MONASH University

AUSTRALIAN & NEW ZEALAND THYROID CANCER REGISTRY

2020 ANNUAL REPORT

AUSTRALIAN & NEW ZEALAND
THYROID CANCER
REGISTRY

CONTENTS

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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 03 August 2021 and pertains to data that relates to patient events from 25 September 2017 to 31 December 2020. 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 third annual report of the ANZTCR for 2020. Firstly, it goes without saying the past 18 months have been enormously challenging for all of us during the COVID-19 pandemic. I would like to thank everyone including all our participants and staff for their extraordinary efforts during this extremely testing time. I hope everyone is remaining safe and well.

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, although still relatively small, 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 2020 Annual Report. Despite the challenges presented during the COVID-19 pandemic, the ANZTCR Coordinating Centre, Management and Steering Committees have continued their hard work on the registry.

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.

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 to their 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. The registry's value as a clinical decision-making tool also continues to grow as the registry is now piloting the collection of patient-reported outcomes and experiences to provide important patient insight.

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 2021 and beyond.

Associate Professor Julie Miller
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 three years of data collection.

In 2020, the ANZTCR implemented an automated extract and import of data from two large surgical databases into the registry, paving the way for this process to be undertaken at other sites. The ANZTCR also commenced research into the collection of patient-reported outcome and experience measures to feedback to sites alongside clinical data.

- As of 31st December 2020, a total of 28 hospitals across four states were participating in the ANZTCR, with 37 contributing surgeons.
- As of 31st December 2020, there were 793 participants in the ANZTCR, comprising 71% females and 29% males; at least some follow-up data was available for 99% of participants.
- The median age of participants was 53 years for females and 54 years for males (median overall age 53 years).
- Diagnosis of thyroid cancer was based on histology (55%), cytology (44%) and histology of metastasis (1%).
- At diagnosis, 44% of participants had at least one specified comorbidity, 3% had previously been exposed to upper body radiation and 4% had previous thyroid surgery.
- At diagnosis, the most common clinical neck finding was a solitary nodular goitre (35%), multinodular goitre (33%) or normal neck examination (12%).
- During diagnostic work-up, 92% of participants had an ultrasound and 91% had fine needle aspiration cytology (FNA); 26% underwent a computed tomography (CT) scan, 6% had a thyroid nuclear scan, 6% a positron emission tomography (PET) scan. Nineteen of 25 participants with evidence of voice abnormality prior to diagnosis underwent a laryngeal examination.
- The majority of participants underwent a total thyroidectomy (57%), or hemithyroidectomy (36%), with 7% undergoing a different procedure. Of those participants who had a subsequent procedure 76% had a completion thyroidectomy.
- Less than half (48%) of participants had a lymph node dissection; 28% with therapeutic intent and 70% with prophylactic intent.
- Pathology was reported for 734 participants, and included 93% with differentiated, 4% with medullary and 1% with poorly differentiated thyroid cancer. Lymph node metastases was reported in 31% of participants at the time of initial procedure, with distant metastases reported only in 1%.
- Additional benign pathology (such as multinodular goitre or lymphocytic thyroiditis) was reported in 82% of participants. For 25% of participants, the finding of cancer was incidental.
- Nerve integrity monitoring was used during the initial procedure in 71% of participants. Eight participants had recurrent laryngeal nerves damaged or sacrificed during their procedure (approximately 1%).
- Surgical complications reported in the registry included temporary RLN palsy (5%); with haemorrhage, infection and seroma reported in less than 1%.
- Postoperative treatment included medical supplementation with calcium (67%), vitamin D (14%) and thyroxine (78%).
- 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 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

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AUSTRALIAN & NEW ZEALAND ENDOCRINE SURGEONS

INTRODUCTION

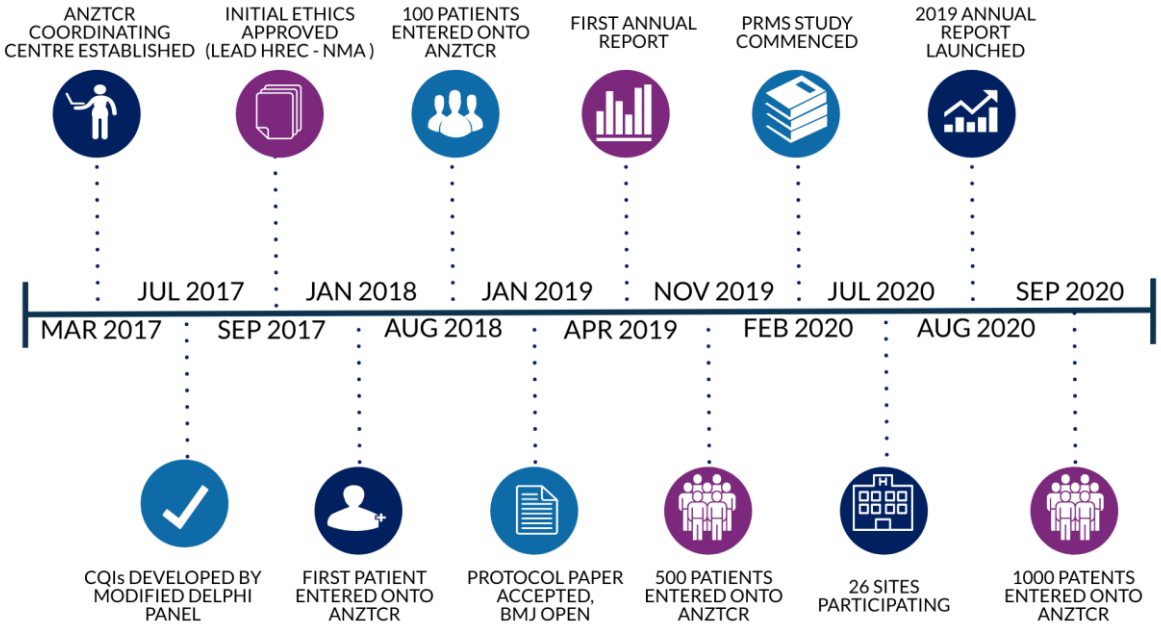
The ANZTCR is a clinical quality registry that was established in 2017 to monitor the quality of care provided to patients diagnosed with thyroid cancer. The ANZTCR collects the diagnosis, treatment and outcome data of individuals with thyroid cancer, in both public and private health services.

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 three years of data collection and aggregate ANZTCR clinical quality indicator (CQI) outcomes.

MILESTONES

The key 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 into 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.

Introducing 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 the Alfred 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.

PATIENT-REPORTED MEASURES

In 2020, the ANZTCR commenced research to inform the collection of patient-reported outcomes (PROs) and patient-reported experiences (PREs). Once data collection commences, PRO and PRE data will be reported back to sites, along with clinical data to provide patient insight into quality of care outcomes.

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 early 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.

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

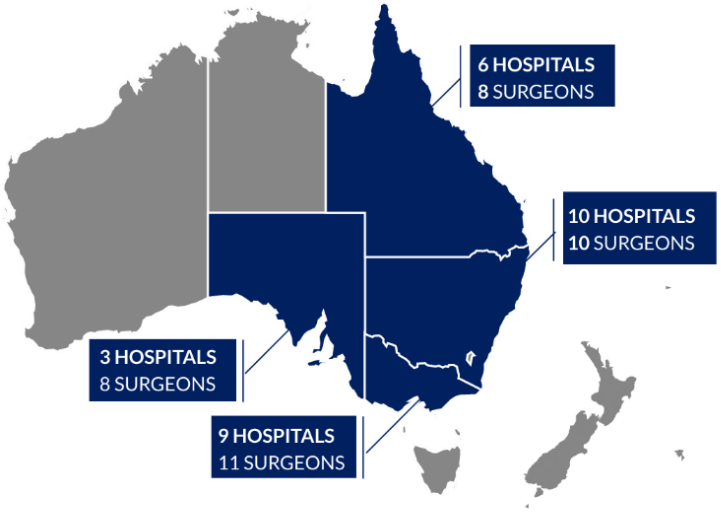
The ANZTCR-RCD allows surgeons to run patient-level and aggregate data reports in real-time. Resources are provided to contributing surgeons with instructions on how to run these reports.

