

## **Thyroid Cancer Patients' Survey – UK Data**

### **Executive Summary**

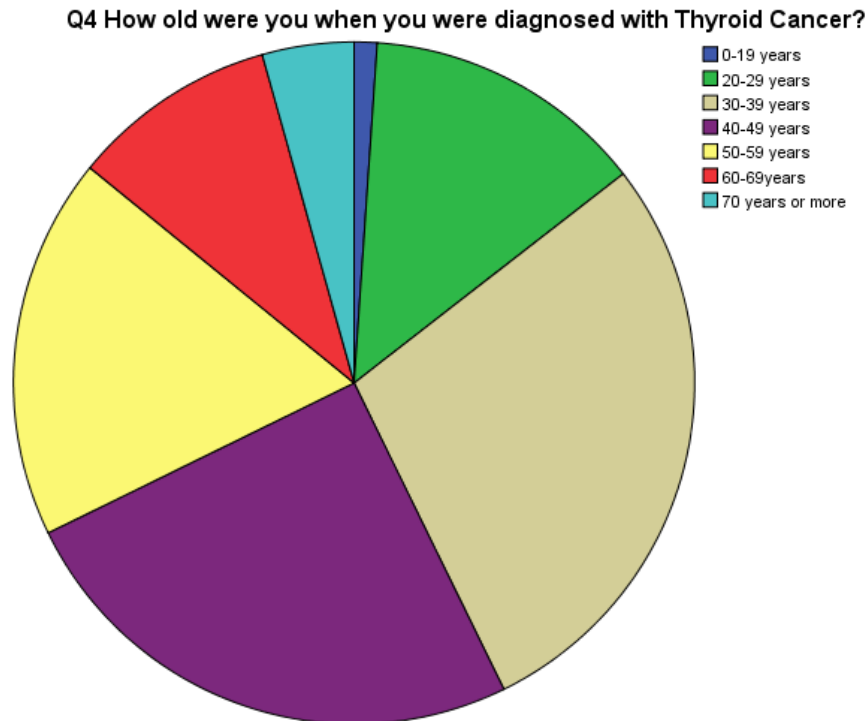
- Most respondents sought help because they had noticed a lump or swelling in their neck
- The majority of respondents were not seen by a thyroid specialist when they were suspected of having thyroid cancer
- Less than half respondents said that they had been offered additional support at the stage of diagnosis, that they had been given details of a patient support organisation or that they had received clear written information about their condition and its treatment
- Over three quarters of respondents sought information from sources outside the hospital. The internet and patient support organisations appeared to be the most helpful sources
- Voice problems and low blood calcium levels were each experienced by almost half the respondents after surgery
- Radioactive iodine treatment normally occurred between one and two months after surgery
- Over half respondents experienced tiredness as a result of hypothyroidism
- Taste disturbance and dry mouth were each experienced by approximately one third of respondents after radioactive iodine treatment
- A minority of respondents were offered thyrogen, but almost all who took it had it paid for by the NHS
- Side effects were much less common from thyrogen than from withdrawal
- Among those who had both withdrawal and thyrogen, there was an overwhelming preference for thyrogen
- Respondents who took thyrogen were more likely to return to their normal range of activities within one month of radioactive iodine treatment
- Receiving a cancer diagnosis was the most frequently identified 'worst point' of the cancer journey
- More information about the disease, psychological support, introduction to patient support groups and quicker access to test results were all identified by approximately one third of respondents as steps that would have improved their cancer journey
- More recently diagnosed patients were more likely to have been provided with clear written information about their disease, specialist support and information about patient support organisations

### **Diagnosis**

Of 276 patients responding to the survey, 58 (21.0%) were male and 218 (79.0%) were female. 28 (10.1%) had a family history of thyroid cancer. 7 (2.5%) had had genetic testing for thyroid cancer and 6 (2.2%) had blood relatives who had had such testing.

