N. IRELAND Cancer Registry

Cancer Services Audit 2001/2 & 2004/5

Thyroid

Queen's University Belfast

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CANCER SERVICES AUDIT 2001/2 & 2004/5
THYROID

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CONTENTS

FOREWORD

There have been significant improvements in cancer services in Northern Ireland. Developments have spanned prevention, early detection and screening, diagnosis, management and palliative care.

Since 1996 we have seen the establishment of cancer units at Altnagelvin, Antrim, Belfast City, Craigavon, and Ulster hospitals and a regional cancer centre in Belfast. The Cancer Units are now the main focus for the delivery of services for people with the more common cancers. In addition, some services for other less common cancers are provided from Cancer Units, in conjunction with the Cancer Centre, on a shared care basis. The N. Ireland Cancer Registry has played an important role and made a vital contribution in monitoring this progress.

This report on thyroid cancer is very welcome. It is the last in a series that examines in detail the pathways of care for patients with cancer here. The reports provide a fascinating insight into how care has changed over the period. They will also facilitate the ongoing work of improving services and patient care.

This work marks a significant step in the evaluation of cancer care and confirms the great value of the Registry as a public health tool. I look forward to future reports which provide updates of the changing process of cancer care.

Dr Michael McBride
Chief Medical Officer

ACKNOWLEDGEMENTS

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- Department of Health, Social Services & Public Safety (DHSSPS)
- Eastern Health and Social Services Board
- Northern Health and Social Services Board
- Regional Medical Audit Group
- Research and Development Office
- Southern Health and Social Services Board
- Western Health and Social Services Board

The quality of data in this project is a result of the work of the Registry Tumour Verification Officers, especially Carmel Canning (retired 30/9/2006) and Bernadette Anderson, who meticulously extracted detailed information from clinical records for analysis and presentation in this report. The analysis of the data was undertaken by Heather Kinnear and Dr. Finian Bannon.

I would like to express our gratitude to the Medical Records staff from all the hospitals in Northern Ireland, who, in the course of the audit for all sites pulled an estimated 10,000 charts.

I am grateful to the clinicians who commented on the detail of the data to be collected, its interpretation and final presentation, especially Prof. B. Atkinson, Mr. C. Russell, Dr. R. Houston, Mr. J. Dolan, Prof. R. Spence and Dr. K. Ritchie.

The work of the N. Ireland Cancer Registry including the production of this report is the result of the work of the team listed below:

Bernadette Anderson	Dr Finian Bannon	Carmel Canning	Dr Denise Catney
Dr David Donnelly	Kate Donnelly	Donna Floyd	Colin Fox
Wendy Hamill	Anita Jones	Jackie Kelly	Heather Kinnear
Gavin Kennedy	Julie McConnell	Susan McGookin	Dr Richard Middleton
Giulio Napolitano	Eamon O'Callaghan	Dr Lisa Ranaghan	Breige Torrans
Rosemary Ward			

I wish also to record my thanks to the Management Group and the Council of the Registry who guide the work.

This presentation, I feel, has been enhanced by the stories from patients who have walked the patient journey. We have attempted to analyse and quantify this journey with a view to identifying current practice, in order that clinicians may be facilitated in improving care.

Dr. Anna Gavin
Director, NICR
2007

PATIENT STORIES

A close relative, who is a nurse, spotted a swelling on one side of my neck. I consulted my GP and was quickly referred to hospital. I had a biopsy taken from the lump and very soon afterwards the results showed that I had thyroid cancer.

I was admitted for a few days and I had surgery to remove my thyroid gland. My calcium levels fell and I had pins and needles like I never had experienced before. This was quickly corrected with tablets which I don't need to take now.

I felt run down after the operation but was quickly put on thyroid hormone tablets which made me feel better.

A couple of months later I had radioactive iodine treatment and had to stay in isolation for one very long week. I felt very alone, the time went slowly in the isolation ward, I was checked on regularly by a nurse or doctor. Visitors were kept to a minimum and could only stay for a short time and remain at a distance from me.

Now I am very well. I only have a very faint scar on my neck, I have to take thyroid hormone tablets every day and I have a blood test every six months when I am reviewed.

It certainly took the wind from my sails when I was diagnosed with cancer at aged 27 but all has gone well and I was very satisfied with the speed of diagnosis and treatment and the skill of the surgeons.

~

Just by chance, one day I noticed one side of my neck was swollen, thicker and harder. Also it didn't move as well as the other. I realised this was something that needed to be examined. I was quickly seen by my GP who was convinced the swelling was from my thyroid gland and I was referred quickly to the local hospital.

When I was seen there by the consultant who agreed it was my thyroid but I was reassured that there was nothing to worry about as most of the time swellings aren't anything serious. It was decided that I needed an ultrasound scan, a needle biopsy and a labelled iodine test. It was going to be a three month wait for the ultrasound scan and so I paid £600 to have this done privately. I had the three tests all in one day which was quite tiring. I felt that once I was in the system I was looked after well but getting into the system was difficult.

The needle biopsy showed some abnormal cells and the surgeons decided that I would have a left thyroidectomy with the removal of the isthmus. I had the surgery in April - five months after noticing the swelling. The lady in the bed next to me had a similar problem and she had waited 13 months for her surgery because she hadn't gone privately for the tests.

One week after the surgery I was told I had follicular cancer of the thyroid, and four weeks later I had the remainder of my thyroid removed. I then had to have a radioactive test to determine if all the thyroid gland had actually gone. The full scan took a long time and, because I had more than 1% of my thyroid tissue remaining, I had to have ablation therapy with radioactive iodine. This was in July and I was admitted for 5 nights to Belvoir Park Hospital where I was kept in isolation. On discharge, I was not allowed to mix for three weeks with young children or pregnant women.

Now four years later, I have six-monthly checkups: once a year with a surgeon and once a year with an oncologist. I didn't mind the tests, the operation, and the isolation with the radioactive iodine, however, I really felt miserable when I had to come off the thyroid hormone to have my levels of thyroid tissue checked. Three months after I had my ablation therapy, I was off the thyroxine for three weeks to determine if it had completely worked. I found the lack of energy, slowness and all the symptoms of low thyroid disease just dreadful.

I take my thyroxine every day and I am currently having some extra tests as my thyroglobulin levels have risen again. I feel great now and I am reassured that I am seen every six months by somebody.

~

About eleven years ago my mother noticed a swelling in my neck - I hadn't noticed it myself. I went to my GP and he thought it was goitre. He offered to send me to the hospital then but I didn't go and we agreed to see how the lump progressed. Then, I started to feel tired and sluggish and I was diagnosed with an underactive thyroid and put on thyroxine.

At that time I felt that when I lay down there was pressure on my neck. Some time later I went to my GP with another problem, he re-examined my neck and sent me for a hospital appointment. About six months later, I was seen by the consultant who took a sample of cells from my neck. Two weeks later when I was seen again at the clinic, I was shocked to be given a diagnosis that I had thyroid cancer.

A month later I had surgery and later had radioactive iodine as a result of which I was kept in isolation for six days. I am feeling very well now and take my thyroxine tablets every day and have regular follow-ups, two a year: one with the endocrinologist and one with the consultant surgeon. I now feel great and am lucky to be alive.

INTRODUCTION

This Report is the eighth in a series which examines in detail the pathway of care for cancer patients in Northern Ireland.

Subsequent to the publication of the Campbell Report "**Cancer Services-Investing for the Future**,"[1] which made 14 recommendations for improving cancer services in Northern Ireland (see Appendix A), the Regional Advisory Committee on Cancer (RACC) was set up and produced a *Report on Endocrine Cancer*[2] in Northern Ireland in 2004 which outlined recommendations for surgery and the overall management of patients with cancer of the thyroid. These are reproduced below:

1 A second surgeon with endocrine surgery expertise should be appointed as soon as possible.

2 Surgery for suspected thyroid carcinoma should be performed by the regional endocrine surgeons in close collaboration with surgeons and endocrinologists throughout Northern Ireland.

3 The Regional Centre for Endocrinology and Diabetes at the Royal Victoria Hospital should be the centre supervising assessment for radioiodine after surgery and then, in monitoring ongoing assessment of suppressive thyroid hormone treatment, marker hormones and repeat scanning. This will require the provision of an additional endocrinologist. Where endocrinology expertise is available locally and there is a sufficient patient base this can be done in close co-operation with trained endocrinologists in the major District General Hospital Cancer Centres.

4 The Regional Endocrinology and Endocrine Surgery Centres should formalize their currently agreed protocols.

5 A computerised register is essential to enable i) the service to know that adequate follow-up is being achieved and ii) to allow ongoing audit of long-term outcomes in these patients.

6 In the near future finance should be made available to allow a more detailed audit of all cases diagnosed as having thyroid carcinoma in Northern Ireland in the past 5 years. This should broadly follow the standards and outcomes measures for thyroid surgery as set out by the British Association of Endocrine Surgeons (BAES) and in the British Thyroid Association (BTA) guidelines.

7 Specialised endocrine histopathology expertise should be obtained urgently for Northern Ireland as the pathologist with a specialist interest retires within the next 2 to 3 years.

8 An agreed staging system of the cancer should be introduced after widespread discussion, for long-term audit purposes and to allow adequate international comparisons. This will in probability be the internationally recognised TNM Classification.

9 Adequate numbers of endocrine specialist nurses would allow their wider involvement in many aspects of the care of this specialised group of patients.

UPDATE

Since these recommendations were made in 2004, one new endocrine surgeon was appointed to the regional centre, however with the retirement of another endocrine surgeon the overall situation remains the same. The appointment of an endocrinologist to work in the Regional Centre for Endocrinology and Diabetes at the Royal Victoria Hospital is still outstanding. Agreement on protocols between the Regional Endocrinology and Endocrine Surgery Centres is still being formalised. There has been no progress made in developing a computerised register. Specialised endocrine histopathology has been secured into the future by the appointment of a new pathologist to replace the pathologist who retired. This report represents the audit mentioned in item 6.

The recommendations of the **Report on Endocrine Cancer**[2] in N. Ireland were in broad agreement with the **British Association of Endocrine Surgeons (BAES) guidelines on the management of patients with thyroid cancer (2000)**[3] which are reproduced below[±]:

1 Surgery for thyroid cancer should be performed by an endocrine surgeon or by a surgeon with an interest in endocrine surgery and with appropriate training.

2 Patients with suspected or proven thyroid cancer should be investigated and managed in a centre with access to appropriate cytology, pathology, endocrinology, nuclear medicine, genetics and oncology support.

3 Patients with differentiated thyroid carcinoma (papillary and follicular) should have a total thyroid lobectomy performed as a minimum procedure. Total thyroidectomy or "completion" thyroidectomy will be required in some circumstances, depending on pre-operative, intra-operative and post-operative cytological and histological assessment.

4 Patients with differentiated thyroid cancer who have undergone total thyroidectomy should be considered for post-operative radioiodine ablative therapy in an attempt to reduce the incidence of loco-regional tumour recurrence and improve survival time.

5 Patients with differentiated thyroid cancer should be treated post-operatively with titrated doses of thyroxine to a level which achieves full thyroid stimulating hormone (TSH) suppression to unrecordable values. Patients should be monitored in ongoing fashion with regular measurement of plasma TSH and thyroglobulin levels. A rising thyroglobulin level suggests recurrent disease.

6 Management decisions for patients with recurrent tumour should be taken by a multidisciplinary team.

7 The management of patients with less frequently seen thyroid cancers such as medullary carcinoma, anaplastic carcinoma and lymphoma should take place in the setting of a specialist centre in which multidisciplinary support in cytology, biochemistry, clinical and molecular genetics, endocrinology and oncology is available.

The Royal College of Physicians of London and the British Thyroid Association produced guidelines in 2002 **"Guidelines for the management of thyroid cancer in adults"**[4] (see Appendix B); these recommendations are similar to those mentioned above.

The NHS produced a document in 2004 **"Improving Outcomes in Head and Neck Cancer"**[5]. The recommendations referring to thyroid cancer are reproduced below:

1 REFERRAL

- Cancer Networks should decide which hospitals will provide diagnostic services for patients with symptoms that might be due to head and neck cancers.
- There should be specific referral routes for patients with persistent hoarseness, neck lumps or thyroid nodules.
- All patients with solitary nodules should be referred to a clinic that deals with patients who may have cancer, which may be a thyroid clinic or a neck lump clinic, depending on local arrangements. If the nodule is increasing in size, urgent referral is necessary.
- GPs should request thyroid function tests for all patients with goitre.
- Patients with goitre and normal thyroid function should be given routine referrals either to a thyroid clinic or a neck lump clinic, unless they fulfil any of the criteria for urgent referral.

[±] The BAES guidelines were updated in 2004, but are not considered here because they were not published prior to the audit data in this report. Latest guidelines available at www.baes.info

2 STRUCTURE OF SERVICES

- Thyroid cancer multi-disciplinary teams (MDT) should include an endocrinologist, a surgeon who specialises in thyroid/endocrine oncology, oncologist, radiologist, nuclear medicine specialist, specialist pathologist, clinical nurse specialist and secretarial and support staff.

