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University

# AUSTRALIAN AND NEW ZEALAND THYROID CANCER REGISTRY

2019  
ANNUAL REPORT

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AUSTRALIAN & NEW ZEALAND  
THYROID CANCER  
REGISTRY

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## Data Period:

The data contained in this document was extracted from the Australian and New Zealand Thyroid Cancer Registry (ANZTCR) on 23 March 2020 and pertains to data that relates to patient events from 25 September 2017 to 31 December 2019. 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).



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REGISTRY



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# 1. FOREWORD

## From the clinical lead of the ANZTCR

It gives me great pleasure to introduce the second Annual Report of the Australian and New Zealand Thyroid Cancer Registry (ANZTCR) for 2019. Firstly, I hope everyone is staying safe and healthy during the COVID-19 pandemic and I wish to thank all of our participants and staff for their efforts during this time.

We continue to enjoy the strong support of Australian and New Zealand Endocrine Surgeons (ANZES), endocrinologists, individual endocrine and ENT/ Head and Neck surgeons and data managers. As of the time of writing, we now have over 699 patients in the Registry with 30 sites and many surgeons contributing. The Registry is continuing to grow and demonstrates in this Annual Report its primary purpose of improving outcomes for thyroid cancer patients. The results contained in this Report, although still relatively small in number, indicate a high quality outcome for our patients.

I would like to thank Professor Susannah Ahern, Dr Liane Ioannou, Elysia Greenhill, Claire Bavor and Jessy Hansen from the Registry Science and Research for their management of the ANZTCR. Further, our strong and committed Steering Committee remains integral to the success of 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.



A handwritten signature of Professor Jonathan Serpell in black ink.

### Professor Jonathan Serpell

Clinical Lead, Australian and New Zealand Thyroid Cancer Registry  
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 Australian and New Zealand Thyroid Cancer Registry (ANZTCR) 2019 Annual Report. 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 is the ANZTCR's second annual report, but the first to monitor clinical care against a consensus set of clinical quality indicators (CQIs) for the early management of thyroid cancer. As CQIs are a valuable tool for reducing variation in clinical care, the ANZTCR is increasingly becoming a valuable tool for guiding clinical decision-making. As the President of the Australian and New Zealand Endocrine Surgeons (ANZES), I am proud of the contribution the specialist endocrine surgeons of ANZES have made to this registry.

It is, however, through the collective effort of ANZES members that the ANZTCR continues to evolve as a comprehensive evidence-base. For this, I would like to sincerely thank all those involved, especially Prof Jonathan Serpell for his continued visionary leadership of the registry. I am excited to watch the ANZTCR grow over 2020.



A handwritten signature of Associate Professor Julie Miller in black ink.

### Associate Professor Julie Miller

President, Australian and New Zealand Endocrine Surgeons (ANZES)  
Head, Thyroid and Endocrine Tumour Group, The Royal Melbourne Hospital

## 2. EXECUTIVE SUMMARY

The Australian and New Zealand Thyroid Cancer Registry (ANZTCR) is a clinical quality registry established in 2017 that collects the diagnosis, treatment and outcome data of individuals with thyroid cancer, presenting at public and private health services. This report presents key findings from the ANZTCR's first two years of data collection.

In 2019, the ANZTCR presented at key College, Society and Jurisdictional meetings in Victoria, Queensland and Bangkok. The registry welcomed new Steering Committee members representing the Australian Society of Head and Neck Surgeons (ASOHS) as well as a radiation oncologist/researcher from Monash University.

The ANZTCR dataset was updated following a User Group meeting in October 2019 resulting in a more streamlined dataset with fewer items. A pilot to extract and import data directly and automatically from a health service database into the ANZTCR has been completed.

Twenty-eight ANZES members completed a clinician survey regarding the ANZTCR in late 2019. Over 70% were aware of the registry, with 75% having accessed the 2018 Annual Report.

- As of March 2020, a total of 30 hospitals across four states are participating in the ANZTCR, with 35 contributing surgeons.
- As of 31st December, 2019, there were 504 participants in the ANZTCR, comprising 71% females and 29% males; at least some follow-up data was available for nearly 95% of participants.
- The median age of participants was 53 years for females and 51.5 years for males (median overall age 53).
- Diagnosis of thyroid cancer was based on histology (59%), biopsy (40%) and histology of metastasis (1%).
- At diagnosis, 39% of participants had at least one specified comorbidity, 5% were on either an antiplatelet agent or anticoagulant; and 82% were euthyroid.
- At diagnosis, the most common clinical neck finding was a solitary nodular goitre (41%), a multi-nodular goitre (34%) or normal neck examination (19%).
- During diagnostic work-up, 91% of participants had an ultrasound (US) and 90% had fine needle aspiration cytology (FNA); 29% underwent a CT scan, 6% had a thyroid nuclear scan, and 6% a PET scan. Fourteen of 15 patients with evidence of voice abnormality prior to diagnosis underwent a laryngeal examination.
- Participants underwent total thyroidectomy (58%), or hemithyroidectomy (36%), with 6% undergoing a different procedure. Of those participants who had a subsequent procedure, 78% had a completion thyroidectomy.
- Less than half (48%) of participants had a lymph node dissection; 31% with therapeutic intent and 67% with prophylactic intent.
- Pathology was reported for 442 participants, and included 94% with differentiated thyroid cancer, 3% with medullary carcinoma and 1% with poorly differentiated carcinoma. 29% of patients had lymph node metastases at the time of the initial procedure, with distant metastases reported in less than 2% of participants.
- Additional benign pathology (such as multinodular goitre or lymphocytic thyroiditis) was reported in 75% of participants. For 31% of patients, the finding of cancer was incidental.
- Nerve integrity monitoring was used in 75% of participants. Five participants had recurrent laryngeal nerves (RLN) damaged or sacrificed during their procedure (approximately 1%).
- Surgical complications reported in the registry included temporary hypocalcaemia and temporary RLN palsy (5.7%); with haemorrhage, infection and seroma reported in less than 1%.
- Postoperative treatment included medical supplementation with calcium, vitamin D, and thyroxine.
- Twelve of thirteen clinical quality indicators (CQIs) are reported using aggregate data.



### 3. FUNDING PARTNERS

As a newly established registry, the Australian and New Zealand Thyroid Cancer Registry (ANZTCR) relies on funding grants from a range of sources to support its operations.

The ANZTCR has received important start-up funding from the Alfred Foundation to enable what was an institutional database to transition into a national registry. The support of the Alfred Foundation in enabling the vision of a registry for thyroid cancer to be achieved is gratefully acknowledged.

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

The ANZTCR is also 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. Without any of these important funders the ANZTCR and this report, would not be possible.

## Medtronic





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.

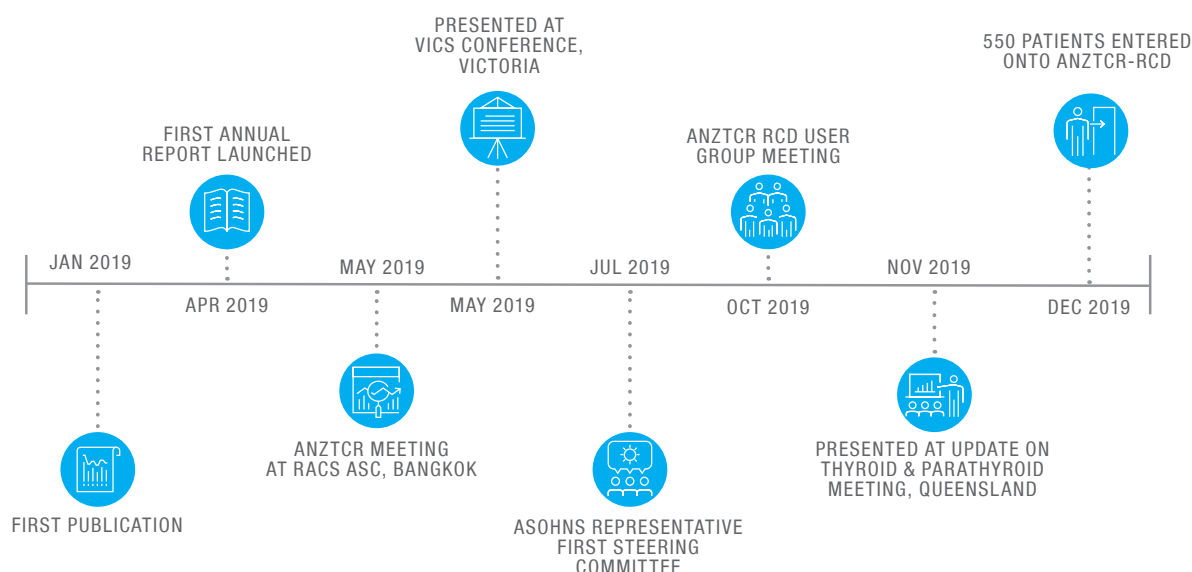
## 4. INTRODUCTION

The Australian and New Zealand Thyroid Cancer Registry (ANZTCR) is a clinical quality registry that monitors the quality of care provided to Australians diagnosed with thyroid cancer. The registry was established in 2017, and is managed by the Registry Science and Research Unit, Monash University. The ANZTCR collects diagnosis, treatment and outcome data of individuals with thyroid cancer, presenting at public and private health services. This report presents the first two years of data collection, and is the first to report aggregate ANZTCR clinical quality indicator (CQIs) outcomes.

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'<sup>1</sup> and the 'Framework for Australian Clinical Registries 2014'<sup>2</sup> published by the Australian Commission for Safety and Quality in Healthcare (ACSQHC).

### 4.1 Milestones

The key ANZTCR milestones for 2019 are highlighted in the diagram below.



### 4.2 Registry Governance

#### Management Committee

A Management Committee oversees the day-to-day operations of the registry undertaken by the ANZTCR Coordination Centre based at Monash University.

