International Thyroid Cancer Patient Survey 2010

www.thyroid-cancer-alliance.org

(Update: October 27, 2010)
Contents

1. Introduction and Objectives
2. Methods
3. Results and Discussion
4. Patient Profiles
5. Diagnosis of Thyroid Cancer
6. Patient Support at Diagnosis
7. Surgery
8. RAI Treatment
9. Follow-Up Regime
10. Assessment of Cancer Journey
11. Index - Questions
1. Introduction and Objectives

Published studies on the thyroid cancer patient journey generally have utilised physician- or nurse-designed rather than patient-designed survey instruments.

Frequently, these studies’ samples have been relatively small, and have comprised only referral centre patients. Moreover, the studies often have focused on particular thyroid cancers and on relatively narrow areas rather than on a broader range of the patient experience.

The Thyroid Cancer Alliance (TCA; www.thyroid-cancer-alliance.org), a coalition of eight national thyroid cancer patient advocacy and support organisations from Europe and the Americas, has sought to address these gaps. We therefore, in cooperation with Genzyme Corporation,

conducted an international survey of patients with any primary thyroid tumour regarding their experiences with their disease and its care, including both treatment and support.

The survey utilised a questionnaire designed by patients with the support of a professional market research firm.
1. Introduction and Objectives

This project’s objectives included:

• Identifying areas for improvement in the care of patients with thyroid cancer
• Elucidating how thyroid cancers have been treated in different nations in recent years, and how treatment protocols differ from country to country
• Assessing the life impacts of a thyroid cancer diagnosis from a wide range of patients.

The TCA will use the survey findings to stimulate further research and to educate the thyroid cancer community, including patients, families, caregivers and administrators.
2. Methods

Assisted by a professional market research firm, representatives of several TCA member organisations designed an anonymous 43-item self-report questionnaire that elicited categorical or quantitative data and took approximately 10 min to complete.

The instrument was developed in English and was translated into French, German and Spanish.

The questionnaire was posted online on a dedicated website, which was linked on the TCA organisations’ websites. TCA organisation members then were invited via e-mail, website notices or both to complete the survey.

Additionally, the questionnaire was administered in person to patients at one thyroid cancer clinic each in the UK and Italy, and was sent by post to patients followed at another UK clinic.

A professional market research firm assisted with data collection and analysis. Data were collected in March 2010. Only fully completed surveys were analysed.
3. Results and Discussion

Respondent characteristics
In total, 2398 people completed the questionnaire, including 2195 (91.5%) online and 203 (8.5%) at the clinics or via postal response. Nearly 90% of respondents were female and nearly 90% had differentiated thyroid carcinoma. Diagnosis occurred at ages 30-59 years in 57.1% of respondents, and <1 (1-5) year(s) before survey completion in 16.4% (55.0%).

First specialist visit frequently delayed
Twenty-seven percent of respondents reported a ≥4-week wait from the time of the referral until their first specialist visit, a situation that was especially common among French, British and Canadian respondents (Q7).
3. Results and Discussion

Support and information gap

The vast majority of respondents were not offered additional support from an oncology nurse or other support specialist, psychological support, or details of a patient organisation (Q15). Additionally, almost 2/3 of respondents reported not receiving clear written information about their disease and its treatment. Disease information, treatment information, psychological support, and introductions to patient support groups or fellow patients comprised the five most commonly suggested areas for improvement in care by survey respondents (Q43).
A little over 54% of respondents reported a single neck surgery for thyroid cancer, and 45.1% reported two or more such procedures. Post-surgery problems were frequent, with several symptoms reported by more than a quarter of respondents undergoing a neck operation (n = 2380) (Slide **). At least some post-surgery symptoms remained unresolved in 1010 respondents, which corresponded to 57.9% of those noting such symptoms (n = 1743) and 42.4% of those undergoing neck operations for thyroid cancer (n = 2380). Several of the symptoms, namely, low blood calcium levels (parathyroid), voice problems, numbness, and restricted neck/shoulder movement, persisted in more than one third of affected respondents (Slide **). The survey did not elicit the time since surgery; however, the mean time since diagnosis was 5.1 years.
4. Patient Profiles

