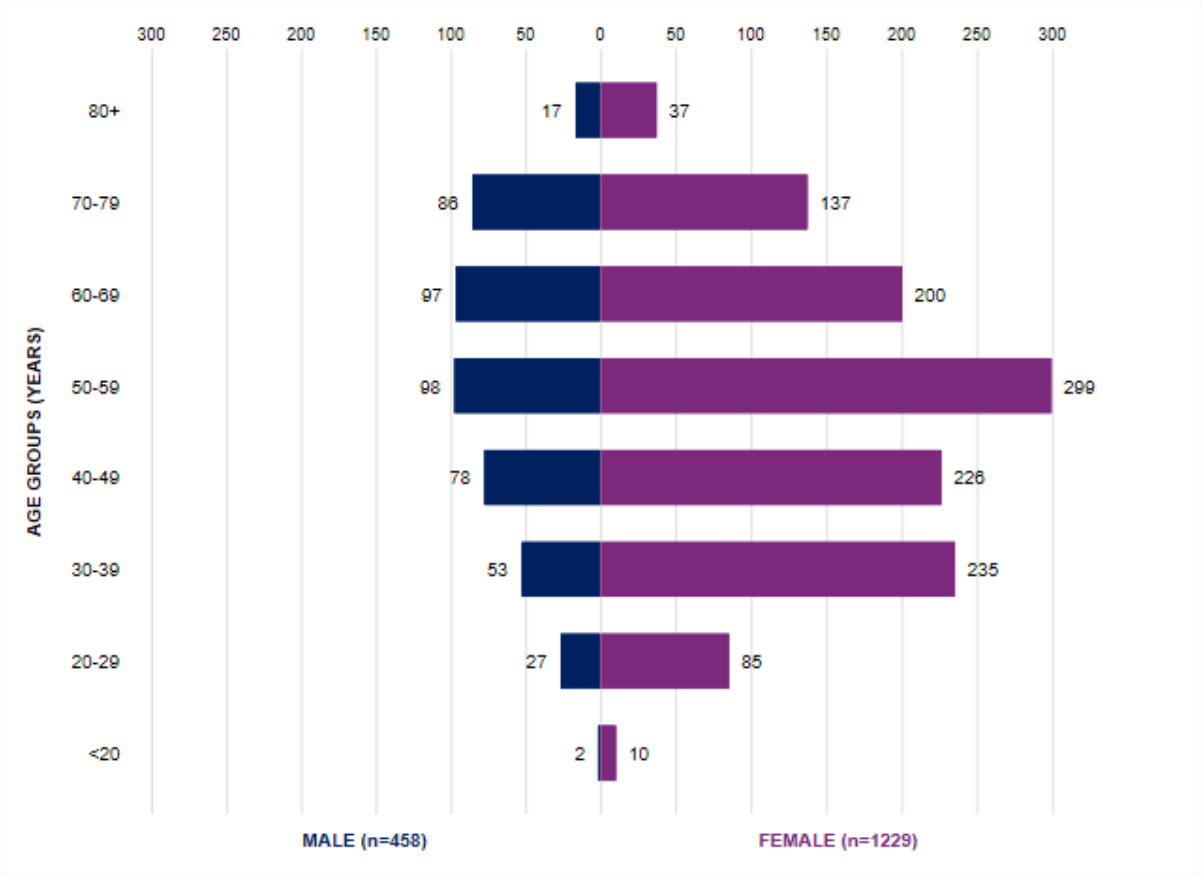


## Participant Characteristics

As of 31 December 2021, there were 1229 (73%) females and 458 (27%) males participating in the registry who had been diagnosed with thyroid cancer.

The median age for patients at diagnosis was 53 (IQR 40-65) years old, with a minor difference in the median age between males (57, IQR 44-69) and females (52, IQR 39-63). Figure 4 demonstrates the sex and age of participants in the registry who have been diagnosed with thyroid cancer since September 2017.

*FIGURE 4* PARTICIPANTS' AGE DISTRIBUTION AT TIME OF DIAGNOSIS STRATIFIED BY SEX (n=1687)




## Participants' Residence by State

Of the 1687 patients participating in the registry, 1022 (60.6%) were residing in New South Wales at the time of recruitment, 360 (21.3%) in Victoria, 257 (15.2%) in Queensland, 36 (2.1%) in South Australia and 10 (0.7%) in the Australian Capital Territory.

Table 2 highlights the frequency and percentage of patient participation in the registry across jurisdictions within Australia based on residence at time of recruitment.

*TABLE 2* PATIENT PARTICIPATION IN THE REGISTRY BY JURISDICTION* (n=1687)

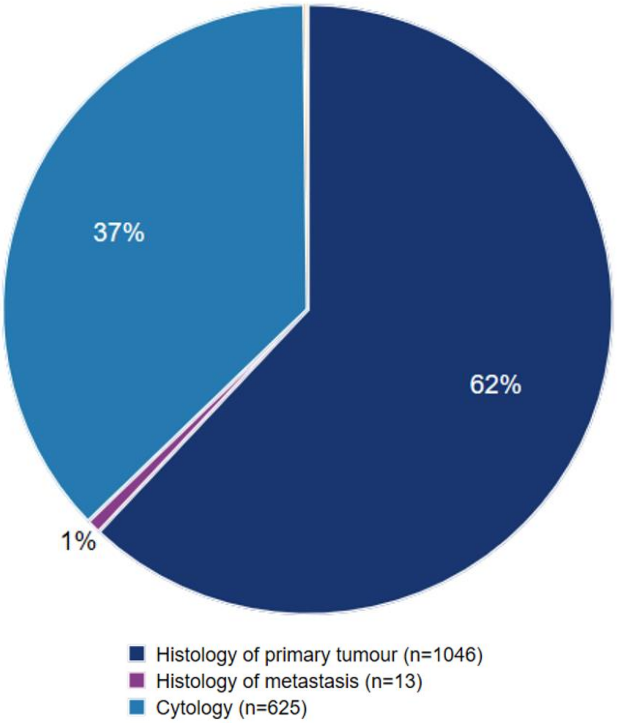
| State | Frequency | % |
|---|---|---|
| New South Wales | 1022 | 60.6 |
| Victoria | 360 | 21.3 |
| Queensland | 257 | 15.2 |
| South Australia | 36 | 2.1 |
| Australian Capital Territory | 10 | 0.6 |
| Tasmania | 2 | 0.1 |
| **Total** | **1687** | **100** |

*Based on participant residential postcodes.

### Method of Diagnosis

Of the 1687 participants, 1046 (62.0%) were diagnosed with primary thyroid cancer based on histology of primary tumour, 625 (37.0%) based on cytology,13 (1.0%) based on histology of metastasis and three were marked as unknown. Figure 5 demonstrates the method of diagnosis for participants recruited to the registry.

*FIGURE 5* METHOD OF DIAGNOSIS OF PRIMARY THYROID CANCER (n=1684*)




Footnote: Excludes three patients with an unknown basis of diagnosis

## FOLLOW-UP DATA COMPLETION

Participating surgeons enter follow-up data for their patients participating in the registry at 90-days post-diagnosis. Of the 1687 participants, 1669 exceeded the 90-day post-diagnosis period and are eligible for follow-up data collection. From this point forward, this report presents data on the patients for which follow-up data has been completed, please see sample sizes reported for each individual data item.

## PREOPERATIVE DETAILS CAPTURED BY THE REGISTRY

### Previous Medical History

At the time of diagnosis, 649 out of 1560 (41.6%) patients presented with a specified comorbidity, of these 99 (15.3%) were obese, 59 (9.1%) were current smokers, and 132 (20.3%) had been diagnosed with cancer other than thyroid cancer. Only 45 (2.9%) out of 1560 participants had previously been exposed to upper body radiation. 62 of 1560 (4.0%) participants had previous thyroid surgery.

Table 3 displays participants' previous medical history at diagnosis.

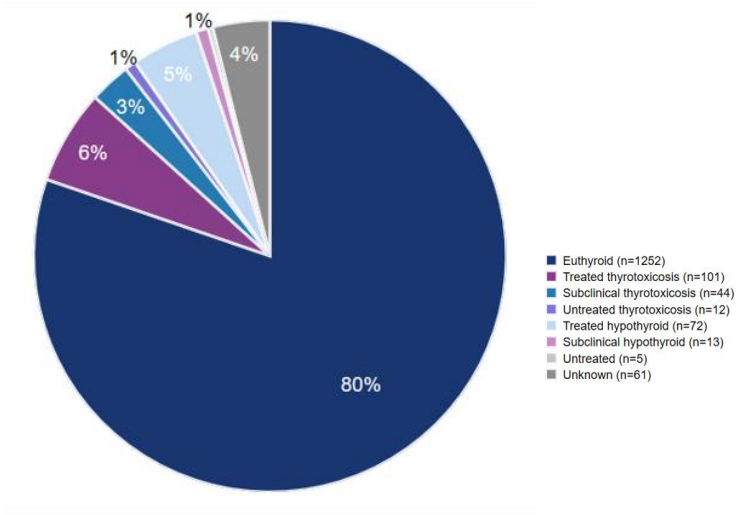
*TABLE 3* PREVIOUS MEDICAL HISTORY (n=1560)

| Variable | Total (n) | Response | Frequency (%) | |
|---|---|---|---|---|
| Specified comorbidity at diagnosis | 1560 | Yes | 649 | (41.6) |
| | | No | 263 | (16.9) |
| | | Unknown | 648 | (41.5) |
| If yes, comorbidity type* | 649 | Obesity | 99 | (15.3) |
| | | Smoking | 59 | (9.1) |
| | | Other cancer | 132 | (20.3) |
| | | Other | 527 | (81.2) |
| Upper body radiation exposure | 1560 | Yes | 45 | (2.9) |
| | | No | 1456 | (93.3) |
| | | Unknown | 59 | (3.8) |
| Previous thyroid surgery | 1560 | Yes | 62 | (4.0) |
| | | No | 1469 | (62.3) |
| | | Unknown | 29 | (1.9) |

*Multiple responses allowed, row percentages of total shown.

A patient's thyroid function is assessed at their first presentation to a surgeon prior to diagnosis. Of the 1560 participants with complete data, 1252 (80.3%) presented with a normal functioning thyroid gland (euthyroid), 101 had treated thyrotoxicosis (6.5%), 72 had treated hypothyroidism (4.6%), 44 had subclinical thyrotoxicosis (2.8%), 12 had untreated thyrotoxicosis (0.8%) and 13 had subclinical hypothyroidism (0.8%) (Figure 6).

*FIGURE 6* THYROID FUNCTION AT FIRST PRESENTATION (N=1560)




## Diagnostic Tests

A total of 1442 out of 1560 participants (92.4%) had an ultrasound prior to diagnosis. Suspicious lymph nodes were present on ultrasound for 168 out of 1442 participants (11.7%). Of the 1560 participants with fine needle aspiration (FNA) information recorded, 1393 (89.3%) underwent a FNA biopsy, of these 1108 (79.5%) had one site biopsied, 225 (16.2%) had two sites, 34 (2.4%) had three sites and 26 (1.9%) with an unknown number of sites biopsied.