SUMMARY OF THE REGISTRY DATA

SITE PARTICIPATION

As of December 31 2020, 28* sites had obtained governance approval. There were 16 public and 12 private health services/ hospital sites across Australia 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

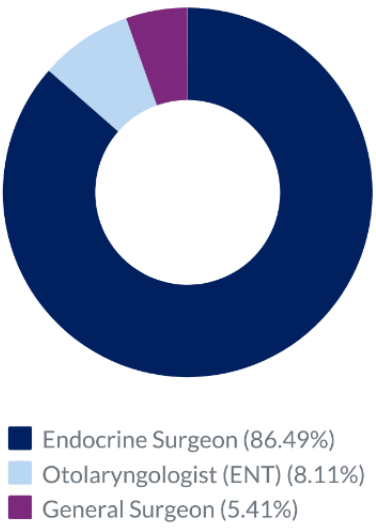


*Victorian sites are counted at the health service level

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 37 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 2020.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. Hence, by December 31 2020, 1143 patients had been enrolled in the registry but only 835 had been invited to participate via mailout. This was due to the impact of COVID-19 on registry operations limiting the ability of staff to send patient letters due to the work from home requirements.

A total of 835 patients have been invited to participate in the registry since January 2018. Of the 835 patients invited, 42 (5.0%) have chosen to opt-out and 11 (1.3%) 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 2020, the ANZTCR confirmed the participation of 793 thyroid cancer patients and their data.

Table 1 demonstrates patient participation in the ANZTCR from 1 January 2018 to 31 December 2020. The registry has an opt-out rate of 5%.

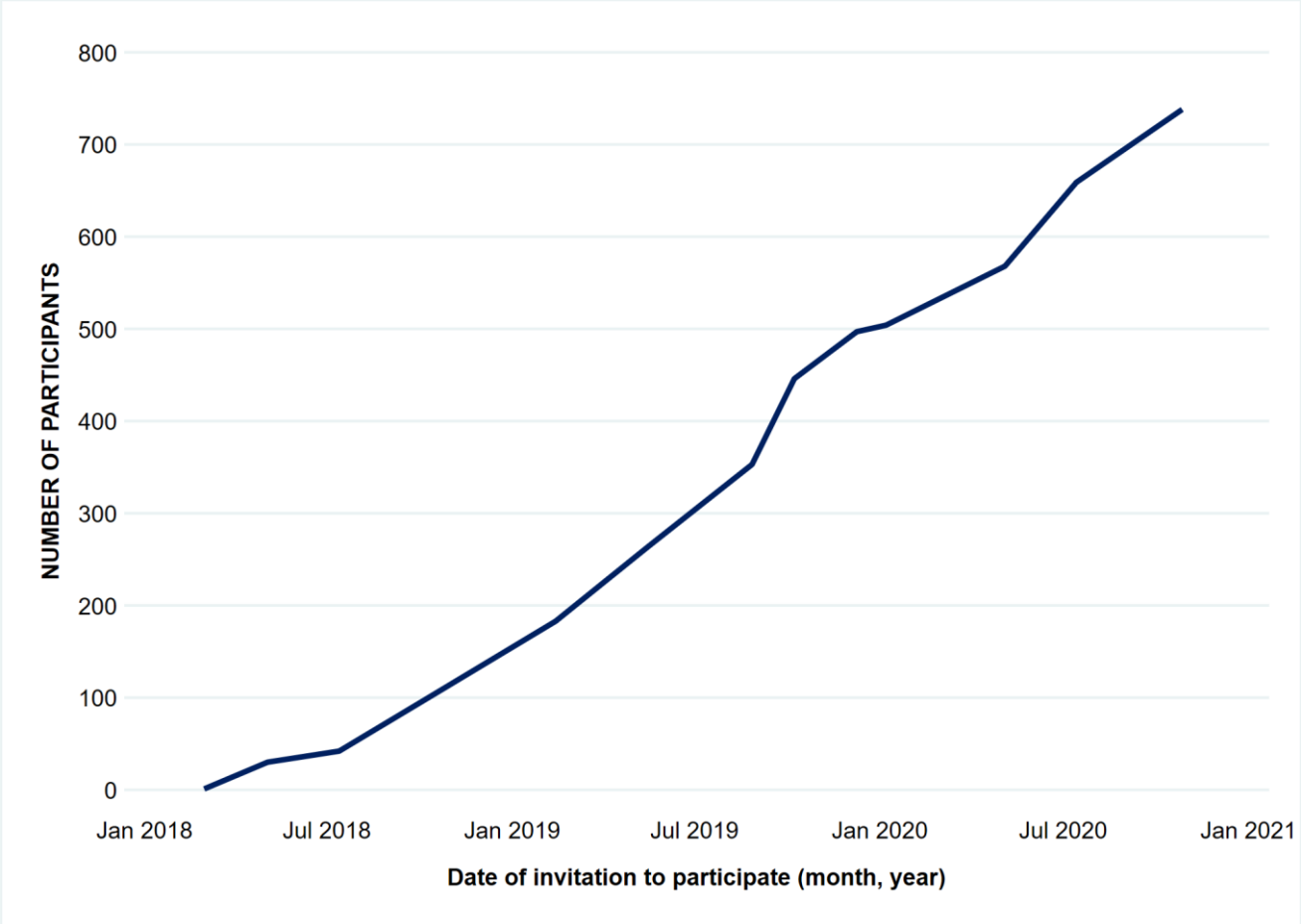
TABLE 1 PATIENT PARTICIPATION IN THE REGISTRY FROM 1 JANUARY 2018 TO 31 DECEMBER 2020

Participation Status	Frequency	%
Enrolled	1143	-
Invited	835	100
Complete Opt-Out	42	5
Participating*	793	95

*11 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 2018-2021 (n=793)