3 INITIAL INVESTIGATION AND DIAGNOSIS

- All patients who present with thyroid nodules should have tests performed of thyroid function. When overt thyroid dysfunction has been excluded, fine needle aspiration cytology should be performed.
- Information for patients and carers should normally cover the following issues: any pre-treatment interventions that may be required, the likely nature, timing and duration of the forms of treatment that are likely to be recommended, a realistic assessment of anticipated outcome, in particular, the probability that initial treatment will eradicate the tumour or that more than one form of treatment may be required, short and long-term adverse effects of different types of intervention, support services, including patient support groups, rehabilitation, other treatment-related issues which may be relevant to the patient and his or her particular form of cancer, members of the MDT responsible for the patient, contact details for the Cancer Nurse Specialist (CNS) and/or other named nurses who will take responsibility for providing support and information, the hospital(s) where interventions are to be provided.

4 PRE-TREATMENT ASSESSMENT AND MANAGEMENT

- Patients who are to undergo surgery which will involve the airways should be assessed by a specialist anaesthetist who works regularly with surgeons in the MDT.

5 PRIMARY TREATMENT

- All patients who are to undergo treatment for any form of head and neck cancer should have been given opportunities to discuss information about the potential effects of that treatment with members of the MDT beforehand, so that they know what to expect. They should have clear and accessible information in written form, describing the potential risks of treatment as well as its anticipated benefits, in a language they understand.
- When primary treatment is complete, each patient should be offered a candid assessment of its success and given the opportunity to discuss any further interventions that are being considered.

6 AFTER CARE AND REHABILITATION

- Patients treated for thyroid cancer should be seen at least once a year by a member of a thyroid cancer MDT in a follow-up clinic. Thyroid hormones and serum calcium should be monitored regularly. Thyroglobulin should be monitored in patients with differentiated thyroid cancer, and calcitonin in those with medullary cancer.

PROJECT AIM

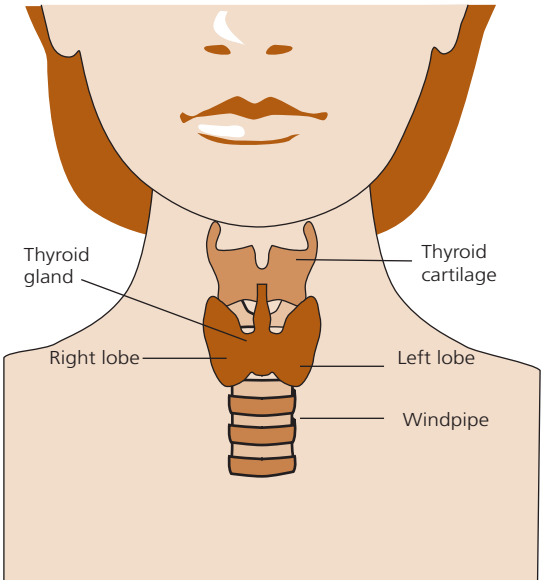
This Report aims to document the process of care for patients diagnosed with thyroid cancer in 2001/2 and 2004/5. The comparison of these two periods aims to assess the amount of change in cancer services for thyroid cancer patients in recent years, and to make service recommendations for the future.

BACKGROUND

Thyroid cancers are rare. In Northern Ireland there are typically 50 cases each year while there are about 1,400 new cases in the UK[6] (male:female ratio is 1:3). A General Practitioner (GP) practice in Northern Ireland can expect to see thyroid cancer only every 21 years. Survival from thyroid cancer is excellent and so there are many people in the community who have been diagnosed in the past with thyroid cancer. By the end of 2004 there were 400 people alive in Northern Ireland who had had a diagnosis of thyroid cancer between 1993 and 2004.

Location of the thyroid gland

The thyroid gland is located in the front of the neck at the base of the throat. The thyroid gland has two lobes, connected by a thinner bridge (or isthmus) of thyroid tissue.



The thyroid gland synthesizes two hormones called tri-iodothyronine (T3) and thyroxine (T4) that regulate the body's metabolic rate. An absence of these hormones will result in hypothyroidism with symptoms such as weight gain, tiredness and lack of energy, whereas an excess of them results in hyperthyroidism leading to weight loss and difficulty in relaxing. Both T3 and T4 require iodine, and the thyroid gland is the only organ in the body that can absorb iodine. Thyroid Stimulating Hormone (THS) stimulates the thyroid to produce T3 & T4; it can also cause an underactive thyroid to grow and enlarge. Another hormone, calcitonin, which plays a role in blood calcium levels, is produced in the thyroid by the parafollicular cells; medullary cancer originates in these cells.

There are four main types of thyroid cancer[6]:

1 **Papillary** makes up 60% of thyroid cancers. It may be multifocal with each tumour confined by a false capsule for prolonged periods of time. It is generally more common in young women. It is usually slow-growing and differentiated but can spread to nearby lymph nodes in the neck; it produces T_3 and T_4.

2 **Follicular** is most often diagnosed in young or middle-aged people and accounts for 15% of thyroid cancers. It is a differentiated cancer producing T_3 and T_4. It can metastasise via the bloodstream most often to the lungs or bones.

3 **Medullary** is a rare type of thyroid cancer, making up 5-10% of thyroid cancers. About a quarter of medullary thyroid cancers are hereditary, being caused by inherited faulty genes. They can spread to the lungs or bones. Medullary cancers produce calcitonin.

4 **Anaplastic** comprises 15% of thyroid cancers. They are typically diagnosed in older people, most commonly in women. Generally, three quarters of the patients are over the age of 60 years at diagnosis. It tends to grow more quickly than other types of thyroid cancer and is nearly always inoperable.

It is possible to get a non-Hodgkin's lymphoma of the thyroid. As it is a rare condition and its treatment is different to thyroid cancers, it is not included in this report.

RISK FACTORS

There are three main risk factors[6]:

1 Gender - thyroid cancer is more common in women than in men.

2 Radiation - People who have had radiotherapy to their neck have an increased risk of thyroid cancer later in life (often 10-30 years later), particularly if treatment was at a young age[7]. There was also a high incidence of thyroid cancer in Belorussian and Ukranian children who were exposed to radiation after the Chernobyl accident[8].

3 Genetic conditions - about 25% of the medullary cancers are hereditary.

There are other conditions that are linked to an increased risk of thyroid cancer.

These are[6]:

1 Having a personal history of non-cancerous thyroid lumps or goitre.

2 Cowden's syndrome, a hereditary syndrome.

3 Hashimoto's thyroiditis.

PREVENTION

People who have a first-degree relative (mother, father, sister, brother) diagnosed with thyroid cancer may wish to discuss the possibility of genetic testing with their family doctor[6], as some types have a genetic predisposition.

SCREENING

There is no screening test available to detect thyroid cancer. However, there are screening tests available to detect the gene faults responsible for some medullary cancers.

SYMPTOMS

Symptoms of thyroid cancer can vary a great deal among individuals. They can include[6]:

1 A lump in the neck that gradually increases in size, with or without pain. Only about 1 in 20 thyroid lumps are cancer.

2 A persistant hoarse voice.

3 Difficulties in swallowing or breathing – this can happen occasionally as a result of the cancer pressing on the oesophagus (food pipe) or trachea (windpipe).

Commonly, these signs and symptoms will indicate problems other than cancer. However, people who notice any symptoms should see their doctor. Unusual symptoms may occur in patients who have medullary thyroid cancer; these relate to calcitonin production and include frequent, loose bowel movements and becoming red in the face (flushed).

DIAGNOSIS

After initial examination of the neck, further tests such as the following may be performed[6,9]:

1 Fine needle aspiration cytology/biopsy – a small needle is passed into the swelling on the patient's neck and a sample of cells is taken and examined under a microscope to check whether there are cancer cells present; this is the main method of diagnosis.

2 Blood tests to check thyroid hormone and thyroid stimulating hormone (TSH) levels.

3 Thyroid radioisotope scan (where radioactive labelled iodine is injected into a vein in the arm) to visualise abnormal areas in the thyroid; this technique is rarely used nowadays.

4 Ultrasound thyroid scan captures an image of the thyroid and its surrounding structures using sound waves from a hand-held transducer placed on the skin over the thyroid.

TREATMENT

Possible treatments for thyroid cancer include[6, 9]:

1 Surgery resection represents the main treatment for most thyroid cancers, except anaplastic cancer, which is rarely operable. The entire thyroid gland can be removed (total thyroidectomy), or part of it removed (lobectomy). To reduce the risk of future recurrence, lymph nodes may be removed during surgery. If the diagnosis is papillary or follicular thyroid cancer, then only lymph nodes likely to contain cancer cells are removed. For operable anaplastic cases, most of the lymph nodes around the thyroid are removed. The majority of patients are prescribed thyroxine after thyroid cancer surgery, to suppress TSH levels to zero, which reduces the risk of cancer recurrence.

2 Radioiodine – Radioactive iodine (I^{131}) treatment is given to kill any cancer cells left behind after surgery, or any cells that have spread to other parts of the body, and to treat recurrence. The treatment uses a radioactive form of iodine, I^{131}, that is only taken up by thyroid cells, wherever they are. This treatment is only suitable for differentiated follicular and papillary thyroid cancer and is facilitated by doing a total thyroidectomy, which removes competing healthy thyroid cells for the radioisotope.

3 External beam radiation is rarely used for differentiated cancer except when nodal disease is particularly advanced, or when uptake of I^{131} is poor, and where surgical clearance is uncertain.

4 Chemotherapy is not usually effective for thyroid cancer, and is not used as a first treatment. However, it is used occasionally to manage otherwise untreatable widespread or recurrent disease. The chemotherapy drugs most often used are doxorubicin (Adriamycin) and cisplatin.

STUDY METHODS

DATA COLLECTION

The diseases covered by this Report are ICD10 C73 (thyroid gland cancers). It excludes C74 and C75 (endocrine gland cancers) and also Hodgkin's disease of the thyroid gland.

Registry Tumour Verification Officers (TVO's) collected the data by reviewing clinical notes of patients with a new primary thyroid cancer which was registered with the N. Ireland Cancer Registry as being diagnosed in the calendar years 2001/2 or 2004/5. This, in many cases, involved review of notes from several hospitals. Data were then entered into an electronic proforma which had been developed with the guidance of relevant clinicians; a copy is available at www.qub.ac.uk/research-centres/nicr/Research under the section on RACC reports.

In addition, one clinician reviewed a sample of patients' case notes from the SHSSB to verify the audit process. Clinicians assisted in classifying patients, surgical operations, and surgeons.

EXCLUSIONS & ANALYSES

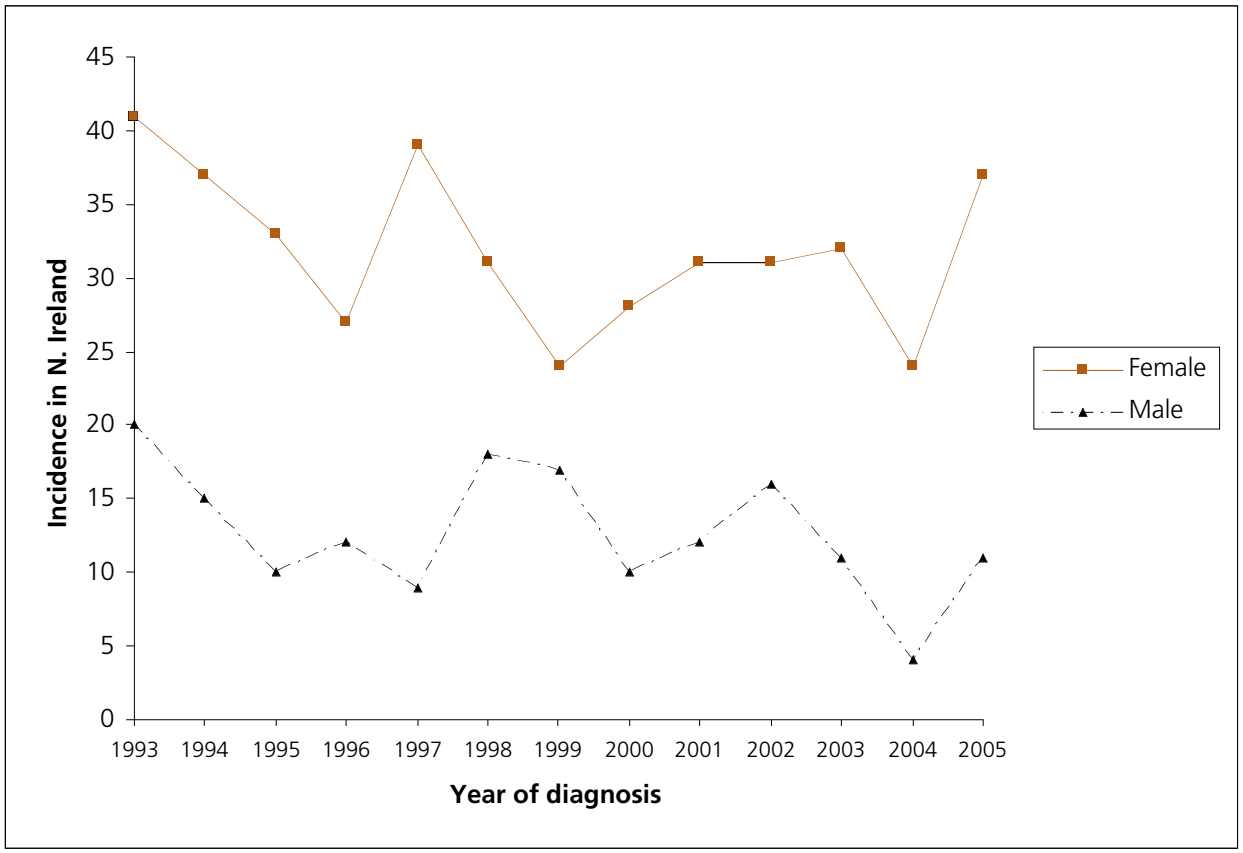
Patients were excluded if their records lacked sufficient information or if information was available only from a death certificate (DCO) or a post mortem report. After cleaning and validation, data analysis was carried out using Stata and SPPS. The chi-square statistic was used to compare frequency distributions between groups of patients, and the Kaplan-Meier method was used in survival analysis.