#### 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 Australian and New Zealand Endocrine Surgeons (ANZES), the Australian Society of Head and Neck Surgeons (ASOHS), the Australian Thyroid Foundation (ATF), 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
- Patient Advocacy
- Data Management
- Registry Science

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

Monash University has custodianship of the data which includes accountability for the privacy, security and integrity of patient information held within the registry. Data are collected and managed using REDCap electronic data capture tools hosted and managed by Helix (Monash University). REDCap (Research Electronic Data Capture)<sup>3</sup> 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.



## 5. REGISTRY METHODOLOGY

### 5.1 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 participating hospital with a confirmed primary thyroid cancer.
- Patients who are ≥ 16 years of age.

#### 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.

The following recruitment process begins once a principal investigator has been appointed at the participating site and authorisation has been granted by the site's research ethics and/or 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 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.

### 5.2 Data Elements

A consensus set of clinical quality indicators (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 G). Aggregate outcomes in relation to these indicators have been included for the first time in this report. When individual sites have sufficient volume, the ANZTCR will produce benchmarked reports of CQIs to sites. It is anticipated that this will occur for the first time in early 2021.

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). In October 2019, the ANZTCR minimum dataset was reviewed in an effort to reduce data burden and enhance the data collection experience. The ANZTCR-RCD User Group in collaboration with the ANZTCR Steering Committee reviewed all data items not required for CQIs, risk adjustment and administrative purposes. The outcome of this review is reflected in a streamlined ANZTCR-RCD in 2020.

### 5.3 Data Collection Processes

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

1. Direct data entry into the ANZTCR-RCD by surgeons (or their staff e.g. data manager). 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.

In preparation for this report, the ANZTCR piloted the automated extraction and import of data from the Royal North Shore Hospital Endocrine Database into the ANZTCR-RCD. This process will be able to be undertaken for other sites who have closely aligned datasets from existing thyroid cancer or endocrine surgery databases.

## 6. CLINICIAN ENGAGEMENT

Surgeons are informed about the registry through ANZES and a number of other sources including a quarterly ANZTCR newsletter as well as principal and associate investigators at each hospital site who are ambassadors for the registry and 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.

### 6.1 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.

### 6.2 Surgeon Evaluation

Between September to November of 2019, ANZES members were invited to participate in an online survey, the aim of which was to evaluate clinician engagement in the first two years of the ANZTCR by assessing the views and opinions of surgeons. The results will help inform the registry's engagement activities as it expands to additional sites within Australia and New Zealand.

Twenty-eight ANZES members completed the survey. The majority of clinicians heard about the registry through ANZES, colleagues, conferences and the ANZTCR newsletter (Table 1). The most well-known benefit of participating in the registry was the distribution of annual reports, although many clinicians were also aware that they could apply to access the data for research purposes and that they would receive RACS CME Audit Activity Points for participation. Finally, the majority of clinicians had accessed the ANZTCR Newsletters, the annual report and biannual infographics, as seen in Table 2.



There are currently 20 public and 10 private hospital sites across Australia participating in the ANZTCR.

**Table 1 – Participant awareness of registry**

	N	%
<b>Have heard about the ANZTCR from*~: (n=28)</b>		
ANZES	22	79
Conference	20	71
Colleagues	20	71
ANZTCR Newsletter	20	71
Social Media	3	11
<b>Awareness of following benefits of registry participation*^: (n=28)</b>		
Registry annual reports	22	79
Ability to apply for data for research purposes	20	71
RACS CME Audit Activity Points	17	61
Provides a standardised format for a minimum data set for thyroid cancer	17	61
Registry benchmarked reports	16	57
Ability to access real-time summary statistics on own patients (audit purposes)	13	46
Ability to access real-time information on own individual patients (clinical care purposes)	9	32
Ability to apply for further statistical analysis on own patient data	9	32

\* Multiple responses allowed, row percentages of total given.

~ Additional text comments: email, on the organising committee.

^ Additional text comments: useful to have a national database, helps surgeons with fellows to publish articles.

**Table 2 – Participant access of ANZTCR communication**

	Accessed	
Communication type* (n=28)	N	%
Newsletters	21	75
Annual Report	18	64
Biannual Infographic	15	54
Publications	11	39
Website	10	36

\* Multiple responses allowed, row percentages of total given.

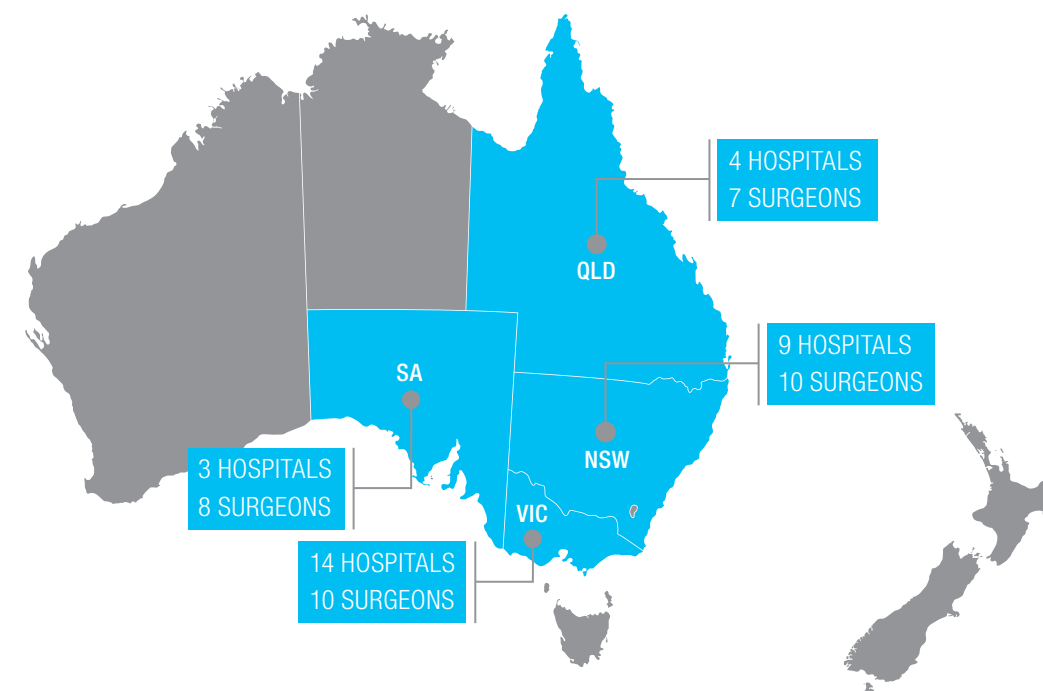


## 7. SUMMARY OF THE REGISTRY DATA

### 7.1 Site Participation

As of March 2020, a total of 30 sites have obtained ethics and/or governance approval. There are currently 20 public and 10 private hospital sites across Australia participating in the ANZTCR. Figure 1 illustrates this expansion of the registry across Australia since its commencement of data collection in early 2018.

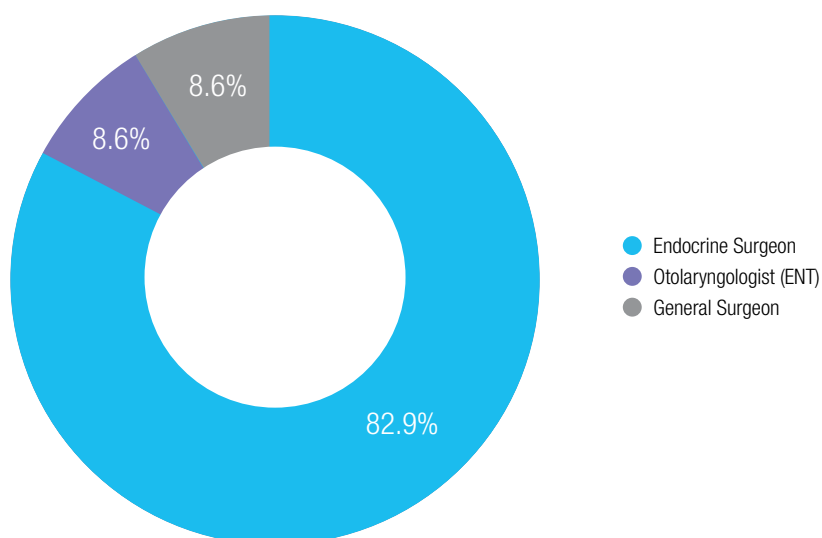
**Figure 1: Number of hospital sites and number of surgeons per state contributing to the registry**



### 7.2 Surgeon Participation

Surgery for thyroid cancer is performed by a number of surgeons from different specialities including: endocrine surgeons, general surgeons and ear-nose-throat (ENT) surgeons (otolaryngologists). 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 35 surgeons currently contributing to the ANZTCR.

**Figure 2: Area of surgeon expertise**



### 7.3 Registry participation

The data presented in this report pertains to patient events from 25 September 2017 to 31 December 2019. The ANZTCR obtained ethics approval in September 2017, and the ANZTCR Database was launched late January 2018. There may be a couple of weeks delay between the patient being entered on the database and the patient receiving their invitation letter.

A total of 571 patients have been invited to participate in the registry since January 2018. At the time of the data extraction, 41 (7.2%) of these patients were pending participation status (i.e. were within the opt-out period). Of the 530 patients where the opt-out period had elapsed, 26 (4.5%) have chosen to opt-out and four (0.7%) chose to partially opt-out, where their data will be kept but no further contact would be made. As at 31 December 2019, the ANZTCR confirmed the participation of 504 thyroid cancer patients and their data.