Figure 7 displays the type of preoperative tests conducted and the percentage of patients who underwent each test.

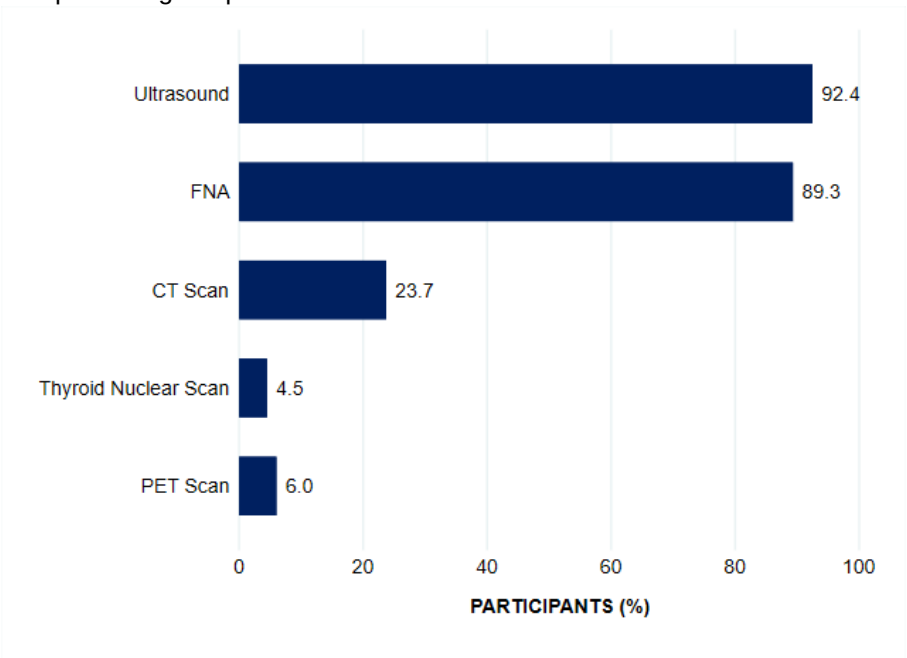



*FIGURE 7* PREOPERATIVE TESTS

## CQI1: Ultrasound

Indicator: Proportion of patients with clinical suspicion of thyroid cancer who had a neck ultrasound prior to surgery and/or treatment.

Numerator: Number of patients with clinical suspicion of thyroid cancer who had a neck ultrasound performed preoperatively.

Denominator: All patients with suspicion of thyroid cancer.

Exclusions: No exclusions.

Outcome: 98.5%

Preoperative neck ultrasound aids in the identification of suspicious lymph nodes and assists with decision making about which nodules to perform FNA on consistently increasing the yield of diagnostic FNA cytology[4]. Of the 1191 participants with complete data who had suspicion of thyroid cancer, 1173 (98.5%) underwent an ultrasound of the neck prior to any treatment. Table 4 demonstrates the calculation for this indicator.

*TABLE 4* ULTRASOUND OF PRIMARY SITE (CQI1)

| Variable | Total (n) | Response | Frequency (%) | |
|---|---|---|---|---|
| Ultrasound at primary site | 1191 | Yes | 1173 | (98.5) |
| | | No | 18 | (1.5) |
| | | Unknown | 40 | |

*40 participants were unknown and not included in the CQI calculation

## CQI2: Fine Needle Aspiration (FNA)

Indicator: Proportion of patients with clinically and/or radiologically suspicious lymph nodes that underwent a biopsy to confirm malignancy before the initiation of treatment.

Numerator: Number of patients with suspicious lymph nodes who underwent a biopsy.

Denominator: All patients with clinically and/or radiologically suspicious lymph nodes.

Exclusions: Patients who did not have suspected malignancy.

Outcome: 96.4%

Preoperative FNA cytology confirms malignancy and informs the management of patients with thyroid cancer to ensure appropriate treatment is delivered[4]. Of the 1555 participants with complete data, 198 (12.7%) had suspected malignancy and presented with clinical and/or radiological suspicious lymph nodes. Of these 197 (1 unknown), 190 (96.4%) went on to have a FNA biopsy to confirm malignancy prior to any treatment. Table 5 provides an overview of the calculations for this indicator.

*TABLE 5* FNA TO CONFIRM MALIGNANCY (CQI2)

| Variable | Total (n) | Response | Frequency (%) | |
|---|---|---|---|---|
| Clinically and/or radiologically suspicious lymph nodes and suspected malignancy | 1555 | Yes | 198 | (12.7) |
| | | No | 1336 | (85.9) |
| | | Unknown | 21 | (1.4) |
| If yes, FNA to confirm malignancy | 197* | Yes | 190 | (96.4) |
| | | No | 7 | (3.6) |
| | | Unknown | 1 | |

*One participant was unknown and not included in the CQI calculation

## Voice Assessment

Voice alteration is an important complication of thyroid surgery affecting patients' quality of life. Preoperative voice assessment provides a necessary baseline reference and is important for planning the extent of surgery and perioperative airway management.[4] It may also lead to the identification of preoperative vocal cord paralysis or paresis, providing evidence of invasive thyroid malignancy[4].

### CQI3: Voice Assessment

| | |
|---|---|
| Indicator: | Proportion of patients with suspicion of thyroid cancer that present with (subjective or objective) evidence of voice abnormality who underwent a laryngeal examination prior to surgery and/or treatment. |
| Numerator: | Number of patients that present with a voice abnormality who undergo a laryngeal examination preoperatively. |
| Denominator: | All patients that present with a voice abnormality. |
| Exclusions: | No exclusions. |
| Outcome: | 84.2% |

Of the 1555 participants with complete data, 48 (3.1%) had evidence of subjective or objective voice abnormality prior to diagnosis. Of these, a laryngeal exam was performed prior to any treatment for 32(84.2%) out of 38 (10 unknown) participants, with 21 (65.6%) returning a normal result, three (9.4%) indicating right palsy, six (18.8%) left palsy and two (6.3%) other.

*TABLE 6* PREOPERATIVE VOICE ASSESSMENT (CQI3)

| Variable | Total (n) | Response | Frequency (%) |
|---|---|---|---|
| Evidence of subjective or objective voice abnormality | 1555 | Yes | 48 (3.1) |
| | | No | 1319 (84.8) |
| | | Unknown | 188 (12.1) |
| If yes, laryngeal exam | 38* | Yes | 32 (84.2) |
| | | No | 6 (12.5) |

*10 participants were unknown and not included in the CQI calculation

## PROCEDURES CAPTURED BY THE REGISTRY

### Primary procedure

Of the 1555 participants with initial procedure information, 843 had a total thyroidectomy (54.2%), 614 (39.5%) a hemithyroidectomy, 15 (1.0%) an isthmusectomy, 14 (0.9%) a nodulectomy, 18 (1.2%) a completion thyroidectomy, 2 (0.1%) a redo-thyroidectomy unilateral, 5 (0.3%) a sub-total thyroidectomy, 33 (2.1%) another procedure type not listed and 11 (0.7%) unknown. The main reason for surgery was malignancy (42.4%) followed by risk of malignancy (37.1%) (Table 7).

Figure 8 outlines the type of procedure initially performed on patients in the registry.

*FIGURE 8* TYPE OF INITIAL PROCEDURE (N=1555)

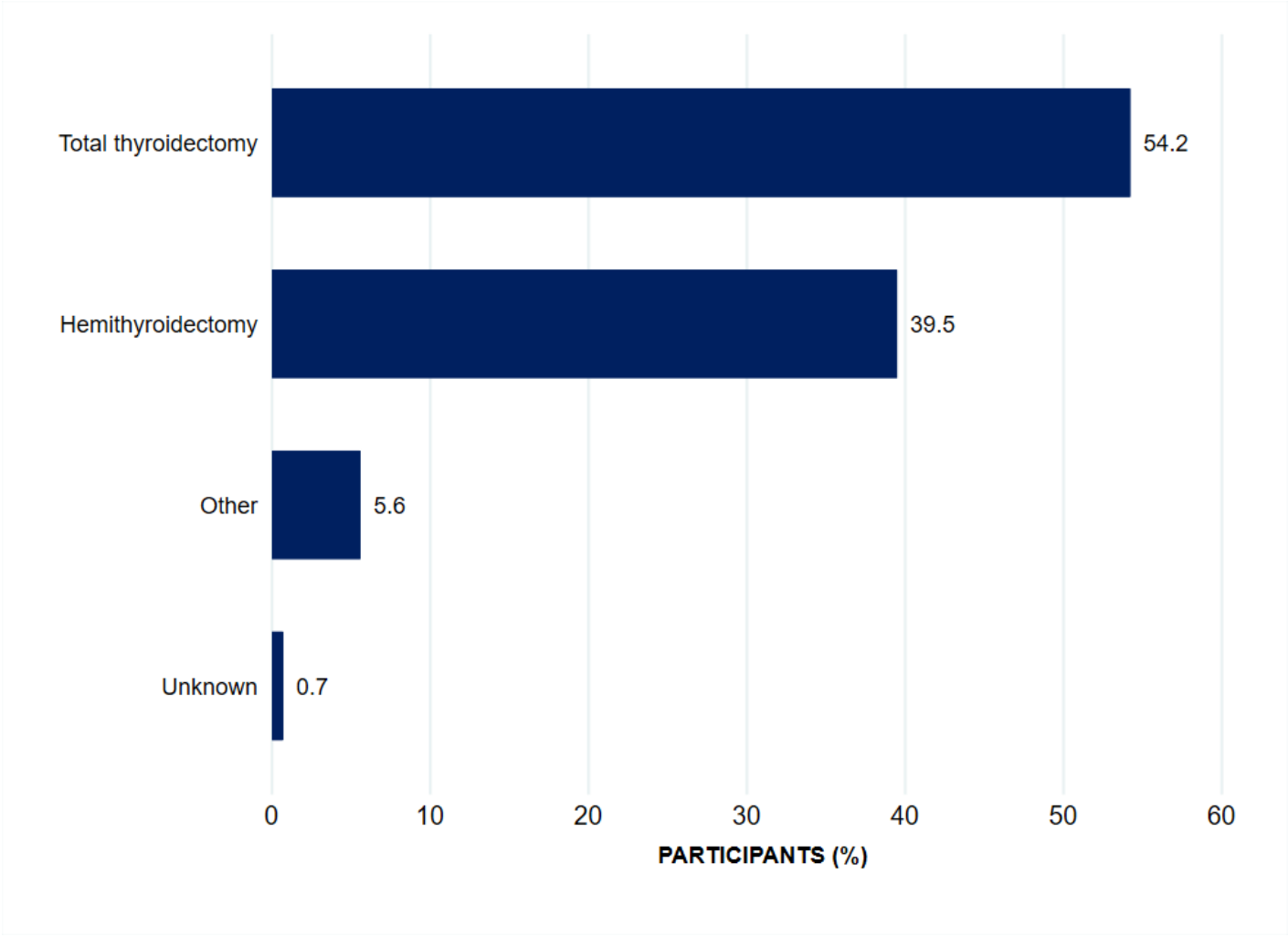



*TABLE 7* REASONS FOR INITIAL PROCEDURE (N=1555)

| Reason for Procedure* | Frequency | % |
|---|---|---|
| Malignancy | 659 | 42.4 |
| Risk of malignancy | 577 | 37.1 |
| Compression | 181 | 11.6 |
| Other | 74 | 4.8 |
| Graves' disease | 62 | 4.0 |
| Retrosternal goitre | 55 | 3.5 |
| MNG toxic | 44 | 2.8 |
| Growth | 50 | 3.2 |
| MNG nontoxic | 46 | 3.0 |
| Single nodule nontoxic | 75 | 4.8 |
| Single nodule toxic | 14 | 0.9 |
| Unknown | 14 | 0.9 |

*Multiple responses were allowed for this data item, row percentages of total shown.

