

Scottish Thyroid Cancer Network

Annual Report

2024/25

Lead Clinician: Vacancy (from 30th June 2024)
Programme Manager: Anna Morton
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Introduction

The Scottish Cancer Network (SCN) currently manages, supports and governs five national cancer networks. The [Scottish Government Cancer Strategy 2023-33](#) ^[66] states:

“Scottish Cancer Network (SCN) will be at the heart of our strategic ambitions. The SCN will also host national networks, where national integration and collaboration for specific cancers can make best use of expert resources and improve outcomes for people with cancer. It will drive ‘Once for Scotland’ work, where appropriate, and work closely with regional networks where work is better delivered at that level.”

The Scottish Thyroid Cancer Network STCN is built upon the existing project infrastructure set up as part of the Scottish Thyroid Cancer Project, originally funded by the Scottish Government and operating since 2019. In 2021, a successful bid was submitted to the Scottish Government to support the establishment of a national managed clinical network for Thyroid Cancer and support for the Scottish Adrenocortical Cancer Group.

From 1st April 2022 the Scottish Cancer Network (SCN) took ownership of the Cancer National Managed Clinical Networks (NMCNs), including the STCN.

Thyroid cancer is a rare cancer with generally good prognosis; there are approximately 300 new diagnoses per year. See table below. However, there is opportunity to drive improvement through identifying and implementing Quality Performance Indicators (QPIs), regular audits, and establishing a national forum to discuss relevant issues.

Morphology grouped (Multiple Items)							
Sum of Incidence	Column Labels						
Row Labels		2017	2018	2019	2020	2021	Grand Total
NHS Ayrshire and Arr.		16	7	12	16	12	63
NHS Borders		3	4	3	3	2	15
NHS Dumfries and Ga		1	7	6	7	4	25
NHS Fife		10	20	10	13	17	70
NHS Forth Valley		10	14	14	12	15	65
NHS Golden Jubilee				1	1	3	5
NHS Grampian		25	26	15	28	23	117
NHS Greater Glasgow		92	107	108	76	88	471
NHS Highland		14	15	4	8	8	49
NHS Lanarkshire		17	32	21	20	18	108
NHS Lothian		45	48	36	35	46	210
NHS Shetland			2			1	3
NHS Tayside		26	33	35	24	27	145
NHS Western Isles		1		1			2
non-NHS provider		26	23	23	24	20	116
Grand Total		286	338	289	267	284	1464

Scotland's diverse geographical area has meant that services have been shaped differently in the various boards and clinical pathways have been adjusted as required. This has resulted in variation in clinical and other outcomes. Although work of the Scottish Thyroid Cancer Project made some progress addressing differences in clinical practice and harmonising treatment protocols across Scotland, a number of issues could not be resolved, and a lot of work remains to be done to ensure equity of service and the best possible outcomes for patients across NHS Scotland. The STCN is helping to ensure:

- Implementation of agreed treatment pathways
- Consistency in the way services are delivered across Scotland
- Support for all patients in their cancer journey

Scottish Thyroid Cancer Network

Annual Report 2024/25

- Adherence to established waiting times for surgery and radioiodine ablation (no QPI audit has been implemented for Thyroid Cancer)
- Opportunities for continued medical education and training of professionals involved in the treatment of this cancer.

In June 2024 the clinical lead for the network stepped down and recruitment for a new clinical lead was paused due to the Scottish Government review of networks. As such the network has not had a clinical lead for Q2,3,4 2025-26.

STCN membership includes representatives from all NHS Scotland health boards and each of the services involved in the detection and treatment of thyroid cancer (Radiology, Pathology, Surgery, Oncology, Nuclear Medicine and Long-Term Follow up). These groups engage with external agencies and other professional bodies.

The network works collaboratively with, and receives input from, the three regional cancer networks in Scotland.

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Current Position

The full network workplan 2024/25 was not achieved due to the lack of clinical lead July 2024-March 2025 and the Scottish Government Network Review however progress was achieved in some areas with the launch of the thyroid genomics testing pathway and supporting educational webinar of particular note.

Highlights

- ✓ The STCN collaborated with the Scottish Strategic Network for Genomic Medicine (SSNGM) launched the thyroid genomic testing pathway
- ✓ New pathology subgroup chair was recruited to support the above process
- ✓ An educational webinar was developed to support the launch of the pathway
- ✓ An extensive patient experience survey was launched in collaboration with the British Thyroid Foundation and the Butterfly Thyroid Cancer Trust looking at all stages of the thyroid cancer pathway from diagnosis to follow up. Over 140 responses were received, and an initial analysis was carried out

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Effective Network Structure and Governance

Throughout 2024-25 the network continued to embed within NSD as part of the wider transition of the SCN. A pathology subgroup chair was recruited and took forward the genomics testing pathway work in the absence of a clinical lead.