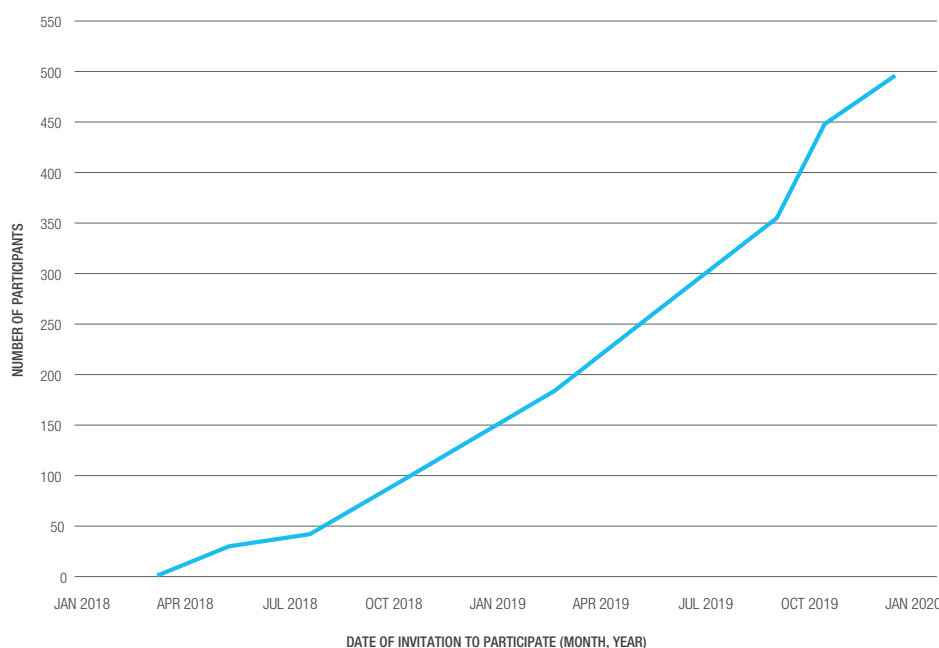
Table 3 demonstrates patient participation in the ANZTCR from 1 January 2018 to 31 December 2019. The registry has an opt-out rate of below 5%.

**Table 3 – Patient participation in the registry from 1 January 2018 to 31 December 2019**

Participation Status	Frequency	%
Invited	571	100
Awaiting Response	41	7.2
Complete Opt-Out	26	4.5
Partial Opt-Out	4	0.7
Participating	500	87.6

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

**Figure 3 - Accumulation Rates Of Participants In The Registry From January 2018-2020**

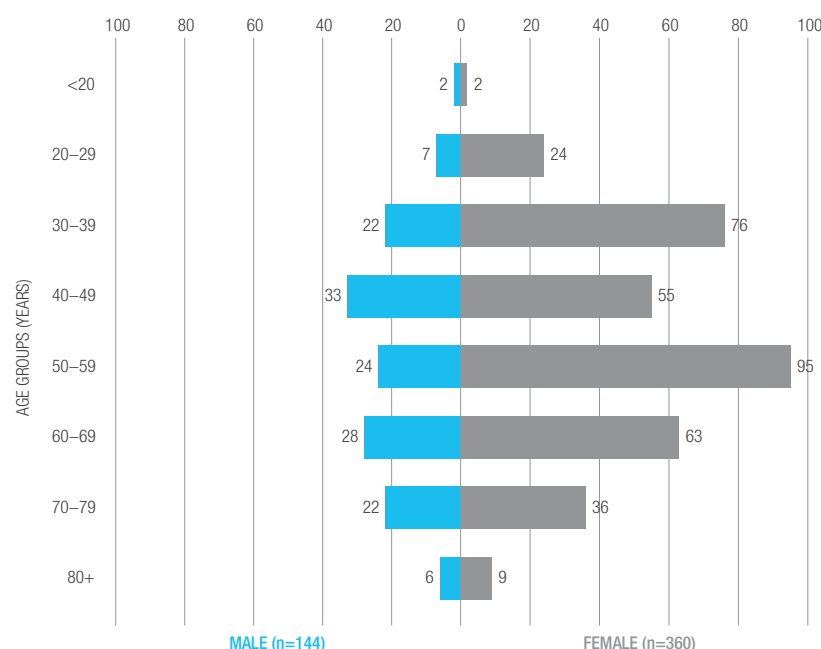


## Participant Characteristics

As at 31 December 2019, there were 360 (71.4%) females and 144 (28.6%) males enrolled in the registry who have been diagnosed with thyroid cancer.

The median age for patients at diagnosis was 53 (IQR 39-64) years old, with no significant difference in median age between males (51.5, IQR 41-65.5) and females (53, IQR 38-63). 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**



## Participants' Residence by State

Of the 504 participants recruited, 290 (57.5%) were residing in New South Wales at the time of recruitment, 135 (26.8%) in Victoria, 58 (11.5%) in Queensland, 16 (3.2%) in South Australia and five (1%) in the Australian Capital Territory (ACT), although the registry does not currently have any sites in the ACT.

Table 4 highlights frequency and percentage of patient participation in the registry across jurisdictions within Australia based on residence at time of recruitment.

**Table 4 – Patient participation in the registry by jurisdiction\***

State	Frequency	%
Victoria	135	26.8
New South Wales	290	57.5
Queensland	58	11.5
South Australia	16	3.2
Australian Capital Territory	5	1
<b>Total</b>	<b>504</b>	<b>100</b>

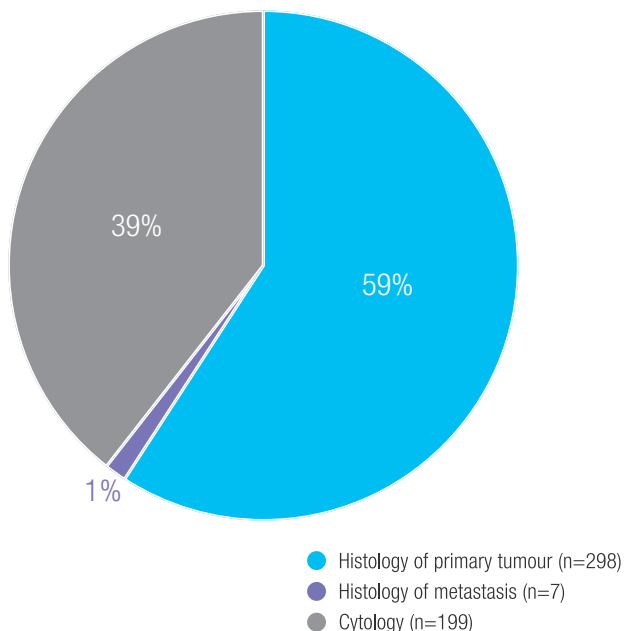
\*Based on participant residential postcodes.



## Method of Diagnosis

Of the 504 participants, 298 (59.1%) were diagnosed with primary thyroid cancer based on histology of primary tumour, 199 (39.5%) based on cytology and 7 (1.4%) based on histology of metastasis. Figure 5 demonstrates the method of diagnosis for participants recruited to the registry.

**Figure 5: Method of diagnosis of primary thyroid cancer**



## 7.4 Follow-Up Data Completion

Participating surgeons enter follow-up data for all of their patients participating in the registry at 90-days following diagnosis. Of the 504 participants, 475 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.

## 7.5 Preoperative Details Captured by The Registry

### Previous Medical History

At the time of diagnosis, 165 out of 429 (38.5%) patients presented with a specified comorbidity, of these 22 (13.3%) were obese, 21 (12.7%) were current smokers, and 30 (18.2%) had been diagnosed with cancer other than thyroid cancer. Only 10 (2.4%) out of 424 participants had previously been exposed to upper body radiation. Seventeen of 424 (4.0%) participants had previous thyroid surgery, with nine (60.0%) of these for malignancy. Twenty-two were on specified medication at diagnosis with eight on antiplatelet drugs (36.4%) and 14 on anticoagulants (63.6%).

Table 5 displays previous medical history at diagnosis.

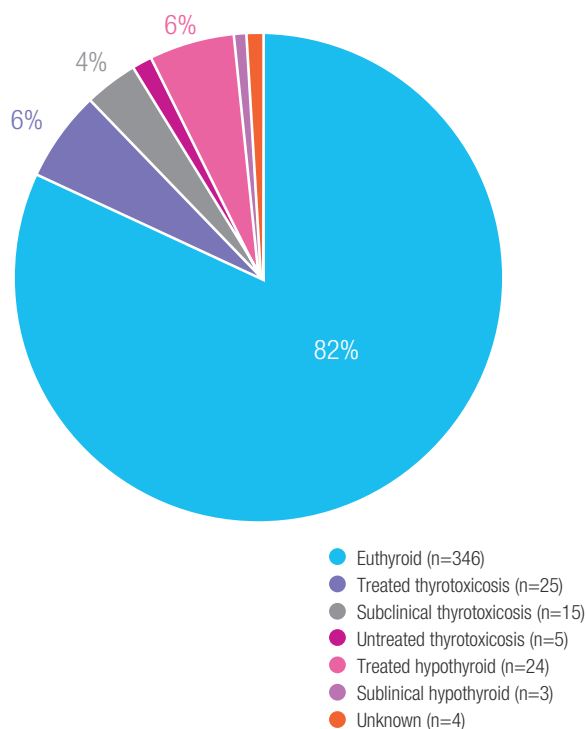
**Table 5: Previous Medical History**

Variable	Total	Response	Frequency%
Specified comorbidity at diagnosis*	429	Yes	165 (38.5)
		No	264 (61.5%)
If yes, comorbidity type	165	Obesity	22 (13.3)
		Smoking	21 (12.7)
		Other cancer	30 (18.2)
		Other	129 (78.2)
Upper body radiation exposure	424	Yes	10 (2.4)
		No	407 (96.0)
		Unknown	7 (1.7)
Previous thyroid surgery	424	Yes	17 (4.0)
		No	403 (95.1)
		Unknown	4 (0.9)
Medication at diagnosis	422	Yes	22 (5.2)
		No	357 (84.6)
		Unknown	43 (10.2)
If yes, medication type at diagnosis	22	Antiplatelet	8 (36.4)
		Anticoagulant	14 (63.6)
		Unknown	0 (0)

\*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 422 participants with complete data, 346 (82%) presented with a normal functioning thyroid gland (euthyroid), 25 had treated thyrotoxicosis (5.9%), 24 had treated hypothyroidism (5.7%), 15 had subclinical thyrotoxicosis (3.6%), five had untreated thyrotoxicosis (1.2%) and three had subclinical hypothyroidism (0.7%) (Figure 6).

