

## Meeting of the PCA Colorectal Site Specific Group

20<sup>th</sup> September 2017; 14:00-17:00

Arundell Arms (Carey Room), Fore Street, Lifton, PL19 0AA

### 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** (to be agreed at the next SSG Meeting)

**Chair:** Melanie Feldman (MF)

#### Reference

- 1.0 Welcome and Introductions; (Please refer to separate list of attendees/apologies via this [link](#)).
- 2.0 **Previous Meeting Minutes and Actions Arising**
- 2.1 Minutes of the Previous SSG meeting held on 29<sup>th</sup> March 2017 were reviewed;
- 2.2 (3.0) It was acknowledged that Plymouth (PHT) had trialled implementing electronic health needs assessments (e-HNA), however the process had been time consuming and difficulties had arisen. There were no representatives from PHT to comment on this.
- 2.3 The need to have an automated system for prompting and chasing up CEA assessment was discussed. Trusts have not managed to organise this across the Peninsula yet.
- 2.4 Clinical Guidelines (4.0) the shared guidelines require updating to reflect the changes from the Network to the Alliance and peer review measures.
- 2.5 **Action:**
- (1) NK will provide a revision draft of the shared clinical guidelines to the group by the next SSG meeting.
  - (2) NK to liaise with Maria Lawson (PHT) in respect of policy/protocol for implementing the NICE guidelines across the Peninsula.
- 2.6 Genetic Testing: refer to section 8.0.

## Peninsula Cancer Alliance

- 2.7 Anal Cancer MDT (6.0): The Peer Review of Anal Cancer stated that there should be one centre for salvage surgery (Exeter—who would also run the MDT). Plans for this have been put back until Spring 2018. There are currently no histopathologists or radiologists available to facilitate a quorate MDT (pending further discussions about job planning).
- 2.8 There are no processes in place to manage transfer of funding for these complex patients in one centre. STP/Specialist Commissioning should be remunerating accordingly, but this is not happening.
- 2.9 When the Anal MDT was in Truro, time was not built into job plans to facilitate this. There was a discussion about whether the Exeter radiology & pathology team were keen to push this issue forward with management; there is a willingness to resolve this.
- 2.10 It was noted that few patients have salvage surgery and that the movement of tariff will not be vast but there are organisational aspects to consider—It was suggested that the CCGs need to centralise the surgery and the MDT and that Vaughn Lewis (Kernow CCG) or John Renninson as PCA Clinical Lead may be best placed approach on this matter.
- 2.11 Exeter suggested that they could facilitate an Anal MDT once a week (as recommended by Peer Review) and that this would equate to approximately 2-3 patient/week to discuss. Centres could dial in after the colorectal MDT.
- 2.12 Plymouth are keen to continue providing salvage surgery and to further develop their service; they are not currently referring patients to Exeter. The Plymouth team feel that it is not unreasonable for them to maintain their service as these patients are complex and may require an extended stay in hospital, therefore it would be preferable for them to be closer to home.
- 2.13 Plymouth would be happy to share the MDT with Exeter.
- 2.14 It was however noted that peer review measures state that salvage surgery should be carried out at one centre and that Exeter has built up their surgical expertise in this field.
- 2.15 RCHT, SDHT and NDT will from now on refer patients for salvage surgery to RDE. PHT are planning to continue to manage salvage surgery locally.
- 2.16 **Action:**
- (1) NK to contact Lynne Kilner to obtain details of who in commissioning for Devon would be responsible for this.

(2) MF to write to the Devon CCG contact/ John R to suggest that discussions within the clinical teams are initiated to resolve this.

2.17 Audit: Liver mets and scans-Plymouth to present at the next SSG meeting.

2.18 Research: nil raised.

2.19 Patient experience: Ken (Patient User Representative) explained that he had distributed exercise information leaflets to his patient group, but was disappointed that no feedback on these had been forthcoming and after one month, none of the patients had tried the exercises.

2.20 AOB: Stephen Mitchell formally handed over chairmanship of the Colorectal SSG to Melanie Feldman. The group expressed their thanks to Steve for his hard work over the last 3 years.

2.21 **Colorectal SSG Considerations**

Changes to personnel;

PHT: Francis Daniels (PHT) has retired; there are also 2 new GI oncologists.