Stakeholder Communication and Engagement

An annual review was carried out of the STCN [website](#).

Scottish Thyroid Cancer Network

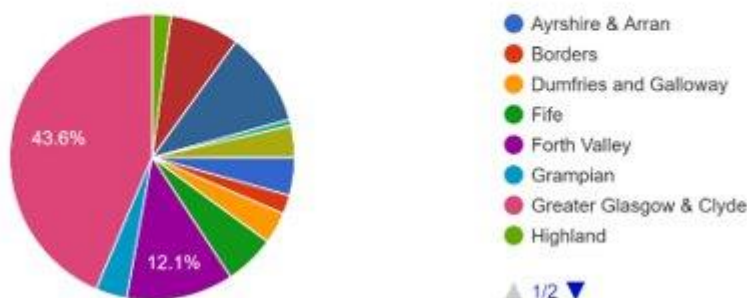
Annual Report 2024/25

The STCN has been collaborating with the British Thyroid Foundation and Butterfly Thyroid Cancer Trust resulting in:

Scottish Patient Experience Survey developed in collaboration with British Thyroid Foundation looking at all stages of the treatment pathway from diagnosis and treatment to follow up. The survey ran from May-August 24 and received over 140 responses from across all Scottish Health Boards.

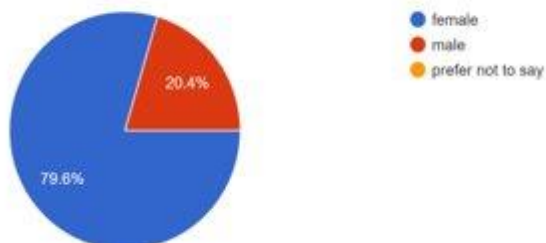
If you live in Scotland please indicate which NHS Health Board you lived in at the time of your diagnosis.

140 responses



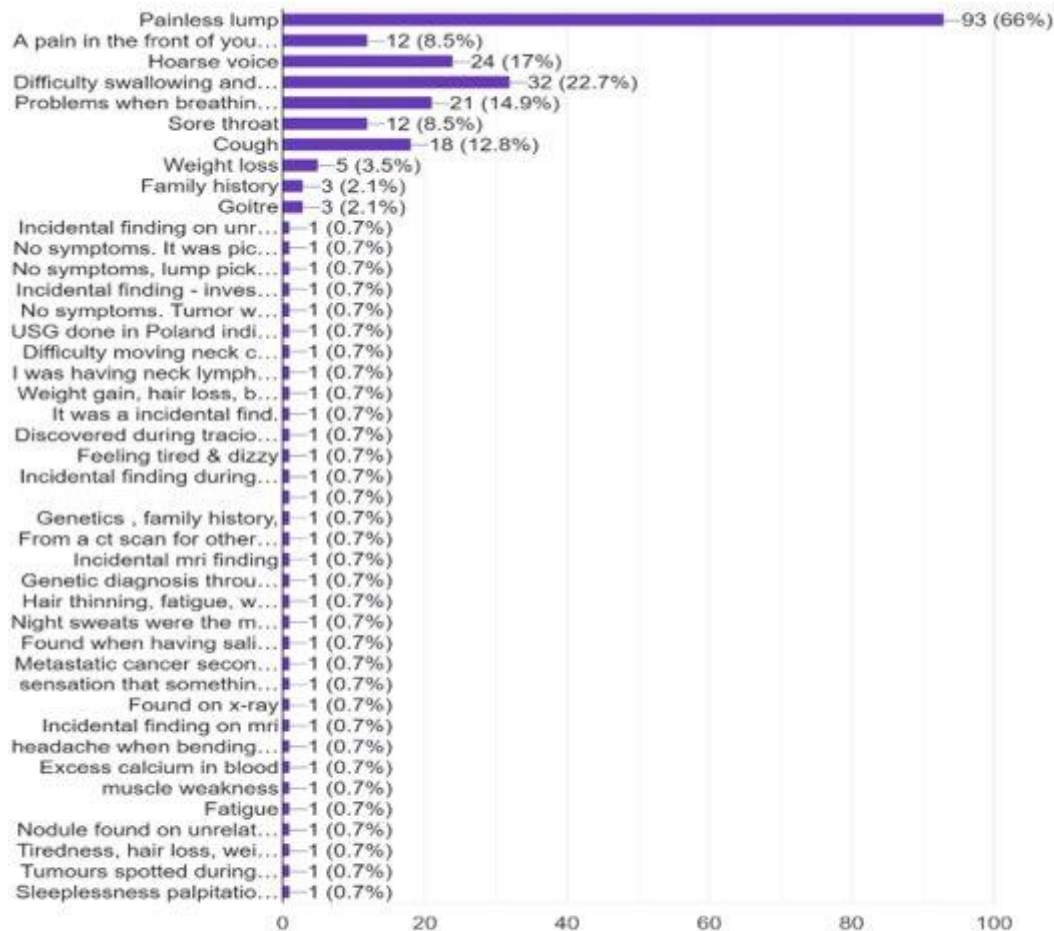
What is your sex?