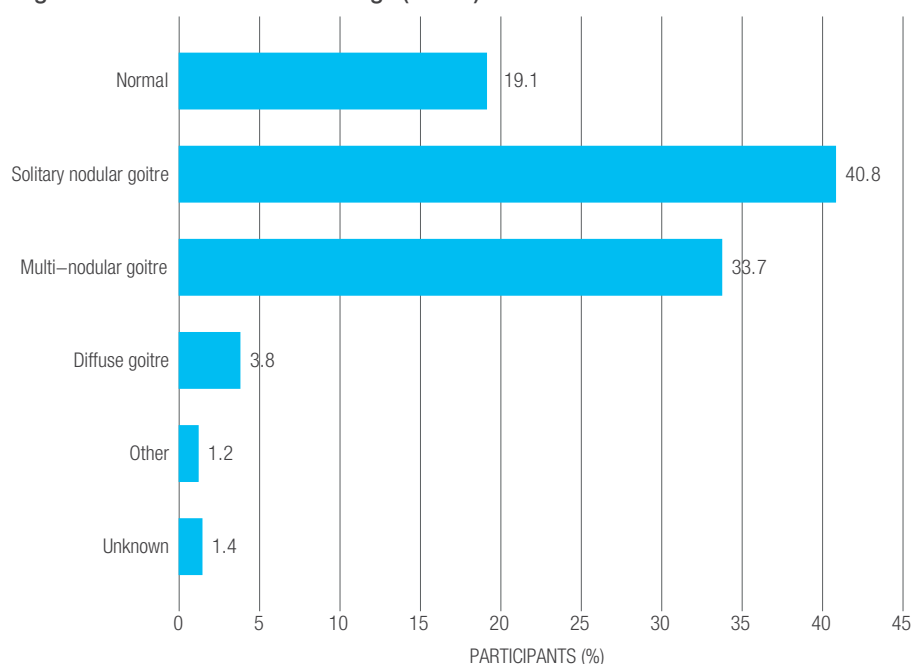
**Figure 6: Thyroid function at first presentation (n=422)**



## Neck Examination

Of the 424 participants with neck examination information recorded, 173 (40.8%) had a solitary nodule, 143 (33.7%) had a multinodular goitre (MNG), 16 (3.8%) had a diffuse goitre and 81 (19.1%) had normal findings upon examination (Figure 7). Only 48 out of 421 participants (11.4%) were reported to have palpable lymph nodes at the time of neck examination.

**Figure 7: Neck examination findings (n=424)**

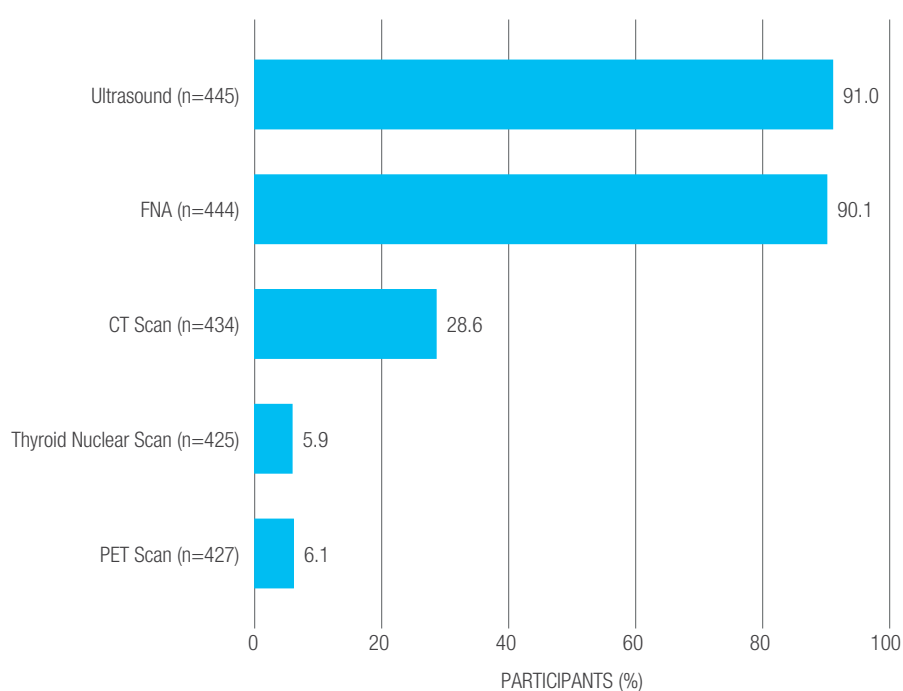


## Diagnostic Tests

A total of 405 out of 445 participants (91.0%) had an ultrasound (US) prior to diagnosis. Suspicious lymph nodes were present on US for 67 out of 389 participants (17.2%). Of the 444 participants with FNA information recorded, 400 (90.1%) underwent a FNA biopsy, with 312 (78.8%) having one site biopsied, 72 (18.2%) having two sites, 10 (2.5%) having three sites and two (0.5%) with unknown number of sites biopsied (data was missing for four participants).

Figure 8 displays the type of preoperative tests conducted and the percentage of patients who underwent each test.

**Figure 8: Preoperative tests**



### CQI1: Ultrasound (US)

<b>Indicator:</b>	Proportion of patients with suspicion of thyroid cancer that had an US of the primary site prior to initiation of treatment.
<b>Numerator:</b>	Number of patients with clinical suspicion of thyroid cancer who had a neck US performed preoperatively.
<b>Denominator:</b>	All patients with suspicion of thyroid cancer.
<b>Exclusions:</b>	No exclusions.
<b>Outcome:</b>	95.2%

Preoperative neck US 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<sup>4</sup>. Of the 351 participants who had suspicion of thyroid cancer, 334 (95.2%) underwent an US of the neck prior to any treatment. Table 6 demonstrates the calculation for this indicator.

Table 6: Ultrasound of primary site (CQI1)

Variable	Total (n)	Response	Frequency (%)
Ultrasound at primary site	351	Yes	334 (95.2)
		No	4 (1.1)
		Unknown	13 (3.7)

### CQI2: Fine Needle Aspiration (FNA)

<b>Indicator:</b>	Proportion of patients with clinically and/or radiologically suspicious lymph nodes that underwent a FNA to confirm malignancy before the initiation of treatment.
<b>Numerator:</b>	Number of patients with suspicious lymph nodes who underwent a FNA.
<b>Denominator:</b>	All patients with clinically and/or radiologically suspicious lymph nodes.
<b>Exclusions:</b>	Patients who did not have suspected malignancy.
<b>Outcome:</b>	97.3%

Preoperative FNA cytology confirms malignancy and informs management of patients to ensure appropriate treatment is delivered to patients with thyroid cancer<sup>4</sup>. Of the 432 participants with complete data, 74 (17.1%) had suspected malignancy and presented with clinical and/or radiological suspicious lymph nodes. Of these, 72 (97.3%) went on to have a FNA biopsy to confirm malignancy prior to any treatment. Table 7 provides an overview of the calculations for this indicator.

Table 7: FNA to confirm malignancy (CQI2)

Variable	Total (n)	Response	Frequency (%)
Clinically and/or radiologically suspicious lymph nodes and suspected malignancy	432	Yes	74 (17.1)
		No	344 (79.6)
		Unknown	14 (3.2)
If yes, FNA to confirm malignancy	74	Yes	72 (97.3)
		No	2 (2.7)
		Unknown	0 (0)

### 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 in planning the extent of surgery and in perioperative airway management.<sup>4</sup> It may also lead to the identification of preoperative vocal cord paralysis or paresis, providing evidence of invasive thyroid malignancy<sup>4</sup>.

### CQI3: Voice Assessment

<b>Indicator:</b>	Proportion of patients with suspicion of thyroid cancer that presented with (subjective or objective) evidence of voice abnormality and/or advanced disease and underwent a laryngeal examination prior to initiation of treatment.
<b>Numerator:</b>	Number of patients that present with a voice abnormality who undergo a laryngeal examination preoperatively.
<b>Denominator:</b>	All patients that present with a voice abnormality.
<b>Exclusions:</b>	No exclusions.
<b>Outcome:</b>	93.3%

Of the 399 participants with information recorded, 16 (4.0%) had evidence of subjective or objective voice abnormality prior to diagnosis. A laryngeal exam was performed prior to any treatment for 14 out of 15 participants (93.3%) (data missing for one participant), with 10 (71.4%) returning a normal result and one (7.1%) indicating right palsy and three (21.4%) left palsy (Table 8).

Table 8: Preoperative voice assessment (CQI3)

Variable	Total (n)	Response	Frequency (%)
Evidence of subjective or objective voice abnormality	399	Yes	16 (4.0)
		No	383 (96.0)
If yes, laryngeal exam	15*	Yes	14 (93.3)
		No	1 (6.7)

\*One participant missing laryngeal exam information.