Incidence in N. Ireland of thyroid cancer (C73) from 1993-2004 by sex

Year	Number of Patients		
	Female	Male	Total
1993*	41	20	61
1994*	37	15	52
1995	33	10	43
1996	27	12	39
1997	39	9	48
1998	31	18	49
1999	24	17	41
2000	28	10	38
2001	31	12	43
2002	31	16	47
2003	32	11	43
2004	24	4	28
2005	37	11	48

* Higher figures in 1993 and 1994 may reflect some prevalent cases; this is to be expected with a new cancer registry (NICR started in 1993), however it could also represent random variation

Incidence in N. Ireland of thyroid cancer (C73) from 1993-2004



- As thyroid cancer has a low incidence rate, its yearly rate may vary considerably. 2004 had an exceptionally low rate of male incidence; the reason for this is not known, but could be due to random variation.

RESULTS

Analyses for this audit were performed for two periods of time, 2001/2 and 2004/5.

Study Patients

Patients	Number of Patients	
	2001 & 2002	2004 & 2005
Total patients registered with NICR	90	78
Exclusions – Lack of information*	0	2
Total reported on	90	76
Total reported on – Females	62 (69%)	61 (80%)
Total reported on – Males	28 (31%)	15 (20%)
Average age at diagnosis – Female	51	50
Average age at diagnosis – Male	59	53

*The only information on two patients in 2004/5 was a death certificate and post mortem report, respectively

- Data were available on 43 and 47 individuals in 2001 and 2002, respectively, and on 28 and 48 in 2004 and 2005, respectively.
- Almost 74% of cases were female.

Socio-economic status of patients

Deprivation Quintile	Number of Patients (%)	
	2001 & 2002 *(n=90)*	2004 & 2005 *(n=76)*
Quintile 1 (Least deprived)	21 (23%)	13 (17%)
Quintile 2	17 (19%)	20 (26%)
Quintile 3	24 (27%)	18 (24%)
Quintile 4	17 (19%)	13 (17%)
Quintile 5 (Most deprived)	11 (12%)	12 (16%)

- There was no evidence of differing incidence rates of thyroid cancer between the socio-economic deprivation quintile populations of N. Ireland (i.e. the χ^2 test did not reject the null hypothesis of equal incidence in each quintile in 2001/2 or 2004/5 [$p>0.05$]).

Source of referral to specialist care

Source	Number of Patients (%)	
	2001 & 2002 *(n=90)*	2004 & 2005 *(n=76)*
General Practitioner (GP)	51 (57%)	47 (62%)
Receiving care for thyroid disorders	16 (18%)	12 (16%)
General Surgeon	4 (4%)	3 (4%)
Physician	4 (4%)	5 (7%)
Radiologist	1 (1%)	-
Other	6 (7%)	6 (8%)
Not Recorded	8 (9%)	3 (4%)

*'Other' includes referrals from non-thyroid specialists or patients self-referring via Accident & Emergency

- Over half of all diagnosed thyroid cancer cases came through GP referrals.

Details of GP referrals

Mode of Presentation	Number of Patients (%)	
	2001 & 2002 *(n=51)*	2004 & 2005 *(n=47)*
Outpatient Referral	43 (84%)	36 (77%)
Medical Emergency Admission	3 (6%)	3 (6%)
Surgical Emergency Admission*	1 (2%)	-
Private patient	2 (4%)	8 (17%)
Other**	2 (4%)	-

*patient had respiratory difficulties

**one patient in 2001/2 was referred after a domiciliary visit; the second was waiting for an operation

- 6% of GP referrals presented as emergencies.
- GPs referring patients privately increased from 4% in 2001/02 to 17% in 2004/5.

Family history of thyroid cancer and other cancers recorded in notes

Family History	Number of Patients (%)	
	2001 & 2002 *(n=90)*	2004 & 2005 *(n=76)*
Thyroid, first degree relative	2 (2%)	3 (4%)
Thyroid, second degree relative	0 (0%)	3 (4%)
Family history other cancer site*	13 (14%)	17 (22%)
No family history of cancer	41 (46%)	31 (41%)
Family history of cancer not recorded	36 (40%)	28 (37%)

*77% of recorded family history of cancer was from first degree relatives

- 4% of all patients had a positive record of a family history of thyroid cancer (first and second degree relatives) in their hospital notes.

Personal history of other thyroid disorders

Site	Number of Patients (%)	
	2001 & 2002 *(n=90)*	2004 & 2005 *(n=76)*
Nodular thyroid goitre	16 (18%)	17 (22%)
Hypothyroidism	3 (3%)	4 (5%)
Hyperthyroidism	2 (2%)	-
Other thyroid disease*	9 (10%)	-
No past history of thyroid disorder	51 (57%)	51 (67%)
Not recorded	9 (10%)	4 (5%)

* Other includes lobe swelling and benign colloid nodule

- About one in three patients had a recorded history of thyroid disorders.

Co-morbidities (NOTE: Patients may have more than one co-morbidity)

Co-morbidity	Number of Patients (%)	
	2001 & 2002 *(n=90)*	2004 & 2005 *(n=76)*
Hypertension	18 (20%)	19 (25%)
Cardiovascular disease	14 (16%)	4 (5%)
COPD*	11 (12%)	10 (13%)
Arthritis	10 (11%)	14 (18%)
Cerebrovascular disease	9 (10%)	3 (4%)
Dementia	4 (4%)	-
Diabetes	3 (3%)	4 (5%)
Other malignancy	9 (10%)	5 (7%)

* COPD = Chronic Obstructive Pulmonary Disease

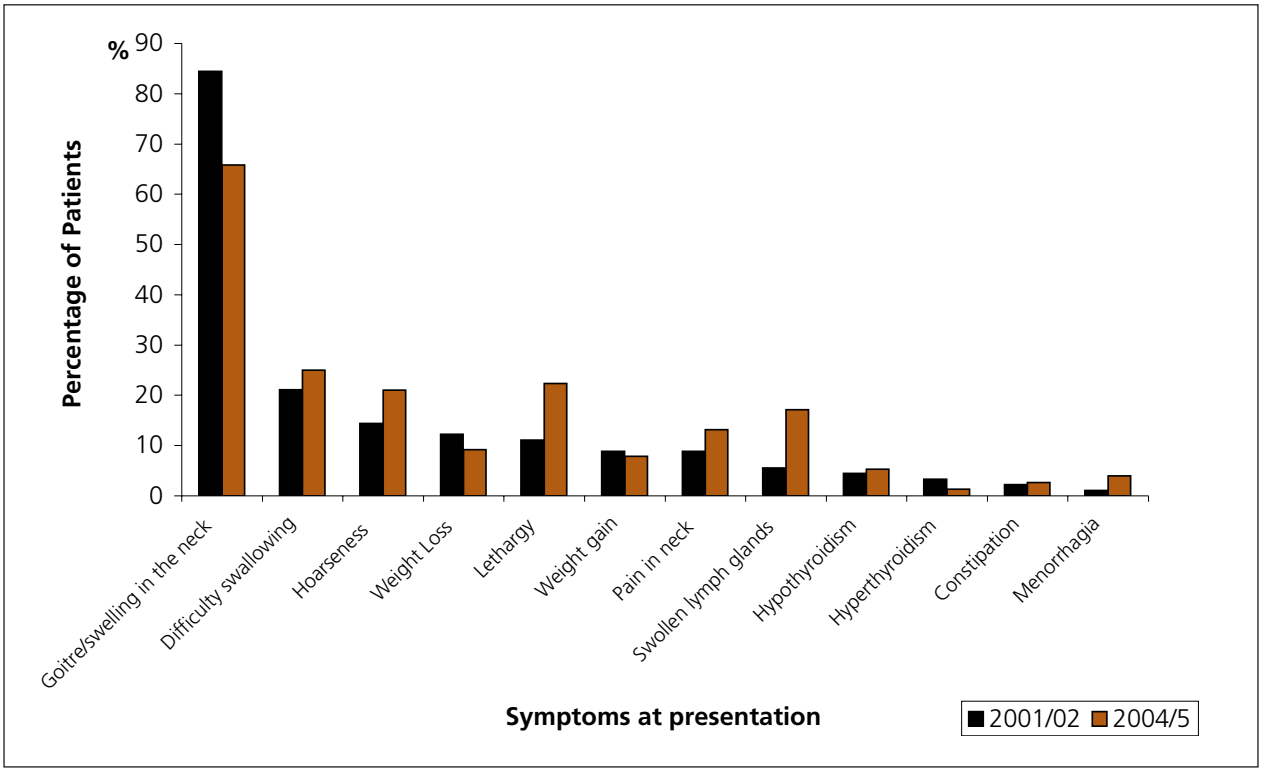
- At least one fifth of patients had a recorded history of hypertension.
- Around 12% of patients had COPD, and 14% had arthritis.
- Four patients were having thyroxine treatment at presentation.

Symptoms/signs at presentation (NOTE: Patients may have presented with more than one symptom/sign)

Symptom/Signs	Number of Patients (%)	
	2001 & 2002 *(n=90)*	2004 & 2005 *(n=76)*
Goitre/swelling in the neck	76 (84%)	50 (66%)
Difficulty swallowing	19 (21%)	19 (25%)
Hoarseness	13 (14%)	16 (21%)
Weight Loss	11 (12%)	7 (9%)
Lethargy	10 (11%)	17 (22%)
Weight gain	8 (9%)	6 (8%)
Pain in neck	8 (9%)	10 (13%)
Swollen lymph glands	5 (6%)	13 (17%)
Hypothyroidism	4 (4%)	4 (5%)
Hyperthyroidism	3 (3%)	1 (1%)
Constipation	2 (2%)	2 (3%)
Menorrhagia	1 (1%)	3 (4%)

- Over two thirds of patients had goitre/swelling in the neck (men comprised 26% of such cases in 2001/2 and 14% in 2004/5).
- The most common presenting symptoms were difficulty swallowing, hoarseness, lethargy, weight loss, and swollen lymph glands.
- A quarter of patients on presentation had goitre or swelling in the neck for at least a month, while almost a third had it for more than a year.

Symptoms/signs for thyroid cancer patients



Patients presenting within their own Health Board of residence

Board of Residence	Number of patients presenting within own Board (% of total patients living in same Board)	
	2001 & 2002 *(n=80)*	2004 & 2005 *(n=64)*
EHSSB	29 (100%)	31 (100%)
NHSSB	16 (84%)	9 (53%)
SHSSB	19 (76%)	12 (80%)
WHSSB	15 (100%)	12 (92%)

- The majority of patients presented to a hospital within their own Health Board of residence. Among the patients who did not present in their own Board of residence, 78% (7/9) went directly to the Royal Victoria Hospital in 2001/2 and 58% (7/12) went there in 2004/5; almost half of these patients (11/21-both periods) were referred directly by the GP while about a quarter (6/21) were already under care for goitres.