1. Introduction and Objectives
2. Methods
3. Results and Discussion
4. Patient Profiles
5. Diagnosis of Thyroid Cancer
6. Patient Support at Diagnosis
7. Surgery
8. RAI Treatment
9. Follow-Up Regime
10. Assessment of Cancer Journey
11. Index - Questions
4. Patient Profiles

Which country do you live in? (Q1; n = 2398)

Others = 35 Countries: Italy 44 (1.8%), Argentina 36 (1.5%)
87.2% (2091) are female (Q2)
Two-thirds of patients reported being diagnosed with papillary thyroid cancer

- Papillary: 65%
- Mix papillary/ follicular types: 12%
- Follicular: 9%
- Medullary: 4%
- Hurthle Cell: 2%
- Anaplastic: 2%
- Other: 3%
- Don't know: 5%

Of those with medullary thyroid cancer, a quarter stated it was familial

- Yes: 7%
- No: 24%
- Don't know: 69%

Q14 What type of thyroid cancer were you diagnosed with?

Base: All respondents
(N=2,398)

Q14a Was this a familial/ genetic type?

Base: (N=105)
4. History of Diagnosis

The average age at diagnosis was 38.4 years

Patients were diagnosed on average 5.1 years ago

Q4 How old were you when you were diagnosed with Thyroid Cancer?

Q5 How long is it since your diagnosis of Thyroid Cancer?

Base: All respondents (N=2,398)
4. Disease Status

57% of patients reported they were currently disease-free

Q39 Are you currently disease free?

Base: All respondents (N=2,398)

*excludes 194 patients with other/don’t know cancers
4. Genetic Profile

Just over 1 in 10 patients reported a family history of Thyroid Cancer: Papillary 13%, Medullary 15% (Q3)

Base: All respondents (N=2,398)
5. Diagnosis of Thyroid Cancer

1. Introduction and Objectives
2. Methods
3. Results and Discussion
4. Patient Profiles
5. Diagnosis of Thyroid Cancer
6. Patient Support at Diagnosis
7. Surgery
8. RAI Treatment
9. Follow-Up Regime
10. Assessment of Cancer Journey
11. Index - Questions
### 5. Initial Consultation

**39% of patients noticed a lump themselves**

<table>
<thead>
<tr>
<th>Reason</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Noticed a lump</td>
<td>39%</td>
</tr>
<tr>
<td>Routine check-up</td>
<td>25%</td>
</tr>
<tr>
<td>Difficulty swallowing</td>
<td>15%</td>
</tr>
<tr>
<td>Imaging test for other reason</td>
<td>12%</td>
</tr>
<tr>
<td>Family member noticed lump</td>
<td>9%</td>
</tr>
<tr>
<td>Hoarse voice</td>
<td>9%</td>
</tr>
<tr>
<td>Difficulty breathing</td>
<td>7%</td>
</tr>
</tbody>
</table>

**Q6 What led you to see your Doctor initially?**

- Noted a lump: 39%
- Routine check-up: 25%
- Difficulty swallowing: 15%
- Imaging test for other reason: 12%
- Family member noticed lump: 9%
- Hoarse voice: 9%
- Difficulty breathing: 7%

### An endocrinologist was the first specialist seen for over a third of patients

<table>
<thead>
<tr>
<th>Specialist</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Endocrinologist</td>
<td>34%</td>
</tr>
<tr>
<td>Head &amp; Neck Surgeon</td>
<td>19%</td>
</tr>
<tr>
<td>Surgeon (general)</td>
<td>19%</td>
</tr>
<tr>
<td>Nuclear Medicine Specialist</td>
<td>11%</td>
</tr>
<tr>
<td>Endocrine Surgeon</td>
<td>6%</td>
</tr>
<tr>
<td>Oncologist</td>
<td>2%</td>
</tr>
<tr>
<td>Vascular Surgeon</td>
<td>1%</td>
</tr>
<tr>
<td>Other</td>
<td>9%</td>
</tr>
</tbody>
</table>

**Q8 Who was the first Thyroid Specialist that you saw when you were suspected of having Thyroid Cancer?**

*Base: All respondents (N=2,398)*
5. Initial Consultation

An endocrinologist was the first specialist seen for over a third of patients, but there are great national differences:

Q8 Who was the first Thyroid Specialist that you saw when you were suspected of having Thyroid Cancer?