142 responses



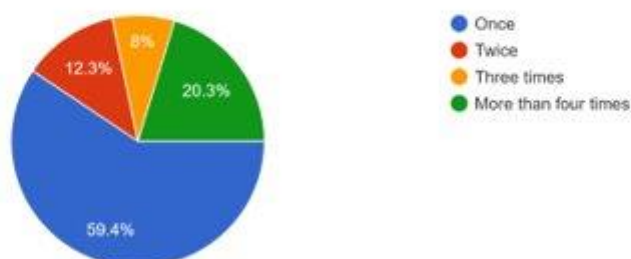
What were the symptoms that led to your diagnosis. Please tick all that apply.

141 responses



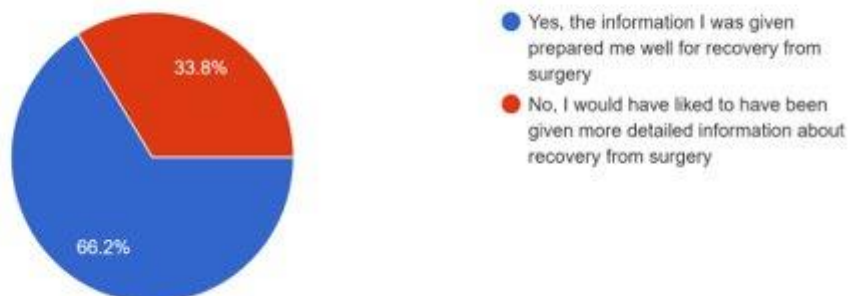
How many times did you visit your GP (or other healthcare professional) before you were referred for further tests?

138 responses



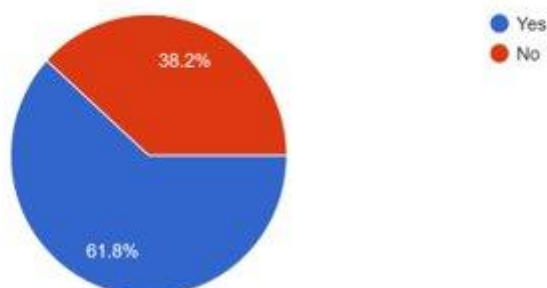
Were you given clear information about what to expect when you were discharged from hospital?

136 responses



Were you given details of a dedicated thyroid cancer Clinical Nurse Specialist (CNS) that you could contact between appointments?

136 responses



Education and Training

A Genomics Testing Pathway Webinar was developed in collaboration with the Genomics Transformation Team, and took place Tuesday 25th September 2024. The session was recorded and is available for ongoing educational purposes.

Programme

- Introduction to New Testing Pathway Nicola Williams, Scientific Lead,
- SSNGM Practical Histopathology Dr Morna MacNeil, Consultant Pathologist Cancer
- Treatments and Prognostic Implications of Specific Mutations Dr Kathryn Graham, Consultant Oncologist
- Mutation Directed Therapy in Practice: Two Case Studies Dr Yaman Rai Albaha, Clinical Oncology
- SpR Genetic Testing in Thyroid Cancer Elspeth Brzezinska, Clinical Scientist

Impact

- ✓ Total attendees: 69 delegates. Speakers and hosts: 11
- ✓ Geographical composition: All attendees based in Scotland.
- ✓ Job titles: Mixed audience comprising mostly of NHS healthcare professionals: clinical scientists, consultant pathologists, ENT consultants and genetic counsellors.
- ✓ The feedback was very positive; overall opinion was that the webinar was excellent, well organised and enjoyable. 100% of respondents rated the programme and organisation of the webinar 'excellent' (60%) or 'good' (40%) and 90% rated the quality of education as 'excellent' (60%) or 'good' (30%) with 10% rating it 'satisfactory'.

Service Development and Delivery

1.) Audit and Continuous Quality Improvement

The development of National Cancer Quality Performance Indicators for Thyroid Cancer. A cross-specialty Thyroid Cancer QPI Development Group was established and met four times in 2023. The QPIs below are now finalised and require to be signed off by the new National Cancer Quality Improvement Board (NCQIB). To enable the signoff of the QPIs, an implementation plan is required to be developed by the National Cancer QPI Coordinator.