Hospital of Presentation

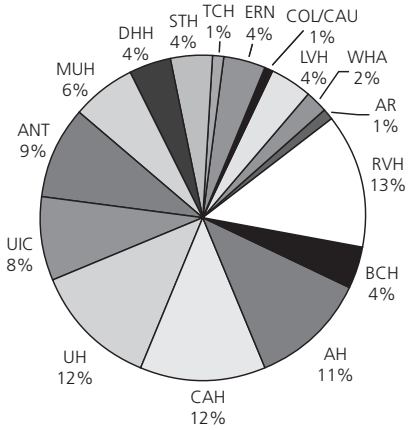
Hospital of Presentation	Number of Patients (%)	
	2001 & 2002 *(n=89)*	2004 & 2005 *(n=76)*
Royal Victoria (RVH)	12 (13%)	20 (26%)
Ulster (UH)	11 (12%)	6 (8%)
Craigavon Area (CAH)	11 (12%)	7 (9%)
Altnagelvin (AH)	10 (11%)	8 (11%)
Antrim (ANT)	8 (9%)	4 (5%)
Mid-Ulster (MUH)	5 (6%)	4 (5%)
Daisy Hill (DHH)	4 (4%)	2 (3%)
Erne (ERN)	4 (4%)	1 (1%)
South Tyrone (STH)	4 (4%)	2 (3%)
Belfast City (BCH)	4 (4%)	9 (12%)
Lagan Valley (LVH)	4 (4%)	-
Whiteabbey (WHA)	2 (2%)	-
Ards Hospital (AR)	1 (1%)	-
Coleraine (COL) / Causeway (CAU)	1 (1%)	1 (1%)
Tyrone County (TCH)	1 (1%)	2 (3%)
Banbridge (BBH)	-	1 (1%)
Moyle (MLE)	-	1 (1%)
Downe (DH)	-	1 (1%)
North-West Independent Clinic* (NWC)	-	1 (1%)
Ulster Independent Clinic* (UIC)	7 (8%)	6 (8%)
Total	89**	76

*The Ulster Independent Clinic, and The North-West Independent Clinic are private hospitals
** One private patient in 2001/2 could not be assigned a hospital of presentation

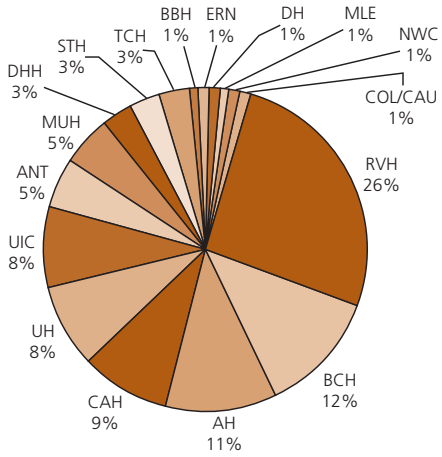
As only about 1 in 20 thyroid lumps are cancerous, the first step in the patient pathway should be presentation at the local hospital for investigation and diagnosis. Patients with cancer should then be referred urgently to the regional centre for further investigations and treatment.

- In 2001/2, 89 patients with cancer of the thyroid presented to 16 hospitals, while in 2004/5, 76 patients presented to 17 hospitals.
- The number and proportion of presentations to the Royal Victoria Hospital and the Belfast City Hospital increased between 2001/2 and 2004/5.

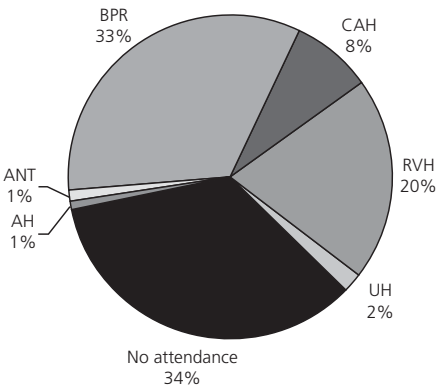
Hospitals* Attended (% Patients)



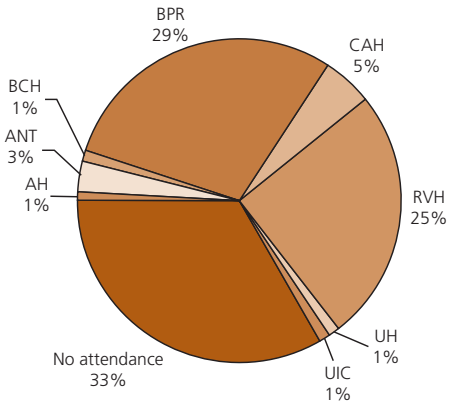
Hospital of Presentation 2001/2 (n=89)**



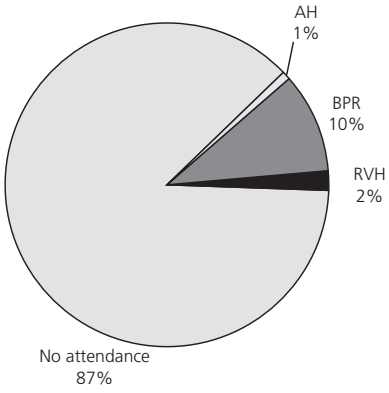
Hospital of Presentation 2004/5 (n=76)



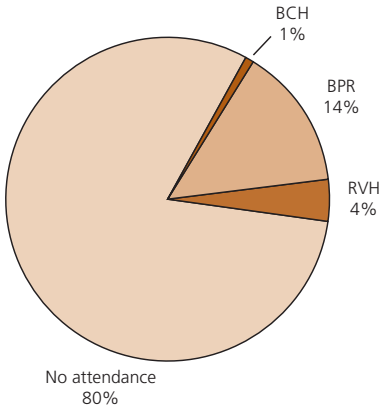
Second Hospital 2001/2 (n=90)



Second Hospital 2004/5 (n=76)



Third Hospital 2001/2 (n=90)



Third Hospital 2004/5 (n=76)

*See Table on Hospital of presentation (page 14) for hospital names and abbreviations
** One patient 2001/2 could not be assigned a hospital of presentation

- The percentage of patients that attended the Royal Victoria Hospital at some stage in their investigations and treatment rose from 36% in 2001/2 to 55% in 2004/5.
- From 2001/2 to 2004/5, there was no decline in the percentage of patients attending only one hospital, and an increase (6%) in the percentage attending three hospitals.
- For second hospital attendance, the Royal Victoria Hospital and Belvoir Park Hospital (the Regional Radiotherapy Centre) account for around 80%, each in approximately equal measure.
- Belvoir Park Hospital accounts for 73% of the third hospital attended.

Investigations (NOTE: Patients may have received more than one type of investigation)

Investigation prior to diagnosis*	Number of Patients (%)	
	2001 & 2002 *(n=90)*	2004 & 2005 *(n=76)*
Key investigations		
Fine needle aspiration*	72 (80%)	56 (74%)
USS thyroid	55 (61%)	45 (59%)
CT neck	25 (28%)	14 (18%)
Additional investigations**		
Thyroid stimulating hormone level	62 (69%)	44 (58%)
T4 level	51 (57%)	37 (49%)
Chest X-ray	38 (42%)	17 (22%)
Isotope scan	10 (11%)	8 (11%)
MRI scan	5 (6%)	3 (4%)
Calcitonin checked	4 (4%)	9 (12%)
X-ray neck	1 (1%)	4 (5%)

*About 50% of the patients who did not have an FNA had incidental findings of thyroid cancer at surgery; it is possible that they received an FNA and a decision to operate on goitre, for instance, a long while before diagnosis of cancer, and this information may not have been picked up by the audit because it predated the presentation period

**These tests are not all considered necessary for good practice but can be useful depending on the stage and cell type of the thyroid cancer

- About three in four patients had a fine needle aspiration of the thyroid recorded in their notes.

STAGING (see also Appendix C)

In 2001/2, TNM stage was recorded in the clinical notes for 8% of patients; in 2004/5, it was 6%. However, when stage was not recorded, but there was sufficient information available in the clinical notes, registry TVO's were able to assign a stage group (registry-assigned stage) using the AJCC Cancer Staging Handbooks[10,11]; in this way, it was possible to achieve staging in 59% of patients in 2001/2, and 78% in 2004/5.

Stage (recorded in notes or registry-assigned)

TNM Stage	Stage recorded in notes		Registry assigned stage	
	2001 & 2002 *(n=90)*	2004 & 2005 *(n=76)*	2001 & 2002 *(n=90)*	2004 & 2005 *(n=76)*
I	3 (3%)	2 (3%)	21 (23%)	30 (39%)
II	-	-	5 (6%)	5 (7%)
III	1 (1%)	-	1 (1%)	13 (17%)
IV*	4 (4%)	2 (3%)	25 (28%)	11 (14%)
Unstaged	82 (92%)	72 (94%)	38 (42%)**	17 (22%)**

* Stage IV includes by definition all anaplastic tumours (2001/2 n=11; 2004/5 n=3)
** Registry assigned staging for these patients was not possible due to a lack of information recorded in the notes

- The distribution of assigned staging differed significantly between 2001/2 and 2004/5; 2004/5 had a much higher percentage of patients with stages I, III, and lower percentage in Stage IV than had 2001/2, partly reflecting the higher levels of anaplastic cancer in 2001/2.
- There was no evidence that assigned staging distribution varied among the Health Boards.
- Anaplastic thyroid cancers (Stage IV by definition) made up 44% (11/25) of the Stage IV assigned patients in 2001/2 and 27% (3/11) in 2004/5.
- It was possible to assign stage to more surgery patients in 2004/5 (76%) than in 2001/2 (53%) due to better information in the notes.

Tumour size (cm) of differentiated cancer types*

Tumour size	Patients tumour size	
	2001 & 2002 *(n=69)*	2004 & 2005 *(n=66)*
Equal to or smaller than 1cm	22 (32%)	15 (23%)
Greater than 1cm	35 (51%)	46 (70%)
Not recorded	12 (17%)	5 (7%)

* Differentiated thyroid cancer types include follicular and papillary types only

- In 2004/5, it was possible to ascertain more tumour sizes of differentiated cancers than in 2001/2 (93% versus 83%, respectively).

- For patients with differentiated cell types and who had a tumour size greater than 1cm, the percentage who received I^{131} ablation therapy increased from 68% in 2001/2 to 89% in 2004/5; this trend concurs well with the recommendation by the Royal College of Physicians of London and the British Thyroid Association[4] that most patients with a tumour size greater than 1cm have I^{131} ablation therapy.

Site of metastases for patients

Site	Number of patients (%)	
	2001 & 2002 *(n=90)*	2004 & 2005 *(n=76)*
Lung	8 (9%)	3 (4%)
Distant lymph nodes	-	2 (3%)
Brain	2 (2%)	-
Liver	2 (2%)	-
Other	3 (3%)	-
None*	35 (39%)	60 (79%)
Not recorded	40 (44%)	11 (14%)

*'None' means that there was a positive record of no metastases

- There was a higher level of "not recorded" metastases (44%) in 2001/2 than in 2004/5 (14%).
- In both 2001/2 and 2004/5, lung was the most frequent site for metastases.
- Patients in 2001/2 had a higher level of metastases (17%) than patients in 2004/5 (7%); the overall level was 12%.

HISTOLOGY

97% of patients in 2001/2 had a record of histopathology or cytology (based on fine needle aspiration) confirming their diagnosis; this increased to 100% in 2004/5; however, some of the morphology codes in the pathology reports were 'not otherwise specified' (NOS) preventing cell type determination.

Histology Type

Cell Type	Number of Patients (%)	
	2001 & 2002 *(n=90)*	**2004 & 2005 *(n=76)***
Papillary	52 (58%)	49 (64%)
Follicular	17 (19%)	17 (22%)
Anaplastic	11 (12%)	3 (4%)
Medullary	1 (1%)	4 (5%)
Not possible to specify*	3 (3%)	-
Morphology code not specified, NOS**	6 (7%)	3 (4%)

* Method of diagnosis was not based on histology or fine needle aspiration, and therefore it was not possible to assign histology type. The method of diagnosis for these three cases was: x-ray, clinical opinion and MRI scan
** Method of diagnosis was based on histopathology type but the morphology code was not specified by the pathologist

- Around 60% of the patients had papillary type tumours.
- The number of anaplastic cancer patients was 11 (12%) in 2001/2 and 3 (4%) in 2004/5.

MULTIDISCIPLINARY TEAM MEETINGS (MDT)

It has long been recognised that the most efficient way to manage thyroid cancer patients is to have input from a range of experts. At the time of writing this report in 2007 multidisciplinary team meetings (MDTs) involving a group of healthcare professionals meeting to discuss the diagnosis and treatment of patients are seen to be of great importance as there are a range of potential treatments to be considered.

With respect to MDTs, it should be noted that although discussions among healthcare professionals, regarding the diagnosis and treatment of patients, frequently took place, there was no evidence in patient notes of formal MDTs; this is in keeping with clinicians' experience.

Frequently, however, there was evidence of inter-professional discussion in the charts audited but, because of variation in possible interpretations of what counted as evidence of inter-professional discussion, this could not be rigorously quantified.

Referrals to specialists in patient's notes

Referral Profession	Number of Patients (% of total)	
	2001 & 2002 *(n=90)*	2004 & 2005 *(n=76)*
Endocrine Surgeon*	43 (48%)	35 (46%)
Endocrinologist*	15 (17%)	10 (13%)
Oncologist	46 (51%)	36 (47%)

*The numbers include patients who were already under the care of an endocrine surgeon or an endocrinologist, respectively, for other thyroid disorders at the time of thyroid cancer diagnosis

- There was little variation between 2001/2 and 2004/5 in the percentages being referred to specialists.
- 47% of patients were referred to an endocrine surgeon.
- 15% of patients had a referral to an endocrinologist.
- 50% of the patients were referred to oncologists.