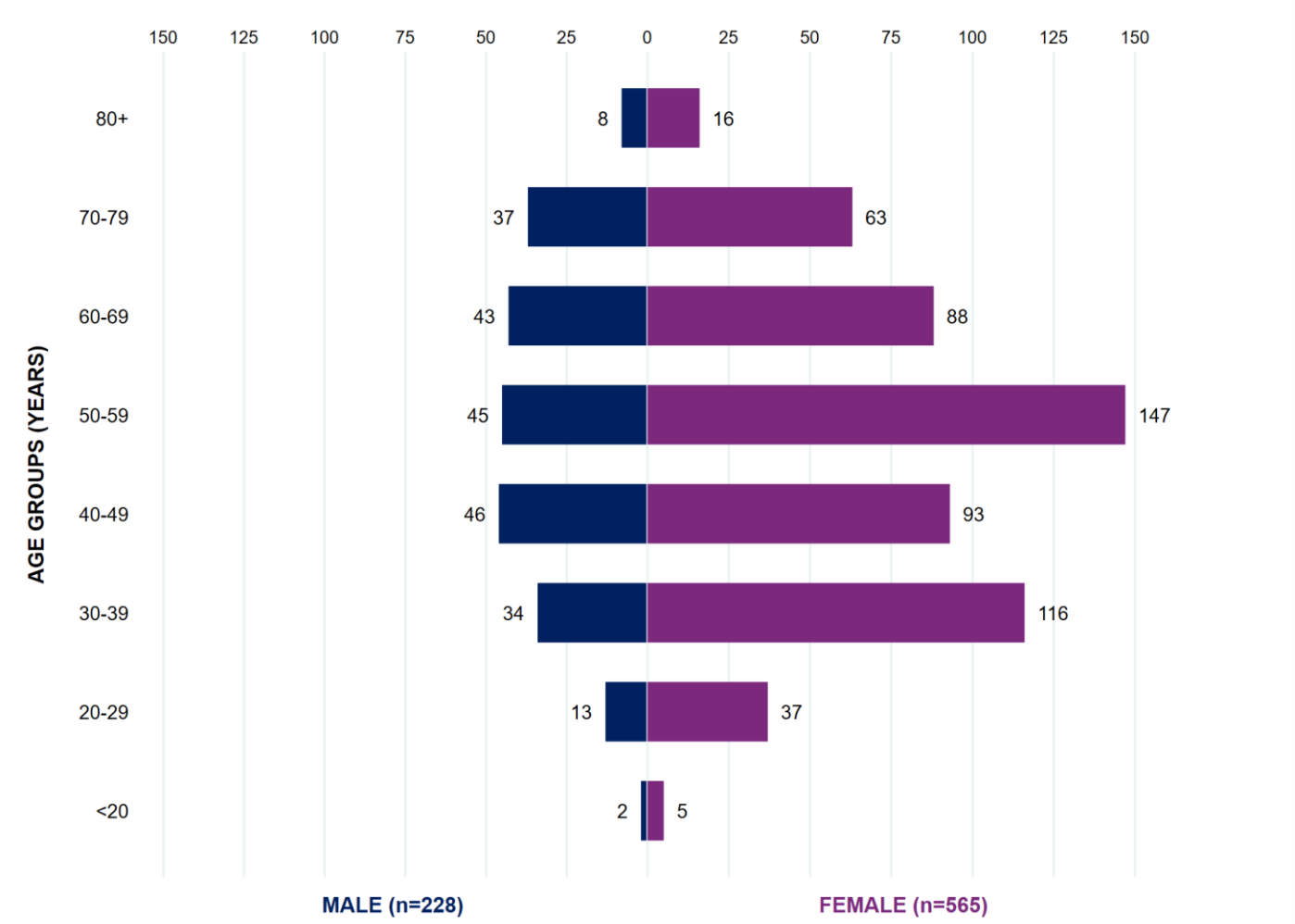


Participant Characteristics

As at 31 December 2020, there were 565 (71%) females and 228 (29%) males participating in the registry who had been diagnosed with thyroid cancer.

The median age for patients at diagnosis was 53 (IQR 39-64) years old, with a minor difference in the median age between males (54, IQR 41-67) and females (53, IQR 38-62). 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=793)



Participants' Residence by State

Of the 793 patients participating in the registry, 494 (62.3%) were residing in New South Wales at the time of recruitment, 196 (24.7%) in Victoria, 70 (8.8%) in Queensland, 26 (3.3%) in South Australia and seven (0.9%) 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=793)

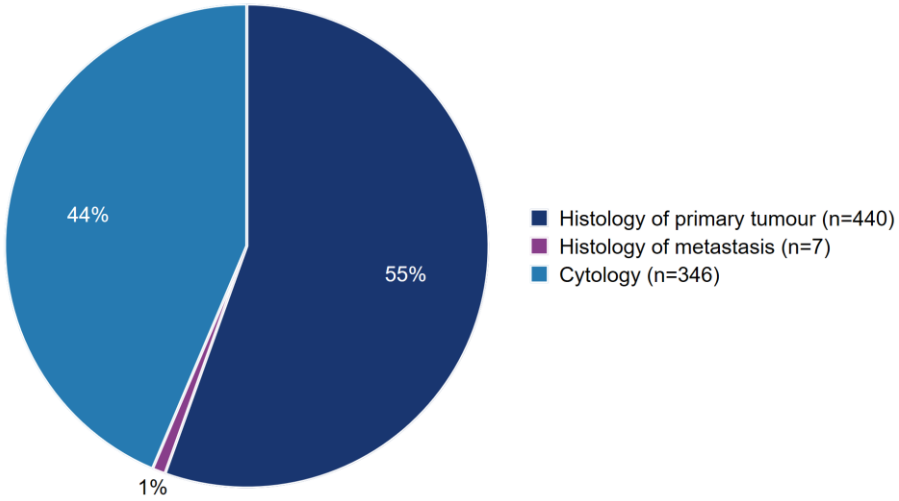
State	Frequency	%
New South Wales	494	62.3
Victoria	196	24.7
Queensland	70	8.8
South Australia	26	3.3
Australian Capital Territory	7	0.9
Total	**793**	**100**

*Based on participant residential postcodes.

Method of Diagnosis

Of the 793 participants, 440 (55.0%) were diagnosed with primary thyroid cancer based on histology of primary tumour, 346 (44.0%) based on cytology and 7 (1.0%) 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 (n=793)



FOLLOW-UP DATA COMPLETION

Participating surgeons enter follow-up data for their patients participating in the registry at 90-days post-diagnosis. Of the 793 participants, 786 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, 323 out of 737 (43.8%) patients presented with a specified comorbidity, of these 46 (14.2%) were obese, 31 (9.6%) were current smokers, and 62 (19.2%) had been diagnosed with cancer other than thyroid cancer. Only 19 (2.6%) out of 737 participants had previously been exposed to upper body radiation. While 32 of 737 (4.3%) participants had previous thyroid surgery.

Table 3 displays participants' previous medical history at diagnosis.

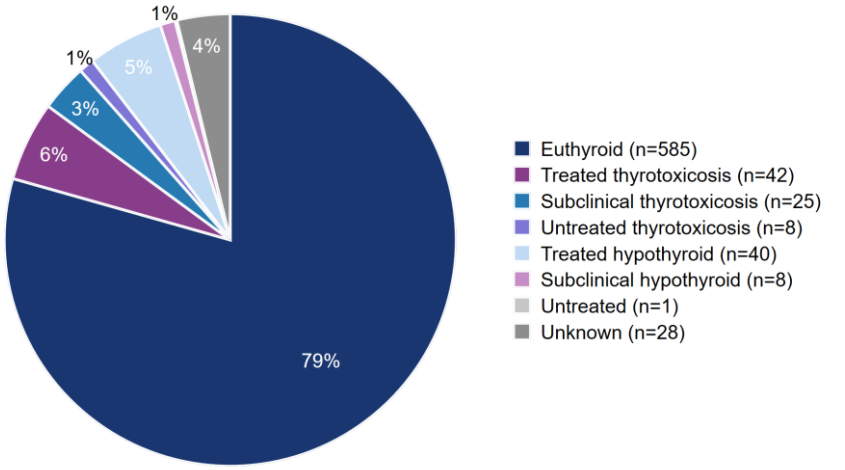
TABLE 3 PREVIOUS MEDICAL HISTORY (n=737)

Variable	Total (n)	Response	Frequency (%)
Specified comorbidity at diagnosis	737	Yes	323 (43.8)
		No	174 (23.6)
		Unknown	240 (32.6)
If yes, comorbidity type*	323	Obesity	46 (14.2)
		Smoking	31 (9.6)
		Other cancer	62 (19.2)
		Other	263 (81.4)
Upper body radiation exposure	737	Yes	19 (2.6)
		No	690 (93.6)
		Unknown	28 (3.8)
Previous thyroid surgery	737	Yes	32 (4.3)
		No	686 (93.1)
		Unknown	19 (2.6)

*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 737 participants with complete data, 585 (79.4%) presented with a normal functioning thyroid gland (euthyroid), 42 had treated thyrotoxicosis (5.7%), 40 had treated hypothyroidism (5.4%), 25 had subclinical thyrotoxicosis (3.4%), eight had untreated thyrotoxicosis (1.1%) and eight had subclinical hypothyroidism (1.1%) (Figure 6).