**CQI4: Extent of Surgery**

Indicator: Proportion of patients with differentiated thyroid cancer who had a tumour size >4 cm or advanced disease (extrathyroidal extension and/or metastatic disease) and underwent a total thyroidectomy (one- or two-stage including completion thyroidectomy).

Numerator: Number of patients with differentiated thyroid cancer who have advanced disease or tumour >4 cm who undergo a total thyroidectomy (one- or two-stage including completion thyroidectomy).

Denominator: All patients with differentiated thyroid cancer who have advanced disease (extrathyroidal extension and/or metastatic disease) or tumour >4 cm.

Exclusions: No exclusions.

Outcome: 98.7%

Extent of initial thyroid surgery can impact disease-specific survival for patients with advanced disease of primary thyroid carcinoma that is greater than 4 cm, as a total (or near-total) thyroidectomy is necessary for the provision of radioactive iodine therapy postoperatively[4]. Of the 1555 participants with surgical information recorded, 628 (40.4%) had advanced differentiated thyroid cancer or a tumour size greater than 4 cm. Of the 521* where details of thyroid surgery were recorded, 514 (98.7%) had a total (or near-total) thyroidectomy. Of the 1555 with tumour size information, 495 (31.8%) had a tumour size of <1 cm, 860 (55.3%) 1-4 cm, 179 (11.5%) >4 cm and 21 (1.4%) unknown.

*TABLE 8* TOTAL (OR NEAR-TOTAL) THYROIDECTOMY FOR PATIENTS WITH ADVANCED DISEASE (CQI4)

| Variable | Total (n) | Response | Frequency (%) |
|---|---|---|---|
| Differentiated thyroid cancer with advanced disease or tumour >4 cm | 1555 | Yes | 628 (40.4) |
| | | No | 917 (59.0) |
| | | Unknown | 10 (0.6) |
| If yes, total (or near total) thyroidectomy (CQI4) | 521* | Yes | 514 (98.7) |
| | | No | 7 (1.3) |
| | | Unknown | 107 |

*107 participants were unknown and were not included in the CQI calculation

**Subsequent procedure(s)**

Of the 1531 participants with complete procedure data, 272 participants (17.8%) recorded a subsequent procedure. The main subsequent procedure was a completion thyroidectomy (82.7%).

*TABLE 9* SUBSEQUENT PROCEDURE TYPE (N=272)

| Variable | Frequency (%) |
|---|---|
| Total thyroidectomy | 11 (4.0) |
| Hemithyroidectomy | 2 (0.7) |
| Completion Thyroidectomy | 225 (82.7) |
| Other | 30 (11.0) |
| Nodulectomy | 1 (0.4) |
| Unknown | 3 (1.1) |

### Lymph node dissection

Of the 1555 participants with initial procedure data, 1486 had known lymph node dissection information.

A total of 785 out of 1486 (52.8%) participants had a lymph node dissection (data missing for 69 participants). Of these, where it was known, it was therapeutic in 178 (22.7%), and prophylactic in 533 (67.9%) these are probably all central, see Table 11 for details. Of the 580 participants who had an initial hemithyroidectomy, 226 (36.8%) had a lymph node dissection. Malignancy was reported in 158 out of 178 (88.8%) participants who underwent a therapeutic dissection and 221 out of 533 (41.5%) who underwent a prophylactic dissection.

*TABLE 10* LYMPH NODE DISSECTION BY INITIAL PROCEDURE TYPE (N=1486*)

| Procedure Type | Yes, N (%) | | No, N (%) | |
|---|---|---|---|---|
| Total-thyroidectomy | 522 | (61.9) | 290 | (34.4) |
| Hemithyroidectomy | 226 | (36.8) | 354 | (57.7) |
| Isthmusectomy | 4 | (26.9) | 11 | (73.3) |
| Redo-thyroidectomy | 2 | (100.0) | 0 | (0.0) |
| Completion | 1 | (5.6) | 15 | (83.3) |
| Nodulectomy | 2 | (14.3) | 12 | (85.7) |
| Subtotal-thyroidectomy | 3 | (60.0) | 2 | (40.0) |
| Other | 23 | (69.7) | 10 | (30.3) |
| Unknown | 2 | (18.2) | 7 | (63.6) |
| **Total** | **785** | **(52.8)** | **336** | **(46.4)** |

*69 with initial procedure data with unknown lymph node dissection

### CQI5: Lateral Lymph Node Dissection

| | |
|---|---|
| Indicator: | Proportion of patients with thyroid cancer who undergo surgery with therapeutic compartmental lateral neck lymph node dissection due to cytological proven lateral lymph node involvement. |
| Numerator: | Number of patients with thyroid cancer with cytological proven lateral lymph node involvement who had a therapeutic compartmental lateral neck lymph node dissection. |
| Denominator: | All patients with thyroid cancer with cytological or core biopsy proven lateral lymph node involvement who had surgery. |
| Exclusions: | Patients who have had a central lymph node dissection, without a lateral lymph node dissection. (N=16) |
| Outcome: | 92.5% |

Compartmental lymph node dissection can reduce the risk of recurrence and, potentially, mortality for patients where nodal disease is evident[4]. A lymph node dissection was performed in 785 out of 1555 participants (50.5%), with 178 (22.7%) of these being classified as a therapeutic lymph node dissection. A further 57 out of the 178 (32.0%%) participants had cytologically confirmed malignancy, or suspicion of malignancy. Of 40 patients with confirmed cytologically malignant lateral lymph nodes, 37 (92.5%) had a lateral lymph node dissection.

*TABLE 11* THERAPEUTIC LYMPH NODE DISSECTION (CQI5)

| Variable | Total (n) | Response | Frequency (%) | |
|---|---|---|---|---|
| Lymph node dissection | 1555 | Yes | 785 | (50.6) |
| | | No | 701 | (45.1) |
| | | Unknown | 69 | (4.4) |
| Type of dissection | 785 | Therapeutic | 178 | (22.7) |
| | | Prophylactic | 533 | (67.9) |
| | | Unknown | 76 | (9.7) |
| Clinical lymph node involvement confirmed cytologically | 1555 | Yes | 57 | (3.7) |
| | | No | 1419 | (91.3) |
| | | Unknown | 79 | (5.1) |
| If yes, lateral lymph node dissection | 40* | Yes | 37 | (92.5) |
| | | No | 3 | (7.5) |
| | | Unknown | 1 | |

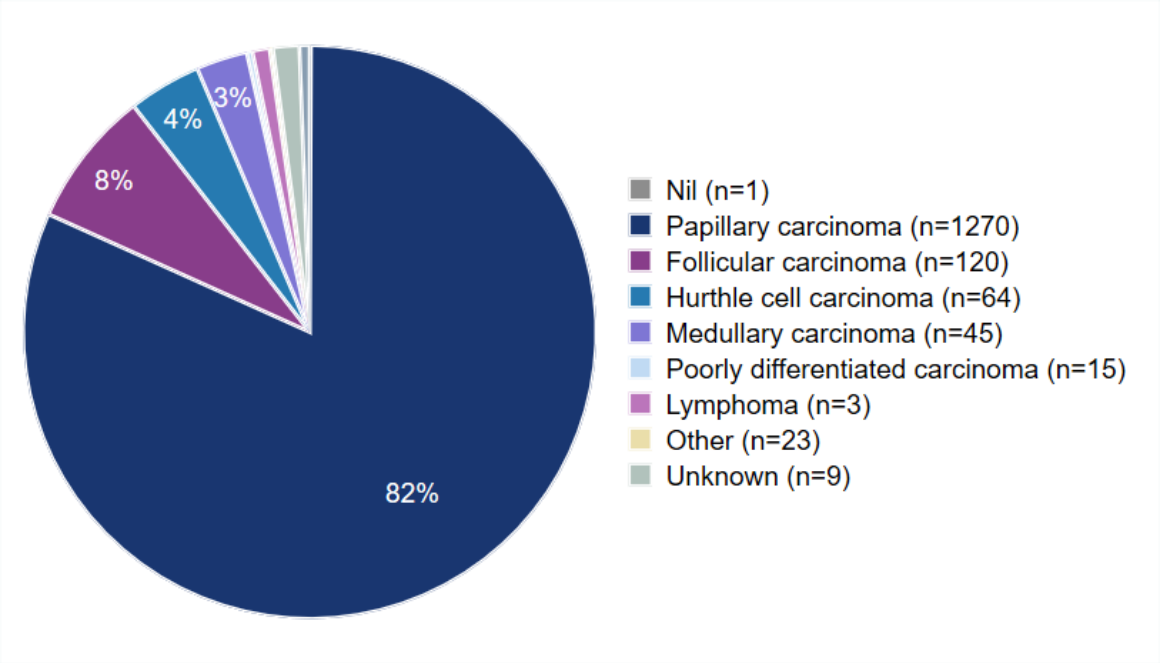
*16 participants with a central lymph node dissection without a lateral lymph node dissection excluded from denominator.

#One participant was unknown and was not included in the CQI calculation.

## Pathology

Of the 1555 participants with complete pathology information, 1270 (81.7%) had papillary carcinoma, 120 (7.7%) follicular cell carcinoma, 64 (4.1%) hürthle cell carcinoma, 45 (2.9%) medullary carcinoma, 15 (1.0%) poorly differentiated carcinoma and three (0.2%) lymphoma (Figure 9).

*FIGURE 10* PATHOLOGY OF PRIMARY TUMOUR (N=1555)




An incidental finding of cancer was observed for 446 out of 1555 (28.7%) of participants in the registry undergoing an initial procedure, see Table 12 for additional pathology features.