## 7.6 Procedures captured by the registry

### Primary Procedure

All 445 participants initially had surgery, with 259 having a total thyroidectomy (58.2%), 161 (36.2%) a hemithyroidectomy, 5 (1.1%) a isthmusectomy, 4 (0.9%) a nodulectomy, 3 (0.7%) a completion thyroidectomy, 1 (0.2%) a redo-thyroidectomy unilateral, 1 (0.2%) a sub-total thyroidectomy and 11 (2.5%) another procedure type not listed. The main reason for surgery was malignancy (46.2%) followed by risk of malignancy (34.9%) (Table 9).

Figure 9 outlines the type of procedure initially performed on patients in the registry.

Figure 9: Type Of Initial Procedure (n=445)

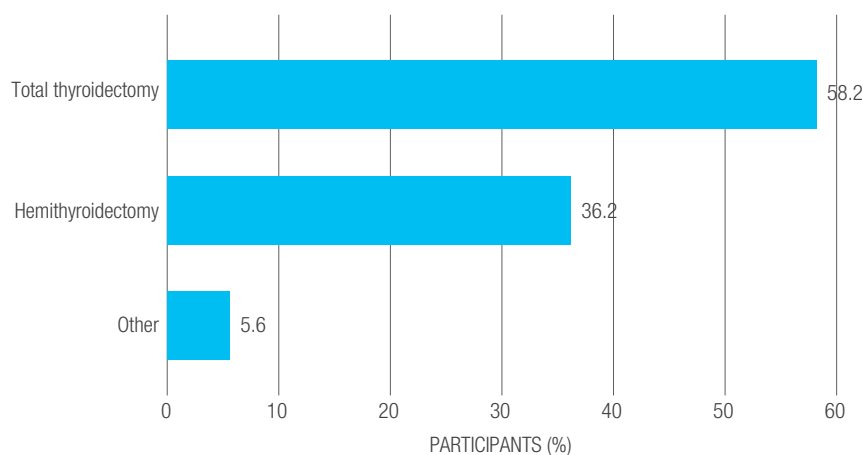


Table 9: Reasons for initial procedure (n=439)

Reason for Procedure	Frequency	%
Malignancy	203	46.2
Risk of malignancy	153	34.9
Compression	60	13.7
MNG nontoxic	9	2.1
Growth	8	1.8
Single nodule nontoxic	6	1.4
MNG toxic	12	2.7
Graves' disease	16	3.6
Single nodule toxic	2	0.5
Retrosternal goitre	15	3.4
Other	18	4.1

\*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 have a tumour size >4 cm or advanced disease (extrathyroidal extension and/or metastatic disease) and underwent a total (or near-total) thyroidectomy.

**Numerator:** Number of patients with thyroid cancer who have advanced disease or tumour >4 cm who undergo a total (or near-total) thyroidectomy.

**Denominator:** All patients with thyroid cancer who have extrathyroidal extension or tumour >4 cm.

**Exclusions:** No exclusions.

**Outcome:** 82.0%

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<sup>4</sup>. Of the 438 participants with surgical information recorded, 168 (38.4%) had advanced differentiated thyroid cancer or a tumour size greater than 4 cm (Table 10). Of these, 137 (82.0%) had a total (or near-total) thyroidectomy. Of the 438 with tumour size information, 140 (32.0%) had a tumour size of <1 cm, 236 (53.9%) 1-4 cm and 62 (14.2%) >4 cm.

Table 10: 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	438	Yes	168 (38.4)
		No	234 (53.4)
		Unknown	36 (8.2)
If yes, total (or near total) thyroidectomy (CQI4)	167*	Yes	137 (82.0)
		No	30 (18.0)
		Unknown	0 (0)

\*One participant missing procedure type data.

### Subsequent procedure(s)

Of the 302 participants with complete data for this item, 64 participants (21.2%) recorded a subsequent procedure, with all (100%) reporting only one subsequent procedure. The main subsequent procedure was a completion thyroidectomy (77.8%) followed by other (14.3%) (data missing for one participant) (Table 11).

**Table 11: Subsequent procedure type (n=63\*)**

Variable	Frequency%
Total thyroidectomy	3 (4.8)
Hemithyroidectomy	2 (3.2)
Completion Thyroidectomy	49 (77.8)
Other	9 (14.3)

\*Data missing for 1 participant.

#### CQI5: Completion Thyroidectomy

<b>Indicator:</b>	Proportion of patients with differentiated thyroid cancer (DTC) with a tumor >4 cm who had a hemithyroidectomy and then underwent a completion thyroidectomy.
<b>Numerator:</b>	Number of DTC patients with tumour >4 cm who initially had a hemithyroidectomy and then underwent a completion thyroidectomy.
<b>Denominator:</b>	All patients with thyroid cancer with tumour >4 cm who had a hemithyroidectomy.
<b>Exclusions:</b>	No exclusions.
<b>Outcome:</b>	72.2%

Completion thyroidectomy may be required in patients with an incidental finding of cancer or tumour size greater than 4 cm to allow for provision of RAI therapy<sup>4</sup>. Of the 18 DTC patients with tumour size greater than 4 cm who initially had a hemithyroidectomy, 13 (72.2%) then underwent a completion thyroidectomy.

### Lymph node dissection

A total of 423 participants had complete data regarding lymph node dissection, of which 419 participants had data relating to procedure type (Table 12).

A total of 201 out of 419 (48%) participants had a lymph node dissection. Of these, where it was known, it was therapeutic in 61 (31.3%), and prophylactic in 131 (67.2%), see Table 13 for details. Of the 161 participants who had an initial hemithyroidectomy, 45 (29.2%) had a lymph node dissection. Malignancy was reported in 57 out of 61 (93.4%) participants who underwent a therapeutic dissection and 49 out of 130 (37.7%) who underwent a prophylactic dissection.

**Table 12: Lymph node dissection by initial procedure type (n=419)**

Variable	Yes, N (%)	No, N (%)
Total thyroidectomy	146 (60.8)	94 (39.2)
Hemithyroidectomy	45 (29.2)	109 (70.8)
Isthmusectomy	1 (20.0)	4 (80.0)
Redo thyroidectomy	1 (100)	0 (0)
Completion	0 (0)	3 (100)
Nodulectomy	0 (0)	4 (100)
Sub-total thyroidectomy	1 (100)	0 (0)
Other	7 (63.6)	4 (36.4)
<b>Total</b>	<b>201</b>	<b>218</b>

#### CQI6: Lymph Node Dissection

<b>Indicator:</b>	Proportion of patients with thyroid cancer with indication of lymph node involvement that underwent therapeutic central and lateral neck lymph node dissection in addition to total (or near-total) thyroidectomy.
<b>Numerator:</b>	Number of patients with thyroid cancer with clinical lymph node involvement who had a therapeutic central and lateral neck lymph node dissection.
<b>Denominator:</b>	All patients with thyroid cancer with clinical lymph node involvement who had a total thyroidectomy.
<b>Exclusions:</b>	No exclusions.
<b>Outcome:</b>	91.1%

Compartmental lymph node dissection can reduce the risk of recurrence and, potentially, mortality for patients where nodal disease is evident<sup>4</sup>. Clinical lymph node involvement was evident in 48 out of 425 participants (11.3%), with 41 (91.1%) of these participants going on to have a therapeutic lymph node dissection, see Table 13 for details.

**Table 13: Therapeutic lymph node dissection (CQI6)**

Variable	Total (n)	Response	Frequency (%)
Lymph node dissection	423	Yes No Unknown	202 (47.8) 220 (52.0) 1 (0.2)
Type of dissection*	195	Therapeutic Prophylactic Unknown	61 (31.3) 131 (67.2) 3 (1.5)
Palpable lymph nodes	425	Yes No Unknown	48 (11.3) 371 (87.3) 6 (1.4)
If yes, therapeutic lymph node dissection~	45	Yes No Unknown	41 (91.1) 3 (6.7) 1 (2.2)

\* Seven participants with a lymph node dissection missing intent information.

~ Three participants with palpable lymph nodes missing dissection or intent information.



Compartmental lymph node dissection can reduce the risk of recurrence and, potentially, mortality for patients where nodal disease is evident<sup>4</sup>.

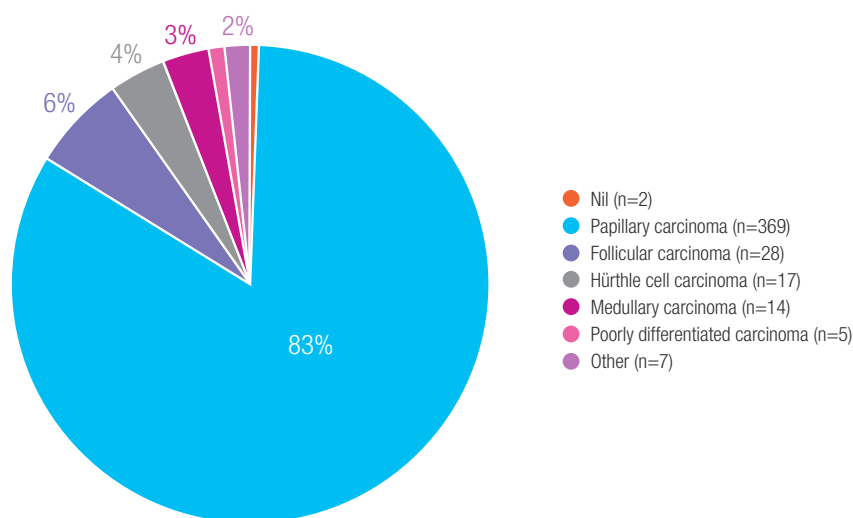




## Pathology

Of the 442 out of 504 (88%) participants with complete pathology information, 369 (83.5%) had papillary carcinoma, 28 (6.3%) follicular cell carcinoma, 17 (3.8%) Hürthle cell carcinoma, 14 (3.2%) medullary carcinoma, and five (1.1%) poorly differentiated carcinoma (Figure 10).