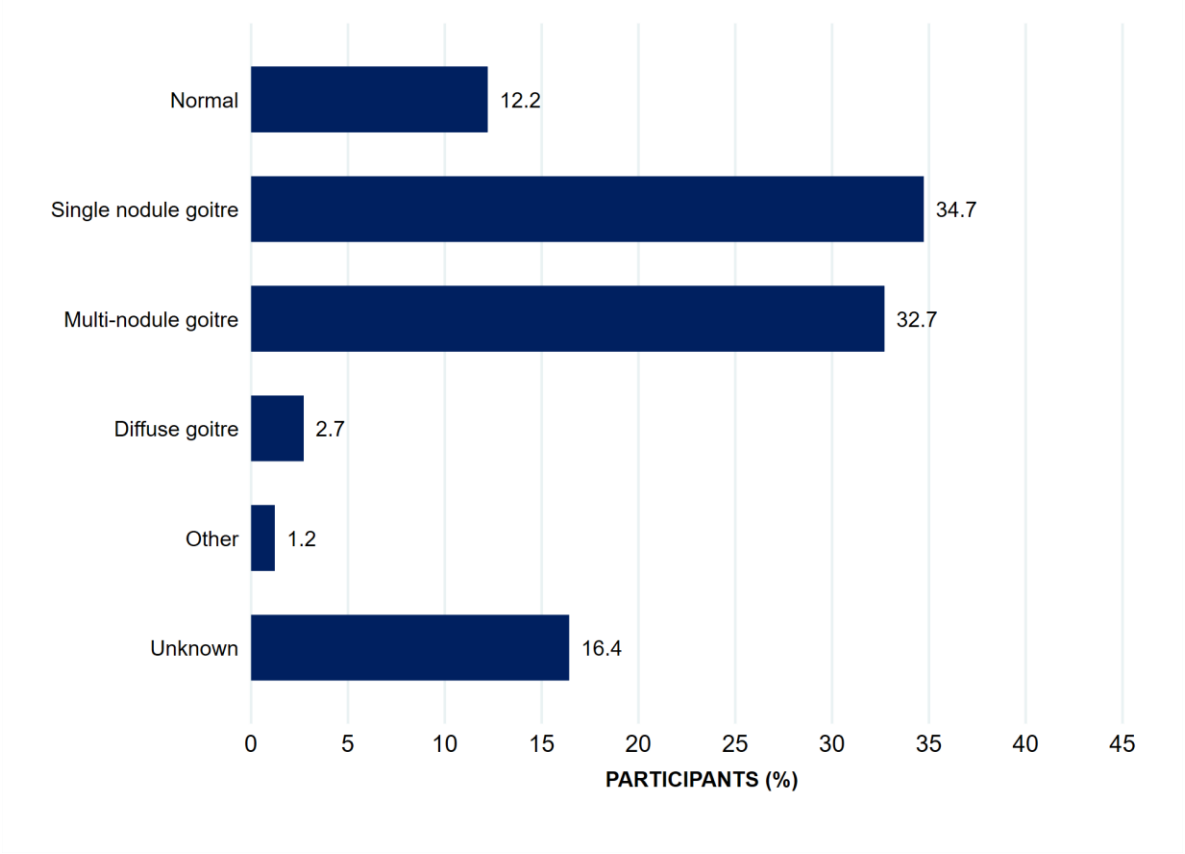
FIGURE 6 THYROID FUNCTION AT FIRST PRESENTATION (N=737)



Neck Examination

Of the 737 participants with neck examination information recorded, 256 (34.7%) had a solitary nodule, 241 (32.7%) had a multinodular goitre (MNG), 20 (2.7%) had a diffuse goitre and 90 (12.2%) had normal findings upon examination (Figure 7). Of 734 participants with complete data, 375 (51.1%) presented with palpable lymph nodes. However, only 63 out of 616 participants (10.2%) with known neck exam results were reported to have palpable lymph nodes at the time of neck examination.

FIGURE 7 NECK EXAMINATION FINDINGS (N=737)

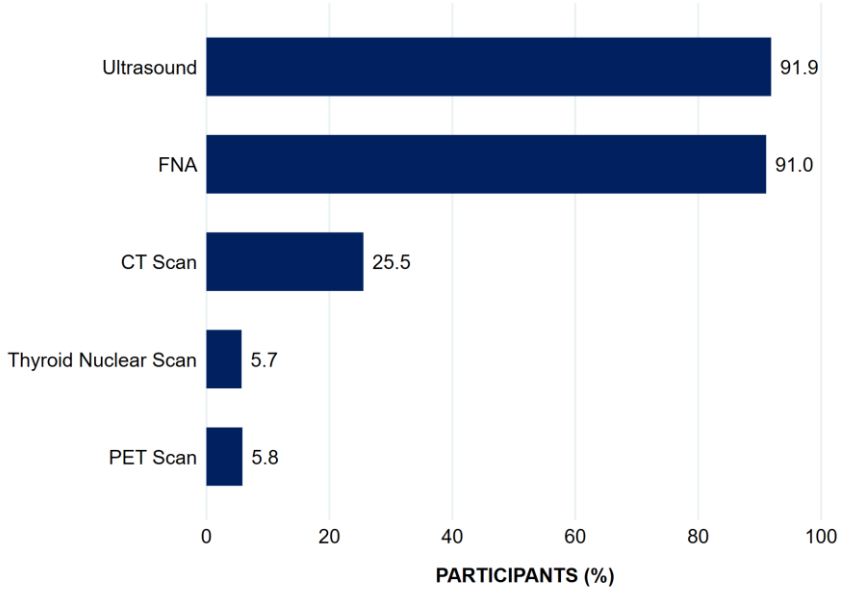


Diagnostic Tests

A total of 677 out of 737 participants (91.9%) had an ultrasound prior to diagnosis. Suspicious lymph nodes were present on ultrasound for 103 out of 626 participants (16.5%). Of the 737 participants with fine needle aspiration (FNA) information recorded, 671 (91.0%) underwent a FNA biopsy, with 534 (79.6%) having one site biopsied, 110 (16.4%) having two sites, 13 (1.9%) having three sites and 14 (2.1%) with an unknown number of sites biopsied.

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

FIGURE 8 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:	98.8%

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 585 participants with complete data who had suspicion of thyroid cancer, 578 (98.8%) 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	607	Yes	578 (98.8)
		No	7 (1.2)
		Unknown	22

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:	98.3%

Preoperative FNA cytology confirms malignancy and informs the management of patients with thyroid cancer to ensure appropriate treatment is delivered[4]. Of the 734 participants with complete data, 119 (16.2%) had suspected malignancy and presented with clinical and/or radiological suspicious lymph nodes. Of these, 116 (98.3%) 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	734	Yes	119 (16.2)
		No	604 (82.3)
		Unknown	11 (1.5)
If yes, FNA to confirm malignancy	119	Yes	116 (98.3)
		No	2 (1.7)
		Unknown	1

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:	86.4%

Of the 734 participants with complete data, 25 (3.4%) had evidence of subjective or objective voice abnormality prior to diagnosis. A laryngeal exam was performed prior to any treatment for 19 out of 25 participants (76.0%), with 13 (68.4%) returning a normal result and two (10.5%) indicating right palsy and four (21.1%) left palsy.