At present the thyroid cancer pathway is not audited. The aim of the QPI programme is to develop a framework, and foster a culture of, continuous quality improvement, whereby real time data is reviewed regularly at an individual Multi-Disciplinary Team (MDT)/Unit level and findings actioned to deliver continual improvements in the quality of cancer care. This is underpinned and supported by a programme of regional and national comparative reporting and review.

New Thyroid Cancer QPIs

- QPI 1** - Multi-Disciplinary Team (MDT) Meeting
- QPI 2** – Molecular testing of differentiated thyroid cancer
- QPI 3** - Volume of Cases per Surgeon (minimum 20/year)
- QPI 4** - Time to Completion thyroidectomy (<3 months)
- QPI 5** - Radioiodine Remnant Ablation (RRA) Treatment following Thyroidectomy for Differentiated Thyroid Cancer (high dose for high-risk tumours)
- QPI 6** - Timing of Radioiodine Remnant Ablation (RRA) following Thyroidectomy for Differentiated Thyroid Cancer (< 3months)
- QPI 7** - Dynamic Risk Stratification (DRS) after Radioiodine for Differentiated Thyroid Cancer

A number of data collection scoping and engagement exercises were carried out in 24/25 by the STCN PM however due to the review of the National Cancer Quality Improvement Board, responsible for the Cancer Quality Programme, and the lack of data collection resource within the individual health boards it has not been possible to progress to the implementation phase of the Thyroid Cancer QPIs. This issue has been escalated within NSS and to the Cancer Policy Team at Scottish Government.

2.) Genomics Testing Pathway

The STCN in collaboration with the Scottish Strategic Network for Genomic Medicine (SSNGM) achieved fully funded genomic testing for whole of Scotland:

- ✓ Improved diagnostic accuracy
- ✓ Improved risk stratification
- ✓ Identification of individuals with advanced disease who may benefit from targeted therapies
- ✓ Development of testing pathway for anaplastic thyroid cancer supported by the QPI process
- ✓ Development of education resource for clinical teams

Molecular Testing Pathway Table

Indication	Genetic Testing for diagnosis & prognosis	Genetic testing for treatment
Lesion of 'uncertain malignant potential'.	TERT; BRAF; RAS-SNVs	Not usually required.
Non-invasive follicular thyroid neoplasm with papillary like nuclei	TERT; BRAF; RAS-SNVs	Not usually required.
Medullary carcinoma	RET-SNVs & fusions.	RET- & NTRK-fusions
Follicular carcinoma	Pre-operative core biopsy – RAS-SNVs. Post-operative – TERT	RET- & NTRK-fusions
Papillary carcinoma	TERT; BRAF; RAS-SNVs	BRAF-SNVs; RET- & NTRK-fusions
Oncocytic Carcinoma	TERT; BRAF; RAS-SNVs	RET- & NTRK-fusions
Poorly differentiated carcinoma	TERT; BRAF; RAS-SNVs	BRAF; RET- & NTRK-fusions
Anaplastic carcinoma	Genetic testing for diagnosis, prognosis & treatment.	
	BRAF resulted within 7 days TERT, BRAF and RAS-SNVs; RET-& NTRK-fusions	

5.) Reduce unwanted variation

- ✓ National clinical management guidelines and optimal thyroid pathways in development
- ✓ National MDT guidelines approved and national MDT pro forma under development
- ✓ Draft national standard MDT form in development and circulated for comment to MDT chairs
see image below:

Draft National standard MDT

Referral form for Thyroid MDT Meeting



Referral date:			
Patient details / Consultant details			
Patient CHI:			
Patient Name:			
Hospital:			
CNS:			
Referrers Name:			
Referrers Email:			
Referrers contact:			
Clinical Details			
Relevant history / reason for MDT: (Presentation)			
Imaging for review:	CT / MRI / USS		
Date of Imaging:			
Imaging report:			
Thyroid Pathology:	Yes / No		
Guided Biopsy:	Yes / No		
Pathology results: (Histological subtype / Grade)			
Diagnostic procedures and date:	1 -		
	2 -		
	3 -		
Patients co-morbidities: (Family History)			
ECOG status:			
Radioiodine Remnant Ablation:	Yes / No – Date:		
Clinical Trials:	Yes / No		
Medication:			
Patients understanding / wishes:			
MDT Outcome:			
Clinic appointment date:			
Date diagnosis confirmed:			

Financial sustainability

The Clinical Lead (CL) for the network stepped down on 30th June 2024. Recruitment for a new lead is on hold pending the outcome of the Scottish Government National Network Review.

Looking forward to 2025/26

Network priorities will be progressed in line with agreed 2025-26 priorities.

Finance

No additional costs were incurred by the network in 2024/25. All NSS costs were incurred by agreed network staffing of 2PA Clinical Lead for Q1 of 24/25. Total cost £10,958.