Torbay: currently one oncologist short and have cover arrangements on a temporary basis

2.22 **Action:**

(1) NK to review current SSG documents/membership lists and amend accordingly.

(2) NK to email all MDT leads to ask them to update their lists of local MDT members (including laparoscopic recognition).

3.0 **The Cancer Alliance**-an update from Lynne Kilner PCA Programme Manager

There has been a change from the former cancer networks to alliances with an emphasis being placed upon influencing healthcare and policy. The purpose of the alliance is to support the delivery of the 96 recommendations of the Independent Cancer Taskforce Report (executive summary available via this [link](#)).

3.1 Currently, focus is on recovery of the 62 day standard; however the long term aim will be to move from a 62 to 28 day pathway by 2020. There was a discussion about whether this means 28 days from referral, diagnosis or decision to treat – this is not clear.

- 3.2 The imperative on local Trusts and network groups is to review pathways to improve speed of patient flow at all stages. It is acknowledged that with increased demand, no increased resource, surgical cancellations due to bed shortages, currently patient pathways are lengthening rather than shortening. Trusts will need to take steps to minimise delay by challenging their own pathways and practices. Individual Trusts will find different solutions depending on local resource and manpower.
- 3.3 At a local level, transformation bids have been made over the summer to obtain additional funding to make the improvements required to meet the 62 day standard. There is also a focus on 104 days.
- 3.4 In the Peninsula, we have been successful in obtaining additional funding arising from our early diagnosis bid (to support implementation of qFIT testing for the 'low risk but not no risk' patient group) which we are now preparing for.
- 3.5 There are no updates available in respect of the bids for Living with and Beyond Cancer (LWBC) as these have not yet been determined, but plans include support with risk stratifying patients on the colorectal pathway (re follow up after treatment) and implementation of the recovery package, e-HNAs and end of treatment summaries.
- 3.6 Within the Peninsula Cancer Alliance, Lynne supports Jon Miller; other key personnel include;
- Alison Diamond (Chair of Board and STP link for Devon)  
Ethna Mccarthy (Cornwall STP Lead)  
John Renninson (Clinical Lead)  
GP Lead TBC in the near future.
- 3.7 Concern has been raised about implementing the Cancer Alliance work plan and overlap with what Trusts are doing. There is a need to work closely together to reduce duplication of work.
- 3.8 **Action**
- NK to contact Lynne Kilner for an update on LWBC and to relay relevant details of any programmes that have been funded.
- 4.0 **qFIT: presented by Lynne Kilner and Rachel Byford (CRUK)**
- 1) FIT presentation (Lynne Kilner) available [here](#).
  - 2) FIT presentation (Rachel Byford) available [here](#).

4.1 **Group Discussion:**

Concern were raised that qFIT will lead to an increase in referrals and activity of colonoscopy, particularly noting that where Trusts have excluded the 'low risk but not no risk > FOB' in NG12 on account of not having FOB available in the region, this is now a new patient group for 2WW. The Devon audit was based on a small number of patients and there is no other data whatsoever to predict how referral patterns might change.

4.2 Research groups in Leeds and York working on qFIT for the established 2WW group (risk >3%) are struggling to find the right place for qFIT and have raised concerns about using it for the 'low risk but not no risk' group. They have supplied data to MF which was shared with the group. This is unpublished data as yet.

4.3 The qFIT pilot is making assessment of referral numbers a key part of the project and this is welcomed.

4.4 Guidance for GPs needs to be clear on both referrals and test results so that there is no confusion between the "low risk but not no risk" group and the established >3% risk 2WW group.

4.5 The benefit of 2WW referrals and 28 day pathways for colorectal patients was also questioned; that there is no difference in survival rates for patients on a 2WW and that patients on a 28 day pathway may not have time to come to terms with their diagnosis prior to surgical intervention. It was however noted that for some patients, surgery cannot come quick enough.

5.0 **Pathway Redesign:** presented by Stephen Mitchell (Consultant Surgeon, Torbay Hospital);

5.1 2WW patients triaged to either 'Straight to test' (40%) or consultant clinic

(1) "Straight to Test" presentation slides available [here](#).