TABLE 6 PREOPERATIVE VOICE ASSESSMENT (CQI3)

Variable	Total (n)	Response	Frequency (%)
Evidence of subjective or objective voice abnormality	734	Yes	25 (3.4)
		No	631 (86.0)
		Unknown	78 (10.6)
If yes, laryngeal exam	22*	Yes	19 (86.4)
		No	3 (13.6)

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

PROCEDURES CAPTURED BY THE REGISTRY

Primary procedure

Of the 734 participants with initial procedure information, 420 had a total thyroidectomy (57.2%), 265 (36.1%) a hemithyroidectomy, 8 (1.1%) an isthmusectomy, 8 (1.1%) a nodulectomy, 4 (0.5%) a completion thyroidectomy, 1 (0.1%) a redo-thyroidectomy unilateral, 2 (0.3%) a sub-total thyroidectomy, 20 (2.7%) another procedure type not listed and 6 (0.8%) unknown. The main reason for surgery was malignancy (48.2%) followed by risk of malignancy (34.7%) (Table 7).

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

FIGURE 9 TYPE OF INITIAL PROCEDURE (N=734)

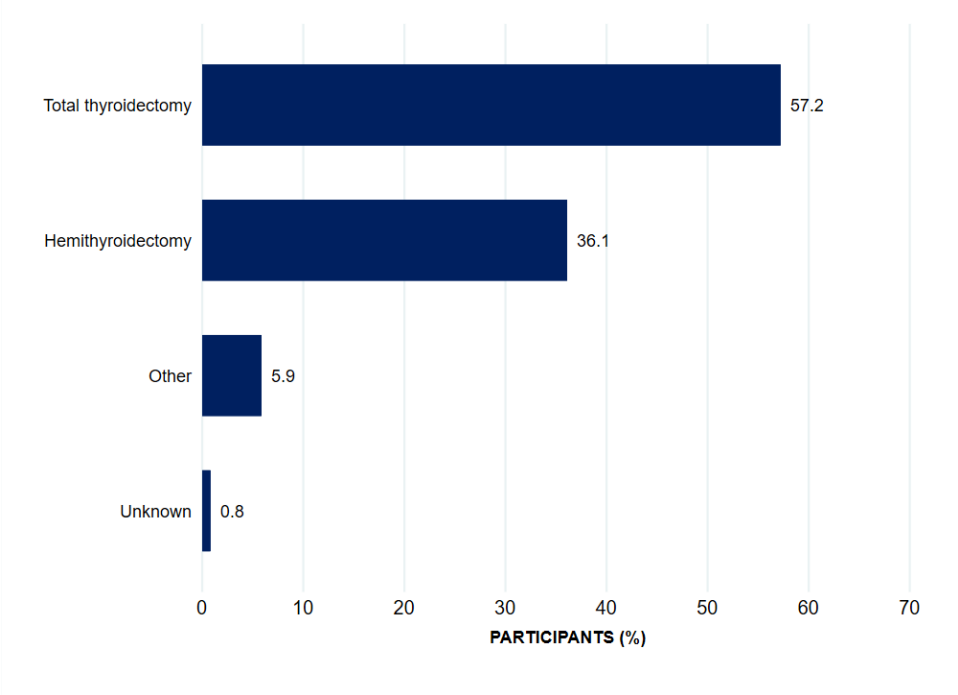


TABLE 7 REASONS FOR INITIAL PROCEDURE (N=734)

Reason for Procedure*	Frequency	%
Malignancy	354	48.2
Risk of malignancy	255	34.7
Compression	75	10.2
Other	30	4.1
Graves' disease	24	3.3
Retrosternal goitre	23	3.1
MNG toxic	22	3.0
Growth	13	1.8
MNG nontoxic	11	1.5
Single nodule nontoxic	10	1.4
Single nodule toxic	3	0.4
Unknown	6	0.8

*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:	98.8%

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 734 participants with surgical information recorded, 289 (39.4%) had advanced differentiated thyroid cancer or a tumour size greater than 4 cm. Of the 246 where details of thyroid surgery were recorded, 243 (98.8%) had a total (or near-total) thyroidectomy. Of the 734 with tumour size information, 170 (23.2%) had a tumour size of <1 cm, 461 (62.8%) 1-4 cm, 94 (12.8%) >4 cm and 9 (1.2%) 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	734	Yes	289 (39.4)
		No	440 (59.9)
		Unknown	5 (0.7)
If yes, total (or near total) thyroidectomy (CQI4)	246*	Yes	243 (98.8)
		No	3 (1.2)
		Unknown	43

*Forty-three participants were unknown and were not included in the CQI calculation

Subsequent procedure(s)

Of the 716 participants with complete procedure data, 135 participants (18.9%) recorded a subsequent procedure. The main subsequent procedure was a completion thyroidectomy (76.3%).

TABLE 9 SUBSEQUENT PROCEDURE TYPE (N=135)

Variable	Frequency (%)
Total thyroidectomy	6 (4.4)
Hemithyroidectomy	2 (1.5)
Completion Thyroidectomy	103 (76.3)
Other	20 (14.8)
Nodulectomy	1 (0.7)
Unknown	3 (2.2)

Lymph node dissection

Of the 734 participants with initial procedure data, 724 had known lymph node dissection information.

A total of 388 out of 724 (53.6%) participants had a lymph node dissection (data missing for 10 participants). Of these, where it was known, it was therapeutic in 102 (26.3%), and prophylactic in 252 (64.9%) these are probably all central, see Table 11 for details. Of the 261 participants who had an initial hemithyroidectomy, 89 (33.6%) had a lymph node dissection. Malignancy was reported in 94 out of 102 (92.2%) participants who underwent a therapeutic dissection and 102 out of 252 (40.5%) who underwent a prophylactic dissection.

TABLE 10 LYMPH NODE DISSECTION BY INITIAL PROCEDURE TYPE (N=724*)

Procedure Type	Yes, N (%)	No, N (%)
Total-thyroidectomy	276 (65.7)	138 (32.9)
Hemithyroidectomy	89 (33.6)	172 (64.9)
Isthmusectomy	3 (37.5)	5 (62.5)
Redo-thyroidectomy	1 (100.0)	0 (0.0)
Completion	0 (0.0)	4 (100.0)
Nodulectomy	1 (12.5)	7 (87.5)
Subtotal-thyroidectomy	1 (50.0)	1 (50.0)
Other	15 (75.0)	5 (25.0)
Unknown	2 (33.3)	4 (66.7)
Total	**388 (53.6)**	**336 (46.4)**

*10 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.
Outcome:	96.3%

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 388 out of 734 participants (52.9%), with 102 (26.3%) of these being classified as a therapeutic lymph node dissection. A further 27 out of the 102 (%) participants had cytologically confirmed malignancy, or suspicion of malignancy, with 26 (%) of these specifically had a lateral lymph node dissection.

