

## Meeting of the *London Cancer* Head and Neck Pathway Board

**Date:** Monday 20<sup>th</sup> May 2019, 9.00-10.30am

**Venue:** 6<sup>th</sup> floor east meeting room, 250 Euston Road, London NW1 2PG

**Chair:** Yogesh Bhatt

### 1. Welcome and introductions and Minutes from last meeting

YB welcomed the group and introductions were made. The minutes from the previous meeting were signed off as accurate.

- The group looked through the actions from the previous meeting;
  - Feb01; CM has been invited to the Eastman dental MDTs. The dental teams are to work closer together.
  - Feb02; NB has shared the RIG admissions paper with Lianne Gordon. This work is ongoing.
  - Feb03; the resource review is ongoing. HS to assist in its completion with YB and KG.
  - Feb04/05/06; SW is awaiting access to the UCLH H&N breach report folder, in order to share reports with AJ and NK who were keen to understand delays to the service.
  - Feb07; a H&N patient information leaflet is being developed. NK will discuss dental patient information with the Barts dental team.
- The workplan/annual report is due to be published very soon, please send any comments to SW.

#### **ACTION:**

- Comments regarding the workplan to be sent to SW as soon as possible

### 2. Patient experience; workshops and patient information – Sarah Josefberg (SJ)

- The patient experience and user involvement team hosted two patient and staff workshops to look at improving patient experience, information and the H&N pathway.
- Following on from CNS plans to redevelop the H&N patient information leaflet; SJ developed and took a first draft of a patient information leaflet to the workshop for patient input.
- Patients at the workshop discussed varying formats the information could be displayed in such as using a Z card however this could be very complex to create and can be expensive.
- SJ worked with a colleague at her university to redesign the leaflet. The new design manage to convey a sense of urgency, it has tick boxes which lets patients know what they can ask for such as a Holistic Needs Assessment (HNA). All the diagnostic and treatment centres in the network have been listed. The leaflet states that patients may be referred to other sites for different parts of their treatment.
- SJ explained that it may be better to have a leaflet for pre-diagnosis and another for post-diagnosis. The leaflet currently drafted is for patients post-diagnosis.
- The next steps will be to test a few options with patients to see how it works and to get feedback.
- SJ requested the board send feedback about the leaflet before it is trialled with patients.
- Feedback/outcomes from the workshop;
  - The attendees liked the new ways of exploring cancer services.

The NCEL cancer alliance brings together hospital trusts, GPs, health service commissioners, local authorities and patients across north and east London and west Essex.

- Three significant themes came out from the workshops which the patients felt were important to understand; expectation setting, abandonment and oral & dental rehab.
- SJ was able to use footage of a patient from the workshop as a case study at the Eastman dental hospital to highlight some issues the patient had with communication. The dental team found this very useful.
- The need to promote the use of peer support allowing patients to use to support each other when anxious.
- SJ confirmed that there was a representative spread of patients from across the network who attended. She also conducted telephone interviews with patients who wanted to feedback but couldn't make it to the workshops.
- YB explained that the methodology for these workshops could be made available via the User Involvement Team so work like this can take place with patients around the network.

**ACTION:**

- Board to send comments to SJ regarding draft patient information leaflet

### **3. Dental discussion**

#### **Dental extractions;**

- AT discussed the variation in the radiotherapy treatment pathway following dental assessment/extractions at Barts Health compared to UCLH. This is due to patients having more teeth extracted at the Eastman; this causes a little more swelling meaning the treatment start date is delayed. Having more teeth out also may mean the patient will lose weight before treatment.
- It was suggested there should be peer review of cases. Barts Health and UCLH dental teams agreed that they are happy to work together to help understand the discrepancy.
- Navdeep Kumar and Matthew Garrett (Eastman) recently completed an internal review of eight NMUH radiotherapy patients (due to be ten patients however two couldn't be reviewed). This review looked at clinical decision making for teeth extractions however they feel it would be more beneficial to review patients seen more recently in order to assess current clinical practice. SKo confirmed that this could be completed very quickly once agreeing the period of time it should cover.