Base: All respondents
(N=2,398)
Q7: How long did you wait to be seen by a thyroid specialist once you were referred?

27% (599) have to wait more than 4 weeks

Base: All respondents (N=2,398)
5. Diagnosis of Thyroid Cancer

Q7: How long did you wait to be seen by a thyroid specialist once you were referred?

27% (599) have to wait more than 4 weeks

Proportion of respondents who waited >4 weeks from referral to the first specialist
5. Diagnostic Tests

Q9 Which tests did you have done to evaluate your thyroid lump before you were diagnosed with thyroid cancer?

*99TC-Scan was not asked. In the ATA-Guidelines 99TC-Scan is only recomended if TSH is low . Cooper 2009, p 1172
5. Time to Diagnosis

Q10 Did you have surgery to gain your diagnosis?

Base: All respondents (N=2,398)
5. Time to Diagnosis

Q11 How long did you wait from seeing your specialist to getting your diagnosis?

Q10 No surgery to get diagnosis (n = 808)

Surgery to get diagnosis (n = 1535)
6. Patient Support at Diagnosis

1. Introduction and Objectives
2. Methods
3. Results and Discussion
4. Patient Profiles
5. Diagnosis of Thyroid Cancer
6. Patient Support at Diagnosis
7. Surgery
8. RAI Treatment
9. Follow-Up Regime
10. Assessment of Cancer Journey
6. Patient Support at Diagnosis

Three-quarters of patients were not offered additional support from a nurse or other support person

93% stated they were not offered psychological support

Q15 Were you offered any additional support at the stage of diagnosis from a specialist oncology/cancer nurse or other support person?

Q17 Were you offered psychological support from a psychologist/counsellor at the stage of diagnosis?

Base: All respondents (N=2,398)
6. Information at Diagnosis

Over 4 in 5 patients were not given details of a patient support organisation.

Almost two-thirds of patients were not given clear written information about their disease and its treatment.

Q16 Were you given details of a patient support organisation’s details at the stage of diagnosis?

Q18 At the time of diagnosis were you given clear written information about your disease and its treatment?

Base: All respondents (N=2,398)
6. Sources of Information/Support

Most patients sought information on their condition from outside sources

- 86% Yes
- 14% No

9 in 10 sought information from the internet; half said it was the most widely used source

- Internet: 88%
- Pamphlets: 42%
- Patient Support Orgs.: 31%
- Books: 30%
- Family doctor: 28%
- Other patients: 28%
- Family/ friends: 26%
- Complementary therapy: 7%
- Other: 11%

Q19 Did you seek information/support from outside the hospital clinic at any point after you were diagnosed?

Q19a Please could you say where you sought information or support?

Q19b Which of these information sources did you find most beneficial to you personally?

Base: All respondents
(N=2,398)

Base: All respondents who sought information (N=2,047)
6. Improvements suggested

Q43 What, if anything, could your medical team have done to improve this?

- **More information about disease:** 45%
- **Introduction to patient support groups:** 43%
- **Psychological support:** 43%
- **Clear information about treatment options:** 34%
- **Introduction to a fellow patient:** 27%
- **Quicker access to test results:** 24%
- **Access to a specialist/oncology nurse:** 17%
- **Easier access to cancer care teams:** 16%
- **Other:** 22%

*Base: All respondents (N=2,398)*
7. Surgery

1. Introduction and Objectives
2. Methods
3. Results and Discussion
4. Patient Profiles
5. Diagnosis of Thyroid Cancer
6. Patient Support at Diagnosis
7. Surgery
8. RAI Treatment
9. Follow-Up Regime
10. Assessment of Cancer Journey
11. Index - Questions
Q20 How many neck surgeries have you had for thyroid cancer? (Diagnosis less than 1 year; n = 385)