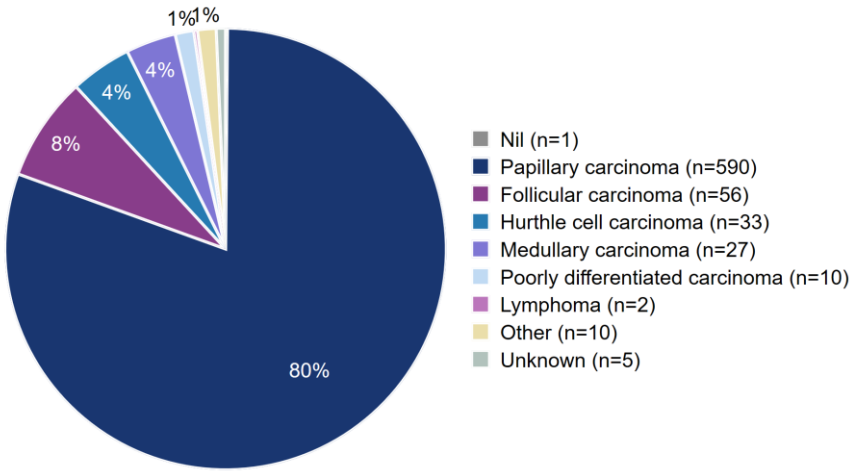
TABLE 11 THERAPEUTIC LYMPH NODE DISSECTION (CQI5)

Variable	Total (n)	Response	Frequency (%)
Lymph node dissection	734	Yes	388 (52.9)
		No	336 (45.8)
		Unknown	10 (1.4)
Type of dissection	388	Therapeutic	102 (26.3)
		Prophylactic	252 (64.9)
		Unknown	34 (8.8)
Therapeutic lymph node dissection with cytologically confirmed malignancy, or suspicion of malignancy	102	Yes	27 (26.5)
		No	75 (73.5)
If yes, lateral lymph node dissection	27	Yes	26 (96.3)
		No	3 (10.3)

Pathology

Of the 734 participants with complete pathology information, 590 (80.4%) had papillary carcinoma, 56 (7.6%) follicular cell carcinoma, 33 (4.5%) hürthle cell carcinoma, 27 (3.7%) medullary carcinoma, ten (1.4%) poorly differentiated carcinoma and two (0.3%) lymphoma (Figure 10).

FIGURE 10 PATHOLOGY OF PRIMARY TUMOUR (N=734)



In addition to malignant pathology, benign pathology was reported in 603 out of 734 patients, with MNG and lymphocytic thyroiditis occurring in 258 (35.1%) and 157 (21.4%) of participants respectively. An incidental finding of cancer was observed for 184 out of 734 (25.1%) 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	734	Yes	184 (25.1)
		No	528 (71.9)
		Unknown	22 (3.0)
Additional benign pathology	734	No benign pathology	131 (17.8)
		MNG	258 (35.1)
		Lymphocytic thyroiditis	157 (21.4)
		Follicular adenoma	22 (3.0)
		Graves' disease	22 (3.0)
		Hürthle cell adenoma	12 (1.6)
		Benign cyst	5 (0.7)
		Other	117 (15.9)
		Unknown	185 (25.2)
Histological margin status	734	Residual tumour cannot be assessed (RX)	3 (0.4)
		No residual tumour (R0)	594 (80.9)
		Microscopic residual tumour (R1)	104 (14.2)
		Unknown	33 (4.5)
Residual tumour at surgery	734	Residual tumour cannot be assessed (RX)	50 (6.8)
		No residual tumour (R0)	587 (80.0)
		Macroscopic residual tumour (R2)	23 (3.1)
		Unknown	74 (10.1)
Multifocal cancer	734	Yes	224 (30.5)
		No	435 (59.3)
		Unknown	75 (10.2)
Lymphovascular invasion	734	Yes	180 (24.5)
		No	509 (69.3)
		Unknown	45 (6.1)
Extrathyroidal extension	734	Sternothyroid muscle	99 (13.5)
		Subcutaneous soft tissues	14 (1.9)
		Prevertebral fascia	2 (0.3)
		No	553 (75.3)
		Unknown	66 (9.0)

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

Of the 734 participants with complete data, 224 (30.5%) were reported to have multifocal cancer with the site of the multifocality reported in the right lobe for 65 (29.0%) participants, in the left lobe for 33 (14.7%) participants, in both lobes for 124 (55.4%) participants and unknown in two (0.9%) participants. Extrathyroidal extension and lymphovascular invasion were observed in 115 (15.7%) and 180 (24.5%) of the 734 participants, respectively. Microscopic residual tumour (R1) was pathologically identified in 104 out of 734 (14.2%) participants and macroscopic residual tumour (R2) reported for 23 out of 734 (3.1%) participants.

Metastatic Disease

Lymph node metastases were reported in 229 out of 734 (31.2%) participants undergoing initial procedure, and distant metastases were reported in eight out of 734 (1.1%) participants. A single distant metastasis was reported in six participants, one in the bone and three in the lung, and two distant metastases were reported in two participants, both with one in the bone and one with one in the lung and the other with one not specified.

Recurrent Laryngeal Nerve

During surgery, the recurrent laryngeal nerve (RLN) on the right remained intact for 598/600 (99.7%) participants, was damaged in one (0.2%) participant and was sacrificed to clear tumour in one (0.2%) participant. While the RLN on the left remained intact for 557/563 (98.9%) participants, was damaged in two (0.4%) participant and sacrificed to clear tumour in four (0.7%) participants. During the initial procedure for 734 participants, 523 (71.3%) had nerve integrity monitoring used, with a loss of signal reported for the left RLN in 20 participant procedures (3.8%) and in the right RLN for nine procedures (1.7%) (data unknown for 13 participants).

TABLE 13 RLN MONITORING DURING INITIAL PROCEDURE

Variable	Total (n)	Response	Frequency (%)
RLN Right	600*	Intact	598 (99.7)
		Damaged	1 (0.2)
		Sacrificed	1 (0.2)
RLN Left	563^	Intact	557 (98.9)
		Damaged	2 (0.4)
		Sacrificed	4 (0.7)
Nerve integrity monitoring used	734	Yes	523 (71.3)
		No	185 (25.2)
		Unknown	26 (3.5)

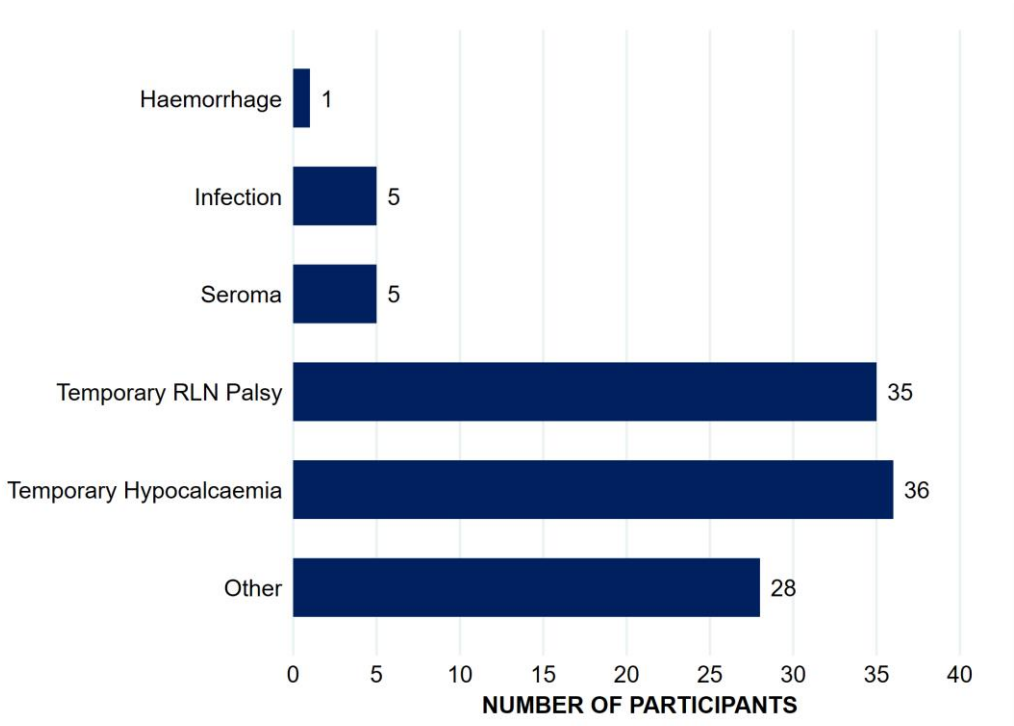
*4 patients not seen, 97 not applicable and 33 unknown

^9 patients not seen, 126 not applicable and 36 unknown

Complications from Surgery

Complications were recorded in a small number of patients at 90-days following the initial procedure. Complications included temporary hypocalcaemia (4.9%), temporary RLN palsy (4.8%), haemorrhage (return to theatre within 48 hours) (0.1%), infection (0.7%), and seroma (0.7%) (Figure 11).