Referral to either an endocrine surgeon or an endocrinologist in the patient record by Health Board of Residence*

Area of Residence	Number of patients by Board of residence		Endocrinology or endocrine surgeon (% of those in Board of residence*)	
	2001 & 2002 *(n=90)*	2004 & 2005 *(n=76)*	2001 & 2002 *(n=90)*	2004 & 2005 *(n=76)*
EHSSB	30	31	20 (67%)	16 (52%)
NHSSB	19	17	13 (68%)	15 (88%)
SHSSB	26	15	6 (23%)	3 (20%)
WHSSB	15	13	7 (47%)	1 (8%)

*The numbers in this table include patients who were already under the care of an endocrine surgeon and/or an endocrinologist for other thyroid disorders at the time of thyroid cancer diagnosis

- The number of patients that had contact with either an endocrine surgeon or an endocrinologist did not increase from 2001/2 to 2004/5, with the exception of the NHSSB. The WHSSB had the largest decline from 47% to 8%.

Referral to an endocrine surgeon in the patient record by hospital of treatment decision*

Hospital	Number of patients referred/total (%)	
	2001 & 2002	2004 & 2005
Royal Victoria (RVH)	15/22 (68%)	20/28 (71%)
Craigavon Area (CAH)	0/17 (0%)	0/10 (0%)
Ulster (UH)	6/12 (50%)	0/3
Antrim (ANT)	8/9 (88%)	6/6 (100%)
Altnagelvin (AH)	1/7 (14%)	0/9 (0%)
Mid-Ulster (MUH)	1/5	1/3
Erne (ERN)	2/4	-
Belfast City (BCH)	3/3	5/9 (55%)
Tyrone County (TCH)	-	0/2
South Tyrone (STH)	0/1	-
Daisy Hill (DHH)	0/1	-
Lagan Valley (LVH)	1/1	-
Whiteabbey (WHA)	0/1	-
Coleraine (COL) / Causeway (CAU)	0/1	-
North-West Independent Clinic (NWC)**	-	0/1
Ulster Independent Clinic (UIC)**	6/6 (100%)	3/5

*The 'hospital of treatment decision' is defined as the hospital of primary surgery, and if no surgery was carried out, it is the hospital of presentation
**The Ulster Independent Clinic and the North West Independent Clinic are private hospitals

- The Royal Victoria Hospital was the 'hospital of main treatment decision' in 2004/5 for 37% of patients, and 71% of these were referred to an endocrine surgeon.
- Antrim Hospital referred all of its patients (100%) to an endocrine surgeon in 2004/5.

Referral to either an endocrinologist or an oncologist in patient records by hospital of treatment decision*

Hospital	Number of patients referred/total (%)	
	2001 & 2002	2004 & 2005
Royal Victoria (RVH)	16/22 (72%)	26/28 (92%)
Craigavon Area (CAH)	13/17 (76%)	10/10 (100%)
Ulster (UH)	9/12 (75%)	2/3
Antrim (ANT)	7/9 (77%)	5/6 (83%)
Altnagelvin (AH)	4/7 (57%)	7/9 (77%)
Erne (ERN)	4/4	-
Belfast City (BCH)	3/3	7/9 (77%)
Mid-Ulster (MUH)	2/5	3/3
Coleraine (COL) / Causeway (CAU)	1/1	-
Daisy Hill (DHH)	1/1	-
Lagan Valley (LVH)	1/1	-
South Tyrone (STH)	1/1	-
Whiteabbey (WHA)	1/1	-
Tyrone County (TCH)	-	2/2
North-West Independent Clinic (NWC)**	-	0/1
Ulster Independent Clinic (UIC)**	4/6 (66%)	4/5

*The 'hospital of treatment decision' is defined as the hospital of primary surgery, and if no surgery was carried out, it is the hospital of presentation

**The Ulster Independent Clinic and the North West Independent Clinic are private hospitals

- In 2004/5, all hospitals showed a high rate of either oncologist or endocrinologist involvement in patient care (66%-100%).
- Craigavon Area Hospital and the Royal Victoria Hospital, between them handling 50% of all patients in 2004/5, achieved 100% and 92% oncologist or endocrinologist involvement, respectively.

Surgery* for thyroid cancer

Type of Surgery	Primary operation (%)		Secondary operation (%)	
	2001 & 2002 *(n=90)*	2004 & 2005 *(n=76)*	2001 & 2002 *(n=90)*	2004 & 2005 *(n=76)*
Total thyroidectomy	30 (33%)	35 (46%)	3 (3%)	4 (5%)
Lobectomy**	34 (38%)	30 (39%)	9 (10%)	27 (36%)
Lymph node resection	-	2 (3%)	2 (2%)	-
Biopsy Alone	3 (3%)	1 (1%)	-	-
Other	5 (6%)	2 (3%)	2 (2%)	-
None	18 (20%)	5 (7%)	74 (82%)	45 (59%)
Not recorded	-	1 (1%)	-	-

*Patients may have had more than one type of procedure during a surgical operation but only the most important procedure is counted

**All lobectomies carried out as a secondary operation were completion thyroidectomies except for one case in 2004/5

- In 2001/2, 72% (28/39) of surgery patients who had a tumour size greater than 1cm had a total thyroidectomy or completion thyroidectomy, and in 2004/5 this increased to 92% (45/49). This concurs with the recommendation by the Royal College of Physicians of London and the British Thyroid Association[4] Appendix B (7,iii).
- The percentage of surgery patients who had a lobectomy alone declined from 35% (25/72) in 2001/2 to 7% (5/71) in 2004/5.
- All medullary type carcinoma patients with recorded surgery (one in 2001/2; three in 2004/5) had a completion thyroidectomy in keeping with the guidelines of the Royal College of Physicians of London and the British Thyroid Association[4] (Appendix B, 9, iv).
- There was a higher rate of completion thyroidectomy in 2004/5 at 83% than in 2001/2 at 26%.

Hospitals performing surgery on thyroid cancer patients

Hospital	Primary operation (%)		Secondary operation* (%)	
	2001 & 2002 *(n=72)*	2004 & 2005 *(n=71)*	2001 & 2002 *(n=15)*	2004 & 2005 *(n=31)*
Royal Victoria (RVH)	22 (31%)	28 (39%)	2 (13%)	14 (45%)
Craigavon Area (CAH)	13 (18%)	9 (13%)	6 (40%)	7 (23%)
Antrim (ANT)	8 (11%)	6 (8%)	4 (27%)	3 (10%)
Ulster (UH)	8 (11%)	3 (4%)	-	1 (3%)
Altnagelvin (AH)	5 (7%)	7 (10%)	-	3 (10%)
Belfast City (BCH)	3 (4%)	8 (11%)	-	3 (10%)
Mid-Ulster (MUH)	3 (4%)	3 (4%)	-	-
Erne (ERN)	2 (3%)	-	1 (7%)	-
Coleraine (C0L) / Causeway (CAU)	1 (1%)	-	-	-
Daisy Hill (DHH)	1 (1%)	-	-	-
Tyrone County (TCH)	-	2 (3%)	-	-
North-West Independent Clinic (NWC)**	-	1 (1%)	-	-
Ulster Independent Clinic (UIC)**	6 (8%)	4 (6%)	2 (13%)	-
Total Patients	**72**	**71**	16***	31

*Secondary operations are the second operation to complete surgical treatment

**The Ulster Independent Clinic and the North West Independent Clinic are private hospitals

*** There was one operation for which the hospital of operation was not recorded

- There was a total of 72 primary surgical procedures carried out in 11 hospitals in 2001/2, while this figure was 71 in 10 hospitals in 2004/5.
- There were 15 secondary surgical procedures in 5 hospitals in 2001/2; this increased to 31 operations in 6 hospitals in 2004/5.
- In 2001, 6 (17%) of primary surgical procedures were carried out on patients who had a record of metastatic disease. In 2002, 2004, 2005, this was not more than one patient per year.

Hospitals performing thyroidectomies* (NOTE: in one or two operations [completion thyroidectomy])

Hospital	Thyroidectomies*		Number of operators***	
	2001 & 2002 *(n=42)*	2004 & 2005 *(n=65)*	2001 & 2002	2004 & 2005
Royal Victoria (RVH)	16 (38%)	32 (49%)	3	4
Craigavon Area (CAH)	7 (17%)	9 (14%)	2	2
Antrim (ANT)	6 (14%)	6 (9%)	1	1
Ulster (UH)	6 (14%)	3 (5%)	2	1
Erne (ERN)	1 (2%)	-	1	-
Mid-Ulster (MUH)	1 (2%)	3 (5%)	1	1
Belfast City (BCH)	1 (2%)	5 (8%)	1	2
Altnagelvin (AH)	-	4 (6%)	-	2
Ulster Independent Clinic (UIC)**	4 (10%)	3 (5%)	1	2

*In the case that a completion thyroidectomy was performed in a hospital different from the initial lobectomy, this completion thyroidectomy was assigned to the hospital that completed the thyroidectomy; this only occured three times and the completion took place in the Royal Victoria Hospital each time

** The Ulster Independent Clinic is a private clinic and the operators quoted are attached to the Royal Victoria Hospital or Belfast City Hospital

***Operators here refer to the 'surgeon in charge' as recorded on the operation sheet; in some cases they were overseeing the work of a trainee registrar.

- In 2004/5, almost 50% of all thyroidectomies or completion thyroidectomies were performed in the RVH increasing from 38% in 2001/2.
- Mid-Ulster Hospital, Belfast City Hospital, and Altnagelvin Hospital have increased the number of thyroidectomies between 2001/2 and 2004/5.
- The percentage of patients receiving either a total thyroidectomy or completion thyroidectomy increased from 46% (42/90) in 2001/2 to 86% (65/76) in 2004/5.
- The number of surgeons performing thyroidectomies remained largely static from 2001/2 to 2004/5; Altnagelvin Hospital increased from zero to two operators over the period.

Patient alive at 30 days post-operation (primary surgery)

Status	Number of Patients (%)	
	2001 & 2002 *(n=72)*	2004 & 2005 *(n=71)*
Yes	71 (99%)	71 (100%)
No	1 (1%)	-

- One 30 day post-operation death was recorded in 2001/2; this patient had an anaplastic thyroid cancer (Stage IV).

Follow up to surgery for patients with differentiated* cancer

Follow up	Number of Patients (%)	
	2001 & 2002 *(n=64)*	2004 & 2005 *(n=66)*
TSH suppression therapy given	61 (95%)	65 (98%)
TSH recorded as suppressed	45 (70%)	34 (52%)
Post surgery scan/post I^{131} scan	36 (56%)	51 (77%)
Initial ablative radioactive iodine	33 (52%)	50 (76%)
External radiation	2 (3%)	3 (5%)

* Differentiated thyroid cancer types are follicular and papillary

- The percentage of I^{131} administered to patients rose from 52% in 2001/2 to 76% in 2004/5.
- Post surgery scans and/or post I^{131} scans increased from 56% in 2001/2 to 77% in 2004/5.
- The use of external radiation remains low at about 3%.

Frequency of operations carried out by surgeon

Procedures	Number of Surgeons (% of primary operators)		Number of Surgeons (% of secondary operators*)	
	2001 & 2002 *(n=72)*	2004 & 2005 *(n=71)*	2001 & 2002 *(n=15)*	2004 & 2005 *(n=31)*
6-15 procedures	6 (38%)	7 (50%)	-	1 (9%)
2-5 procedures	7 (44%)	4 (29%)	5 (83%)	8 (73%)
1 procedure	3 (18%)	3 (21%)	1 (17%)	2 (18%)
Total named operators**	16	14	6	11
Total procedures	72	71	16	31

* secondary operators are those who operated at the second operation to complete surgical treatment

** primary and secondary operators were those who were named on the surgery sheet as 'surgeon in charge'; they may have been supervising trainee registrars

- 72 primary operations were carried out by 16 operators in 2001/2, and 71 primary operations were performed by 14 operators in 2004/5.
- Between both periods 2001/2 and 2004/5, four surgeons performed only one operation which included a lobectomy.
- The highest number of operations performed by one surgeon in one 12 month period was: 2001, 8 operations; 2002, 7; 2004, 9; 2005, 11.
- The number of secondary operators almost doubled in 2004/5 compared with that of 2001/2.

Measurement of TSH level (units per litre) at presentation and at last review for surgery patients with differentiated* cancer types

Time	Number of Patients (% of total)	
	2001 & 2002 *(n=64)*	**2004 & 2005 *(n=66)***
TSH checked at presentation	44 (69%)	37 (56%)
TSH recorded at last review	57 (89%)	56 (85%)

* Differentiated thyroid cancer types are follicular and papillary

- The recording of TSH at last review for surgery patients with differentiated cancer types remained high from 2001/2 to 2004/5 at around 85%.

TSH levels (units per litre) recorded at last review for surgery patients with differentiated* cancer types

Level	Number of Patients at last review (%)	
	2001 & 2002 *(n=64)*	**2004 & 2005 *(n=66)***
TSH less than or equal to 0.1	38 (59%)	36 (55%)
0.1 - 1.0	10 (16%)	9 (14%)
Greater than 1.0 and less than 5.0	7 (11%)	10 (15%)
Greater than 5.0	2 (3%)	1 (1%)
Not recorded	7 (11%)	10 (15%)

* Differentiated cancer types are follicular and papillary

- 57% of patients had a TSH measurement at last review of less than or equal to 0.1. **The Guidelines of the Royal College of Physicians of London and the British Thyroid Association**[4] state: "Patients should be started on T_4 three days after I^{131} in a dose sufficient to suppress TSH to <0.1mu/l".