#### **Dental pathway;**

- DR highlighted the benefits of patients having a dental assessment during the investigations stage of their pathway and not waiting until treatment has been decided to make a referral. SKo agreed that this was a better way to do this and explained that following the move to the phase 5 building in September this should be achievable as everyone will be in the same clinic. AT explained that this will mostly benefit patients having investigations at UCLH instead of the other NCL sites.
- The group discussed the importance of ensuring patients have their teeth extractions at time of surgery. NB explained that the issue with ENT patients not having extractions during surgery has been resolved.
- DR asked if patients can be referred back to the dental team post-treatment i.e. after two years. SKo confirmed that the Eastman has a review clinic patients can be booked into within special care. At RLH they sometimes see patients for 3-4 years.
- KR suggested getting patient feedback maybe a year after treatment as patients sometimes feel lost. Often patients think their teeth will be replaced immediately after treatment, it's important to manage expectations. The Eastman dental team have drafted a patient information leaflet. Patient information is also required for after treatment.
- SJ has had discussions regarding the creation of a H&N surgical school which could be an opportunity for previous patients to attend and could help manage current patient expectations.
- DR explained that surgery school may not be suitable for pre-treatment patients as they have a lot of competing appointments/investigations. DR suggested having an end of treatment school instead as this is also on the Macmillan agenda. This can be used to inform patients of the next steps in their pathways can be used to complete a HNA and treatment summary. This will likely be arranged in the next 6 months. An end of treatment school is also good opportunity for patients to meet other patients for peer support. DR also explained changes

to pre-assessment. They have two band 6 pre-op nurses (one for ENT and one for OMFS) who are responsible for a caseload of patients. These patients are allocated to one of these nurses and receive individualised support. The CNS group plan to meet to look at the pathway and will invite SE and radiographers to the meeting.

- AT recommended the team to start thinking about delivering patient information via apps as patients are getting younger. MF explained that UCLH hold an apps competition every year. SJ confirmed that she can link this in with patients. YB briefly explained Project Swallow which is an app developed for the UGI service and is worth exploring for H&N patients.

#### **14 day radiotherapy pathway;**

- The dental service is under pressure due to the new 14 day standard (maximum 14 days from DTT to radiotherapy treatment). NHSE published a new criteria/target for patients to begin radiotherapy treatment within 14 days from decision to treat (DTT) date.
- Services are discussing when the clock start date should be and whether it should start after the dental assessment. The group discussed whether it's possible to meet the target or if it would be better to highlight the issues that H&N patients and staff face when trying to meet this target.
- AT explained that the service will need to look across London at the wider picture. Anecdotal feedback from some places has been that they are no longer doing dental work prior to treatment.
- The specialist board now has a restorative dentist as a member which is positive.
- The group discussed the number of osteoradionecrosis (ORN) clinics in the network as patients often get referred to Guys hospital. The Eastman has a bone clinic on Friday's which is run by oral surgery; Mark McGurk (MM) will be joining this clinic. There is scope for an ORN clinic to be set up at Barts, the current clinic is run by oral surgery but would want restorative team involved.

#### **ACTION:**

- CNS group to invite SE/radiographers to their next meeting
- Barts Health and UCLH dental teams to engage in peer review with Lorna McCaul, RD-UK Lead
- Dental teams to explore the development of local ORN clinics at EDH and Barts

#### **4. Clinical trials update**

- MF shared information about current clinical trials in the network with the group.
- Recent successes;
  - MM has received funding to look at ORN which is a good opportunity to look at pathways.
  - MM and Claire Shilling received funding for a sentinel node biopsy (SNB) study, looking at contralateral SNB.
- Locally the PATHOS study is now open at UCLH and is awaiting the first patient. Wisteria, the surgical trial, is open at UCLH. RET and NTRAK studies are also open at UCLH.
- The SAVER study looking at high grade dysplasia is due to open later this year. POPPY is opening in a few weeks' time. The NICO study led by teams in Liverpool and the Oberon trial being led by teams in Manchester have both been approved at UCLH and will open in the next few months.
- COMPARE isn't opening at Barts but will open at BHRUT.
- BHRUT will be opening the POPPY trial.
- The KURA study was due to open across the network. This has been developed through the NHS so this could lead to it becoming a standard of care throughout the NHS.
- The group discussed how the pathway board could support recruitment into trials. MF is happy to consolidate all the trials across the network and turn it into a newsletter. *London Cancer* can support this. MF could possibly also present one slide with trials and successes at each audit day.
- If many people are aware of the trials available this could empower smaller sites. This would provide patients with the opportunity to enter trials at different sites. This overcomes the inequity of access issue.
- MF will send the slides to SW to share with the board.