5.2 **Group Discussion:**

It would be sensible to define criteria for different groups (as has been done in Cornwall). This would lead to greater consistency with which tests patients get.

5.3 Plymouth has a protocol; 2ww + nurse led telephone clinic; practice differs across Trusts.

5.4 It was thought that Cornwall's protocol of telephone triage, straight to test and clinic appointment achieved consistency.

## Peninsula Cancer Alliance

5.5 Concern about patient accountability was raised (in respect of tests carried out and results reported which had not been seen by the consultant).

5.6 **Action:** NK to obtain information from RCH relating to the criteria for which patient groups get which tests and to circulate to the MDT Leads.

### 6.0 Patient Pathway

It was agreed that each Trust needs to evolve their individual colorectal pathways.

6.1 There was a discussion about the possibility of GPs requesting colonoscopy directly rather than making a 2WW referral. Trusts do not feel that they have sufficient capacity in endoscopy to facilitate this. It is not clear exactly whether GPs wish to have this or whether the pressure is to cut clinic waiting times and tariffs involved.

6.2 The 2WW proforma was also discussed and the group felt that it needed to be re-designed. However, the process for doing this was noted to be complex with a large amount of consultation required in the process. As Devon and Cornwall have separately negotiated with their local GPs it may be difficult to have absolute uniformity across the network.

### 7.0 Radiofrequency Ablation (RFA)

There was lack of clarity as to the level of service currently being provided at Exeter. It was noted that this would be discussed at the lead nurse/cancer manager meeting on 22<sup>nd</sup> September and that Trusts would be updated thereafter.

7.1 It was noted that PHT can also provide this service.

### 7.2 Action:

(1) NK to invite the clinical team from PHT to present their service at the next SSG meeting.

(2) NK to ask RDE cancer services manager to circulate the outcome of the meeting on 22<sup>nd</sup> September.

### 8.0 Lynch Syndrome Testing-discussion led by Nangi Lo

The guidance is that we should be testing patients at point of diagnosis and that counselling is required prior to testing.

## Peninsula Cancer Alliance

- 8.1 Torbay raised concern that they are currently unable to offer this test routinely and they do not have anyone to provide genetic counselling.
- 8.2 Plymouth undertakes an MSI test in the first instance; a positive test result initiates counselling.
- 8.3 Concern was raised about equity of access to Lynch Syndrome testing-we should be doing this routinely across the Peninsula but a lack of resources impedes the ability to do so.
- 8.4 The ethics of testing patients routinely without pre-counselling was discussed; Ken (patient user representative) commented that he would want to know if there was a genetic link, but he would not be happy if the test had been carried out without being told. Ken thought that it might be a good idea to discuss this with the patient group to obtain feedback on genetic testing and at what point the patient would want this discussion.
- 8.5 The group agreed that a standard approach to testing was needed across the Peninsula.
- 8.6 **Actions**
- (1) MF to liaise with our patient representative to ask if he can conduct a survey in his group.
  - (2) MF to circulate the NICE guideline to Trusts who should actively identify barriers to implementation and work to implement the recommendations.
  - (3) NK to seek clarification on the policy for implementing NICE guidelines.
  - (4) NK to identify what written information is used in other Trusts and what pathways for consent exist to see whether they are suitable for us.
  - (5) MF to contact the genetics service at RDE to collaborate on implementation.
- 9.0 **Living with and Beyond Cancer**
- Practices across the Peninsula were shared: Torbay hold LWBC event twice yearly and also provide a 6 week “moving on” group course. They are about to pilot a pre-enablement course (pre-chemotherapy) with input from Clinical Nurse Specialists (CNSs), psychology and oncology.
- 9.1 Concern was raised that there are not enough CNSs to ensure equitable

provision of LWBC initiatives to patients across the Peninsula and that the ability for CNSs to undertake this work is being severely compromised by a lack of CNS support/availability. It was also noted that some patients are receiving their cancer diagnosis without the benefit of a CNS being present because of sparse resources.

9.2 Current recommendations state that there should be 1 WTE CNS per 100k population. RCHT therefore should have 5 but have 2, these individuals also run the cancer follow up service. Torbay should have 2.7 but have 1.2. Exeter have 4. PHT feel they have plenty of CNS support, their CNSs run the cancer follow up service and the telephone 2WW clinic service.