The chart below shows that most people were aged 30-60 when they were diagnosed with thyroid cancer:

Chart 1: Age at Diagnosis of Thyroid Cancer



The table below shows that the majority of respondents were completing the questionnaire 1-5 years after they had been diagnosed:

Table 1: Length of Time Since Diagnosis of Thyroid cancer

Length of time	Frequency	Percent
Less than 1 year	28	10.1
1-5 years	160	58.0
More than 5 years	88	31.9
Total	276	100.0

Respondents were asked why they had approached their doctor initially and gave the following responses (more than one response could be given):

Table 2: Reason for Approaching Doctor

Reason for approaching doctor	Frequency (%)
Noticed lump or swelling in neck	194 (70.3%)
Family member noticed lump or swelling in neck	51 (18.5%)
Difficulty swallowing	49 (17.8%)
Hoarse voice	30 (10.9%)
Difficulty breathing	23 (8.3%)
Imaging check for another reason	15 (5.4%)
Check up (family history or routine)	9 (3.3%)
Other	40 (14.5%)

As the table below shows, just over one half of respondents were seen by a specialist within four weeks of referral:

Table 3: Length of Time Waiting to See a Specialist Once Referred

Length of time	Frequency	Percent
Less than 2 weeks	52	18.8
2 weeks - 4 weeks	94	34.1
4 weeks - 3 months	86	31.2
More than 3 months	31	11.2
I was seen immediately	4	1.4
Don't know	9	3.3
Total	276	100.0

However, in the majority of cases, the first specialist seen was not a thyroid cancer specialist, as is shown below:

Table 4: First Specialist Seen

Specialist	Frequency	Percent
Surgeon (general)	116	42.0
Endocrinologist	36	13.0
Endocrine Surgeon	43	15.6
Head and Neck Surgeon	54	19.6
Vascular Surgeon	4	1.4
Oncologist	6	2.2
Other	17	6.2
Total	276	100.0

The table below indicates that the majority of respondents were diagnosed within four weeks of seeing a specialist:

**Table 5: Time Between Getting Diagnosis and Seeing Specialist**

Length of time	Frequency	Percent
Less than 2 weeks	86	31.2
2 weeks - 4 weeks	106	38.4
More than 4 weeks	73	26.4
Don't know	11	4.0
Total	276	100.0

A small majority of respondents (141 or 51.1%) said that they had been given the diagnosis by a thyroid cancer specialist, rather than another health professional. However, there was some ambiguity in the responses to this question: 119 (43.1%) answered 'other', with common answers being endocrinologist, ENT surgeons and surgeons. The large majority of respondents, 240 or 87%, were told of the diagnosis in person at the hospital.

The most common diagnosis was papillary thyroid cancer, as is shown below:

**Table 6: Type of Thyroid Cancer Diagnosed**

Type	Frequency	Percent
Papillary	144	52.2
Follicular	41	14.9
Mix papillary/follicular types of thyroid cancer	21	7.6
Medullary	17	6.2
Hurthle Cell	9	3.3
Anaplastic	5	1.8
Don't know	31	11.2
Other	8	2.9
Total	276	100.0

### **Patient Support at Diagnosis**

105 of the 276 respondents (38%) were offered additional support at the stage of diagnosis from a specialist. 88 (31.9%) were given details of a patient support organisation. 121 (43.8%) received clear written information about their condition and its treatment.

216 respondents (78.3%) sought information from outside the hospital clinic. The outside sources that were consulted are listed below (more than one could be chosen by each respondent), together with the numbers saying that the source was most helpful:

Table 7: Source of Information and Support Used And Their Helpfulness

Source of information	Number / per cent	Number / per cent saying most helpful
Internet	172 (62.3%)	87 (31.5%)
Pamphlets from thyroid cancer organisations	99 (35.9%)	30 (10.9%)
Patient support organizations	63 (22.8%)	34 (12.3%)
Books about thyroid cancer	60 (21.7%)	7 (2.5%)
Family doctor	55 (19.9%)	13 (4.7%)
Family and friends	52 (18.8%)	7 (2.5%)
Other patients / survivors	46 (16.7%)	17 (6.2%)
Complementary therapy	14 ( 5.1%)	0
Other	21 ( 7.6%)	13 (4.7%)

This suggests that the most helpful forms of additional information were the internet and patient support organisations. Moderately helpful information sources were pamphlets produced by thyroid cancer organisations and other patients / survivors. Unhelpful sources were the family doctor, books, family and friends and complementary therapies.