#### **ACTION:**

- MF to work with *London Cancer* to develop clinical trials newsletter
- MF to give an update at each audit day regarding clinical trials

- MF's slides will be shared with the board

## 5. Pathology – protocols and audit

- Pathology protocols were developed by AJ and Kim Piper with comments and input from pathology teams across the network. As specimens are being reviewed centrally there is a concern regarding the time this may take and whether this could be causing delays and contributing to breaches.
- YB explained that every diagnostic biopsy from Royal Free gets reviewed centrally. CL and AT explained that all surgical and oncology cases are reviewed centrally. The group queried to what extent everything should be reviewed centrally. DP discussed the potential governance issues that would be raised around a central MDT providing a treatment plan without having reviewed pathology.
- This was discussed with the head of the school of pathology for London who felt it was appropriate for pathologists who are EQA approved to make a diagnosis.
- Complicated at PAH as some cases go to Barts and some goes to Addenbrookes.
- Some patients are added to the MDT list but can't be discussed as AJ is waiting to receive the slides.
- At the last H&N pathway board meeting there was agreement to conduct an audit of pathology cases being sent to UCLH from RFL and PAH. Milestones can then be compared to the timed pathway and the Faster Diagnosis Standard. The group looked at the draft audit form and were happy for the audit to take place. Any comments about the form should be sent to SW.
- SE confirmed that HPV staining can actually be done at Chase Farm.

### ACTION:

- Pathology audit to be conducted to assess timeline of biopsy to central review – comments to be sent to SW

## 6. Performance and Faster Diagnosis Standard (FDS)

- HS presented an update about Head and Neck performance and FDS. The slides will be sent to the board.
- Overall 62 day performance showed quarter four of 2018/19 BHRUT and Barts were close to achieving 85% whilst other teams struggled to meet the target.
- At the next pathway board breach reallocation will be included in the performance update. SE believes the data won't really change for NMUH even with breaches reallocated.
- The group discussed which day is accepted as the inter trust referral (ITR) received date. NB explained that this date is when the last item of information is received.
- This new standard will ensure patients are told they have cancer, or that cancer has been excluded, within a maximum of 28 days from GP referral date. This was piloted around the UK before coming into effect nationally in April 2019; when Trusts began to collect the data. Trusts will start being measured against the standard from April 2020 onwards. The threshold is yet to be set.
- There was a discussion about how well H&N teams are currently meeting the standard. It was felt that there may be some constraints to achieving the target due to a lack of resource. Moving from a 2 week wait pathway to 1 week wait has been quite challenging for teams. There is less opportunity to triage patients into two the appropriate H&N clinic (ENT or OMFS). The service at UCLH has been using Saturday clinics but is trying to stop these and ensure there are enough slots for patients to be seen during the week.
- Further investment is required within radiology and on faster pathology turnaround. Patient information will be very helpful in the pre-diagnosis part of the pathway to set appropriate expectations for patients. This will help ensure patients make themselves available for appointments and investigations.
- There are now straight to ultrasound slots available at UCLH which will be bookable through EPIC. Patients are triaged by ENT fellows to check if they should go straight to ultrasound or be booked into a normal outpatient appointment. This is not a triage to remove patients, everyone will be seen.
- When the service moves into the Phase 5 building there will be a clinic room dedicated to biopsies so patients can have biopsies on the same day as their appointments. There's a chance the service could move to patients seeing a radiologist at their first appointment instead of seeing a consultant and can be discharged from that first visit. This will help to take a proportion of patients off the pathway quite early; with fewer patients to track this will allow more time to focus on the patients who require it.

- The group discussed the appropriateness of some GP 2ww referrals. GPs often tick that the patient has a neck lump on the 2ww form when they don't. There is an appetite to offer GP education. The E-Referrals system has the ability to allow GPs to book into available slots. However before this step, UCLH has built in the ability for someone clinical to triage patient; Referral Assessment Service (RAS).
- There is hope that the MDT protocols will support FDS by ensuring that all appropriate investigations have been completed in time for the MDT discussion by day 25. Pre-MDT meetings have also been discussed. Another plan to speed up the pathway is to educate centres to refer patients to local and central MDTs at the same time.

#### 7. Macmillan Capturing Outcomes project – Donna Chung (DC)

- DC gave an update regarding the two recent project engagement meetings held with patient representatives and Head and Neck clinicians across the network. This meeting helped define the project outline.
- DC will circulate the slides and the proposed project governance structure to the attendees. There will be a working copy of the project paper on google drive which will be editable.
- DC will begin sending updates via a fortnightly bulletin.
- Project meetings/working groups will be conducted using WebEx and some will be face to face. This will allow more people to be involved without having to travel.
- The group discussed the importance of understanding recurrence as well as survival. They would also like to develop something that would support audits which can be used nationally. DC explained that instead of trying to collect more data, it's better to try to understand the existing dataset and where gaps are.
- There was discussion regarding Holistic Needs Assessments. There is an OMFS surgeon in Liverpool who is developing a HNA unit. The group agreed that this could guide services here, especially at peripheral hospitals. All felt it would be beneficial to have a single framework in the central and peripheral hospitals.
- DC confirmed that this project will also look at patient experience.