- **Total**: 3% >=3, 27% 2, 70% 1
- **US**: 25% >=3, 74% 2, 7% 1
- **Canada**: 20% >=3, 77% 2, 3% 1
- **Germany**: 9% >=3, 42% 2, 48% 1
- **France**: 14% >=3, 83% 2, 7% 1

n 385* 167 44 66 36

(*9 respondents without surgery are not included; UK and each other country n < 30)
7. Numbers of Surgery

Q20 How many neck surgeries have you had for thyroid cancer? (Diagnosis 1 - 5 years; n = 1.311)

(*7 respondents without surgery are not included)
7. Numbers of Surgery

Q20  How many neck surgeries have you had for thyroid cancer?  
(Diagnosis  > 5 years; n = 684)

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>US</th>
<th>Canada</th>
<th>Germany</th>
<th>France</th>
<th>UK</th>
</tr>
</thead>
<tbody>
<tr>
<td>&gt;=5</td>
<td>2,9%</td>
<td>42,7%</td>
<td>36,4%</td>
<td>6,4%</td>
<td>9,9%</td>
<td>13,6%</td>
</tr>
<tr>
<td>4</td>
<td>2,9%</td>
<td>34,3%</td>
<td>53,0%</td>
<td>59,6%</td>
<td>31,0%</td>
<td>51,1%</td>
</tr>
<tr>
<td>3</td>
<td>42,7%</td>
<td>44,0%</td>
<td>50,4%</td>
<td>42,7%</td>
<td>42,7%</td>
<td>42,7%</td>
</tr>
<tr>
<td>2</td>
<td>29,5%</td>
<td>29,5%</td>
<td>29,5%</td>
<td>29,5%</td>
<td>29,5%</td>
<td>29,5%</td>
</tr>
<tr>
<td>1</td>
<td>15,6%</td>
<td>15,6%</td>
<td>15,6%</td>
<td>15,6%</td>
<td>15,6%</td>
<td>15,6%</td>
</tr>
</tbody>
</table>

|        | n     | 684 *  | 248    | 66      | 156    | 71     |

(*2 respondents without surgery are not included)
39% of patients experienced low blood calcium levels and 36% experienced voice problems following surgery.

Q21 Please could you indicate if you experienced any of the following post-surgery complications?

- Low blood calcium levels (parathyroid): 39%
- Voice problems: 36%
- Numbness: 28%
- Restricted neck/shoulder movement: 28%
- Vocal cord palsy: 11%
- Infection: 3%
- Other: 18%

(Base: N=2,380)
7. Unresolved Complications

Respondents with surgery and with time since diagnosis more than 1 year (n=1,995). Percentage with still unresolved complications (dark blue).

- Low blood calcium levels (parathyroid): 14% unresolved, 39% total
- Voice problems: 13% unresolved, 36% total
- Numbness: 13% unresolved, 29% total
- Restricted neck/shoulder movement: 10% unresolved, 27% total
- Vocal cord palsy: 5% unresolved, 12% total
- Infection: 3% unresolved
- Other: 9% unresolved, 17% total

Base: All whose diagnosis more than 1 year and surgery (N=1,995)

Q22a Which of your post surgery complications have not been resolved yet?
7. Unresolved Complications

Respondents with surgery and with time since diagnosis more than 1 year (n=1,995). Percentage with still low blood calcium levels.

**Base:** All whose diagnosis more than 1 year and surgery (N=1,995)

Q22a Which of your post surgery complications have not been resolved yet?
8. RAI Treatment

1. Introduction and Objectives
2. Methods
3. Results and Discussion
4. Patient Profiles
5. Diagnosis of Thyroid Cancer
6. Patient Support at Diagnosis
7. Surgery
8. RAI Treatment
9. Follow-Up Regime
10. Assessment of Cancer Journey
11. Index - Questions
84% of patients had undergone radioactive iodine treatment. More than half had received one treatment.

Q23 Have you had radioactive iodine treatment?

Base: All respondents (N=2,398)

88% of patients had undergone radioactive iodine treatment. More than half had received one treatment.