*TABLE 12* ADDITIONAL PATHOLOGY FEATURES

| Variable | Total (n) | Response | Frequency (%) |
|---|---|---|---|
| Incidental findings of cancer | 1555 | Yes | 446 (28.7) |
| | | No | 1060 (68.2) |
| | | Unknown | 49 (3.2) |
| Histological margin status | 1555 | Residual tumour cannot be assessed (RX) | 7 (0.5) |
| | | No residual tumour (R0) | 1265 (81.4) |
| | | Microscopic residual tumour (R1) | 213 (13.7) |
| | | Unknown | 70 (4.5) |
| Residual tumour at surgery | 1555 | Residual tumour cannot be assessed (RX) | 105 (6.8) |
| | | No residual tumour (R0) | 1273 (81.9) |
| | | Macroscopic residual tumour (R2) | 41 (2.6) |
| | | Unknown | 136 (18.7) |
| Multifocal cancer | 1555 | Yes | 477 (30.7) |
| | | No | 925 (59.5) |
| | | Unknown | 153 (9.8) |
| Lymphovascular invasion | 1555 | Yes | 368 (23.7) |
| | | No | 1103 (70.9) |
| | | Unknown | 84 (5.4) |
| Extrathyroidal extension | 1555 | Sternothyroid muscle | 216 (13.9) |
| | | Subcutaneous soft tissues | 41 (2.6) |
| | | Prevertebral fascia | 5 (0.3) |
| | | No | 1158 (74.5) |
| | | Unknown | 135 (8.7) |

Of the 1555 participants with complete data, 477 (30.7%) were reported to have multifocal cancer with the site of the multifocality reported in the right lobe for 151 (31.6%) participants, in the left lobe for 87 (18.2%) participants, in both lobes for 235 (49.2%) participants and unknown in five (1.0%) participants. Extrathyroidal extension and lymphovascular invasion were observed in 262 (16.8%) and 368 (23.7%) of the 1555 participants, respectively. Microscopic residual tumour (R1) was pathologically identified in 213 out of 1555 (13.7%) participants and macroscopic residual tumour (R2) reported for 41 out of 1555 (2.6%) participants.

### Metastatic Disease

Lymph node metastases were reported in 465 out of 1555 (29.9%) participants undergoing initial procedure, and distant metastases were reported in 18 out of 1555 (1.2%) participants. A single distant metastasis was reported in 13 participants, two in the bone, ten in the lung and one not specified, two distant metastases were reported in four participants, three with one in the bone and one with one in the lung and the other with one in the bone and the other not specified, and three distant metastases were reported in one participant, in the bone, lung and liver.

### Recurrent Laryngeal Nerve

During surgery, the recurrent laryngeal nerve (RLN) on the right remained intact for 1230/1236 (99.5%) participants, was damaged in four (0.3%) participants and was sacrificed to clear tumour in two (0.2%) participants. The RLN on the left remained intact for 1128/1139 (99.0%) participants, was damaged in six (0.5%) participant and sacrificed to clear tumour in five (0.4%) participants. During the initial procedure for 1555 participants, 1166 (75.0%) had nerve integrity monitoring used, with a loss of signal reported for the left RLN in 31 participant procedures (2.7%) and in the right RLN for 24 procedures (2.1%) (data unknown for 21 participants).

*TABLE 13* RLN MONITORING DURING INITIAL PROCEDURE

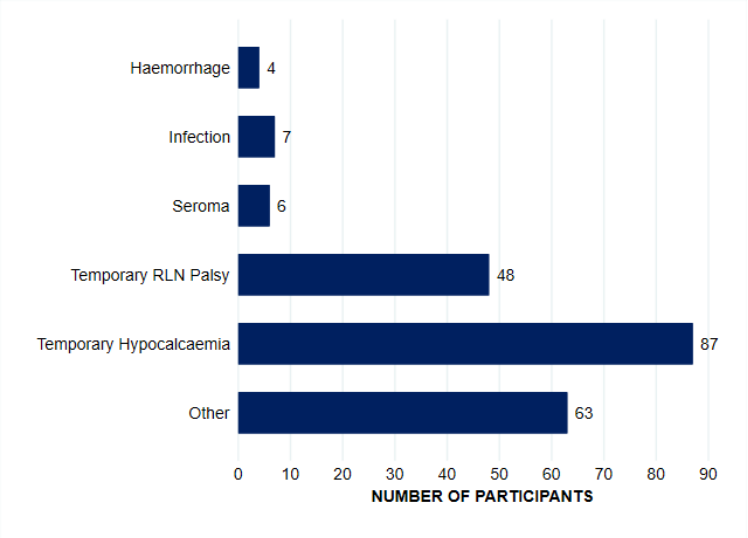
| Variable | Total (n) | Response | Frequency (%) |
|---|---|---|---|
| RLN Right | 1236* | Intact | 1230 (99.5) |
| | | Damaged | 4 (0.3) |
| | | Sacrificed | 2 (0.2) |
| RLN Left | 1139^ | Intact | 1128 (99.0) |
| | | Damaged | 6 (0.5) |
| | | Sacrificed | 5 (0.4) |
| Nerve integrity monitoring used | 1555 | Yes | 1166 (75.0) |
| | | No | 306 (19.7) |
| | | Unknown | 83 (5.3) |

*9 patients not seen, 231 not applicable and 32 unknown.
^19 patients not seen, 309 not applicable and 32 unknown.

### Complications from Surgery

Complications were recorded in a small number of patients at 90-days following the initial procedure. Complications included temporary hypocalcaemia (5.6%), temporary RLN palsy (3.1%), haemorrhage (return to theatre within 48 hours) (0.2%), infection (0.5%), and seroma (0.4%) (Figure 10).

*FIGURE 10* SURGICAL COMPLICATIONS FOLLOWING INITIAL PROCEDURE (N=1555)



### CQI6: Temporary Recurrent Laryngeal Nerve (RLN) Palsy

Indicator: Proportion of patients with thyroid cancer who presented with temporary RLN palsy that has not resolved within 3-months following thyroidectomy.

Numerator: Number of patients with thyroid cancer who present with temporary RLN palsy that has not resolved within three months following thyroidectomy.

Denominator: All patients with thyroid cancer who had a thyroidectomy (all procedure types including other and unknown from initial and subsequent procedures).

Exclusions: Patients with any RLN sacrificed (N=5).

Rate: 3.4%*#

*This rate reflects RLN palsy in the early postoperative period. The data item will be updated to record persisting RLN palsy at 3- and 6-months post-surgery and will be reported in future annual reports.

#The denominator for this indicator is different in-text for RLN Palsy as it excludes those with RLN sacrificed.

### CQI7: Temporary Hypoparathyroidism (Hypocalcaemia)

Indicator: Proportion of patients with thyroid cancer who present with persisting hypoparathyroidism at 3 months following thyroidectomy, as evidence by need for ongoing calcium and/or vitamin D.

Numerator: Number of patients with thyroid cancer who present with hypoparathyroidism as evidenced by need for ongoing calcium and/or vitamin D, at 3-months post-thyroidectomy.

Denominator: All patients with thyroid cancer who had a total or completion thyroidectomy.

Exclusions: No exclusions.

### CQI8: Haemorrhage Requiring Return to Theatre

Indicator: Proportion of patients with thyroid cancer who underwent a thyroidectomy and had postoperative haemorrhage within 48 hours requiring return to theatre following thyroidectomy.

Numerator: Number of patients with thyroid cancer who have postoperative haemorrhage within 48-hours requiring return to theatre following thyroidectomy.

Denominator: All patients with thyroid cancer who had a thyroidectomy (all procedure types including other and unknown).

Exclusions: No exclusions.

Rate: 0.3%

The rates of these complications are similar to those reported in the literature. The mean incidence of temporary RLN palsy for all thyroid surgery is 9.8% in the literature, while our rate in patients with cancer only was lower at 3.4%[5]. The literature has shown that temporary hypoparathyroidism, resulting in hypocalcaemia, occurs in approximately 19-38% of patients undergoing total thyroidectomy[6]. Unfortunately, we were unable to determine an accurate rate of temporary hypoparathyroidism in the registry as we were unable to ascertain whether calcium supplementation was being reported in the immediate postoperative period or at 3-months post-surgery. Hemorrhage has been reported to occur in approximately 0.6-2.9% of patients undergoing thyroid surgery, while our rate is lower at 0.3%[8]. Permanent complications are less common and require presentation at 6-months post-surgery, but the registry currently does not collect this data. However, the 6-month follow-up data will be collected in the future.

*TABLE 14* SURGICAL COMPLICATIONS FOLLOWING PROCEDURE (CQI6 & 8)

| Variable | Total | Response | Frequency (%) |
|---|---|---|---|
| Temporary RLN palsy (CQI6) | 1442* | Yes | 49 (3.4) |
| | | No | 1393 (96.6) |
| | | Unknown | 7 |
| Haemorrhage requiring return to theatre (CQI9) | 1542^ | Yes | 5 (0.3) |
| | | No | 1573 (99.7) |
| | | Unknown | 12 |

*Seven participants were unknown and were not included in the CQI calculation

^12 participants were unknown and were not included in the CQI calculation

## POSTOPERATIVE DETAILS CAPTURED BY THE REGISTRY

### Staging & Treatment Planning

Staging to describe extent of disease progression for thyroid cancer patients uses the American Joint Committee on Cancer (AJCC) TNM Cancer Staging Manual, Eighth Edition[8].

### CQI9: Postoperative Tumour, Node, Metastasis (TNM) Staging

| | |
|---|---|
| Indicator: | Proportion of patients with thyroid cancer who have staging recorded postoperatively using the TNM staging system. |
| Numerator: | Number of patients with thyroid cancer with TNM staging recorded. |
| Denominator: | All patients with thyroid cancer. |
| Exclusions: | No exclusions. |
| Compliance: | 75.6% |

Postoperative TNM staging for thyroid cancer, as for other cancer types, is used to provide prognostic information, enable risk-stratified description of patients, and for research purposes[4]. Of the 1520 participants with staging details recorded, 1149 (75.6%) had complete TNM staging recorded.

