Peninsula Cancer Alliance

Meeting of the PCA Endocrine and Thyroid Site Specific Group

15th September 2017; 10:00-12:50

Lifton Farm Shop (Strawberry Fields Conference Room), Lifton, PL16 0DE

FREEDOM OF INFORMATION

This group will observe the requirements of the Freedom of Information Act (2000) which allows a general right of access to recorded information including minutes of meetings, subject to specific exemptions. No one present today had any objections to their names being distributed in the minutes.

Draft Notes

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Reference	
1.0	Welcome and introductions.
	Please refer to separate record of attendees/apologies here.
2.0	**Patient Experience**
2.1	It was noted that that the National Cancer Patient Experience Survey (NCPES) does not differentiate between Thyroid and Head and Neck Patients. It was acknowledge that the needs of these patients are very different and it would be helpful to understand the experiences of Thyroid specific patients.
2.2	It was suggested that undertaking a patient experience survey at local level may be a good way of capturing thyroid patient experiences.
2.3	**Action**:
2.4	The group will establish a patient satisfaction survey specifically for thyroid patients; this will be shared across the Peninsula Trusts.
2.5	Nina Kamalarajan (NK) to liaise with Tass Malik (TM) and Steph Murgatroyd (SM) to initiate development of the Peninsula wide survey.
3.0	**Attendance at/Structure of SSG Meetings**
3.1	Concern was raised as to the balance of clinicians attending the SSG meeting; it was noted that the majority of attendees are thyroid specialists and that there were few endocrine representatives. This group focuses on Thyroid and Parathyroid pathology, whereas other endocrine malignancies are discussed in the Neurology/ neuroendocrine MDTs.
3.2	Tass Malik (current SSG Chair) confirmed that he is happy to continue in his role as chair, however, he will stand down should any nominees for a new chair be forthcoming.
4.0	**Clinical Guidelines**
4.1	No specific changes highlighted.

4.2 Reference was made to; 1. British Thyroid Association Guidelines for the Management of Thyroid Cancer (2014) (available here). 2. UK Multidisciplinary Head and Neck Guidelines, 5th Edition, 2016, pp S150- 160: Management of Thyroid Cancer.

4.3 Pathology

4.4 Changes to the classification of TNM staging were briefly raised (refer to section 5.0). It was noted that the Royal College of Pathologists have issued an addendum regarding reclassification.

4.5 No new guidelines for reporting of histology.

4.6 Radiology

4.7 The TIRAD system of reporting is generally not being utilised; it was suggested that reference should be made to the BTA classification instead.

5.0 **Updated AJCC/TNM Staging system for differentiated and anaplastic thyroid cancer-**Presented by Tass Malik.

5.1 Discussion: It was noted that there is lack of clarity as to the date when the changes to TNM staging will be implemented in the UK and that there will be a period of time where people are using different staging classifications

6.0 **Patient Pathways**

6.1 A number of issues were raised:

6.2 Discussion is required as to the management of U3 nodules and how these are classified.

6.3 The Thyroid MDT for Taunton is held in Exeter-this meeting is attended by 2 thyroid surgeons from Taunton on alternate weeks.

6.4 It was suggested that the focus of a future audit could be to look at the correlation between radiology, FNA and subsequent histology results. This is a RCPath recommended audit (Details from TM).

6.5 There are many examples of sonographer led Ultrasound guided-FNAs. However, sonographers often do not attend the MDTs and should be encouraged to do so It was noted that the reason for introducing U classification was to reduce the need for unnecessary FNAs.

6.6 Incidental Findings of thyroid nodules on imaging: BTA guidelines are that incidental nodules require only clinical assessment; high risk patients need an ultrasound scan.

6.7 The centralisation of Medullary thyroid cancer cases in the Peninsula to Plymouth was reiterated.

6.9 **Action**: TM to send a proforma for audit to each member trust to use for standardising pre referral investigations across the Peninsula.

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7.0 **Research**

It was acknowledged that there are few studies undertaken for Head and Neck and Thyroid patients across the Peninsula.

7.1 There is a national study in Cardiff which may be appropriate to refer patients to. Pathology and blood tests are required and in surviving patients a further blood test would be desirable. Cardiff is happy to see patients to properly consent.

8.0 **Anaplastic Thyroid Cancer (ATC): Review-Presented by Tass Malik**

Comments:

8.1 Is there a local protocol for tissue collection for this group of patients, or patients with suspected ATC?

8.2 What are the benefits of tracheostomy in ATC and what lessons can be learned in managing end of life in ATC patients?

9.0 **Cowden's Disease-**presented by Tass Malik

9.1 Comments: it is acknowledged that there appears to be lack of coordination of care for these patients and that geneticists would be ideally placed to coordinate the patient pathway

9.2 **Action**: TM to discuss with Genetics dept in Exeter.

10.0 **Difficult Case Presentations.**

11.0 **Prescription and Funding of T3**

11.1 Some patients are sourcing T3 privately because it is not currently funded by the CCG.

11.2 It was noted that T3 is not recommended by the British Thyroid Association as there is no evidence of benefit, however it is acknowledged that there is a small cohort of patient who do appear to derive benefit from T3, and this is supported anecdotally by clinicians across the Peninsula.

12.0 **AOB**

12.1 Nil raised.

13.0 **Date of Next Meeting**

Date: Friday 16th March 2018

Time: 10am-12:30 (followed by Lunch and then the Head and Neck SSG meeting.

Venue: Roadford Lakes (PL16 0ES)

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For further details, please follow this link.

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