Last Thyroglobulin level recorded for patients* with total thyroid removal

Level (units per litre)	Number of Surgery Patients** (%)	
	2001 & 2002 *(n=33)*	2004 & 2005 *(n=54)*
Less than or equal to 1	26 (79%)	43 (79%)
1 - 5	4 (12%)	2 (4%)
Greater than 5	2 (6%)	2 (4%)
Not recorded	1 (3%)	7 (13%)

*Includes only patients with differentiated cancer types, i.e. follicular and papillary
**Further patients were excluded from this statistic if they had antibodies to thyroglobulin, or their chart was inaccessible, or their patient failed to attend review appointments, or their cancer was an incidental finding of a non-invasive microscopic tumour

- 79% of patients with a record of thyroglobulin level had it at a level of less than or equal to one unit per litre. 77% of those patients with a thyroglobulin level of less than or equal to one unit per litre all had papillary type tumours.
- In 2001/2, 97% (32/33) of patients had their thyroglobulin level checked post-operatively; in 2004/5, it was 87% (47/54). Guidelines set out by the Royal College of Physicians of London and the British Thyroid Association[4] state that all post-operative patients should have their thyroglobulin levels checked sometime from three months after surgery. Thyroglobulin level is a marker for recurrence.

Thyroglobulin measurement for patients who had their thyroid completely removed and with differentiated cancer* by hospital of primary operation

Hospital	Number of patients** with level checked/total (%)	
	2001 & 2002 *(n=34)*	2004 & 2005 *(n=56)*
Royal Victoria (RVH)	12/12 (100%)	22/23 (96%)
Antrim (ANT)	6/6 (100%)	6/6 (100%)
Ulster (UH)	5/5 (100%)	2/2 (100%)
Craigavon Area (CAH)	6/6 (100%)	9/9 (100%)
Mid-Ulster (MUH)	1/1 (100%)	3/3 (100%)
Altnagelvin (AH)	-	4/4 (100%)
Erne (ERN)	1/1 (100%)	-
Belfast City (BCH)	-	5/5 (100%)
Tyrone County (TCH)	-	1/1 (100%)
Ulster Independent Clinic (UIC)***	3/3 (100%)	3/3 (100%)

*Differentiated cancer types are follicular and papillary
**Further patients were excluded from this statistic if they had antibodies to thyroglobulin, or their chart was inaccessible, or their patient failed to attend review appointments, or their cancer was an incidental finding of a non-invasive microscopic tumour
***The Ulster Independent Clinic is a private hospital

- Antrim Hospital and Mid-Ulster Hospital had a 100% record in thyroglobulin recording post surgery.
- The Royal Victoria Hospital, Antrim Hospital, Craigavon Area Hospital, and Belfast City Hospital showed an increase in recorded thyroglobulin measurement from 2001/2 to 2004/5.

Site of recurrence

Site	Number of Patients (cell type or % of total)	
	2001 & 2002 *(n=90)*	**2004 & 2005 *(n=76)***
Bone	1 (Papillary)	1 (Follicular)
Neck	1 (Anaplastic)	-
Lymph node	2 (Papillary)	-
Thoracic spine	-	1 (Follicular)
Sphenoid bone	-	1 (Papillary)
Tracheal wall	1 (Anaplastic)	-
Right temple	1 (Follicular)	-
"No recurrence" recorded in notes	38 (42%)	61 (81%)
No record in notes	46 (51%)	12 (16%)

* Note that the average follow up per patient in 2001/2 and 2004/5 was 3.9 and 1.7 years, respectively

- 6% of patients in 2001/2 had a history of cancer recurrence within this time period. The rate of recurrence in 2004/5 was 4%; however, note that follow up in 2004/5 was shorter than for 2001/2.
- There was no discernible pattern between cell type and recurrence in either period - mainly due to the low numbers in the study.

Radiotherapy/I^{131} ablation therapy

Status	Number of Patients (%)	
	2001 & 2002	**2004 & 2005**
External Radiation for all cancers	13 (14%)*(n=90)*	8 (11%) *(n=76)*
Initial Ablative Radioactive Iodine for differentiated cancers*	35 (51%) *(n=69)*	50 (76%) *(n=66)*

*Differentiated cancer types are follicular and papillary

- 13% of patients received external radiation.
- From 2001/2 to 2004/5, the percentage of patients with differentiated cancers receiving I^{131} increased from 51% to 76%.
- For patients with differentiated cancer who had a tumour greater than 1cm, 66% (23/35) received I^{131} in 2001/2, while this increased to 89% in 2004/5. The Royal College of Physicians of London and the British Thyroid Association Guidelines[4] (2002) state: "The majority of patients with a tumour size of more than 1cm in diameter, should have I^{131} ablation therapy."

Radiotherapy/I^{131} Ablation therapy by Board of residence

HSSB Residence	Radiotherapy (% of total in Board)		I^{131} Ablation therapy (% of total differentiated cancer in each Board)*	
	2001 & 2002 *(n=13)*	2004 & 2005 *(n=8)*	2001 & 2002 (n=35)	2004 & 2005 (n=50)
EHSSB	6 (20%)	2 (6%)	12 (52%)	18 (67%)
NHSSB	1(5%)	-	8 (57%)	15 (88%)
SHSSB	4 (15%)	3 (20%)	10 (48%)	13 (92%)
WHSSB	2 (13%)	3 (23%)	5 (45%)	4 (50%)

*only patients with differentiated cancers are considered in these columns

- In general, the proportion of patients who received radiotherapy declined from 2001/2 to 2004/5 in EHSSB and the NHSSB, however the numbers in any one year receiving external radiotherapy are small.
- The proportion of patients with differentiated cancer cell types that received I^{131} ablation therapy increased markedly from 2001/2 to 2004/5 in all Health Boards except the WHSSB.

Professions administering I^{131} ablation therapy to patients with differentiated* cancer types

Status	Number of Patients (%)	
	2001 & 2002 *(n=35)*	2004 & 2005 *(n=50)*
Received I^{131} from an oncologist	17 (49%)	20 (40%)
Received I^{131} from an endocrinologist	18 (51%)	30 (60%)

*Differentiated cancer types are follicular and papillary

- From 2001/2 to 2004/5, there was an increasing trend for patients to receive I^{131} from an endocrinologist, 53% to 60%, respectively.

Professions administering I^{131} ablation therapy to patients with differentiated* cancer types by Health Board of presentation

HSSB of presentation	Total patients in each Board who received I^{131}		Received I^{131} from an Oncologist (% of total)		Received I^{131} from an Endocrinologist (% of total)	
	2001 & 2002 *(n=35)*	2004 & 2005 *(n=50)*	2001 & 2002 *(n=17)*	2004 & 2005 *(n=20)*	2001 & 2002 *(n=19)*	2004 & 2005 *(n=30)*
EHSSB	15	26	7 (47%)	7 (27%)	8 (53%)	19 (73%)
NHSSB	7	9	1 (14%)	0 (0%)	6 (86%)	9 (100%)
SHSSB	8	11	7 (87%)	10 (91%)	1 (13%)	1 (9%)
WHSSB	5	4	2 (40%)	3 (75%)	3 (60%)	1 (25%)

*Differentiated cancer types are follicular and papillary

- From 2001/2 to 2004/5, there was an increasing tendency for the EHSSB and NHSSB to send patients for I^{131} to an endocrinologist, for SHSSB and WHSSB there was an increasing tendency to send patients to an oncologist.

Input from Health Professionals recorded in notes

Service	Number of Patients (%)	
	2001 & 2002 *(n=90)*	2004 & 2005 *(n=76)*
Management discussed with endocrinologist	26 (29%)	32 (42%)
Management discussed with endocrine surgeon	39 (43%)	36 (47%)
Treatment plan discussed with patient	81 (90%)	75 (99%)
Written information given	6 (7%)	4 (5%)
Thyroglobulin ongoing assessment explained	27 (30%)	21 (28%)
Management plan recorded in notes	81 (90%)	73 (96%)
Prognosis discussed with patient	73 (81%)	66 (87%)

- Although the Royal College of Physicians of London and the British Thyroid Association guidelines state that all patients should be offered full verbal and written information about their condition and treatment, only 7% and 5% of patients had a record of having been given written information in 2001/2 and 2004/5, respectively.
- 90% of patients in 2001/2 and 99% in 2004/5 had a discussion about their treatment plans.
- Around one third of patients had their management discussed with an endocrinologist and around 45% had their management discussed with an endocrine surgeon.
- At least 90% of patients had a record that their diagnosis and treatment plans had been discussed with them.
- About 34% of patients had a record in their notes that their diagnosis had been discussed with their families.
- One patient in 2001/2 took part in a clinical trial.

Onward referral

Service	Number of Patients (%)	
	2001 & 2002 *(n=90)*	2004 & 2005 *(n=76)*
MacMillan Nurse	8 (9%)	2 (3%)
Care centre	1 (1%)	3 (4%)
Genetics	1 (1%)	1 (1%)
Psychologist	-	1 (1%)
Social Worker	-	2 (3%)
Other	2 (2%)	-
No onward referral recorded	78 (87%)	67 (88%)

- The breakdown of all patients onwardly referred to various services (n=21; all periods) among cancer cell type was: 7, anaplastic, 6 papillary, 2 follicular, 1 medullary, 5 unknown.

- The breakdown of all patients onwardly referred to other services (*n*=21; all periods) by stage (assigned in registry) was: 13 Stage IV, 2 Stage III, 1 Stage II, 2 Stage I, 3 unknown. Two patients, with Stage I and II, were referred for genetic counselling.

Timelines/Waiting Times

Time	Referral – First seen at hospital		First seen – Diagnosis confirmed	
	2001 & 2002 *(n=90)*	2004 & 2005 *(n=76)*	2001 & 2002 *(n=90)*	2004 & 2005 *(n=76)*
Same day	20 (22%)	15 (20%)	16 (18%)	14 (18%)
1 - 14 days	12 (13%)	21 (28%)	13 (14%)	6 (8%)
15 - 31 days	16 (18%)	8 (11%)	9 (10%)	7 (9%)
32 - 62 days	19 (21%)	15 (20%)	11 (12%)	11 (14%)
More that 62 days	9 (10%)	12 (16%)	31 (34%)	33 (43%)
Minus values*	-	-	-	2 (3%)
Not recorded	14 (16%)	5 (7%)	10 (11%)	3 (4%)

* Patient was attending for some other reason and then was referred to thyroid specialist after diagnosis

- From 2001/2 to 2004/5, there was an increase in the percentage of patients who were seen within two weeks of referral, 35% to 48%.
- From 2001/2 to 2004/5, there was a slight decline in the percentage of patients who were diagnosed within 31 days of being first seen, 42% to 35%.

Timelines/Waiting Times

Time	Diagnosis confirmed – Primary surgery		Diagnosis confirmed – I^{131} therapy	
	2001 & 2002 *(n=72)*	2004 & 2005 *(n=71)*	2001 & 2002 *(n=36)*	2004 & 2005 *(n=50)*
Same day*	54 (75%)	57 (80%)	-	-
1 - 14 days	5 (7%)	1 (1%)	-	-
15 - 31 days	5 (7%)	4 (6%)	1 (3%)	1 (2%)
32 - 62 days	5 (7%)	5 (7%)	9 (25%)	7 (14%)
More that 62 days	2 (3%)	4 (6%)	26 (72%)	42 (84%)
Not recorded	1 (1%)	-	-	-

*The reasons why the % diagnosis on same day of surgery is so high is because, firstly, many patients were waiting for an operation for a separate thyroid disorder, and their thyroid cancer was an incidental finding, and secondly, surgery (often lobectomy) is, in some situations, the only definitive way of diagnosing a suspected thyroid cancer

- 75% of patients in 2001/2 had diagnosis confirmed on the same day as surgery and 80% in 2004/5.
- In 2001/2, 72% of patients that received I^{131} therapy received it more than two months after their diagnosis; in 2004/5 it was 84%.

FOLLOW-UP CARE DETAILS

These relate to the information recorded in the discharge letter from the hospital to the GP. (Patients may have had more than one referral)

GP Letter (NOTE: A patient may be recorded in more than one row)

Information	Number of Patients (%)	
	2001 & 2002 *(n=90)*	2004 & 2005 *(n=76)*
Management plan	81 (90%)	73 (96%)
Prognosis recorded	58 (64%)	36 (47%)
Patient awareness	73 (81%)	66 (87%)
Family awareness	29 (32%)	28 (37%)

- Overall, information in the letter to GP was well recorded with 90% or greater having a positive record of a management plan.