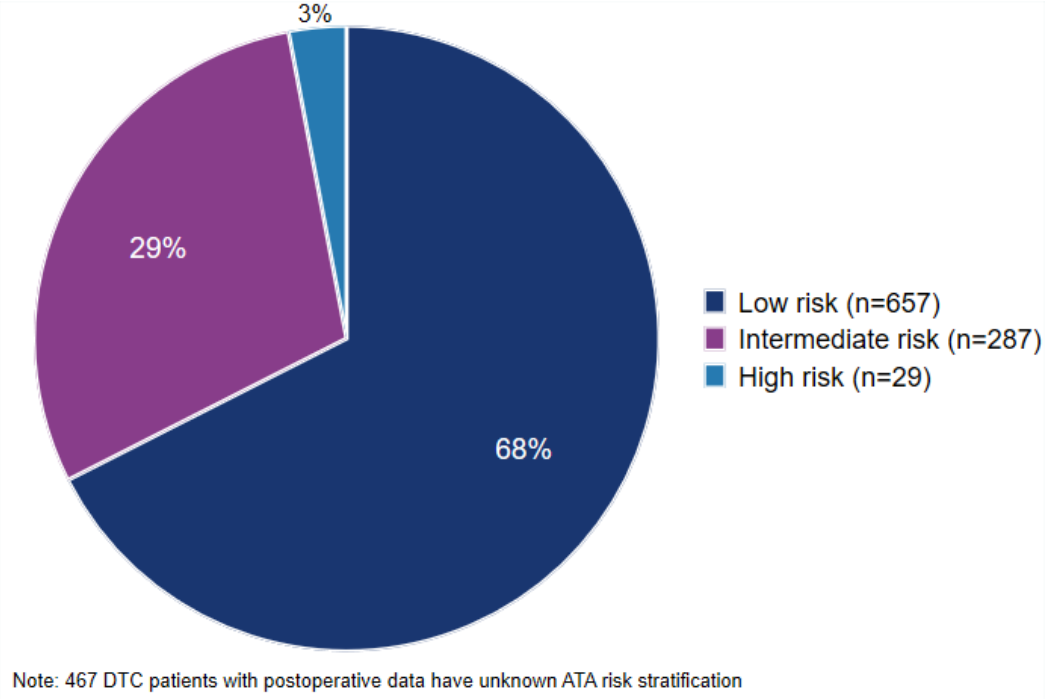
*TABLE 15* TNM STAGING RECORDED (CQI9)

| Variable | Total (n) | Response | Frequency (%) |
|---|---|---|---|
| TNM staging recorded | 1520 | Yes | 1149 (75.6) |
| | | No | 371 (24.4) |
| | | Unknown | 3 |

*Three participants were unknown and were not included in the CQI calculation

For participants with differentiated thyroid cancer for whom TNM staging was available (N=973), patients were stratified by risk of structural disease recurrence according to the American Thyroid Association (ATA) guidelines[4], with 657 (67.5%) patients being classified as low risk, 287 (29.5%) as intermediate risk and 29 (3.0%) as high risk of disease recurrence.

*FIGURE 11* ATA RISK STRATIFICATION (N=973)



### CQI10: Multi-disciplinary Team (MDT) Meeting

Indicator: Proportion of patients with thyroid cancer who were presented at a tumour-specific MDT meeting.
Numerator: Number of patients with thyroid cancer reviewed at a MDT meeting.
Denominator: All patients with thyroid cancer.
Exclusions: Patients with tumour size <1 cm (unless N1a, N1b or M1 staged).
Outcome: 62.0%

Evidence suggests that patients with cancer managed by an MDT have a better outcome[4]. As a result of this, tumour-specific MDT meetings are regularly held within each site or health service. Of the 970* participants with complete data and tumour size greater than 1 cm, 601 (62.0%) were presented at a thyroid cancer specific MDT meeting.

*135 unknown responses were not included in the calculation

*TABLE 16* PRESENTATION AT MDT MEETING (CQI10)

| Variable | Total (n) | Response | Frequency (%) |
|---|---|---|---|
| Presented at MDT | 1541 | Yes | 701 (45.5) |
| | | No | 651 (42.2) |
| | | Unknown | 189 (12.3) |
| Presented at MDT meeting with tumour size >1 cm | 970* | Yes | 601 (62.0) |
| | | No | 369 (38.0) |
| | | Unknown | 135 |

*135 participants were unknown and were not included in the CQI calculation

### Supplementation & Therapy

In the postoperative period, 676 of 1086 participants who had a total or completion thyroidectomy were receiving thyroxine therapy (62.2%), with 50 (4.6%) having supplementation, 319 (29.4%) replacement and 307 (28.3%) suppression. Furthermore, in the early postoperative period, 912 out of 1541 (59.2%) were receiving supplementation with calcium and 182 out of 1541 (11.8%) receiving supplementation with activated vitamin D (Table 17).

*TABLE 17* POSTOPERATIVE SUPPLEMENTATION & THERAPY

| Variable | Total (n) | Response | Frequency (%) |
|---|---|---|---|
| Supplementation with calcium | 1541 | Yes | 912 (59.2) |
| | | No | 571 (37.1) |
| | | Unknown | 58 (3.8) |
| Supplementation with vitamin D | 1541 | Yes | 182 (11.8) |
| | | No | 1302 (84.5) |
| | | Unknown | 57 (3.7) |
| Supplementation with thyroxine (total/ completion thyroidectomy) | 1086 | No | 49 (4.5) |
| | | Supplementation | 50 (4.6) |
| | | Replacement | 319 (29.4) |
| | | Suppression | 307 (28.3) |
| | | Unknown | 361 (33.2) |

## Postoperative Treatment

Postoperative thyroglobulin (Tg) was recorded for 734 out of 1362 (53.9%) participants. Of the 1362 participants with complete data, 455 (33.4%) had radioactive iodine (RAI) remnant ablation (RRA) following surgery. The main reasons for not having RRA were that the participant was classified as low risk according to the ATA risk stratification (73.3%) or that the participant had a micropapillary thyroid cancer (<20mm) (60.8%). For more details see Table 18 below.

*TABLE 18* POSTOPERATIVE TREATMENT DETAILS

| Variable | Total (n) | Response | Frequency (%) | |
|---|---|---|---|---|
| Postoperative Tg recorded | 1362 | Yes | 734 | (53.9) |
| | | No | 436 | (32.0) |
| | | Unknown | 192 | (14.1) |
| RRA following thyroid surgery | 1362 | Yes | 455 | (33.4) |
| | | No | 769 | (54.5) |
| | | Unknown | 138 | (10.1) |
| If no, reason for no RRA* | 769 | PTC ≤10mm | 342 | (44.5) |
| | | PTC 11-20mm | 123 | (16.0) |
| | | Hemithyroidectomy only | 88 | (11.4) |
| | | Patient age | 8 | (1.0) |
| | | Low risk | 564 | (73.3) |
| | | Comorbidities | 24 | (3.1) |
| | | Patient declined | 16 | (2.1) |
| | | MTC | 3 | (0.4) |
| | | Other | 45 | (5.9) |
| | | Unknown | 22 | (2.9) |

*Multiple responses were allowed, row percentages of total shown.

### CQI11: Serum thyroglobulin (Tg)

| | |
|---|---|
| Indicator: | Proportion of patients with differentiated thyroid cancer that underwent a total (or completion) thyroidectomy and have serum Tg recorded postoperatively. |
| Numerator: | Number of patients that underwent total thyroidectomy for differentiated thyroid cancer and had serum Tg recorded postoperatively. |
| Denominator: | All patients with differentiated thyroid cancer that underwent a total thyroidectomy. |
| Exclusions: | No Exclusions. |
| Outcome: | 73.9% |

Research has shown that the recording serum Tg levels postoperatively, prior to RAI therapy, can assist in assessing persistent disease and the probability of recurrent disease[4]. Of the 825* participants with differentiated thyroid cancer who underwent a total thyroidectomy, 610 (73.9%) had serum Tg recorded postoperatively. This figure may be low as the ANZTCR is a surgeon-based registry and surgeons may not be able to access this information, or it may not be available at 90-days post-diagnosis.

### CQI12: Radioactive Iodine (RAI)

| | |
|---|---|
| Indicator: | Proportion of patients with high-risk differentiated thyroid cancer that underwent RAI remnant ablation (RRA) following a total (or completion) thyroidectomy. |
| Numerator: | Number of patients with high-risk differentiated thyroid cancer that underwent a total (or near total) thyroidectomy and received RRA. |
| Denominator: | All patients with high-risk differentiated thyroid cancer that had total thyroidectomy. |
| Exclusions: | Patients with differentiated thyroid cancer who are classified as low and/or intermediate risk according to the ATA risk stratification. |
| Outcome: | 100.0% |

The postoperative administration of RAI after total (or completion) thyroidectomy can facilitate the detection of recurrent disease, treat persistent disease in high risk patients and improve disease-specific and disease-free survival[4]. Currently in the registry there are only 12 participants who were diagnosed with high-risk differentiated thyroid cancer and underwent a total or completion thyroidectomy, with all 12 of these participants receiving RRA therapy postoperatively. For more details please see Table 19.

*TABLE 19* POSTOPERATIVE TREATMENT (CQI11 & 12)

| Variable | Total (n) | Response | Frequency (%) | |
|---|---|---|---|---|
| Total/completion thyroidectomy and not medullary/ anaplastic thyroid cancer | 1361 | Yes | 895 | (65.8) |
| | | No | 466 | (34.2) |
| | | Unknown | 0 | (0.0) |
| If yes, serum Tg reported | 825* | Yes | 610 | (73.9) |
| | | No | 105 | (24.2) |
| | | Unknown | 70 | |
| High-risk differentiated thyroid cancer and a total/completion thyroidectomy | 1361 | Yes | 23 | (1.7) |
| | | No | 1338 | (98.3) |
| | | Unknown | 0 | (0.0) |
| If yes, RAI | 23 | Yes | 23 | (100.0) |
| | | No | 0 | (0.0) |
| | | Unknown | 0 | (0.0) |

*70 participants were unknown and were not included in the CQI calculation.

# PATIENT-REPORTED MEASURES (PRMs) – INITIAL PILOT STUDY

## RESPONSE RATE

As at August 31st 2021, there were 1247 participants registered in the ANZTCR from 29 sites across NSW, QLD, and VIC. Of the 1247 ANZTCR participants, there were 141 eligible participants who were 3-, 6- and 12-months post-diagnosis (give or take one-month either side).

One participant was excluded due to needing an English interpreter. There were three participants with no email or mobile number recorded in the ANZTCR. They were called on their home phone number and informed of the study. Of these three, one provided their email address in order to receive the PRM invitation and two declined to receive the invitation. A total of 138 participants were eligible to participate in this pilot study from across the three timepoints.

*TABLE 20* RESPONSE RATE OF PATIENT-REPORTED MEASURES

| Timepoints | Eligible Participants (N=138) | Participants (N=54) |
|---|---|---|
| 3-months | 29 | 14 (48.3) |
| 6-months | 53 | 18 (34.0) |
| 12-months | 56 | 22 (39.3) |

Of the 138 eligible participants, 29 were at 3-months, 53 were at 6-months, and 56 were at 12-months (see Table 20). All 138 eligible participants were invited to participate, with 130 (95.6%) sent a link to the PRM via text message and 8 (5.1%) via email.

Overall, a total of 54 (39.1%) participants completed the PRMs, 14/29 (48.3%) at 3-months, 18/53 (34.0%) at 6-months, and 22/56 (39.3%) at 12-months (Table 20). At the conclusion of the four-week period, following three-reminders, 81 (58.7%) participants did not respond, one (0.7%) participant left their questionnaire incomplete and two (1.4%) participants opted-out of PRMs by contacting the registry. Of those invited via text message (n=130), 46 participants completed the PRMs (35.4%) while all eight participants invited via email completed the PRMs (100%).