### **Surgery**

Almost all respondents had experienced neck surgery, with a little more than half having had two surgical procedures, as is shown in the table below:

Table 8: Number of Neck Surgeries for Thyroid Cancer

Number of Surgeries	Frequency	Percent
0	3	1.1
1	98	35.5
2	148	53.6
3	19	6.9
4	7	2.5
5	1	.4
Total	276	100.0

65 respondents (23.6%) did not experience any post surgery complications. The frequency with which specific complications occurred is shown in the table below:

Table 9: Incidence of Post-Surgery Complications

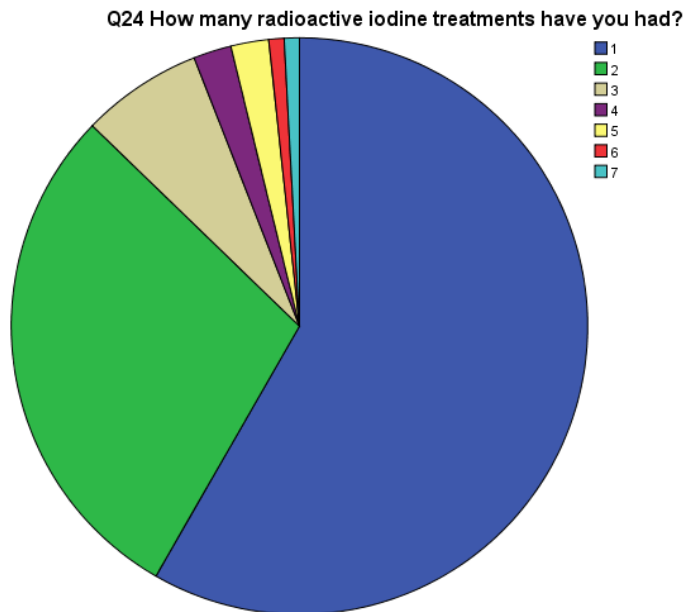
Type of post-surgery complication	Frequency / percentage of respondents experiencing	Number of respondents with problem still unresolved
Voice problems	124 (44.9%)	53 (19.2%)
Low blood calcium levels	122 (44.2%)	46 (16.7%)
Numbness	81 (29.3%)	42 (15.2%)
Restricted neck/shoulder movement	73 (26.4%)	Question not asked
Vocal cord palsy	39 (14.1%)	18 (6.5%)
Infection	20 (7.2%)	3 (1.1%)
Other	41 (14.9%)	18 (6.5%)

So voice problems and low blood calcium levels were the most likely difficulties for respondents to have experienced post-surgery. The number of patients with each type of problem unresolved was largely in proportion to the number who experienced the problem, although numbness was particularly likely to remain unresolved and infection was particularly likely to have been resolved.

**RAI Treatment**

235 (85.1%) of patients had had radioactive iodine treatment. Of these, the majority had just one treatment, as is shown by the chart below:

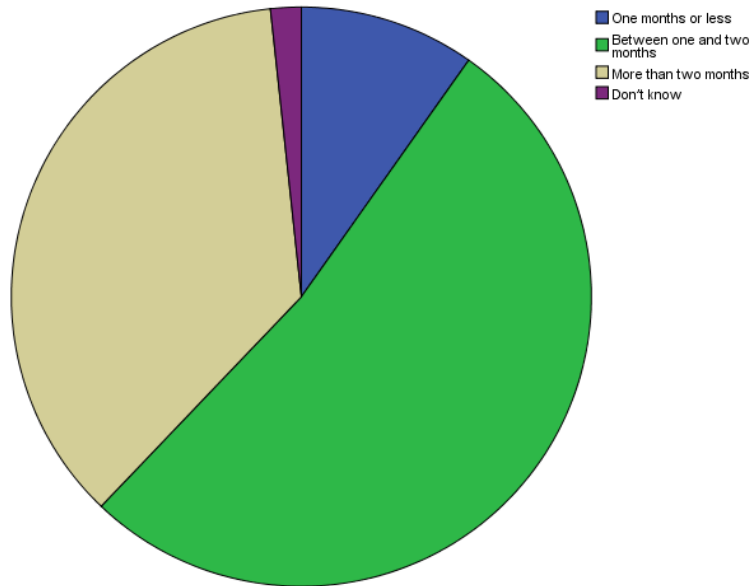
Chart 2: Number of Radioactive Iodine Treatments