**Figure 10: Pathology of primary tumour (n=442)**



In addition to malignant pathology, benign pathology was reported in 267 out of 355 patients, with MNG and lymphocytic thyroiditis occurring in 173 (48.7%) and 91 (25.6%) of participants respectively. An incidental finding of cancer was observed for 132 out of 425 (31.1%) of participants in the registry undergoing an initial procedure, see Table 14 for additional pathology features.

**Table 14: Additional pathology features**

Variable	Total (n)	Response	Frequency (%)
Incidental findings of cancer	425	Yes	132 (31.1)
		No	287 (67.5)
		Unknown	6 (1.4)
Additional benign pathology*	355	No benign pathology	85 (23.9)
		MNG	173 (48.7)
		Lymphocytic thyroiditis	91 (25.6)
		Follicular adenoma	16 (4.5)
		Graves' disease	16 (4.5)
		Hürthle cell adenoma	7 (2)
		Benign cyst	2 (0.6)
		Other	63 (17.7)
		Unknown	3 (0.8)
Histological margin status	418	Residual tumour cannot be assessed (RX)	1 (0.2)
		No residual tumour (R0)	348 (83.3)
		Microscopic residual tumour (R1)	56 (13.4)
		Unknown	13 (3.1)
Residual tumour at surgery	410	Residual tumour cannot be assessed (RX)	24 (5.8)
		No residual tumour (R0)	359 (87.6)
		Macroscopic residual tumour (R2)	16 (3.9)
		Unknown	11 (2.7)
Multifocal cancer	395	Yes	124 (31.4)
		No	265 (67.1)
		Unknown	6 (1.5)
Lymphovascular invasion	421	Yes	95 (22.6)
		No	312 (74.1)
		Unknown	14 (3.3)
Extrathyroidal extension	421	Sternothyroid muscle	50 (11.9)
		Subcutaneous soft tissues	12 (2.9)
		Prevertebral fascia	1 (0.2)
		No	350 (83.1)
		Unknown	8 (1.9)

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



Of the 395 participants with complete data, 124 (31.4%) were reported to have multifocal cancer with the site of the multifocality reported in the right lobe for 35 (28.5%) participants, in the left lobe for 22 (17.9%) participants and in both lobes for 66 (53.7%) participants (data missing for one participant). Extrathyroidal extension and lymphovascular invasion were observed in 63 out of 421 participants (15.0%) and 95 out of 421 (22.6%) participants, respectively. Microscopic residual tumour (R1) was pathologically identified in 56 out of 418 (13.4%) participants and macroscopic residual tumour (R2) reported for 16 out of 410 (3.9%) participants.

### Metastatic Disease

Lymph node metastases were reported in 123 out of 426 (28.9%) participants undergoing initial procedure, and distant metastases were reported in six out of 410 (1.5%) participants. Of the six participants with distant metastases, four reported a single metastatic site and two reported two metastatic sites. For the participants with a single metastatic site, one participant had metastasis in the bone, another in the lung and site was not specified for the remaining two participants. Of the two participants with two metastatic sites, one participant had metastases in both the bone and lung while the other had metastases in the bone and the second site was not specified.

### Recurrent Laryngeal Nerve

During surgery, the RLN remained intact on the right for 356 out of 358 participants (99.4%), was damaged in one participant (0.3%) and was sacrificed in one participant (0.3%) (Table 15). Temporary RLN Palsy reported in 15 (4.2%) of the 356 participants with an intact right RLN. The RLN on the left remained intact for 336 out of 339 (99.1%) participants, was damaged in one (0.3%) participant and sacrificed in two (0.6%) participants. Temporary RLN Palsy was reported in 20 (6.0%) of the 336 participants with an intact left RLN. Of 429 participants, 320 (74.6%) had a nerve integrity monitor used during the initial procedure, with a loss of signal reported for the left RLN in 11 participant procedures (3.5%) and in the right RLN for five procedures (1.6%) (data missing for seven participants).

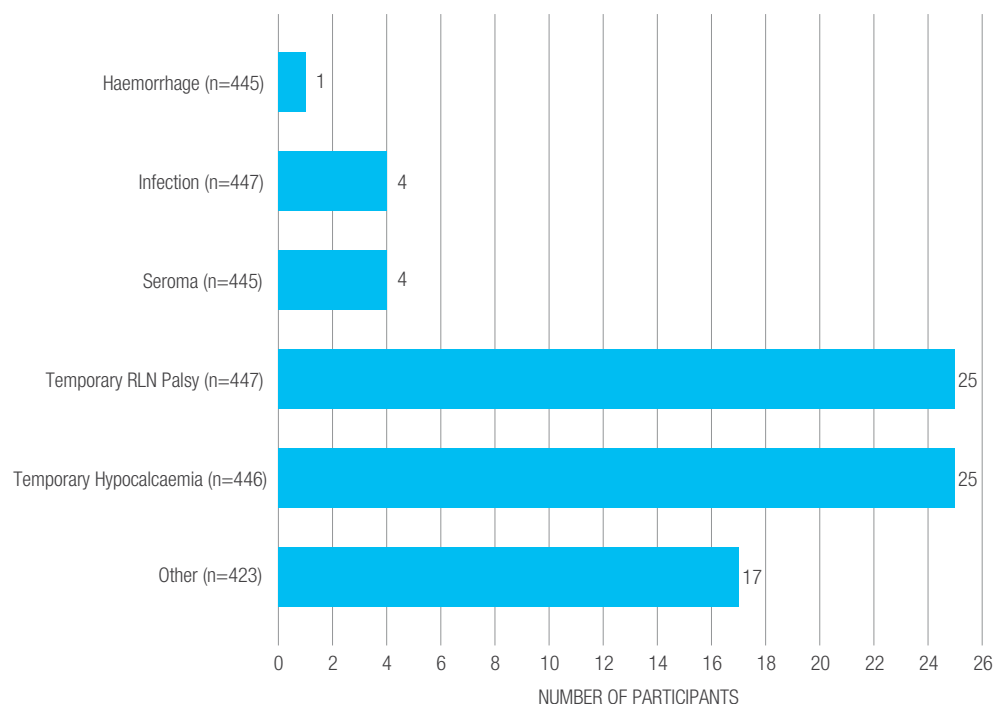
**Table 15: Recurrent laryngeal nerve monitoring during initial procedure**

Variable	Total (n)	Response	Frequency (%)
RLN Right	358	Intact	356 (99.4)
		Damaged	1 (0.3)
		Sacrificed	1 (0.3)
RLN Left	339	Intact	336 (99.1)
		Damaged	1 (0.3)
		Sacrificed	2 (0.6)
Nerve integrity monitoring used	429	Yes	320 (74.6)
		No	103 (24.0)
		Unknown	6 (1.4)

### 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 (5.6%), haemorrhage (return to theatre within 48 hours) (0.2%), infection (0.9%), and seroma (0.9%) (Figure 11).

**Figure 11: Surgical complications following initial procedure**



### CQI7: Temporary Recurrent Laryngeal Nerve (RLN) Palsy

<b>Indicator:</b>	Proportion of patients with thyroid cancer who presented with temporary recurrent laryngeal nerve (RLN) palsy following thyroidectomy.
<b>Numerator:</b>	Number of patients with thyroid cancer who present with temporary RLN palsy post-thyroidectomy.
<b>Denominator:</b>	All patients with thyroid cancer who had a thyroidectomy.
<b>Exclusions:</b>	Patients with RLN sacrificed.
<b>Outcome:</b>	5.7%*

\* This rate reflects RLN palsy in the early postoperative period. The data item will be updated to record persisting RLN palsy at 3-months post-surgery and will be reported in the 2020 Annual Report.

~ The denominator for this indicator is different in-text for RLN Palsy.

### CQI8: Temporary Hypoparathyroidism (Hypocalcaemia)

<b>Indicator:</b>	Proportion of patients with thyroid cancer who present with persisting hypoparathyroidism at 3 months evidenced following thyroidectomy, as evidenced by need for ongoing calcium and/or vitamin D.
<b>Numerator:</b>	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.
<b>Denominator:</b>	All patients with thyroid cancer who had a total or completion thyroidectomy.
<b>Exclusions:</b>	No exclusions.
<b>Rate:</b>	We are currently unable to report on this indicator due to an issue with the data item. This data item will be changed to report calcium supplementation at 3-months post-surgery and will be reported in the 2020 Annual Report.

### CQI9: Haemorrhage Requiring Return to Theatre

<b>Indicator:</b>	Proportion of patients with thyroid cancer who underwent a thyroidectomy and had postoperative haemorrhage within 48 hours requiring return to theatre.
<b>Numerator:</b>	Number of patients with thyroid cancer who had postoperative haemorrhage within 48 hours requiring return to theatre following thyroidectomy.
<b>Denominator:</b>	All patients with thyroid cancer who had a thyroidectomy.
<b>Exclusions:</b>	No exclusions.
<b>Rate:</b>	0.2%

The rates of these complications are similar to those reported in the literature. The mean incidence rates of temporary voice change, due to RLN palsy, are 9.8% in the literature while our rate was slightly lower at 5.6-5.7%<sup>5</sup>. The literature has shown that temporary hypoparathyroidism, resulting in hypocalcaemia, occurs in approximately 19-38% of patients undergoing total thyroidectomy<sup>6</sup>. 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. Haemorrhage has been reported to occur in approximately 0.6-2.9% of patients undergoing thyroid surgery, while our rate is lower at 0.2%<sup>7</sup>. Permanent complications are less common and require presentation at 6-months post-surgery, but the registry currently does not collect this data.