## PARTICIPANT CHARACTERISTICS

Of the 54 participants, 42 were female (77.8%) and 12 (22.2%) were male, with a mean age of 53.1 years (SD=15.2). More participants from private hospitals (n=41, 75.9%) completed the PRMs than those from public hospitals (n=13, 24.0%). There were the same number of participants that underwent a total thyroidectomy and hemi-thyroidectomy, (n=24, 44.4). There were two participants that underwent another form of surgery, and four others reported missing data on their surgery type.

The majority of the participants had PTC (n=43,82.6%), followed by FTC (n=4,7.7%) and MDTC (n=3,5.8%), no participants had ATC and data on pathology was missing for two participants. The participant characteristics are presented in Table 21.

*TABLE 21* PATIENT-REPORTED MEASURES PARTICIPANT CHARACTERISTICS

| Characteristic | Category | Total n (%) |
|---|---|---|
| Sex (N=54) | Male | 12 (22.2) |
| | Female | 42 (77.8) |
| Hospital type (N=54) | Public hospital | 13 (24.0) |
| | Private hospital | 41 (75.9) |
| Site state (N=54) | NSW | 42 (77.8) |
| | VIC | 8 (14.8) |
| | QLD | 4 (7.4) |
| Residential location (N=54) | Metropolitan | 46 (85.2) |
| | Rural | 8 (14.8) |
| Cancer Type (N=52) | Papillary | 43 (82.6) |
| | Follicular | 4 (7.7) |
| | Medullary | 3 (5.8) |
| | Other | 2 (3.8) |
| Cancer Stage (N=38) | Low risk | 20 (52.6) |
| | Intermediate risk | 17 (44.7) |
| | High risk | 1 (2.6) |
| Type of Surgery (N=50) | Total thyroidectomy | 24 (48.0) |
| | Partial/hemi-thyroidectomy | 24 (48.0) |
| | Other | 2 (4.0) |
| Radioactive Iodine (RAI) administered (N=54) | Yes | 16 (29.6) |
| | No | 38 (70.4) |
| Lymph node (LN) dissection (N=50) | Yes | 34 (68.0) |
| | No | 15 (30.0) |
| | Unknown | 1 (2.0) |

## QUALITY OF LIFE

Participants were asked to select from a Likert scale from 1 to 4, where 1 was ‘not at all, and 4 was ‘very much’. All of the scores range from 0-100. For functioning domains, a score closer to 100 suggests higher functioning, whereas a high score for the symptom domain represents higher level of symptom burden.

The overall quality of life (QOL) in this sample was generally good with a median of 75 out of 100 (IQR=50;83.3). The median scores at each timepoint ranged from 70-80, with a median score of 70.83 (IQR=66.7-83.3) at 3-months, 75.0 (IQR= 50;83.3) at 6-months and 83.3 (IQR=58.3;91.7) at 12-months.

Scores for functioning were also high, with the highest functioning scales being physical functioning (M=90, SD=15.4), role functioning (M=87, SD=18.1), and social functioning (M=82.4, SD=23.0). The lowest functioning scale was social support (M=24.7, SD=26.8). Scores for the symptom scales were generally low indicating low symptom burden in these participants. The symptom scales that had the highest overall scores, indicating greater burden to participants, were; fatigue, worry about others, insomnia, joint pain, voice concerns and fear of recurrence.

The EORTC-QLQ-C30 and THY34 scores as well as the distribution of the mean and standard deviation of the functioning and symptom domains are shown in Table 22 and 23.

*TABLE 22* EORTC-QLQ-C30 SCORES AT 3-, 6-, & 12-MONTHS

| EORTC-QLQ-C30 | 3 months (N=14) Mean (SD±) | 6 months (N=18) Mean (SD±) | 12 months (N=22) Mean (SD±) | Overall (N=54) |
|---|---|---|---|---|
| Physical functioning* | 93.8(±10.9) | 88.5(±17.8) | 92.2(±10.2) | 90(15.4) |
| Role functioning* | 88.1(±12.1) | 83.3(±22.9) | 90.9(±16.9) | 87.7(18.1) |
| Emotional Functioning* | 69.1(±17.2) | 74.1(±20.8) | 79.6(±22.7) | 75.2(20.8) |
| Cognitive functioning* | 62.9(±18.8) | 64.8(±24.6) | 67.6(±26.4) | 65.6(23.7) |
| Social functioning* | 78.6(±17.82) | 80.6(±23.0) | 86.4(±26.0) | 82.4(23.0) |
| Fatigue# | 27.0(±14.3) | 31.5(±25.92) | 30.8(±24.2) | 30.0(22.4) |
| Nausea/vomiting# | 7.14(±12.6) | 4.63(±9.6) | 1.5(±4.9) | 3.7(8.4) |
| Pain# | 10.7(±14.0) | 14.8(±15.0) | 11.4(±17.4) | 12.3(15.6) |
| Dyspnoea# | 16.7(±17.3) | 16.7(±20.6) | 19.7(±28.5) | 17.9(23.1) |
| Insomnia# | 31.0(±24.3) | 22.2(±30.3) | 31.8(±33.3) | 28.4(30.0) |
| Appetite loss# | 14.3(±21.5) | 11.1(±19.8) | 6.1(±16.7) | 9.9(19.0) |
| Constipation# | 26.2(v32.5) | 5.6(±12.8) | 18.2(±19.9) | 16.0(23.1) |
| Diarrhoea# | 4.8(±12.1) | 9.3(±19.2) | 10.6(±15.9) | 8.6(16.1) |
| Financial difficulties# | 21.4(±31.0) | 3.7(±10.8) | 6.1(±13.2) | 9.3(19.9) |
| Global Health/QOL^ | 73.8(±18.7) | 68.1(±21.8) | 74.6(±20.7) | 70.37(22.8) |

Footnote: *Functioning scales: A higher score out of 100 indicates higher function. #Symptom scales: A higher score out of 100 represents a higher level of symptom burden; ^QOL scales: A higher score out of 100 represents better QOL.

*TABLE 23* THY34 SCORES AT 3-, 6-, & 12-MONTHS

| EORTC-QLQ-THY34 | 3 months (N=14) Mean (SD±) | 6 months (N=18) Mean (SD±) | 12 months (N=22) Mean (SD±) | Overall (N=54) |
|---|---|---|---|---|
| Social support* | 19.0(±25.6) | 23.46(17.00) | 28.79(±17.1) | 24.7(26.8) |
| Fatigue# | 25.4(±20.2) | 33.3(±25.0) | 24.8(±28.7) | 27.8(25.3) |
| Discomfort in head/neck# | 31.0(±17.0) | 17.9(±15.8) | 16.2(±20.8) | 20.6(19.0) |
| Voice concerns# | 32.5(±24.8) | 24.7(±30.9) | 18.7(±27.3) | 24.3(28.0) |
| Hair problems# | 23.8(±27.5) | 25.0(±22.3) | 12.1(±20.7) | 19.4(23.5) |
| Swallowing# | 10.7(±14.0) | 3.7(±9.1) | 14.4(±23.17) | 9.9(17.6) |
| Dry mouth# | 14.3(±17.1) | 22.2(±34.3) | 21.2(±28.3) | 19.8(27.9) |
| Altered temperature# | 11.9(±21.1) | 16.7(±23.6) | 27.3(±33.6) | 19.8(27.9) |
| Body Image# | 11.9(±16.6) | 18.5(±26.1) | 12.1(±19.4) | 14.2(21.1) |
| Restlessness# | 22.6(±19.2) | 17.6(±14.54) | 15.9(±20.2) | 18.2(18.1) |
| Shoulder functioning# | 4.8(±12.1) | 3.7(±10.8) | 7.6(±14.3) | 5.6(12.5) |
| Fear of recurrence# | 24.6(±13.2) | 31.5(±23.6) | 18.2(±18.3) | 24.3(19.7) |
| Joint pain# | 23.8(±20.4) | 14.8(±17.0) | 36.4(±35.5) | 25.9(28.0) |
| Tingling or numbness# | 17.9(±17.9) | 7.4(±10.3) | 9.1(±13.3) | 11.1(14.1) |
| Cramps# | 16.7(±21.7) | 5.6(±12.8) | 21.2(±26.3) | 14.8(22.1) |
| Worry about others# | 43.5(±19.1) | 29.2(±22.2) | 21.2(±24.6) | 29.8(23.8) |
| Impact on job or education# | 23.8(±30.5) | 5.6(±12.8) | 9.1(±23.4) | 11.1(23.3) |

Footnote: *Functioning scales: A higher score out of 100 indicates higher function. #Symptom scales: A higher score out of 100 represents a higher level of symptom burden.

## EVALUATION SURVEY

Of the 54 participants who completed the PRMs, 40 participants completed the evaluation survey giving a response rate of 74.1%. The evaluation survey was completed by 9/14 participants at the 3-month time point, 15/18 participants at the 6-month time point, and 16/22 participants at the 12-month time point.

Responses to the survey were generally positive, see Table 24 below. Majority of all 40 participants (95%) found the PRMs “very easy” to complete and the instructions “very easy” to follow. Similarly, 38 (96%) participants found the length of the questionnaire to be appropriate and the remaining two (5%) were unsure. Overall, 27 (67.5%) of participants were satisfied with the questionnaire.

Interestingly, 38 participants (96%) stated they would prefer to complete the questionnaire online rather than over the phone or via hardcopy, while the remaining two (4%) had no preference. In terms of how frequently the participants would want to complete the questionnaire, responses were quite varied. Just under half of participants (n= 17, 42.5%) would prefer to complete the PRMs every 6-months, while nine (22.5%) would be happy to complete it every three months and seven (17.5%) responded every month.

*TABLE 24* PATIENT-REPORTED MEASURES PARTICIPANT CHARACTERISTICS

| PRM Evaluation Question | Responses | N(%) | |
|---|---|---|---|
| How easy was it to complete the questionnaire? (N=40) | Very Easy | 38 | (95.0) |
| | Somewhat Easy | 1 | (2.5) |
| | Neither Easy nor Hard | 1 | (2.5) |
| | Somewhat Difficult | 0 | (0.0) |
| | Very Difficult | 0 | (0.0) |
| Were the instructions provided easy to follow? (N=40) | Very Easy | 38 | (95.0) |
| | Somewhat Easy | 1 | (2.5) |
| | Neither Easy nor Hard | 1 | (2.5) |
| | Somewhat Difficult | 0 | (0.0) |
| | Very Difficult | 0 | (0.0) |
| How would you rate the length of the questionnaire? (N=40) | Too Short | 0 | (0.0) |
| | About Right | 38 | (95.0) |
| | Too Long | 0 | (0.0) |
| | Unsure | 2 | (5.0) |
| How often would you prefer to complete the questionnaire? (N=40) | Every month | 7 | (17.5) |
| | Every 3 month | 9 | (22.5) |
| | Every 6 month | 17 | (42.5) |
| | Yearly | 5 | (12.5) |
| | Other | 2 | (5.0) |
| How would you prefer to complete the questionnaire? (N=40) | Online | 38 | (96.0) |
| | Telephone | 0 | (0.0) |
| | Hardcopy | 0 | (0.0) |
| | No preference | 2 | (4.0) |
| How would you feel about providing the responses to doctors in the future? (N=38) | Yes | 33 | (86.8) |
| | Unsure | 4 | (10.5) |
| | No | 1 | (2.6) |
| **If Yes,** who would you like to receive the responses to your questionnaire? (N=29) | GP | 4 | (13.8) |
| | Surgeon | 1 | (3.4) |
| | Endocrinologist | 6 | (19.0) |
| | All of the above | 18 | (62.0) |
| Overall, how would you rate your satisfaction with the questionnaire? (N=40) | Very dissatisfied | 1 | (2.5) |
| | Dissatisfied | 0 | (0.0) |
| | Neutral | 3 | (7.5) |
| | Satisfied | 27 | (67.5) |
| | Very Satisfied | 9 | (22.0) |

### Realtime Reporting of PRMs

A sizable proportion of the participants (n=38, 86.8%) would be happy for their responses to the PRMs to be provided to their doctors, with one (2.6%) not wanting their responses to be shared with their doctors and four (4.5%) unsure.