Papillary (1558) 88%
Follicular (209) 92%
Mixed (281) 90%
Hurthle Cell (40) 89%
Medullary (105) 9%
Anaplastic (11) 82%

% who have had RAI by cancer type

*excludes 194 patients with other/don’t know cancers
8. RAI Treatment

Almost half of patients had their first RAI treatment 1-2 months after surgery.

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

<table>
<thead>
<tr>
<th>Time Interval</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>One month or less</td>
<td>22%</td>
</tr>
<tr>
<td>Between one and two months</td>
<td>48%</td>
</tr>
<tr>
<td>More than two months</td>
<td>28%</td>
</tr>
<tr>
<td>Don’t know</td>
<td>2%</td>
</tr>
</tbody>
</table>

Proportion of respondents who waited >2 months for RAI for each country:

- **US**: 28%
- **Canada**: 58%
- **Germany**: 9%
- **France**: 33%
- **UK**: 36%

*Base: All who had radioactive iodine treatment (N=2,011)*
8. RAI Treatment

Two-thirds of patients received RAI as an inpatient

On average, one third received RAI as an outpatient

Q29 Was your treatment given…?

Base: All who had radioactive iodine treatment

*excludes countries with <37 patients

In Argentina (35) 91% of patients received RAI as an outpatient
8. RAI Treatment

62% of patients judged the treatment facilities as good or very good

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

Base: All who had radioactive iodine treatment (N=2,011)
8. RAI Treatment

Q24 How many radioactive iodine treatments have you had?

* In the question was no differentiation between RAI in a treatment dose and RAI in a test or scanning dose

Base: All with time since diagnosis less than 1 year and who had radioactive iodine treatment (N=270, US 177, Germany 55, each other country <30)
Q24 How many radioactive iodine treatments have you had?

* In the question was no differentiation between RAI in a treatment dose and RAI in a test or scanning dose

Base: All with time since diagnosis 1-5 years and who had radioactive iodine treatment (N=1,140, US 433, Canada 143, Germany 238, France 92, UK 145)
8. RAI Treatment

Q24 How many radioactive iodine treatments have you had?

* In the question was no differentiation between RAI in a treatment dose and RAI in a test or scanning dose

Base: All with time since diagnosis more than 5 years and who had radioactive iodine treatment (N=599, US 221, Canada 59, Germany 132, France 61, UK 74)
8. Side Effects of Withdrawal

97% of patients experienced one or more symptoms of hypothyroidism when thyroid hormone replacement was stopped.

- Tiredness: 94%
- Inability to concentrate/think straight: 72%
- Feeling cold: 63%
- Weight gain: 56%
- Depression: 51%
- Constipation: 40%
- Prolonged headache: 24%
- I did not experience any symptoms of hypothyroidism: 3%
- Other: 21%

Q27: Did you experience any symptoms of hypothyroidism when you stopped thyroid hormone replacement?

Base: All with withdrawal (N=1,621)
### 8. Side Effects of rhTSH

22% of patients who had rhTSH experienced side effects

- 13% reported experiencing fatigue
- 12% reported a headache

**Q34** If you had rhTSH (Thyrogen) did you experience any side effects?

**Q34a** Please could you say what these side effects were?

**Base: All who had rhTSH (N=995)**
8. Side Effects of RAI Treatment

82% of patients who underwent radioactive iodine treatment with withdrawal experienced one or more side effects.

- Taste disturbance: 45%
- Dry mouth: 45%
- Salivary gland/parotid gland swelling or pain: 35%
- Nausea/vomiting: 33%
- Sore neck: 24%
- Changes in menstrual cycle (only women): 17%
- Skin problems: 16%
- Stomach pain: 14%
- Dry eyes: 13%
- Excessive watering of the eyes: 6%
- Red eyes: 5%
- Burning nasal passages: 5%
- Blocked tear duct: 4%

*Base: All who had radioactive iodine treatment with withdrawal (N=1,621)*
8. Side Effects of RAI Treatment

Less side effects of RAI Treatment with rhTSH.
27% of the respondents have no side effects (vs. 18% withdrawal) (*)