The next chart demonstrates that, of those who had had radioactive iodine treatment, the majority had had this treatment between one and two months after surgery:

**Chart 3: Time Between Surgery and First Radioactive Iodine Treatment**

Q25 How long after surgery did you have your first radioactive iodine treatment?



The majority of those who had experienced radioactive iodine treatment, 164 or 69.8%, had stopped taking thyroid hormone replacement in preparation for the treatment. Of the 164 who stated the number of weeks for which they had stopped taking thyroid hormone replacement, three quarters had stopped taking it for three weeks or less. The mean number of weeks for which these patients stopped taking thyroid hormone replacement was 2.78.

58 of the 235 respondents who had radioactive iodine treatment (21.0%) did not experience any side effects of hypothyroidism. The number and percentage of the 235 who had experienced different side effects are shown in the table below:

**Table 10: Incidence of Side Effects of Hypothyroidism**

Side effect	Number / percentage experiencing
Tiredness	157 (56.9%)
Feeling cold	108 (39.1%)
Inability to concentrate / think straight	100 (36.2%)
Weight gain	79 (28.6%)
Constipation	70 (25.4%)
Depression	69 (25.0%)
Prolonged headache	46 (16.7%)
Other	39 (14.1%)

Considering next the time after treatment, 66 of the 235 patients who had experienced radioactive iodine treatment (23.9%) did not experience any side effects in the immediate post-treatment period. The frequency with which different side effects were reported immediately after treatment are shown in the table below:

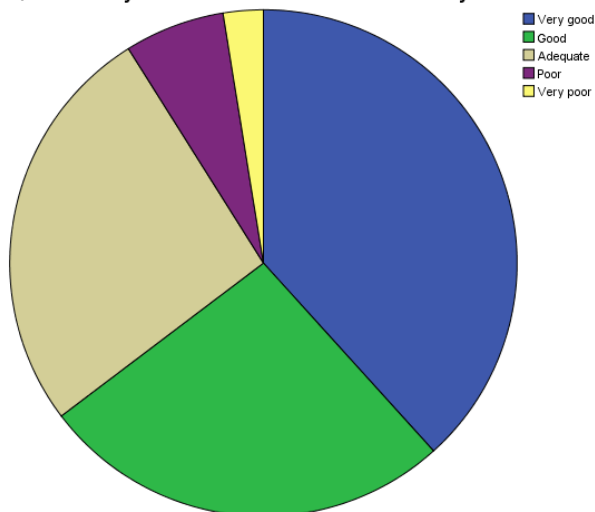
**Table 11: Side Effects Immediately After Radioactive Iodine Treatment**

Side effect	Number / percentage reporting
Taste disturbance	101 (36.6%)
Dry mouth	94 (34.1%)
Parotid gland swelling or pain	65 (23.6%)
Nausea / vomiting	62 (22.5%)
Sore neck	57 (20.7%)
Skin problems	33 (12.0%)
Changes in menstrual cycle	24 (8.7%)
Stomach pain	16 (5.8%)
Dry eyes	13 (4.7%)
Excessive watering of the eyes	12 (4.3%)
Cystitis	10 (3.6%)
Other	34 (12.4%)

Only 8 (2.9%) of the patients who received radioactive iodine treatment did so as an outpatient. Approximately two thirds rated the facilities where the treatment was given as good or very good, as is shown by the chart below:

**Chart 4: Assessment of Facilities**

Q30 How did you find the facilities in the room where your treatment was given?