After Care/Follow Up

After care	Number of Patients (%)	
	2001 & 2002 *(n=89*)*	2004 & 2005 *(n=76)*
Follow up with clinician	75 (84%)	71 (93%)

*There was one patient who died less than a month after surgery

- 84% and 93% of patients in 2001/2 and 2004/5, respectively, had a record of some form of follow up with a clinician.

SURVIVAL

Survival analysis was performed on all patients with a subgroup analysis for cell type and for stage.

Percentage of patients alive at various times after diagnosis

Time	All patients	
	2001 & 2002 *(n=90)*	2004 & 2005 *(n=76)*
30 days	94%	98%
60 days	85%	98%
6 months	82%	94%
1 year	80%	94%*
2 years	76%	-

*Death information was followed up until the end of 2005, therefore, for 2004/5 there was only up to one year survival estimates

- 2004/5 had better survival than 2001/2 reflecting the higher proportion of patients with anaplastic thyroid cancer in 2001/2.

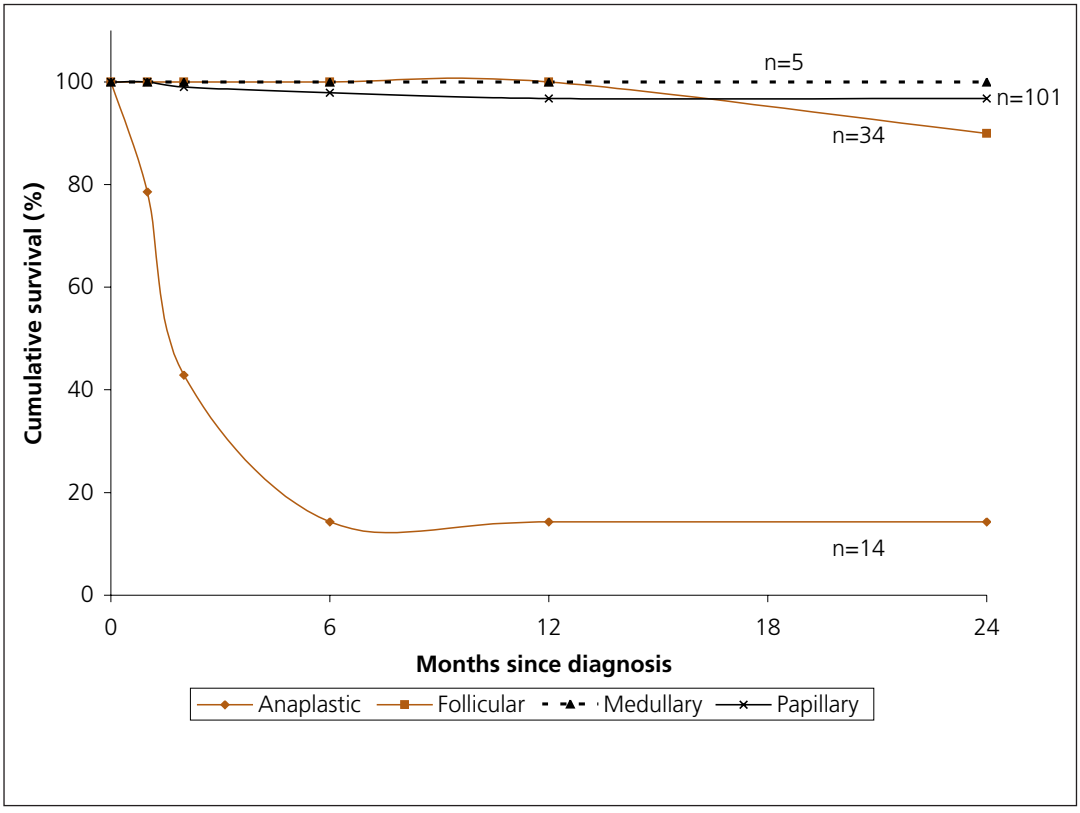
Percentage of patients alive at various times after diagnosis by cell type

Time	Cell type			
	Anaplastic *(n=14)*	Follicular *(n=34)*	Medullary *(n=5)*	Papillary *(n=101)*
1 month	79%	100%	100%	100%
2 month	43%	100%	100%	99%
6 month	14%	100%	100%	98%
12 month	14%	100%	100%	97%
24 month	14%	90%	100%	97%

*Death information was followed up to the end of 2005, so there are differing levels of follow up depending on the year of diagnosis

- Anaplastic cell type had poor survival – 14% after 2 years.
- The survival of the other cancers was quite good at two years with papillary cell type performing better than follicular.

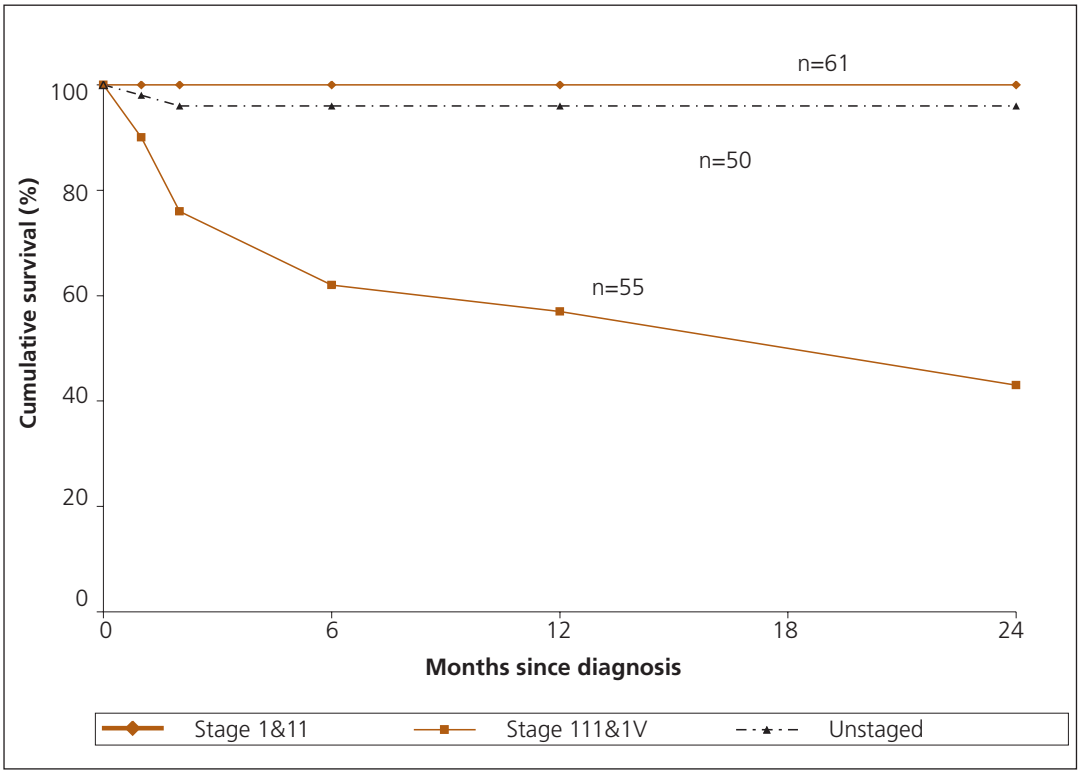
Thyroid cancer observed survival for cancer type



Percentage of patients alive at various times after diagnosis with different assigned stage of disease at presentation

Time	Stage I & II (n=61)	Stage III & IV (n=50)	Unstaged (n=55)
30 days	100%	90%	98%
60 days	100%	76%	96%
6 months	100%	62%	96%
1 year	100%	57%	96%
2 years	100%	43%	96%

Thyroid cancer observed survival by stage



- There was a significant difference in survival across patients with different assigned stages of disease with patients who present with earlier stage disease showing better observed survival ($p<0.001$).

THYROID CANCER SUMMARY

PATIENTS

- 166 patients were included from years, 2001/2, 2004/5; two were excluded for lack of information.
- 74% of cases occurred in females.
- There was no association of incidence rates with socio-economic status.
- Average age of diagnosis was 50 years in females and 57 years in males.
- 4% of patients had a positive family history of thyroid cancer.
- About one in three patients had a recorded history of thyroid disorders.
- Four patients were having thyroxine treatment when their cancer was diagnosed.

SYMPTOMS

- Over two thirds of patients had goitre/swelling in the neck.
- The most common presenting symptoms were difficulty swallowing, hoarseness, lethargy and weight loss.
- Of the patients who presented with goitre/neck swelling, a quarter reported having it for less than one month while one third had it for more than a year.

PRESENTATION

- Over half of all diagnosed thyroid cancer cases came from GP referrals.
- 6% of GP referrals presented as emergencies.
- In 2001/2, 89 patients with cancer of the thyroid presented to 16 hospitals, while in 2004/5, 76 patients presented to 17 hospitals.
- The majority of patients presented to a hospital within their own Health Board of residence.
- The number of presentations to the Royal Victoria Hospital and Belfast City Hospital increased between 2001/2 and 2004/5; in the Royal Victoria Hospital, the number of presentations went from 12 to 20, in Belfast City Hospital, it went from 4 to 9.

HOSPITALS ATTENDED

- The percentage of patients that attended the Royal Victoria Hospital at some stage in their investigations and treatment rose from 36% in 2001/2 to 55% in 2004/5.

INVESTIGATIONS PRE-TREATMENT

- 77% of patients had a record of having had a fine needle aspiration of the thyroid.

HISTOPATHOLOGY

- 97% of patients in 2001/2 had a record of histopathology or cytology based on fine needle aspiration as the basis of their diagnosis; this increased to 100% in 2004/5.
- 60% of patients had papillary cell type tumours and 20% had follicular cell type.
- The number of anaplastic cancer patients varied from 11 (12%) in 2001/2 to 3 (4%) in 2004/5.

STAGING

- In 2001/2, TNM stage was recorded in the clinical notes for 8% of patients; in 2004/5, it was 6%.
- With Registry staff assigning a stage, it was possible to achieve staging in 58% of patients in 2001/2, and 78% in 2004/5; there was no evidence that these percentages varied among the Health Boards of residence.
- Over both periods, the rate of metastases was 12%; lung was the most frequent site for metastases (55%).
- In 2004/5, it was possible to ascertain more tumour sizes of differentiated cancers than in 2001/2 (93% versus 83%, respectively).
- For patients with differentiated cancer cell types and who had a tumour size greater than 1cm, the percentage who received I^{131} ablation therapy increased from 66% in 2001/2 to 89% in 2004/5; this trend concurs well with the recommendation by the Royal College of Physicians of London and the British Thyroid Association[3] that most patients with a tumour greater than 1cm should have I^{131} ablation therapy.

MULTIDISCIPLINARY TEAM MEETING

- There was no evidence of formal multidisciplinary team meetings although they are now being established.
- There was evidence of interprofessional discussion in many cases but was not formally recorded in the patients notes

REFERRAL TO AN ENDOCRINE SURGEON, ENDOCRINOLOGIST OR ONCOLOGIST.

- 47% of the patients had a record in their notes of referral to an endocrine surgeon.
- 15% of patients had a referral to an endocrinologist recorded in their notes.
- 50% of the patients had records in their notes of referral to oncologists.

SURGERY

- There was a total of 72 primary surgical procedures carried out in 11 hospitals in 2001/2, while this figure was 71 in 10 hospitals in 2004/5.
- There were 15 secondary surgical procedures in 5 hospitals in 2001/2; this increased to 31 operations in 6 hospitals in 2004/5.
- In 2001/2, 72% (28/36) of surgery patients who had a tumour size greater than 1cm had total [on completion] thyroidectomy and in 2004/5 this increased to 92% (45/49).
- There was a higher rate of completion thyroidectomy in 2004/5 at 87% than in 2001/2 at 26%.
- The percentage of surgery patients who had a lobectomy alone declined from 35% (25/72) in 2001/2 to 7% (5/71) in 2004/5.

- In 2004/5, almost 50% of all thyroidectomies or completion thyroidectomies were performed in the RVH increasing from 38% in 2001/2.

SURGEON WORKLOAD

- 72 primary operations were carried out by 16 operators in 2001/2, and 71 primary operations were performed by 14 operators in 2004/5.
- The highest number of operations performed by one surgeon in one 12 month period was: 8 operations in 2001; 7 in 2002; 9 in 2004; and 11 in 2005.
- The number of secondary operators almost doubled in 2004/5 compared to 2001/2 (*n*= 6 and *n*=11, respectively).
- Between both periods 2001/2 and 2004/5, 4 surgeons were recorded as performing only one operation, which included a lobectomy, on thyroid cancer patients.

TEST FOR THYROID STIMULATING HORMONE (TSH) AT LAST REVIEW

- The recording of TSH at last review for surgery patients with differentiated cancer remained high in both periods 2001/2 and 2004/5 at around 85%.