**Table 16: Surgical complications following procedure (CQI7 & 9)**

Variable	Total	Response	Frequency (%)
Temporary recurrent laryngeal nerve palsy (CQI7)	405	Yes	23 (5.7)
		No	382 (94.3)
		Unknown	0 (0)
Haemorrhage requiring return to theatre (CQI9)	434	Yes	1 (0.2)
		No	433 (99.8)
		Unknown	0 (0)

## 7.7 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<sup>8</sup>.

#### CQI10: Postoperative TNM Staging

<b>Indicator:</b>	Proportion of patients with thyroid cancer who have recorded postoperative tumour node metastasis (TNM) staging.
<b>Numerator:</b>	Number of patients with thyroid cancer with TNM staging recorded.
<b>Denominator:</b>	All patients with thyroid cancer.
<b>Exclusions:</b>	No exclusions.
<b>Outcome:</b>	71.2%

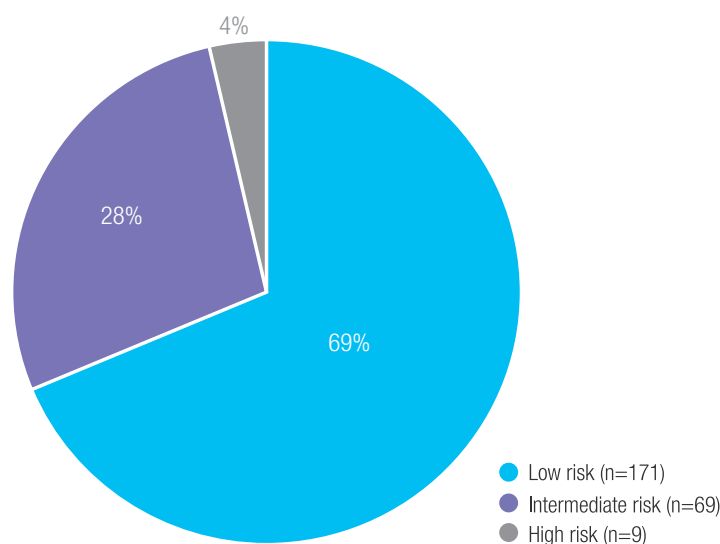
Postoperative TNM staging for thyroid cancer, as for other cancer types, is used to provide prognostic information, enable risk-stratified description of patients, and for research purposes<sup>4</sup>. Of the 417 participants with staging details recorded, 297 (71.2%) had complete TNM staging recorded (Table 17).

**Table 17: TNM staging recorded (CQI10)**

Reason for Procedure	Total (n)	Response	Frequency (%)
TNM staging recorded (CQI10)	417	Yes	297 (71.2)
		No	3 (0.7)
		Unknown	117 (28.1)

For participants with DTC for whom TNM staging was available (n=249), patients were stratified by risk of structural disease recurrence according to the American Thyroid Association (ATA) guidelines<sup>4</sup>, with 171 (69%) patients being classified as low risk, 69 (28%) as intermediate risk and nine (4%) as high risk of disease recurrence (Figure 12).

**Figure 12: American Thyroid Association (ATA) risk stratification (n=249)**



#### CQI11: Multidisciplinary Team (MDT) Meeting

<b>Indicator:</b>	Proportion of patients with thyroid cancer who were presented at a tumour-specific multidisciplinary team meeting.
<b>Numerator:</b>	Number of patients with thyroid cancer reviewed at a MDT meeting.
<b>Denominator:</b>	All patients with thyroid cancer.
<b>Exclusions:</b>	Patients with tumour size <1 cm.
<b>Outcome:</b>	62.6%

Evidence suggests that patients with cancer managed by a multidisciplinary team have a better outcome<sup>4</sup>. As a result of this, tumour-specific multidisciplinary team (MDT) meetings are regularly held within each site or health service. Of the 265 participants with complete data and tumour size greater than 1 cm, 166 (62.6%) were presented at a thyroid cancer specific MDT meeting (Table 18).

**Table 18: Presentation at multidisciplinary team meeting (CQI11)**

Variable	Total (n)	Response	Frequency (%)
Presented at MDT	412	Yes	219 (53.2)
		No	192 (46.6)
		Unknown	1 (0.2)
Presented at MDT meeting with tumour size >1 cm	265	Yes	166 (62.6)
		No	99 (37.4)

*\*75 participants missing serum thyroglobulin data.*

## Supplementation and Therapy

In the postoperative period, 267 out of 281 participants who had a total or completion thyroidectomy were receiving thyroxine therapy (95.0%), with 38 (13.5%) having supplementation, 105 (37.4%) replacement and 124 (44.1%) suppression (33 participants with a total/completion thyroidectomy missing information on thyroxine supplementation). Furthermore, in the early postoperative period, 282 out of 437 (64.5%) were receiving supplementation with calcium and 64 out of 441 (14.5%) received supplementation with vitamin D (Table 19).

**Table 19: Postoperative supplementation & therapy**

Variable	Total (n)	Response	Frequency (%)
Supplementation with calcium	437	Yes	282 (64.5)
		No	147 (33.6)
		Unknown	8 (1.8)
Supplementation with vitamin D	441	Yes	64 (14.5)
		No	370 (83.9)
		Unknown	7 (1.6)
Supplementation with thyroxine (total/ completion thyroidectomy)	281	No	5 (1.8)
		Supplementation	38 (13.5)
		Replacement	105 (37.4)
		Suppression	124 (44.1)
		Unknown	9 (3.2)

## Postoperative Treatment

Postoperative Thyroglobulin (Tg) was recorded for 175 out of 356 (49.2%) participants and 118 of 345 (34.2%) had TSH stimulation. Of those with DTC, 129 out of 354 (36.4%) 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 (69.9%) or that the participant had a micropapillary thyroid cancer (<20 mm) (63.6%). For more details see Table 20 below.

**Table 20: Postoperative treatment details**

Variable	Total (n)	Response	Frequency (%)
Postoperative Tg recorded	356	Yes	175 (49.2)
		No	133 (37.4)
		Unknown	48 (13.5)
Thyroid stimulating hormone stimulation	345	Yes	118 (34.2)
		No	188 (54.5)
		Unknown	39 (11.3)
RRA following thyroid surgery	354	Yes	129 (36.4)
		No	217 (61.3)
		Unknown	8 (2.3)
If no, reason for no RRA*	209	PTC ≤10 mm	104 (49.8)
		PTC 11-20 mm	29 (13.9)
		Hemithyroidectomy only	20 (9.6)
		Patient age	6 (2.9)
		Low risk	146 (69.9)
		Comorbidities	7 (3.3)
		Patient declined	5 (2.4)
		MTC	2 (1)
		Other	5 (2.4)
		Unknown	3 (1.4)

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

### CQI12: Serum Thyroglobulin (Tg)

<b>Indicator:</b>	Proportion of patients undergoing a total thyroidectomy for thyroid cancer that have serum Tg recorded postoperatively.
<b>Numerator:</b>	Number of patients that underwent total thyroidectomy for thyroid cancer and had serum Tg recorded postoperatively.
<b>Denominator:</b>	All patients that underwent a total thyroidectomy for thyroid cancer.
<b>Exclusions:</b>	Patients diagnosed with medullary thyroid cancer or anaplastic thyroid cancer.
<b>Outcome:</b>	49.7%

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<sup>4</sup>. Of the 351 participants who underwent a total thyroidectomy, 174 (49.6%) 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.

### CQI13: Radioactive Iodine (RAI)

<b>Indicator:</b>	Proportion of patients with high-risk differentiated thyroid cancer (DTC) that underwent radioactive iodine remnant ablation (RRA) following a total (or near total) thyroidectomy.
<b>Numerator:</b>	Number of patients with high-risk differentiated thyroid cancer (DTC) that underwent a total (or near total) thyroidectomy and received RAI remnant ablation.
<b>Denominator:</b>	All patients with high-risk differentiated thyroid cancer (DTC) that underwent a total (or near total) thyroidectomy.
<b>Exclusions:</b>	Patients with differentiated thyroid cancer (DTC) who are classified as low and/or intermediate risk according to the American Thyroid Association (ATA) risk stratification.
<b>Outcome:</b>	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<sup>4</sup>. Currently in the registry there are only seven participants who were diagnosed with high-risk DTC and underwent a total or completion thyroidectomy, with all seven of these participants receiving RRA therapy postoperatively. For more details please see Table 21.

**Table 21: Postoperative treatment details (CQI12 & 13)**

Variable	Total (n)	Response	Frequency (%)
Total/completion thyroidectomy and not medullary/anaplastic TC	442	Yes No Unknown	425 (96.2) 17 (3.9) 0 (0)
If yes, serum thyroglobulin reported	350*	Yes No Unknown	174 (49.7) 130 (37.1) 46 (13.1)
High-risk DTC and a total/completion thyroidectomy	254	Yes No Unknown	7 (2.8) 247 (97.2) 0 (0)
If yes, RAI	7	Yes No Unknown	7 (100) 0 (0) 0 (0)

\*75 participants missing serum thyroglobulin data.'





## 8. ACADEMIC OUTPUTS

### 8.1 Publications

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Ioannou, L., Serpell, J., Dean, J., Bendinelli, C., Gough, J., Lisewski, D., Miller, J., Meyer-Rochow, W., Sidhu, S., Topliss, D., Walters, D., Zalcborg, 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

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### 8.2 2019 Presentations

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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 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).

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## 9. FUTURE DEVELOPMENTS

### 9.1 New Sites

Since the last Annual Report, the ANZTCR has welcomed nine hospitals: St Vincent's Hospital Melbourne (VIC), St Vincent's Private Hospital Melbourne (VIC); Newcastle Private Hospital (NSW), Maitland Private Hospital (VIC), The Mater Hospital – North Sydney (NSW); and four Western Health (VIC) sites. A further three sites are currently under review and two site applications are in progress. The ANZTCR-CC aims to submit an additional 11 applications by end of 2020, including expansion into New Zealand.