FIGURE 11 SURGICAL COMPLICATIONS FOLLOWING INITIAL PROCEDURE (N=734)



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:	5.1%*#

*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 4.8-5.1%[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 (CQI7)	711	Yes	36 (5.1)
		No	668 (94.0)
		Unknown	7
Haemorrhage requiring return to theatre (CQI9)	734	Yes	2 (0.3)
		No	723 (99.7)
		Unknown	9

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:	70.5%

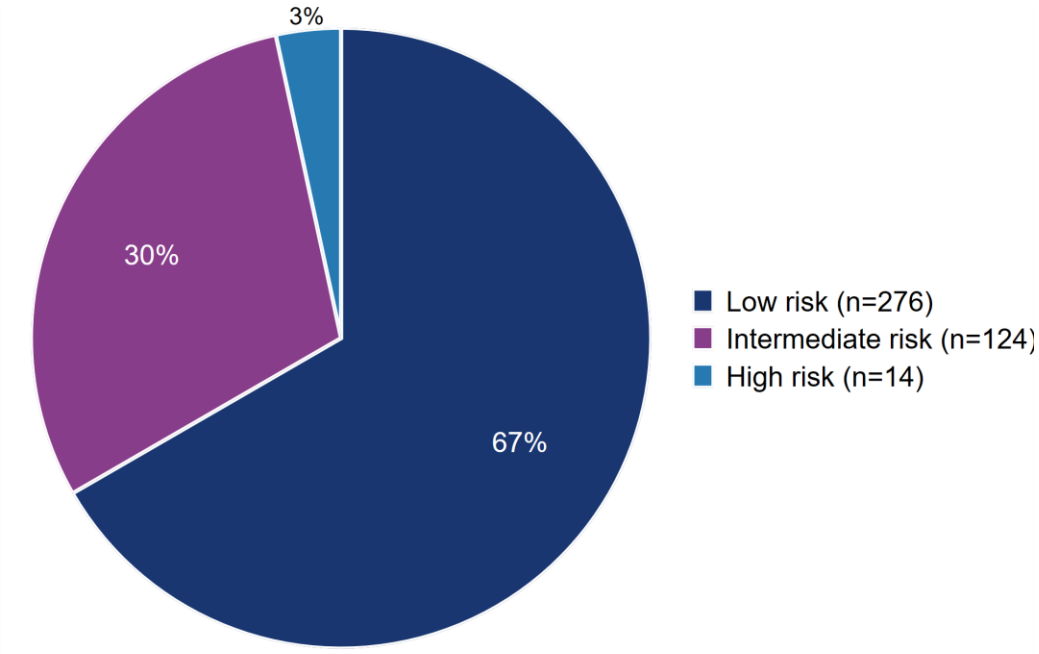
Postoperative TNM staging for thyroid cancer, as for other cancer types, is used to provide prognostic information, enable risk-stratified description of patients, and for research purposes[4]. Of the 722 participants with staging details recorded, 509 (70.5%) had complete TNM staging recorded.

TABLE 15 TNM STAGING RECORDED (CQI9)

Variable	Total (n)	Response	Frequency (%)
TNM staging recorded	722	Yes	509 (70.5)
		No	213 (29.5)

For participants with differentiated thyroid cancer for whom TNM staging was available (N=414), patients were stratified by risk of structural disease recurrence according to the American Thyroid Association (ATA) guidelines[4], with 276 (66.7%) patients being classified as low risk, 124 (29.9%) as intermediate risk and 14 (3.4%) as high risk of disease recurrence.

FIGURE 12 ATA RISK STRATIFICATION (N=414)



Note: 259 DTC patients with postoperative data have unknown ATA risk stratification

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: 60.8%

Evidence suggests that patients with cancer managed by a 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 526 participants with complete data and tumour size greater than 1 cm, 320 (60.8%) were presented at a thyroid cancer specific MDT meeting.

TABLE 16 PRESENTATION AT MDT MEETING (CQI10)

Variable	Total (n)	Response	Frequency (%)
Presented at MDT	728	Yes	377 (51.8)
		No	294 (40.4)
		Unknown	57 (7.8)
Presented at MDT meeting with tumour size >1 cm	567	Yes	320 (60.8)
		No	206 (39.2)
		Unknown	41

Supplementation & Therapy

In the postoperative period, 411 out of 529 participants who had a total or completion thyroidectomy were receiving thyroxine therapy (77.7%), with 44 (8.3%) having supplementation, 146 (27.6%) replacement and 221 (44.8%) suppression. Furthermore, in the early postoperative period, 491 out of 728 (67.4%) were receiving supplementation with calcium and 102 out of 728 (14.0%) receiving supplementation with activated vitamin D (Table 17).

TABLE 17 POSTOPERATIVE SUPPLEMENTATION & THERAPY

Variable	Total (n)	Response	Frequency (%)
Supplementation with calcium	728	Yes	491 (67.4)
		No	221 (30.4)
		Unknown	16 (2.2)
Supplementation with vitamin D	728	Yes	102 (14.0)
		No	611 (83.9)
		Unknown	15 (2.1)
Supplementation with thyroxine (total/ completion thyroidectomy)	529	No	18 (3.4)
		Supplementation	44 (8.3)
		Replacement	146 (27.6)
		Suppression	221 (41.8)
		Unknown	100 (18.9)

Postoperative Treatment

Postoperative thyroglobulin (Tg) was recorded for 376 out of 707 (53.2%) participants and 228 of 707 (32.2%) had thyroid stimulating hormone (TSH) stimulation. Of the 707 participants with complete data, 276 (39.0%) 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	707	Yes	376 (53.2)
		No	214 (30.3)
		Unknown	117 (16.5)
TSH stimulation	707	Yes	228 (32.2)
		No	295 (41.7)
		Unknown	184 (26.0)
RRA following thyroid surgery	707	Yes	276 (39.0)
		No	359 (50.8)
		Unknown	72 (10.2)
If no, reason for no RRA*	359	PTC ≤10mm	132 (36.8)
		PTC 11-20mm	86 (24.0)
		Hemithyroidectomy only	33 (9.2)
		Patient age	6 (1.7)
		Low risk	263 (73.3)
		Comorbidities	11 (3.1)
		Patient declined	7 (1.9)
		MTC	3 (0.8)
		Other	21 (5.8)
		Unknown	9 (2.5)

*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: 75.8%

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 443 participants with differentiated thyroid cancer who underwent a total thyroidectomy, 328 (75.8%) 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 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	707	Yes	478 (67.6)
		No	229 (32.4)
		Unknown	0 (0.0)
If yes, serum Tg reported	478	Yes	328 (75.8)
		No	105 (24.2)
		Unknown	45
High-risk differentiated thyroid cancer and a total/completion thyroidectomy	707	Yes	12 (1.7)
		No	695 (98.3)
		Unknown	0 (0.0)
If yes, RAI	12	Yes	12 (100.0)
		No	0 (0.0)
		Unknown	0 (0.0)

PATIENT-REPORTED MEASURES

In 2020, the ANZTCR started exploring the collection of PRO and PRE data. As part of an Honours student's project by Udhaya Senthil Kumar, a literature review to identify patient-reported measures (PRMs) for patients diagnosed with thyroid cancer was conducted. A qualitative study, in collaboration with the Australian Thyroid Foundation was then undertaken to ascertain the views and opinions of thyroid cancer survivors towards the proposed PRMs for inclusion in the registry.