I^{131} ABLATION THERAPY/EXTERNAL RADIATION THERAPY

- From 2001/2 to 2004/5, the percentage of patients receiving I^{131} increased from 51% to 76%, while that of external radiation remained static (around 13%). 95% of patients receiving external radiation were Stage IV patients.
- For patients who had a tumour size greater than 1cm, the percentage who received I^{131} ablation therapy increased from 66% in 2001/2 to 89% in 2004/5.
- The percentage of patients who received I^{131} therapy increased markedly from 2001/2 to 2004/5 in all Health Boards except the WHSSB, which experienced a small decline.
- From 2001/2 to 2004/5, there was an increasing tendency for the EHSSB and NHSSB to send patients for I^{131} to an endocrinologist, while for the SHSSB and WHSSB there was an increasing tendency to send patients to an oncologist. However, from 2001/2 to 2004/5, there was an increasing overall trend for patients to receive I^{131} from an endocrinologist, 53% to 60%.

TIMELINES

- From 2001/2 to 2004/5, there was an increase in the percentage of patients who were seen within two weeks of referral, 35% to 48%.
- From 2001/2 to 2004/5, there was a slight decline in the percentage of patients who were diagnosed within 31 days of being first seen, 42% to 35%.
- 75% of patients in 2001/2 had diagnosis confirmed on the same day as surgery and in 2004/5 it was 80%.
- In 2001/2, 72% of patients that received I^{131} therapy received it more than two months after their diagnosis; in 2004/5 it was 82%. in 2004/5 it was 84%.

ONWARD REFERRAL

- Most patients receive no onward referral, e.g. to palliative care, which is appropriate as survival from thyroid cancer is, in general, good.
- Overall, information in the letter to GP was well recorded with 90% or greater having a positive record of a management plan.
- 84% and 93% of patients in 2001/2 and 2004/5, respectively, had a record of some form of follow up with a clinician.

COMMUNICATION

- On average over all periods 35% of patients had their management discussed with an endocrinologist, 45% of patients had their management discussed with an endocrine surgeon; in both cases this improved between 2001/2 and 2004/5.
- Only 5-7% of patients had a record in their notes of having been given written information (Note however that all those who received I^{131} were given written information about this treatment).
- 90% of patients in 2001/2 had a discussion about their prognosis and treatment plans, and in 2004/5 this increased to 99%.
- About 34% of patients had a record that their diagnosis was discussed with their families.
- One patient in 2001/2 took part in a clinical trial.

SURVIVAL

- Survival depended on cell type: two year observed suvival was 90% for follicular, 100% for medullary and 97% for papillary types. The expected poor survival of the rarer anaplastic group was 14%.
- Variations in survival between 2001/2 and 2004/5 is probably due to different proportions of type and stages of thyroid cancer in the two time periods.
- Stage I & II differentiated type had a 100% one year survival, whereas Stage III & IV had 57% one year survival.
- 6% of patients in 2001/2 had a history of cancer recurrence within 3.9 years of follow up; for 2004/5 it was 4% within 1.7 years of follow-up.

KEY ISSUES AND RECOMMENDATIONS

KEY ISSUES

- A high number of surgeons (*n*=16 in 2001/2; *n*=14 in 2004/5) operated on a small volume of thyroid cancer disease operations (*n*=88 cases in 2001/2; *n*=102 cases in 2004/5).
- Stage was poorly recorded in a formal fashion (7% TNM overall).
- Not all patients have follow up appointments recorded in their notes.
- Guidelines for the management of patients set by the Royal College of Physicians and the British Thyroid Association are not all being met.
- There was no evidence of formal multidisciplinary team meetings, but clear evidence of interdisciplinary discussion.

RECOMMENDATIONS

- Management of thyroid cancer - a complex clinical scenario - requires input from various specialists in a regional multidisciplinary team meeting setting.
- Protocols for investigation and follow up of thyroid cancer patients should be developed and their use audited.
- The use of fine needle aspiration should be further audited.

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APPENDIX A

Campbell Report[1]: Recommendations regarding Cancer Services in N. Ireland, 1996

1. The management of patients with cancer should be undertaken by appropriately trained, organ and disease specific medical specialists.
2. All patients with cancer should be managed by multidisciplinary, multiprofessional specialist cancer teams.
3. A Cancer Forum should be established involving all key interests in the delivery of cancer services.
4. Cancer Units should, in conjunction with local GPs and other providers, develop an effective communication strategy.
5. Northern Ireland should have one Cancer Centre, which in addition to its regional role, should act as a Cancer Unit to its local catchment population of around half a million.
6. There should be four other Cancer Units, one in each Board area, each serving a population of around a quarter of a million.
7. Radiotherapy services, together with chemotherapy services, should be moved as soon as possible to the Belfast City Hospital and become an integral part of the regional Cancer Centre.
8. Each Cancer Unit should develop a chemotherapy service. This service should be staffed by designated specialist nurses and pharmacists, and should be overseen by the non-surgical oncologist attached to the unit, with back-up from a haematologist.
9. There should be a minimum target of 13 consultants in non-surgical oncology for Northern Ireland by 2005.
10. Any new appointments of trained cancer specialists should be to the Cancer Units or to the Cancer Centre.
11. Guidelines should be drawn up and agreed for the appropriate investigation and management of patients presenting to non-Cancer Unit hospitals who turn out to have cancer.
12. The Cancer Centre and Cancer Units should each develop a specialist multiprofessional palliative care team.
13. There should be a comprehensive review of palliative care services in Northern Ireland.
14. The Northern Ireland Cancer Registry should be adequately resourced.

The above recommendations outlined the change that was necessary to improve cancer care.

APPENDIX B

The Royal College of Physicians of London and the British Thyroid Association produced guidelines in 2002 "**Guidelines for the management of thyroid cancer in adults"**[4]**.** Key recommendations are reproduced below.

1 Access to a multidisciplinary thyroid cancer team

i. The management of differentiated thyroid cancer (a highly curable disease) and of medullary thyroid cancer should be the responsibility of a specialist multidisciplinary team (MDT), membership of which will normally be appointed by the Regional Cancer Network.

ii. The multidisciplinary team will normally comprise a surgeon, endocrinologist and oncologist (or nuclear medicine physician) with support from a pathologist, medical physicist, biochemist, radiologist, specialist nurse (if available), all with expertise and interest in the management of differentiated thyroid cancers.

iii. Patients will normally be seen by one or more members of the MDT; a combined clinic is recommended.

2 Patient focus

i. Patients should be offered full verbal and written information about their condition and their treatment. In addition to this type of material, patient support groups and associated websites can provide information.

ii. Patients should have continuing access to a member of the core team for guidance and support.

3 Surgery

The surgeon should have expertise and interest in the management of thyroid cancer, be a member of the multidisciplinary team, and maintain continuing professional development.

4 Pathology

i. Pathologists dealing with thyroid tumours should have expertise and interest in thyroid pathology.

ii. All patients should be staged by clinical and pathological TNM staging (tumour size, node metastases and distant metastases).

5 Radioiodine therapy and external beam radiotherapy

i. An oncologist (or nuclear medicine physician) with expertise and an interest in the management of differentiated thyroid cancer should supervise this treatment, be a member of the MDT, and maintain continuing professional development in this area of treatment.

ii. Those administering therapeutic radioiodine must hold an appropriate Administration of Radioactive Substances Advisory Committee (ARSAC) certificate.

iii. Radioiodine therapy should be carried out only in centres with appropriate facilities.

6 Aims of treatment

The aims of treatment are:

i. the removal of all the tumour,

ii. no clinical, radiological and biochemical evidence of recurrence of tumour,

iii. minimal unwanted effects of treatment.

7 Summary of treatment

i. All new patients should be seen by a member of the MDT, and the treatment plan should be discussed by the MDT.

ii. Fine needle aspiration cytology (FNAC) should be used in the planning of surgery.

iii. Most patients with tumours more than 1cm in diameter should undergo near total or total thyroidectomy with central node dissection.

iv. Serum thyroglobulin (Tg) should be checked in all post-operative patients with differentiated thyroid cancer (but usually not within three months of surgery).

v. Patients will normally start on T_3 20μg tds (normal adult dosage) after the operation. This should be stopped two weeks before radioiodine therapy. If radioiodine therapy is scheduled within 3 – 4 weeks of surgery the patient need not be started on thyroid hormone replacement until after the administration of radioiodine.

vi. The majority of patients with a tumour size of more than 1cm in diameter, should have ^{131}I ablation therapy.

vii. **Always exclude pregnancy and breast feeding before administering radioactive iodine.**

viii. Patients should be started on T_4 three days later than 1^{131} in a dose sufficient to suppress TSH to <0.1mu/l.

ix. Reassessment with a post-ablation diagnostic scan (after stopping T_4 for four weeks) is indicated 4 – 6 months after ^{131}I ablation, although in low-risk patients measurement of Tg alone may be adequate. If significant uptake of the tracer is detectable, a further ^{131}I ablation therapy dose should be given and a post-treatment scan performed. Following this the patients should restart T_4.

x. If there is a suspicion of residual disease, further scans should be carried out, usually six months later.

xi. Recombinant human TSH (rhTSH) can be used instead of stopping T_3 or T_4 in appropriate cases as decided by the MDT.

xii. External beam radiotherapy is only occasionally used, for patients with T_4 tumours (TNM staging) or distant metastases.

8 Follow-up

This should be life-long because:

i. The disease has a long natural history,

ii. Late recurrences can occur, and these can be successfully treated,

iii. Cure and prolonged survival are common, even after tumour recurrence,

iv. Regular follow-up is also necessary for monitoring of treatment (TSH suppression, the consequences of supraphysiological T_4 replacement, treatment of hypocalcaemia),

v. **Life-long suppression** of serum TSH level below normal (<0.1mu/l) is one of the main components of treatment,

vi. Late side-effects of I^{131} treatment should be monitored.

Surveillance for recurrence of disease is essential and is based on:

i. Annual clinical examination.

ii. Annual measurement of serum Tg and TSH.

iii. Diagnostic scanning when indicated (isotopic imaging and/or ultrasound or CT scan).

iv. Support and counselling are necessary, particularly in relation to pregnancy.

9 Medullary thyroid cancer (MTC)

i. The initial evaluation of suspected MTC includes Fine Needle Aspiration Cytology (FNAC) and measurement of plasma calcitonin.

ii. The multidisciplinary team meeting should include or have access to a Clinical Genetics Service and RET proto-oncogene (Rearranged during Transfection) gene testing.

iii. Familial MTC represents 25% of all cases of MTC and associated endocrinopathies should be sought. All new patients should be screened biochemically for phaeochromocytoma.

iv. The mainstay of treatment is total thyroidectomy and central node dissection.

v. Prophylactic surgery should be considered in disease-free carriers of germ line RET mutations, ideally at the age of five years or soon after. MTC occurs early in MEN2B and is particularly aggressive; thyroid surgery should be done as early as possible after the age of one year.

vi. Life-long follow-up is essential and includes monitoring of the tumour marker calcitonin.

vii. Any new patient with MTC should be referred for RET mutation testing whether or not there is an evident family history.

viii. RET mutation testing include exons 10, 11, 13, 14 and 15; screening of exons 10 and 11 is an incomplete test.

APPENDIX C

Staging of thyroid cancer

Clinical staging

Clinical staging involves careful inspection and palpation of the gland and regional nodes. Indirect laryngoscopy to evaluate the vocal cords is essential. Imaging techniques such as radioisotope scans, ultrasound, CT, and MRI scans provide additional useful information on the extent of the primary tumour (T), the involvement of regional nodes (N) and the presence or absence of distant metastases.

Pathological staging

This information results from examination of the surgically resected specimen.

Tumour

T0	no evidence of primary tumour
T1	tumour 2cm or less in greatest dimension limited to thyroid
T2	tumour more than 2cm but less than 4cm in greatest dimension limited to thyroid
T3	tumour more than 4cm or any tumour with minimal extrathyroid extension
T4	a tumour of any size extending beyond the thyroid capsule to invade subcutaneous soft tissues, larynx, trachea, oesophagus, or recurrent laryngeal nerve
T4b	tumour invades prevertebral fascia or encases carotid artery or mediastinal vessels

**All anaplastic tumours are considered T_4*

T4a	Intrathyroidal anaplastic carcinoma, surgically resectable
T4b	*Extrathyroidal anaplastic carcinoma, surgically unresectable*

Nodes

NX	regional nodes not assessed
N0	no regional nodes involved
N1	regional lymph node metastases
N1a	metastases to level VI nodes
N1b	metastases to unilateral, bilateral, or contralateral cervical or superior mediastinal nodes

Metastases

M0	no distant metastases
M1	distant metastases

In order to facilitate survival analysis the assigned TNM profile is condensed into a stage group category of which there are 6 (Stages I, II, III, IVA, IVB, IVC, Table 2).

Table 1 **Stage group thyroid cancer**

Stage	***T***	***N***	***M***
Papillary or follicular under 45 years			
I	any T	any N	M0
II	any T	any N	M1
Papillary or follicular over 45 years			
I	T1	N0	M0
II	T2	N0	M0
III	T3	N0	M0
	T1	N1a	M0
	T2	N1a	M0
	T3	N1a	M0
IVA	T4a	N0	M0
	T4a	N1a	M0
	T1	N1b	M0
	T2	N1b	M0
	T3	N1b	M0
	T4a	N1b	M0
IVB	T4b	anyN	M0
IVC	anyT	anyN	M1

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