9.3 Lorraine Long (Kernow CCG) confirmed that the CCG are aware of these issues and lack of resources.

9.4 The group contemplated how they might be able to work in collaboration with charitable partners (such as Macmillan) to maximise effectiveness.

10.0 **Research Update**-presented by Melanie Feldman on behalf of Julie Cunningham; (slides available via these links);

1. [Research update \(1\) Colorectal.](#)
2. [Research update \(2\) Colorectal research recruitment.](#)
3. [Research update \(3\) Current recruitment vs target speciality.](#)

10.1 **Comments:** recruitment to studies is decreasing year on year, this is particularly noticeably in the last 2 years. It was queried whether this may correlate to financial and time pressures. As an Alliance we need to increase uptake.

#### 11.0 **Quality Indicators/Audits and Data Collection**

It was suggested that this could be addressed in a separate educational day in January/February 2018. Tuesdays may be the best for the majority of attendees (additional details to follow).

#### 12.0 **National Cancer Patient Experience Survey (NCPES)**

Results across the Trusts were briefly shared, and over all, Trusts were happy with their results.

#### **Patient Representative Role**

Our Patient representative felt that attendance at the group was valuable as a route to engage with commissioners, the Cancer Alliance and Trusts. This enables him to feedback to patient groups and for them to feel they can be



heard by decision makers.

13.0 **National Bowel Cancer Audit (NBOCAP)**

It was suggested that this is also discussed at a separate educational meeting in between SSG meetings.

14.0 **AOB**

Nil raised.

15.0 **Date of Next Meeting**

TBC.

DRAFT

**Colorectal SSG Meeting -Summary of Actions**

| Reference | Subject Matter  | Summary   | Action  |
|-----------|---|---|---|
| 2.5       | Clinical Guidelines   | Shared Clinical guidelines require updating to reflect the move from Networks to Alliances. | <b>Action:</b> NK to draft a revision to the current document prior to the next SSG meeting.<br><br>NK to contact Maria Lawson (PHT) to establish what the policy/protocol is for implementing the NICE guidelines across the Peninsula.                  |
| 2.16      | Service Provision   | RCHT, SDHT and NDT will from now on refer patients for salvage surgery to RDE               | (1)NK to confirm Devon CCG contact with Lynne Kilner.<br><br>(2)MF to contact CCG/John R to initiate discussions at local level.  |
| 2.22      | SSG Issues  | SSG membership lists need to be updated.  | (1)NK to review current SSG documents and amend accordingly.<br><br>(2)NK to email all MDT leads to ask them to update their lists of local MDT members (including laparoscopic recognition).   |
| 3.8       | Living With and Beyond Cancer                               | Plans for LWBC project work across the Peninsula.   | NK to contact Lynne Kilner for an update on LWBC and to relay relevant details of any programmes that have been funded.   |
| 5.6       | Patient Pathways  | 2WW Pathways  | <b>Action:</b> NK to obtain information from RCH relating to the criteria for which patient groups get which tests and to circulate to the MDT Leads.   |
| 7.2       | Provision of Clinical Services                              | Radiofrequency Ablation   | (1)PHT Service: NK to invite the clinical team from PHT to present their service at the next SSG meeting.<br><br>(2)NK to ask RDE cancer services manager to circulate the outcome of the meeting on 22 <sup>nd</sup> September.                          |
| 8.6       | Provision of Clinical Services/Equity of Access to Services | A Standardised approach to Lynch Syndrome Testing is required across the Peninsula          | (1)MF to liaise with our patient representative to ask if he can conduct a survey in his group.<br><br>(2)MF to circulate the NICE guideline to Trusts who should actively identify barriers to implementation and work to implement the recommendations. |

|  |  |  |   |
|--|--|--|---|
|  |  |  | <p>(3)NK to seek clarification on the policy for implementing NICE guidelines.</p> <p>(4)NK to identify what written information is used in other Trusts and what pathways for consent exist to see whether they are suitable for us.</p> <p>(5)MF to contact the genetics service at RDE to collaborate on implementation.</p> |
|--|--|--|---|

DRAFT