<table>
<thead>
<tr>
<th>Side Effect</th>
<th>Base: All who had radioactive iodine treatment with withdrawal (N= 1,621)</th>
<th>With rhTSH (N=390)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Taste disturbance</td>
<td>36%</td>
<td>45%</td>
</tr>
<tr>
<td>Dry mouth</td>
<td>34%</td>
<td>45%</td>
</tr>
<tr>
<td>Salivary gland/parotid gland swelling or pain</td>
<td>30%</td>
<td>35%</td>
</tr>
<tr>
<td>Nausea/vomiting</td>
<td>24%</td>
<td>33%</td>
</tr>
<tr>
<td>Sore neck</td>
<td>24%</td>
<td>24%</td>
</tr>
<tr>
<td>Changes in menstrual cycle (only women)</td>
<td>8%</td>
<td>17%</td>
</tr>
<tr>
<td>Skin problems</td>
<td>9%</td>
<td>16%</td>
</tr>
<tr>
<td>Stomach pain</td>
<td>8%</td>
<td>14%</td>
</tr>
<tr>
<td>Dry eyes</td>
<td>7%</td>
<td>13%</td>
</tr>
<tr>
<td>Excessive watering of the eyes</td>
<td>3%</td>
<td>6%</td>
</tr>
<tr>
<td>Red eyes</td>
<td>3%</td>
<td>5%</td>
</tr>
<tr>
<td>Burning nasal passages</td>
<td>4%</td>
<td>5%</td>
</tr>
<tr>
<td>Blocked tear duct</td>
<td>3%</td>
<td>4%</td>
</tr>
</tbody>
</table>

*Respondents with rhTSH have less numbers of RAI than with withdrawal, so this statistical effect could be also an effect of the numbers and kind of RAI
**The base of percentage of changes in menstrual cycle are women and men.
8. Side Effects of RAI Treatment

Less side effects of RAI Treatment in France (?)

Base: All who had radioactive iodine treatment (N=2,011)
8. Recovery after RAI Treatment

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

* **% of the respondents with rhTSH have also expierence with withdrawal, so the data for only rhTSH should be much better.

Base: All who had radioactive iodine treatment and time since diagnosis more than 1 year: withdrawal (N=1,455) rhTSH (N=295)
8. Treatment with rhTSH

37% of patients were offered rhTSH instead of withdrawal

Q33 Did your Thyroid Specialist offer rhTSH instead of withdrawal from thyroid hormone?

Base: All who had radioactive iodine treatment (N=2,011)
8. Treatment with rhTSH

Q33 Did your Thyroid Specialist offer rhTSH instead of withdrawal from thyroid hormone?

**Base:** All who had radioactive iodine treatment \( (N=2,011) \)

<table>
<thead>
<tr>
<th>Time since diagnosis</th>
<th>Total</th>
<th>US</th>
<th>Canada</th>
<th>Germany</th>
<th>France</th>
<th>UK</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 1 year</td>
<td>41%</td>
<td>42%</td>
<td>50%</td>
<td>47%</td>
<td>50%</td>
<td></td>
</tr>
<tr>
<td>1-5 years</td>
<td>42%</td>
<td>38%</td>
<td>37%</td>
<td>47%</td>
<td>50%</td>
<td>48%</td>
</tr>
<tr>
<td>More than 5 years</td>
<td>27%</td>
<td>20%</td>
<td>32%</td>
<td>27%</td>
<td>34%</td>
<td>31%</td>
</tr>
</tbody>
</table>
8. Treatment with rhTSH

Over 9 in 10 of those who were offered rhTSH said that the option was explained to them

Q33a Was the option of rhTSH explained to you?

Base: All who were offered rh TSH (N=752)
8. Treatment with rhTSH

Just under 1 in 10 patients had to pay for rhTSH themselves

Q34b Please could you say who covered the costs for your treatment with Thyrogen?

Base: All who received rhTSH (Thyrogen) (N=995)
8. Treatment with rhTSH

Just under a half of those who paid for rhTSH themselves were placed under financial difficulty.

Q34c Did this place you and/or your family under financial difficulty?