### 9.2 Data Importing

A semi-automated data import program has been piloted by the ANZTCR. This program will minimise the need for data duplication where sites are maintaining their own database and the ANZTCR. This process will be available from mid-2020, for sites who have closely aligned datasets or existing thyroid cancer databases to the ANZTCR.

### 9.3 Site Reporting

As the ANZTCR continues to expand its coverage and recruitment of patients it will be able to undertake reporting back to sites regarding the CQIs. 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. The ANZTCR anticipates generating site benchmarked reports in early 2021. In the interim, participating sites can log onto the database and access their patient information and download data reports at any time.

### 9.4 Patient-Reported Outcomes

The ANZTCR aims to expand to include the routine collection of patient-reported outcomes. A systematic review is being undertaken to identify and evaluate disease-specific patient-reported outcome measures (PROMs) (i.e. questionnaires) that have been administered to patients diagnosed with thyroid cancer, to identify whether an appropriate PROM exists for use by the registry. Following this, a qualitative study, in collaboration with the ATF, will be conducted to ascertain the views and opinions of consumers towards the proposed PROM(s).

### 9.5 Risk Adjustment

The ANZTCR will undertake a systematic review to identify prognostic factors that predict surgical morbidity and recurrence in patients with DTC. The results of this literature review will be used, in consultation with experts, to determine the risk adjustment required for each indicator when providing benchmarked reports to sites.

### 9.6 Expansion of Surgical Modules

The Clinician Survey highlighted expressed interest of a number of surgeons in expanding the registry to include additional thyroidectomy, parathyroid and adrenal surgical modules. An opportunity to expand the registry in the future may be possible pending Steering Committee approval and further funding.

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## 11. 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
ATF	Australian Thyroid Foundation
CQI	Clinical Quality Indicator
DTC	Differentiated Thyroid Cancer
ENT	Ear Nose Throat
FNA	Fine Needle Aspiration
MDM	Multidisciplinary Team Meeting
MNG	Multinodular Goitre
RRA	Radioactive Iodine Remnant Ablation
RLN	Recurrent Laryngeal Nerve
Tg	Thyroglobulin
TNM	Tumour, Node, Metastasis
TSH	Thyroid Stimulating Hormone
US	Ultrasound

## 12. APPENDICES

### 12.1 APPENDIX A List of Tables

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Table 10	Total (or near-total) thyroidectomy for patients with advanced disease (CQI4)
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### 12.2 APPENDIX B List of Figures

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Figure 2	Area of surgeon expertise
Figure 3	Accumulation rates of participants in the registry for 2018-2020
Figure 4	Participants' age distribution at time of diagnosis stratified by sex
Figure 5	Method of diagnosis of primary thyroid cancer
Figure 6	Thyroid function at first presentation
Figure 7	Neck examination findings
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Figure 9	Type of initial procedure
Figure 10	Pathology of primary tumour
Figure 11	Surgical complications following initial procedure
Figure 12	American Thyroid Association (ATA) risk stratification



## 12.3 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
Date of Diagnosis
Basis of Diagnosis
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
Family History of Thyroid Disease
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
Papillary, Follicular and Hürthle Cell Variants
Incidental Finding of Cancer
Thyroid Benign Pathology
Largest Tumour Diameter
Margin Status
Multifocal Cancer
Lymphovascular Invasion
Extrathyroidal Extension
Lymph Node Metastases
Distant Metastases
Surgical Complications

### Postoperative (at 90-days)

Presented at MDM
TNM Staging
Supplementation
Biobank Sample
Genetic Testing

### Treatment (at 90-days)

Postoperative Tg
TSH Stimulation
RAI Remnant Ablation (RRA)
Other Adjuvant Therapy

## 12.4 APPENDIX D Committees & staff

### Steering Committee Members

Professor Jonathan Serpell	Committee Chair, Endocrine Surgeon
Professor Susannah Ahern	Head, Registry Science and Research, School of Public Health, Monash University
Associate Professor Julie Miller	ANZES President, Endocrine Surgeon
Ms Madeleine Allnutt	Australian Thyroid Foundation, Consumer Advocate
Dr Cino Bendinelli	Endocrine Surgeon
Dr Chhavi Bhatt	Database Manager
Dr Daron Cope	Otolaryngologist
Dr Anthony Glover	Endocrine Surgeon
Dr Jenny Gough	Breast and Endocrine Surgeon
Dr Simon Harper	Endocrine and General Surgeon
Dr James Lee	Endocrine Surgeon
Dr Win Meyer-Rochow	Endocrine and General Surgeon
Professor Jeremy Millar	Radiation Oncologist
Professor Stan Sidhu	Endocrine Surgeon
A/Prof Mark Sywak	Endocrine Surgeon
Professor Duncan Topliss	Endocrinologist
Dr David Walters	Breast and Endocrine Surgeon
Professor John Zalcborg	Head, Cancer Research Program, School of Public Health, Monash University

### Registry Leads

Professor Jonathan Serpell, Clinical Lead

Professor Susannah Ahern, Academic Lead

### ANZTCR Coordinating Centre, Monash University

Dr Liane Ioannou, Research Fellow

Ms Elysia Greenhill, Registry Coordinator

Ms Claire Bavor, Research Assistant

## 12.5 APPENDIX E: List of participating sites & surgeons

### Participating Sites

VIC	Alfred Hospital
	Casey Hospital
	Dandenong Hospital
	Footscray Hospital
	Frankston Hospital
	Monash Medical Centre Clayton
	Monash Medical Centre Moorabbin
	Peninsula Private Hospital
	Royal Melbourne Hospital
	St Vincent's Hospital Melbourne
	St Vincent's Private Hospital Melbourne
	Sunshine Hospital
	Sunshine Radiation Therapy Centre
NSW	Williamstown Hospital
	Dudley Private Hospital
	Hornsby Ku-ring-gai Hospital
	John Hunter Hospital
	Lake Macquarie Private Hospital
	Manly District Hospital
	Royal North Shore Hospital
	Royal North Shore Private Hospital
	The Mater Hospital
	Newcastle Private Hospital
QLD	Maitland Private Hospital
	Greenslopes Private Hospital
	North West Private Hospital
	Townsville Hospital
SA	Wesley Hospital
	Flinders Medical Centre
	Royal Adelaide Hospital
	The Queen Elizabeth Hospital

### Participating Surgeons

Dr Cino Bendinelli	Mr Jason Tan
Dr Janne Bingham	Dr Robert Tasevski
Dr Melissa Bochner	Dr Leong Tiong
Dr Jason Boldery	Dr Domenika Turkiewicz
Dr Jared Chang	Dr David Walters
Dr Daron Cope	Dr Robert Whitfield
Prof Leigh Delbridge	Dr David Wright
Dr Robert Eisenberg	Dr Meei Yeung
Mr Stephen Farrell	
Dr Linda Fenton	
Mr Bill Fleming	
Dr Anthony Glover	
Dr Jenny Gough	
Mr Simon Grodski	
Dr Andrew Kiu	
Dr Jim Kollias	
Dr Christine Lai	
Mr James Lee	
A/Prof Julie Miller	
Dr Sally Meade	
Dr Teresa Nano	
Dr Christine O'Neil	
Prof Jonathan Serpell	
Prof Stan Sidhu	
Dr Anita Skandarajah	
Dr Kate Stringer	
A/Prof Mark Sywak	

## 12.6 APPENDIX F: List of ANZTCR policies & procedures

### ANZTCR Policies and Procedures

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Protocol

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Data Dictionary

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Data Access & Publication Policy

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Privacy Policy

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ANZTCR-RCD User Manual

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Conflict of Interest Statement

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## 12.7 APPENDIX G: ANZTCR clinical quality indicators

### Preoperative

CQI1	Proportion of patients with suspicion of thyroid cancer had an ultrasound (US) of the primary site before the initiation of treatment.
CQI2	Proportion of patients with clinically and/or radiologically suspicious lymph nodes that underwent fine needle aspiration (FNA) to confirm malignancy before the initiation of treatment.
CQI3	Proportion of patients with suspicion of thyroid cancer that presented with (subjective or objective) evidence of voice abnormality and underwent a laryngeal examination before the initiation of treatment.

### Surgery

CQI4	Proportion of patients with differentiated thyroid cancer (DTC) who had advanced disease (extrathyroidal extension and/or metastatic disease) or tumour size >4 cm and underwent a total (or near-total) thyroidectomy.
CQI5	Proportion of patients with DTC with tumour >4 cm who had a hemithyroidectomy and then underwent a completion thyroidectomy.
CQI6	All patients with thyroid cancer with indication of lymph node involvement that underwent therapeutic central and lateral neck lymph node dissection in addition to total (or near-total) thyroidectomy.

### Surgical Complications

CQI7	Proportion of patients with thyroid cancer who presented with recurrent laryngeal nerve (RLN) palsy at 3 months following thyroidectomy.
CQI8	Proportion of patients with thyroid cancer who present with persisting hypoparathyroidism at 3 months following thyroidectomy, as evidenced by need for ongoing calcium and/or vitamin D.
CQI9	Proportion of patients with thyroid cancer who underwent a thyroidectomy and had postoperative haemorrhage within 48 hours requiring return to theatre.

### Staging & Postoperative Treatment Planning

CQI10	Proportion of patients with thyroid cancer who have recorded postoperative Tumour Node Metastasis (TNM) staging.
CQI11	Proportion of patients with thyroid cancer who were reviewed by a multidisciplinary team.

### Postoperative Treatment

CQI12	Proportion of patients undergoing surgery for thyroid cancer that have serum thyroglobulin (Tg) recorded postoperatively.
CQI13	Proportion of patients with high-risk DTC that underwent radioactive iodine remnant ablation (RRA) following a total (or near total) thyroidectomy.

## FURTHER INFORMATION

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