Part 1: Health-related quality of life after the diagnosis and treatment of thyroid cancer

Eleven semi-structured interviews were conducted with participants to gain insight into what factors are, or have been most important to their health-related quality of life (HRQoL) after being diagnosed and treated for thyroid cancer. The themes and subthemes that emerged from these interviews are summarised below.

Theme	*Subtheme*
Support	Family, friends, peers (including others diagnosed with thyroid cancer), treating team
Patient autonomy	Facilitated through shared decision-making, having information needs met, effective doctor-patient communication, and self-advocacy
Overall wellbeing	Addressing physical symptoms, psychological stress and social wellbeing

The importance of the treating team was ubiquitous across these themes in their role as gatekeepers to ensuring patients were receiving adequate support.

Postoperative Treatment Part 2: Thyroid cancer survivor perspectives on thyroid cancer-specific PRMs

Participants were then asked to complete and evaluate two thyroid cancer-specific HRQoL PRMs; the European Organisation for Research and Treatment of Cancer (EORTC) QLQ-THY34 and the Quality of Life- Thyroid Version (QOL-TV). Participants provided feedback on the length, content, wording, layout, response options, recall period, and the PRM they preferred.

The majority of participants preferred the QOL-TV. While both PRMs assessed similar domains, the QOL-TV required participants to consider their wellbeing across multiple timepoints in their thyroid cancer journey. It was thus seen as more relevant to their current HRQoL status. This may have been because the time since diagnosis for participants ranged from 12-months to 29-years, with the average time being 11.5 years. Participants noted that they felt the EORTC QLQ-THY34 would have been more relevant around the time of their diagnosis/ treatment. It is important to note that ANZTCR would collect PRMs within the first year of diagnosis, where the EORTC QLQ-THY34 may be more suitable.

Finally, participants thought that PRMs could act as a ‘catalyst for discussion’ if shared with their treating team and encourage multidisciplinary support. However, the importance of patients also deciding whether they wanted this information shared with their treating team was noted. Other important considerations raised by participants included the relevance of the questions and the burden of completing the PRM.

Future Directions

These findings are being used to pilot the processes for collecting PRMs in 2021. Patient-reported data that measures patient outcomes, including quality of life, and patient experiences will be collected by administering the validated EORTC general quality of life questionnaire (QLQ-C30) and the thyroid cancer-specific module (THY34) to eligible registry participants.

Aggregate patient responses will be reported back to sites, together with the clinical data, in order to provide important insights from the patient perspective into the impact of a thyroid cancer diagnosis and treatment on patient outcomes and experiences.

ACADEMIC OUTPUTS

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

NEW SITES

Since the last Annual Report, the ANZTCR has welcomed eight sites: St Vincent's Hospital Melbourne (VIC), St Vincent's Private Hospital Melbourne (VIC); Western Health (VIC), Cabrini Health (VIC), Mater Hospital, North Sydney (NSW), Maitland Private Hospital (NSW), Redland Hospital (QLD), and Logan Hospital (QLD). The ANZTCR aims to onboard 10 new sites in 2021, including expansion into New Zealand.

RISK ADJUSTMENT

The ANZTCR will undertake a systematic review to identify prognostic factors that predict surgical morbidity and recurrence in patients with differentiated thyroid cancer. 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.

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.

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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
FNA	Fine Needle Aspiration
HRQoL	Health-related Quality of Life
MDT	Multi-disciplinary Team
MNG	Multinodular Goitre
PET	Positron Emission Tomography
PRE	Patient-reported Experience
PRM	Patient-reported Measure
PRO	Patient-reported Outcome
RACS	Royal Australasian College of Surgeons
RAI	Radioactive Iodine
RLN	Recurrent Laryngeal Nerve
RRA	Radioactive Iodine Remnant Ablation
Tg	Thyroglobulin
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
- 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

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

Treatment

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

APPENDIX D: COMMITTEES & STAFF

Steering Committee Members

Professor Jonathan Serpell	Committee Chair, Endocrine Surgeon
Professor Susannah Ahern	Head, Clinical Outcomes data Reporting and Research Program, 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
Associate Professor Anthony Glover	Endocrine Surgeon
Dr Jenny Gough	Breast and Endocrine Surgeon
Dr Simon Harper	Endocrine and General Surgeon
Associate Professor James Lee	Endocrine Surgeon
Dr Win Meyer-Rochow	Endocrine and General Surgeon
Professor Jeremy Millar	Radiation Oncologist
Professor Stan Sidhu	Endocrine Surgeon
Associate Professor Mark Sywak	Endocrine Surgeon
Professor Duncan Topliss	Endocrinologist
Dr David Walters	Breast and Endocrine Surgeon
Professor John Zalcberg	Head, Cancer Research Program, Monash University

Registry Leads

Professor Jonathan Serpell, Clinical Lead
Professor Jeremy Millar, Co-academic Lead
Professor John Zalcberg, Co-academic Lead
Professor Susannah Ahern, Academic Lead (Note: until Sep 2020)

ANZTCR Coordinating Centre, Monash University

Dr Liane Ioannou, Research Fellow
Ms Elysia Greenhill, Registry Coordinator (Note: until Sep 2020)
Ms Claire Bavor, Research Assistant
Mr Benjamin Brown, Masters of Health Information Management (HIM) Student
Ms Udhaya Senthil Kumar, Bachelor of Biomedical Sciences Honours Student

APPENDIX E: LIST OF PARTICIPATING SITES & CLINICIANS

Participating Sites	
VIC	Alfred Health
	Cabrini Health
	Monash Health
	Peninsula Health
	Peninsula Private
	St Vincent's Hospital Melbourne
	St Vincent's Private Hospital Melbourne
	The Royal Melbourne Hospital
	Western Health
NSW	Dudley Private Hospital
	Hornsby Hospital
	John Hunter Hospital
	Lake Macquarie Private 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
QLD	Greenslopes Private Hospital
	Logan Hospital
	North West Private Hospital
	Redland Hospital
	Townsville Hospital
	Wesley Hospital
SA	Flinders Medical Centre
	Royal Adelaide Hospital
	The Queen Elizabeth Hospital

Participating Clinicians	
Dr Cino Bendinelli	Dr 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
A/Prof Robert Eisenberg	Dr Meei Yeung
Mr Stephen Farrell	
Dr Linda Fenton	
Mr Bill Fleming	
A/Prof Anthony Glover	
Dr Jenny Gough	
Dr Simon Grodski	
A/Prof Justin Gundara	
Dr Andrew Kiu	
Dr James Kollias	
Dr Christine Lai	
A/Prof James Lee	
A/Prof Julie Miller	
Dr Sally Meade	
Dr Joanna Morgan	
Dr Teresa Nano	
A/Prof Chris O'Neill	
Prof Jonathan Serpell	
Prof Stan Sidhu	
Dr Anita Skandarajah	
Dr Kate Stringer	
A/Prof Mark Sywak	

APPENDIX F: LIST OF DATA MANAGERS

Data Managers	
Adam Aniss	Royal North Shore Hospital, Endocrine Surgical Unit's Database
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 INDICATIORS

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