Base: All who had to pay for Thyrogen themselves (N=73)
8. Treatment with rhTSH

87% of those who had experienced both rhTSH and withdrawal preferred rhTSH

Q35 If you have experienced both rhTSH (Thyrogen) and withdrawal, please could you say which you preferred?

Base: All who experienced both rhTSH and withdrawal (N=915)
9. Follow-Up Regime

1. Introduction and Objectives
2. Methods
3. Results and Discussion
4. Patient Profiles
5. Diagnosis of Thyroid Cancer
6. Patient Support at Diagnosis
7. Surgery
8. RAI Treatment
9. Follow-Up Regime
10. Assessment of Cancer Journey
11. Index - Questions
9. Currently Responsible

Q38 Who is currently responsible for your care?

Base: All respondents (N=2,398)
84% of patients were currently on T4 replacement

Q37 What is your current replacement hormone regime?

Base: All respondents (N=2,398)
9. Treatment Centre

A quarter of patients had changed hospitals/centres

Q38b If you have changed hospitals/centres, please could you indicate the reason for this?

 Moved house: 28%
 Dissatisfied with care: 21%
 Needed more specialised care: 16%
 To access RAI/thyrogen: 8%
 Convenience/closer to home: 5%
 Insurance reasons: 4%
 To stay with same doctor: 3%
 For operation: 2%
 Other: 11%

Base: All respondents (N=2,398)
Base: All who changed hospitals/centres (N=575)
9. Disease Status

57% of patients reported they were currently disease-free

Q39 Are you currently disease free?

Base: All respondents (N=2,398)

*excludes 194 patients with other/don't know cancers

% disease-free by time since diagnosis

- Less than 1 year (394): 34%
- 1 – 5 years (1318): 62%
- More than 5 years (686): 64%

% disease-free by cancer type

- Papillary (1558): 59%
- Follicular (209): 58%
- Mixed (281): 62%
- Hurthle Cell (40): 55%
- Medullary (105): 28%
- Anaplastic (11): 18%
9. Disease Status

14% of patients had metastatic disease

Q40 Do you have any metastatic disease outside the neck?

Base: All respondents (N=2,398)

Observation was the commonest method of management

Q40a How is this being managed?

Base: All with metastatic disease (N=338)
10. Assessment of Cancer Journey

1. Introduction and Objectives
2. Methods
3. Results and Discussion
4. Patient Profiles
5. Diagnosis of Thyroid Cancer
6. Patient Support at Diagnosis
7. Surgery
8. RAI Treatment
9. Follow-Up Regime
10. Assessment of Cancer Journey
11. Index - Questions
Receiving a cancer diagnosis and uncertainty/anxiety about the future were the most difficult aspects for one fifth of patients.

Q42 Overall what would you say was the most difficult aspect of your cancer journey?

*Base: All respondents (N=2,398)*
10. Assessment of Cancer Journey

Just under half of patients stated that more information about their disease could have improved their cancer journey.

- More information about the disease: 45%
- Psychological support: 43%
- Introduction to patient support groups: 42%
- Clear information about treatment options: 34%
- Introduction to a fellow patient: 27%
- Quicker access to test results: 24%
- Access to a specialist/ oncology nurse: 17%
- Easier access to your cancer care teams: 16%
- Other: 22%

Q43 What, if anything, could your medical team have done to improve this?

Base: All respondents (N=2,398)
10. Introduction to patient support groups

Q43 What, if anything, could your medical team have done to improve this?

Answer: Introduction to patient support groups

Base: All respondents (N=2,398)
10. Given information about patient support groups

Q43 Given information about patient support groups at the stage of diagnosis?

Base: All respondents (N=2,398)
10. Given information about patient support groups

Q43 Given information about patient support groups at the stage of diagnosis? In the last years only a little improvement.

