

Meeting of the PCA CUP Site Specific Group

Tuesday 12th November 2019

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 (to be ratified at the next SSG meeting)

CUP SSG Chair: Naomi Clatworthy (NC)

Reference	Notes
1.0	<p>Welcome and Introductions – NC</p> <p>Please refer to the separate attendance record via the SWCN website.</p>
2.0	<p>The draft minutes of the CUP SSG meeting held on the 8th November 2018 were considered;</p> <p>2.1 (Ref: 2.2) AM informed the group that the remit of AOS at Exeter remains unclear and the team is still getting referrals that are not cancer. Since the last meeting AM has emailed teams requesting that patients are not referred until a cancer diagnosis has been given. AM will keep the team updated if she gets a response.</p> <p>2.2 (Ref: 2.2) at a previous meeting the team agreed that the CUP meeting would also include AOS. NC would like this to agree this formally.</p> <p>ACTION: BK to look at updating the Terms of Reference for the group to cover the AOS service.</p> <p>ACTION: BK to change the meeting name of the group to encompass AOS.</p> <p>(Ref:2.3) AM has emailed Exeter’s histopathologists about creating a standardised proforma that can then be used across the Peninsula. SWAG have a proforma in place, and this has been emailed to the Histopathologists for comments. AM to update the group when there is progress.</p>
2.2	<p>Clinical Guidelines</p> <p>The group discussed their progress towards agreeing their clinical guidelines.</p> <p>ACTION: BK to send out draft guidelines for final comments before signing off before the next meeting.</p>

	<p>ACTION: Once signed off BK to upload guidelines onto the SWCN website for teams to access.</p>
<p>2.3</p>	<p>Trust Updates</p> <p><u>Exeter</u></p> <p>The AOS teams are triaging all telephone calls and try to have 2 nurses covering the service at one time. This can be difficult due to sickness.</p> <p>CUP patients are sitting under AOS and currently the AOS are seeing a large volume of patients.</p> <p>Teams need to be aware that the AOS is an advisory service, and teams can always call to seek advice prior to referring. It is also an advisory service for patients and the AOS team are under pressure to admit less.</p> <p>Patients are on the CUP MDT that should not be, and the team are trying to request that a biopsy is done before referring. AM is the only CUP lead but some Upper GI consultants will sit with her on the MDT to offer different opinions.</p> <p>The team discussed guidelines that are in place for those patients with comorbidities. There can be a misunderstanding when it comes to managing CUP patient's expectations.</p> <p>ACTION: Exeter AOS team to send these guidelines to BK to circulate with the minutes.</p> <p>The team agreed that often a referral to ESC would be more appropriate to provide good palliative care with a good quality of life.</p> <p>ED explained that it could be difficult for GPs to manage and often prefer to give secondary care a chance to say what is reasonable in the way of treatment and what is not.</p> <p>Exeter now has an Immunotherapy CNS in place.</p> <p><u>Plymouth</u></p> <p>AOS is now triaging all the calls (previously done by the wards).</p> <p>The team now have a full time band 7 and band 6 in place and one part time band 6. They have 3 hours of consultant time a day meaning no patient is waiting longer than 24hours before seeing an oncologist.</p> <p>The consultant team share the CUP patients and will remain their patient if they see them first. When a primary site is identified, it can be a challenge to get that patient back to the right team and this can lengthen a patients pathway.</p>

	<p>ACTION: BK to share Brain pathways with the team once they have been finalised at the upcoming Brain SSG.</p> <p><u>Cornwall</u></p> <p>CT has recently taken over as CUP lead at the trust.</p> <p>The team is trying to resist the floodgates of MUO.</p> <p>WD is currently splitting her time between Brain, Cup and AOS, which is challenging.</p> <p><u>North Devon</u></p> <p>CUP sits under the AOS team at the trust.</p> <p>The AOS is due to expand to a 7-day service in January made up of one band 7; four band 6's and one Band 4.</p> <p>Funding for an Immunotherapy CNS is agreed.</p> <p>The band 4 who is very competent is doing call triage. This has freed up nurses time.</p> <p>The CUP MDT currently sits in the Upper GI MDT, which has its challenges as often the MDT patients are coming through oncology when they do not have a cancer diagnosis.</p> <p>The trust are piloting the Care Flow App for 3 months as a tool for communication within the team, which has meant going paperless. This system so far is working really well.</p>
<p>2.4</p>	<p>CUP Patient Decision Making Tool</p> <p>The group spent some time looking at the CUP Decision Making Tool created by the Cancer of Unknown Primary Foundation in collaboration with Sue Ryder.</p> <p>ACTION: BK to circulate to the group to get feedback. BK to ask this to be discussed at the next joint meeting as SWAG are looking to pilot.</p>
<p>2.5</p>	<p>Vague Symptom Pathway</p> <p>ED shared a draft referral form for those patients with Nonspecific but concerning symptoms.</p> <p>ED explained that GPs like a checklist.</p> <p>Torbay hospital offers direct access to CT scans to GPs and from a recent audit, the pickup rate for cancer has been between 20-25% from those referred.</p> <p>The referral form aims to avoid bounce back between secondary and primary care and avoids delays to the pathway.</p>

	<p>AM expressed concern that she has not had any discussion regarding this pathway at Exeter.</p> <p>ED confirmed that the GPs are keen to adopt this form but they need to work through the issues of who has the responsibility of talking to the patient.</p> <p>Consensus was that the referral form was good but there is concern amongst the team about where this pathway will sit.</p>
3.1	<p>Genomics Update</p> <p>Ana Juett provided the group with a short update on the work from the SW genomics team and laboratory.</p> <p>AM explained that currently the teams would be unable to action any results from genetic testing.</p> <p>AJ discussed the red flags that are being put onto patient details (now implemented in Cornwall) that will show whether a patient has had genomic testing in the past.</p> <p>Please see slides circulated with minutes for details of where to access further education resources on genomics.</p> <p>The genomics team are holding an education day on the 29th January 2020.</p> <p>ACTION: BK to circulate flyer with minutes.</p>
3.2	<p>Research and Audits</p> <p>CUPISCO trial is the main trial currently recruiting. This is open in Bath, but sometimes difficult to refer patients onto if they do not want to travel.</p> <p>From the CUP, conference last year the team would like to audit the prognosis of those patients with abnormal CRP and against those with raised CRP and low Albumin.</p> <p>ACTION: each team to begin auditing this in December over a 3-month period and report back at the next meeting.</p>
11.0	<p>Date of next meeting</p> <p>The next meeting will be the annual joint SWAG/PCA CUP meeting on the 6th may 2020. The group would be keen to meet as a peninsula on this day either before or after the meeting.</p> <p>ACTION: BK to discuss with Helen in SWAG.</p> <p>The group would like the November meeting to be held on a Tuesday at Lifton.</p> <p>ACTION : BK to send out a save the date</p>