Of the participants who would be happy to provide their PRM responses to their doctors,18(62%) would like their responses provided to their general practitioner, surgeon, and endocrinologist with six (19%) wanting their responses provided to their endocrinologist only, four (13.8%) GP only and one (3.4%) surgeon only (see Table 24). Data was missing for nine participants.

# ASSOCIATED STUDIES

## IMPACT OF DELAYED TREATMENT DUE TO COVID-19

*Project Lead(s):* A/Professor Anthony Glover, Dr Brooke Nickel, Dr Liane Ioannou, Bianka D'souza

### Aims

The overall aim of this research is to provide an Australian-based perspective on the impact of COVID-19 on the diagnosis and treatment of patients with thyroid cancer in Australia. This will be addressed using a two-phase approach. Phase I will focus on the qualitative interviewing of patients who experienced delayed diagnosis or treatment due to COVID-19. Phase II will quantitatively explore the impact of COVID-19 on patterns of treatment for patients diagnosed with thyroid cancer. It is hypothesised that diagnosis and both surgical and postsurgical treatment will be significantly delayed due to COVID-19 and that, subsequently, these delays will negatively impact on patients with thyroid cancer in Australia. This research may provide an insight into the impact of diagnosis and treatment delays on patients with thyroid cancer. The findings of this research may also improve our understanding of how delayed thyroid cancer treatments can be clinically managed in the future.

### Methods

*Phase I*

Semi-structured interviews were conducted with people diagnosed with thyroid cancer who experienced delayed diagnosis or treatment during COVID-19. The data was analysed using the thematic framework analysis, and reported using the Consolidated Criteria for Reporting Qualitative Research (COREQ).

*Phase II*

A data access request was submitted to the ANZTCR steering committee to allow access to de-identified registry data for analysis. Data was extracted from the ANZTCR for all participants over the age 18 years who were not diagnosed with NIFT-P from 2017-2020. The data was analysed using a Chi-squared test, with a Benjamini-Hochberg procedure, and a Wilcoxon rank-sum (Mann-Whitney) test for the statistical analysis.

### Conclusions

This research indicates an increased burden of anxiety on patients with thyroid cancer who experienced delayed diagnosis and/or treatment during COVID-19, however further research is required to assess the clinical impact of possible disease progression to patients impacted by COVID-19 delays.

### Output

- A manuscript on the qualitative study (Phase I) is under review at the Journal of American Medical Association (JAMA) Otolaryngology.
- A manuscript on the quantitative study (Phase II) is currently in preparation.
- A manuscript will be prepared for a systematic review on the impact of delayed treatment for patients with thyroid cancer.

# ACADEMIC OUTPUTS

Note: Due to COVID in 2020 and 2021 attendance at conferences and publications have been delayed. We have a number of academic outputs that will be published and presented in 2022.

## PUBLICATIONS

Ioannou, L., Serpell, J., Dean, J., Bendinelli, C., Gough, J., Lisewski, D., Miller, J., Meyer-Rochow, W., Sidhu, S., Topliss, D., Walters, D., Zalcberg, J., Ahern, S. Development of a Bi-National Thyroid Cancer Clinical Quality Registry: A Protocol Paper. *BMJ Open*; 9: bmjopen-2018-023723. Doi: 10.1136/bmjopen-2018-023723

## PRESENTATIONS

Ioannou, L., Serpell, J., Bendinelli, C., Walters, D., Gough, J., Lisewski, D., Meyer-Rochow, W., Miller, J., Topliss, D., Fleming, B., Farrell, S., Kid, A., Kollias, J., Sywak, M., Aniss, A., Fenton, L., Ghusn, D., Harper, S., Popadich, A., Stringer, K., Watters, D., Ahern, S. Development of a Core Set of Clinical Indicators to Measure Quality of Care for Early Thyroid Cancer Management: A Modified-Delphi Approach. Royal Australian College of Surgeons (RACS) 88th Annual Scientific Congress (ASC), Bangkok, Thailand (6-10 May 2019) (Oral Presentation).

Ioannou, L., Serpell, J., Bendinelli, C., Walters, D., Gough, J., Lisewski, D., Meyer-Rochow, W., Miller, J., Topliss, D., Fleming, B., Farrell, S., Kiu, A., Kollias, J., Sywak, M., Aniss, A., Fenton, L., Ghusn, D., Harper, S., Popadich, A., Stringer, K., Watters, D., Ahern, S. Development of a Core Set of Clinical Indicators to Measure Quality of Care for Thyroid Cancer: A Modified-Delphi Approach. A verbal presentation at the Victorian Integrated Cancer Services (VICS) Conference, Melbourne, Australia (8-10 May 2019) (Oral Presentation).

Serpell, J., Ioannou, L., Greenhill, E., Bendinelli, C., Walters, D., Gough, J., Lisewski, D., Meyer-Rochow, W., Miller, J., Topliss, D., Fleming, B., Farrell, S., Kiu, A., Kollias, J., Sywak, M., Aniss, A., Fenton, L., Ghusn, D., Harper, S., Popadich, A., Stringer, K., Watters, D., Ahern, S. Development of the Australian and New Zealand Thyroid Cancer Registry. A verbal presentation at the 8th Multidisciplinary Update on Thyroid and Parathyroid Surgery, Noosa, Australia (14-16 November 2019) (Oral Presentation).

Ioannou, L., Serpell, J., Bendinelli, C., Walters, D., Gough, J., Lisewski, D., Meyer-Rochow, W., Miller, J., Topliss, D., Fleming, B., Farrell, S., Kiu, A., Kollias, J., Sywak, M., Aniss, A., Fenton, L., Ghusn, D., Harper, S., Popadich, A., Stringer, K., Watters, D., Ahern, S. Development of a Core Set of Clinical Indicators to Measure Quality of Care for Thyroid Cancer: A Modified-Delphi Approach. 88th Annual Meeting of the American Thyroid Association (ATA), Washington D.C., United States (3-7 October 2018) (Oral Presentation).

Ioannou, L., Serpell, J., Dean, J., Bendinelli, C., Gough, J., Lisewski, D., Miller, J., Meyer-Rochow, W., Sidhu, S., Topliss, D., Walters, D., Zalcberg, J., Ahern, S. Development of a Bi-National Thyroid Cancer Clinical Quality Registry. Alfred Health Research Week, Melbourne, Australia (June 2018) (Poster Presentation).

Ioannou, L., Serpell, J., Dean, J., Bendinelli, C., Gough, J., Lisewski, D., Miller, J., Meyer-Rochow, W., Sidhu, S., Topliss, D., Walters, D., Zalcberg, J., Ahern, S. Development of a Bi-National Thyroid Cancer Clinical Quality Registry. Victorian Comprehensive Cancer Centre (VCCC) Postdoctoral Symposium, Melbourne, Australia (1 June 2018) (Poster Presentation).

Ioannou, L., Serpell, J., Dean, J., Bendinelli, C., Gough, J., Lisewski, D., Miller, J., Meyer-Rochow, W., Sidhu, S., Topliss, D., Walters, D., Zalcberg, J., Ahern, S. Development of a Bi-National Thyroid Cancer Clinical Quality Registry. Royal Australian College of Surgeons (RACS) Annual Scientific Congress (ASC), Sydney, Australia (7-11 May 2018) (Oral Presentation).

# FUTURE DEVELOPMENTS

## BASELINE PRMS

Currently, the ANZTCR is unable to collect PRMs at baseline (i.e., time of diagnosis and/or surgery) as patients are entered into the registry at a later timepoint. Due to the nature of thyroid cancer, with the majority being diagnosed following surgery this can be a very stressful time for patients and assessing their quality of life at this time point is of extreme importance. The ANZTCR will pilot a 'PRM Postcard' that can be provides to patients by their surgeons at their pre- or postoperative consultation (as close to surgery as practicable), once a thyroid cancer diagnosis has been confirmed. The 'PRM Postcard' will contain a QR code that directs the patient to the ANZTCR patient-reported questionnaire. Informed consent is implied if the patient completes the questionnaire. The first page of the questionnaire will include demographic details in order to link the patient to their registry record.

## CASE ASCERTAINMENT & QUALITY ASSURANCE

To ensure that the data collected by the registry is accurate and epidemiologically sound, the ANZTCR will be undertaking quality assurance activities to ensure records are complete for all participants. Furthermore, HIS extracts from sites will be reviewed to ensure that 100% of the eligible patients from a site are being captured.