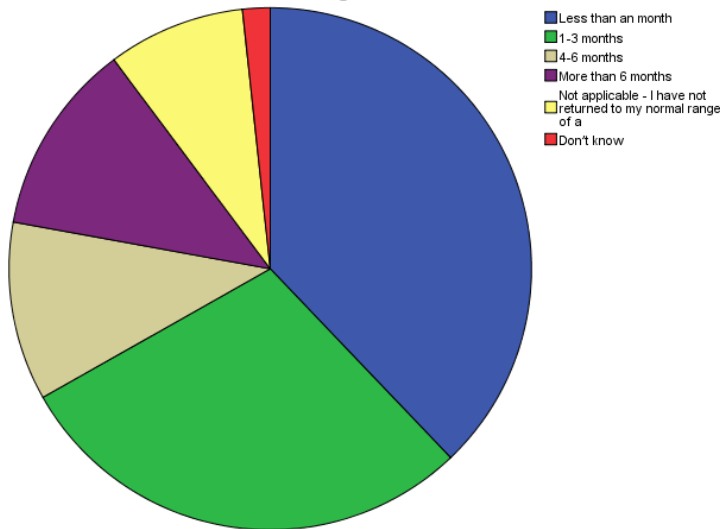


61 (22.1%) of the respondents who had radioactive iodine treatment consulted the family doctor in the period before or after the treatment and 33 (12.0%) required antidepressants during this time.

Approximately two thirds of respondents were able to return to their normal range of activities within three months of radioactive iodine treatment, as is shown by the chart below:

**Chart 5: Length of Time Before Returning to Normal Range of Activities**

Q36 How long after radioactive iodine treatment did you feel able to return to your normal range of activities?



### **Thyrogen v Withdrawal**

100 of the 235 respondents who had radioactive iodine treatment (42.6%) were offered thyrogen instead of withdrawal and 89 of these respondents had the option of thyrogen explained to them. However there was a discrepancy in the data, with 109 patients answering questions about thyrogen treatment. 97 of these respondents said that the costs of thyrogen were covered by the NHS, 10 that they were covered by private medical insurance and two that they paid for thyrogen themselves. One of the respondents who had paid for thyrogen themselves reported that this caused financial difficulties for themselves or their family. Only 21 of these 109 respondents (19.3%) reported side effects, most frequently fatigue, followed by headaches.

Of the 63 patients who had experienced both thyrogen and withdrawal, 56 said that they preferred thyrogen and 7 answered neither.

## Follow-up Regime

253 respondents (91.7%) had T4 as their current replacement hormone regime. The job titles of the staff who were administering this regime to respondents are shown in the table below:

Table 12: Staff Administering Replacement Hormone Regime

Staff	Frequency	Percent
Oncologist	172	62.3
Endocrine surgeon	13	4.7
Endocrinologist	30	10.9
Head and Neck Surgeon	20	7.2
Doctor (not a specialist)	14	5.1
Surgeon (not a thyroid specialist)	3	1.1
Nuclear Physician	6	2.2
Other	18	6.5
Total	276	100.0

The current status of respondents with regard to disease is shown below:

Table 13: Whether Respondents Were Disease Free

Disease free?	Frequency	Percent
Yes	173	62.7
No	42	15.2
Don't know	61	22.1
Total	276	100.0

29 respondents (10.5%) had metastatic disease outside the neck. The methods by which this disease was being managed are shown in the table below:

Table 14: Method of Treatment for Metastatic Disease

Method of treatment	Frequency / percentage of respondents with metastatic disease
Observation	18 (62.1%)
Surgery	14 (48.3%)
Radioactive iodine	10 (34.5%)
Radiotherapy	5 (17.2%)
Other	8 (27.5%)

## **Assessment of Cancer Journey**

Respondents were asked about the most difficult aspect of their cancer journey, with diagnosis being the most frequently identified element:

**Table 15: Most Difficult Aspect of Cancer Journey**

Aspect	Frequency	Percent
Receiving a cancer diagnosis	93	33.7
Lack of information about thyroid cancer and treatment options	21	7.6
Lack of psychological/emotional support	22	8.0
Negative changes in lifestyle	10	3.6
Uncertainty/ anxiety about the future	59	21.4
Side effects of treatment	17	6.2
Effect on relationships	5	1.8
Financial/career worries	10	3.6
How others see me	3	1.1
Other	36	13.0
Total	276	100.0

Respondents were finally asked about anything that the medical care team could have done to improve their cancer journey; there were a number of popular options, as is shown by the table below:

**Table 16: Step that Would Improve Medical Journey**

Step to improve medical journey	Frequency / percentage choosing
More information about the disease	91 (33.0%)
Psychological support	89 (32.2%)
Introduction to patient support groups	86 (31.2%)
Quicker access to test results	81 (29.3%)
Introduction to a fellow patient	72 (26.1%)
Clearer information about treatment options	65 (23.6%)
Access to a specialist / oncology nurse	47 (17.0%)
Easier access to cancer care teams	38 (13.8%)

## **Comparisons Between People Diagnosed at Different Times**

When comparing those respondents who were diagnosed one year ago, 1-5 years ago and more than five years ago, there were few differences in terms of waiting times, the job titles of staff who people met with or post-surgery

symptoms. However, more recently diagnosed patients were more likely to have been offered additional support at the time of diagnosis from a specialist oncology/cancer nurse or other support person: 50% of patients diagnosed within last year said that they had received such an offer, compared to 43.8% of those diagnosed 1-5 years ago and only 23.9% of those diagnosed over five years ago.

Another area where there had been an improvement was the provision of information; recent patients were more likely to say that they had received clear written information about the disease and its treatment:

Table 17: Length of Time Since Treatment by Received Clear Written Information

			Q5 How long is it since your diagnosis of Thyroid Cancer?			Total
			Less than 1 year	1-5 years	More than 5 years	
Q18 At the time of diagnosis were you given clear written information about your disease and its treatment?	Yes	Count % within Q5 How long is it since your diagnosis of Thyroid Cancer?	15 53.6%	76 47.5%	30 34.1%	121 43.8%
	No	Count % within Q5 How long is it since your diagnosis of Thyroid Cancer?	13 46.4%	79 49.4%	53 60.2%	145 52.5%
	Don't know	Count % within Q5 How long is it since your diagnosis of Thyroid Cancer?	0 .0%	5 3.1%	5 5.7%	10 3.6%
Total	Count % within Q5 How long is it since your diagnosis of Thyroid Cancer?	28 100.0%	160 100.0%	88 100.0%	276 100.0%	

Further differences emerged in terms of information about patient support organisations: 50% of patients diagnosed in the previous year said that they had received such information, compared to 36.3% of those diagnosed 1-5 years ago and 18.2% of those diagnosed more than five years ago.

## Comparison Between Respondents Who Took Thyrogen and Others

Another difference examined was between those who took thyrogen and those who did not in terms of how long after radioactive iodine treatment they returned to their normal range of activities. Although those who had took thyrogen were more likely to answer less than one month, the differences were quite small:

Table 18: Whether Took Thyrogen by How Soon Returned to Normal Range of Activities

			did you take thyrogen		Total
			yes	no	
Q36 How long after radioactive iodine treatment did you feel able to return to your normal range of activities?	Less than an month	Count	45	44	89
		% within did you take thyrogen	41.3%	34.9%	37.9%
	1-3 months	Count	30	38	68
		% within did you take thyrogen	27.5%	30.2%	28.9%
	4-6 months	Count	11	15	26
		% within did you take thyrogen	10.1%	11.9%	11.1%
	More than 6 months	Count	14	14	28
	% within did you take thyrogen	12.8%	11.1%	11.9%	
Not applicable - I have not returned to my normal range of a	Count	9	11	20	
	% within did you take thyrogen	8.3%	8.7%	8.5%	
Don't know	Count	0	4	4	
	% within did you take thyrogen	.0%	3.2%	1.7%	
Total	Count	109	126	235	
	% within did you take thyrogen	100.0%	100.0%	100.0%	