Base: All respondents (N=2,398)
11. Index - Questions

1. Introduction and Objectives
2. Methods
3. Results and Discussion
4. Patient Profiles
5. Diagnosis of Thyroid Cancer
6. Patient Support at Diagnosis
7. Surgery
8. RAI Treatment
9. Follow-Up Regime
10. Assessment of Cancer Journey
11. Index - Questions
11. Index - Questions

Question

Q1 Which country do you live in?
Q2 Are you female ...
Q3 Do you have a family history of Thyroid Cancer?
   Q3A Have you had any genetic testing done for thyroid cancer?
   Q3B Has one or more of your blood relatives (family members) had genetic testing done for thyroid cancer?
Q4 How old were you when you were diagnosed with Thyroid Cancer?
Q5 How long is it since your diagnosis of Thyroid Cancer?
Q6 What led you to see your Doctor initially?
Q7 How long did you wait to be seen by a Thyroid Specialist once you were referred?
Q8 Who was the first Thyroid Specialist that you saw when you were suspected of having Thyroid Cancer?
Q9 Which tests did you have done to evaluate your thyroid lump before you were diagnosed with thyroid cancer?
Q10 Did you have surgery to gain your diagnosis?
Q11 How long did you wait from seeing your specialist to getting your diagnosis?
Q11A Please would you say exactly how long you waited?
Q12 Who told you that you had thyroid cancer?
Q13 How was the diagnosis given?
Q14 What type of thyroid cancer were you diagnosed with?
Q14A Was this a familial/genetic type?
Q15 Were you offered any additional support at the stage of diagnosis from a specialist oncology/ cancer nurse or other support person?
Q16 Were you given details of a patient support organisation’s details at the stage of diagnosis?
Q17 Were you offered psychological support from a psychologist/ counsellor at the stage of diagnosis?
Q18 At the time of diagnosis were you given clear written information about your disease and its treatment?
Q19 Did you seek information/ support from outside the hospital clinic at any point after you were diagnosed?
Q19A Please could you say where you sought information or support?
Q19B Which of these information sources did you find most beneficial to you personally?
11. Index - Questions

Q20 How many neck surgeries have you had for thyroid cancer?
Q21 Please could you indicate if you experienced any of the following post surgery complications?
Q22 Have these post surgery complications now been resolved?
Q22A Which of your post surgery complications have not been resolved yet?
Q23 Have you had radioactive iodine treatment?
Q24 How many radioactive iodine treatments have you had?
Q25 How long after surgery did you have your first radioactive iodine treatment?
Q25A Please would you say how long it was before you had radioactive iodine treatment after your first Thyroid Cancer surgery?
Q26 Did you stop taking all thyroid hormone replacement in preparation for your radioactive iodine treatment?
Q26A Please would you say how many weeks you stopped taking all thyroid hormone replacement?
Q27 Did you experience any symptoms of hypothyroidism when you stopped thyroid hormone replacement?
Q28 Did you experience any side effects immediately following RAI treatment?
Q29 Was your treatment given as an inpatient or outpatient?
11. Index - Questions

Q30 How did you find the facilities in the room where your treatment was given?
Q31 Did you seek help from your family doctor/physician during the period before and/or after treatment?
Q32 Did you require antidepressants and/or sleeping tablets during this time?
Q33 Did your Thyroid Specialist offer rhTSH instead of withdrawal from thyroid hormone?
Q33A Was the option of rhTSH explained to you?
Q34 If you had rhTSH did you experience any side effects?
Q34A Please could you say what these side effects were?
Q34B Please could you say who covered the costs for your treatment with rhTSH?
Q34C Did this place you and/or your family under financial difficulty?
Q35 If you have experienced both rhTSH and withdrawal, please could you say which you preferred?
Q36 How long after radioactive iodine treatment did you feel able to return to your normal range of activities?
Q37 What is your current replacement hormone regime?
Q38 Who is currently responsible for your care?
Q38b If you have changed hospitals/centres, please could you indicate the reason for this?
Q39 Are you currently disease free?
Q40 Do you have any metastatic disease outside the neck?
Q40 A How is this being managed?
Q41 Have you been given access to a clinical trial or ‘off label’ drugs?
Q41 A Could you tell us which one?
Q42 Overall what would you say was the most difficult aspect of your cancer journey?
Q43 What, if anything, could your medical team have done to improve this?

www.thyroid-cancer-alliance.org

(Update: October 27, 2010)