# REFERENCES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# LIST OF ABBREVIATIONS

| | |
|---|---|
| ACSQHC | Australian Commission on Safety and Quality in Health Care |
| ANZES | Australian and New Zealand Endocrine Surgeons |
| ANZTCR | Australian and New Zealand Thyroid Cancer Registry |
| ANZTCR-RCD | ANZTCR REDCap Database |
| ASOHNS | Australian Society of Otolaryngology Head & Neck Surgery |
| ATA | American Thyroid Association |
| CME | Continuing Medical Education |
| CQI | Clinical Quality Indicator |
| CT | Computed Tomography |
| ENT | Ear Nose Throat |
| EORTC | European Organisation for Research and Treatment of Cancer |
| FNA | Fine Needle Aspiration |
| HIS | Health Information Services |
| HRQoL | Health-related Quality of Life |
| MDT | Multi-disciplinary Team |
| MNG | Multinodular Goitre |
| MTC | Medullary Thyroid Cancer |
| NIFT-P | Non-Invasive Follicular Thyroid Neoplasm with papillary like features |
| PET | Positron Emission Tomography |
| PRE | Patient-reported Experience |
| PRM | Patient-reported Measure |
| PRO | Patient-reported Outcome |
| PTC | Papillary Thyroid Cancer |
| QLQ-C30 | Quality of Life Questionnaire |
| QOL | Quality of Life |
| RACS | Royal Australasian College of Surgeons |
| RAI | Radioactive Iodine |
| RLN | Recurrent Laryngeal Nerve |
| RRA | Radioactive Iodine Remnant Ablation |
| Tg | Thyroglobulin |
| THY34 | Thyroid Specific Module (Quality of Life Questionnaire) |
| TNM | Tumour, Node, Metastasis |
| TSH | Thyroid Stimulating Hormone |

# APPENDICES

## APPENDIX A: LIST OF TABLES



## APPENDIX B: LIST OF FIGURES

## APPENDIX C: DATA ELEMENTS CAPTURED

### Recruitment

- Patient ID
- Given Name(s)
- Surname
- Date of Birth
- Sex
- Country
- Street Address
- Suburb
- State/City
- Postcode
- Contact Number
- Email Address
- Medical Record Number
- Surgeon Name
- Site of Diagnosis
- Date of Diagnosis
- Basis of Diagnosis
- Diagnosed with only a microPTC
- Diagnosed with primary NIFT-P
- Disclosure of Diagnosis to Patient
- Vital Status
- Date of Death
- Cause of Death

### Preoperative

- Interpreter Required
- Aboriginal, Torres Strait Islander Status
- Maori Status
- Presence of Comorbidities
- Medication at Diagnosis
- Thyroid Function at First Presentation
- Neck Examination
- Palpable Lymph Nodes
- Previous Exposure to Radiation
- Previous Thyroid Surgery
- Preoperative Imaging
- Presence of Suspicious Lymph Nodes
- Largest Thyroid Nodule Diameter
- Fine-Needle Aspiration
- Clinical Voice Abnormality
- Preoperative Laryngeal Exam

### Procedure(s)

- Date of procedure
- Procedure Type
- Indication for Procedure
- Residual Tumour
- Lymph Node Dissection
- Lymph Node Dissection Intent
- Lymph Node Dissection Levels
- Recurrent Laryngeal Nerve
- Nerve Integrity Monitor
- Primary & Secondary Pathology
- Incidental Finding of Cancer
- Largest Tumour Diameter
- Margin Status
- Multifocal Cancer
- Lymphovascular Invasion
- Extrathyroidal Extension
- Lymph Node Metastases
- Distant Metastases
- Surgical Complications

### Postoperative

- Presented at MDM
- TNM Staging
- Supplementation
- Biobank Sample
- Genetic Testing

### Treatment

- Postoperative Tg
- RAI Remnant Ablation (RRA)
- Other Adjuvant Therapy

### Recurrent Thyroid Disease

- Recurrent Thyroid Cancer
- Date of Recurrence
- Surgeon Name
- Hospital Name
- Diagnostic Testing
- Site of Recurrence
- Treatment for Recurrent Disease

## APPENDIX D: COMMITTEES & STAFF

### Steering Committee Members

| | |
|---|---|
| Professor Jonathan Serpell | Committee Chair, Endocrine Surgeon |
| Professor Jeremy Millar | Radiation Oncologist |
| Professor John Zalcberg | Head, Cancer Research Program, Monash University |
| Professor Susannah Ahern | Head, Clinical Outcomes data Reporting and Research Program, Monash University |
| Ms Madeleine Allnutt | Australian Thyroid Foundation, Consumer Advocate |
| Dr Adam Aniss | Database Manager |
| Dr Cino Bendinelli | Endocrine Surgeon |
| Dr Daron Cope | Otolaryngologist |
| A/Professor Anthony Glover | Endocrine Surgeon |
| Dr Jenny Gough | Breast and Endocrine Surgeon |
| Dr Simon Harper | Endocrine and General Surgeon |
| A/Professor James Lee | Endocrine Surgeon |
| A/Professor Julie Miller | ANZES Immediate Past-President, Endocrine Surgeon |
| Dr Win Meyer-Rochow | Endocrine and General Surgeon |
| Professor Andrew Scott | Nuclear Medicine Physician |
| Professor Stan Sidhu | Endocrine Surgeon |
| A/Professor Mark Sywak | Endocrine Surgeon |
| Professor Duncan Topliss | Endocrinologist |
| Dr David Walters | Breast and Endocrine Surgeon |

### Registry Leads

Professor Jonathan Serpell, Clinical Lead
Professor Jeremy Millar, Co-academic Lead
Professor John Zalcberg, Co-academic Lead

### ANZTCR Coordinating Centre, Monash University

Dr Liane Ioannou, Research Fellow
Ms Claire Bavor, Operations Manager
Mr Benjamin Brown, Data Manager
Ms Bianka D'souza, Masters of Public Health Student
Ms Sharon Lim, Bachelor of Health Services Honours Student

## APPENDIX E: LIST OF PARTICIPATING SITES & CLINICIANS

### Participating Sites

| | |
|---|---|
| VIC | Alfred Health |
| | Austin Health |
| | Barwon Health |
| | Cabrini Health |
| | Eastern Health |
| | Linacre Private Hospital |
| | Monash Health |
| | Peninsula Health |
| | Peninsula Private |
| | St Vincent's Hospital Melbourne |
| | St Vincent's Private Hospital Melbourne |
| | The Royal Melbourne Hospital |
| | Western Health |
| NSW | Baringa Private Hospital |
| | Campbelltown Hospital |
| | Dudley Private Hospital |
| | Hornsby Hospital |
| | John Hunter Hospital |
| | Lake Macquarie Private Hospital |
| | Liverpool Hospital |
| | Maitland Private Hospital |
| | Manly District Hospital (Site closed) |
| | Mater Hospital, North Sydney |
| | Newcastle Private Hospital |
| | Royal North Shore Hospital |
| | Royal North Shore Private Hospital |
| | Sydney Adventist Hospital |
| QLD | Greenslopes Private Hospital |
| | Logan Hospital |
| | North West Private Hospital |
| | Redland Hospital |
| | St Vincent's Private Hospital Northside |
| | Townsville Hospital |
| | Wesley Hospital |
| SA | Flinders Medical Centre |
| | Royal Adelaide Hospital |
| | St Andrew's Hospital |
| | The Queen Elizabeth Hospital |
| NZ | Waikato Hospital |
| | Wellington Regional Hospital |

### Participating Clinicians

| | |
|---|---|
| Dr Earl Abraham | Dr Joanna Morgan |
| Dr Cino Bendinelli | Dr Teresa Nano |
| Dr Janne Bingham | A/Prof Navin Niles |
| Dr Melissa Bochner | A/Prof Chris O'Neill |
| Dr Jason Boldery | Dr Leo Pang |
| Dr Richard Carroll | Dr Andrew Parasyn |
| Dr Alvin Cham | A/Prof Robert Parkyn |
| Dr Jared Chang | Dr Tony Phang |
| Dr Michael Cheng | Dr Siva Ravindran |
| Dr Laura Chin-Lenn | Prof Jonathan Serpell |
| Dr Joanne Chionh | Prof Stan Sidhu |
| Dr Daron Cope | A/Prof Anita Skandarajah |
| Prof Leigh Delbridge | Dr Kate Stringer |
| A/Prof Robert Eisenberg | A/Prof Mark Sywak |
| Dr Stephen Farrell | Dr Jason Tan |
| Dr Linda Fenton | Dr Robert Tasevski |
| Dr Bill Fleming | Dr Leong Tiong |
| A/Prof Anthony Glover | Dr Cyril Tsan |
| Dr Jenny Gough | Dr Domenika Turkiewicz |
| Dr Simon Grodski | Dr David Walsh |
| A/Prof Justin Gundara | Dr David Walters |
| Dr Simon Harper | Prof David Watters |
| Dr Suren Jayaweera | Dr Robert Whitfield |
| Dr Andrew Kiu | Dr David Wright |
| Dr James Kollias | Dr Meei Yeung |
| Dr Russel Krawitz | |
| Dr Christine Lai | |
| Dr Tracey Lam | |
| A/Prof James Lee | |
| Dr Stephanie Manning | |
| Dr Sally Meade | |
| Dr David Merenstein | |
| Dr Win Meyer-Rochow | |
| A/Prof Julie Miller | |
| Dr Sue Moore | |

## APPENDIX F: LIST OF DATA MANAGERS

### Data Managers

| | |
|---|---|
| Dr Adam Aniss | Royal North Shore Hospital, Endocrine Surgical Unit's Database |
| Dr Afsaneh Koohestani | Alfred Monash University Endocrine Surgery Database |

## APPENDIX G: LIST OF ANZTCR POLICIES & PROCEDURES

| ANZTCR Policies and Procedures |
|---|
| Protocol |
| Data Dictionary |
| Data Access & Publication Policy |
| Privacy Policy |
| ANZTCR-RCD User Manual |
| Conflict of Interest Statement |

## APPENDIX H: ANZTCR CLINICAL QUALITY INDICATORS

### Preoperative

CQI1 Proportion of patients with clinical suspicion of thyroid cancer who had a neck ultrasound prior to surgery and/or treatment.

CQI2 Proportion of patients with clinically and/or radiologically suspicious lymph nodes that underwent a biopsy to confirm malignancy before the initiation of treatment.

CQI3 Proportion of patients with suspicion of thyroid cancer that present with (subjective or objective) evidence of voice abnormality who underwent a laryngeal examination prior to surgery and/or treatment.

### Surgery

CQI4 Proportion of patients with differentiated thyroid cancer who had a tumour size >4 cm or advanced disease (extrathyroidal extension and/or metastatic disease) and underwent a total thyroidectomy (one- or two-stage including completion thyroidectomy).

CQI5 Proportion of patients with thyroid cancer who undergo surgery with therapeutic compartmental lateral neck lymph node dissection due to cytological proven lateral lymph node involvement.

### Surgical Complications

CQI6 Proportion of patients with thyroid cancer who presented with temporary RLN palsy that has not resolved within 3-months following thyroidectomy.

CQI7 Proportion of patients with thyroid cancer who present with persisting hypoparathyroidism at 3 months following thyroidectomy, as evidence by need for ongoing calcium and/or vitamin D.

CQI8 Proportion of patients with thyroid cancer who underwent a thyroidectomy and had postoperative haemorrhage within 48 hours requiring return to theatre following thyroidectomy.

### Staging & Postoperative Treatment Planning

CQI9 Proportion of patients with thyroid cancer who have staging recorded postoperatively using the tumour, node, metastasis (TNM) staging system.

CQI10 Proportion of patients with thyroid cancer who were presented at a tumour-specific MDT meeting.

### Postoperative Treatment

CQI11 Proportion of patients with differentiated thyroid cancer that underwent a total (or completion) thyroidectomy and have serum Tg recorded postoperatively.

CQI12 Proportion of patients with high-risk differentiated thyroid cancer that underwent RAI remnant ablation (RRA) following a total (or completion) thyroidectomy.

MONASH University

AUSTRALIAN & NEW ZEALAND
**THYROID CANCER**
REGISTRY