#### ACTION:

- DC to circulate slides and project governance structure to attendees of the engagement meetings

#### 8. Cancer alliance and governance review

- Following a recent governance review conducted by Prof Mike Richards it has been decided that our cancer alliance (UCLH Cancer Collaborative) will separate into the North Central London and North East London cancer alliances. The rationale behind this was around the need for more direction over funds and regarding screening uptake and primary care.
- This will have an effect on some of the *London Cancer Pathway Boards*. Some boards may split if there aren't significant patient flows across North Central and East London. There will be a review of all the pathway boards conducted soon.
- The UCLH Cancer Collaborative board will be split into two and will be chaired by Trust CEOs which will give it more senior oversight. However this could mean having to report to two boards on some projects.
- During this year of transition, the UCLHCC will change its name to the North Central and East London Alliance.
- HS is available to discuss this further with anyone who would like more information.

**In future there will not be an AOB item on the agenda. If you would like to add anything to the agenda let SW in advance.**

#### 9. Next Meeting

- Monday 23<sup>rd</sup> September 2019, 9-10.30am, 6<sup>th</sup> floor east meeting room, 250 Euston Road, London NW1 2PG
- Monday 16<sup>th</sup> December 2019, 9-10.30am, 6<sup>th</sup> floor west meeting room, 250 Euston Road, London NW1 2PG

#### ACTION LOG

Action reference	Action	Owner	Date Due	Status
Feb02	NB to share RIG admissions summary paper	NB	May 2019	
Feb05	Breach reports highlighting dental factors to be	SW	May 2019	Complete

	sent to NK			
Feb06	Breach reports highlighting pathology factors to be sent to AJ	SW	May 2019	Complete
Feb07	NK to circulate the patient information leaflet.	NK	May 2019	
May01	Comments regarding the workplan to be sent to SW as soon as possible	ALL	June 2019	
May02	CNS group to invite SE/radiographers to their next meeting	DR	June 2019	
May03	Barts Health and UCLH dental teams to engage in peer review with Lorna McCaul, RD-UK Lead	NK/CM	Sept 2019	
May04	Dental teams to explore the development of local ORN clinics at EDH and Barts	NK/CM	Sept 2019	
May05	MF to work with <i>London Cancer</i> to develop clinical trials newsletter	MF/SW	Sept 2019	
May06	MF to give an update at each audit day regarding clinical trials	MF	Sept 2019	
May07	MF's slides will be shared with the board	MF	June 2019	
May08	Pathology audit form comments to be sent to SW	ALL	June 2019	
May09	DC to circulate slides and project governance structure to attendees of the engagement meetings	DC	June 2019	

#### Attendees

Name	Initials	Trust/Organisation
Dharmesh Patel	DP	UCLH
Jessica Crowther	JC	Barts Health
Sarah Josefburg	SJ	Patient experience and user involvement team
Sonita Koshal	SKo	UCLH Eastman Dental
Kali Ranshi	KR	Barts Health Dental
Laura Dopson	LD	UCLH
Denise Redmond	DR	UCLH
Shelly English	SE	NMUH
Anna Thompson	AT	NMUH/UCLH/PAH
Sebi Kukran	SKu	UCL Medical student
Martin Forster	MF	UCLH
Colin Liew	CL	UCLH
Neil Bourke	NB	UCLH
Yogesh Bhatt	YB	<i>London Cancer</i>
Helen Saunders	HS	<i>London Cancer</i>
Sherrice Weekes	SW	<i>London Cancer</i>
Donna Chung	DC	Centre for Cancer Outcomes

#### Apologies

Name	Initials	Trust/Organisation
Colin Liew	CL	UCLH
Karen Guner	KG	BHRUT
Amrita Jay	AJ	UCLH
Claire Morgan	CM	Barts Health
Jessica Harris	JH	UCLH
Navdeep Kumar	NK	UCLH Eastman dental
Daniel Young	AS	Homerton
Lisa O'Leary	LO	RFL
Vanessa Smith	VS	Patient representative
Tony Smith	TS	Patient representative

<b>Name</b>	<b>Initials</b>	<b>Trust/Organisation</b>
Paul Stimpson	PS	Barts Health
Amen Sibtain	AS	Barts Health
Hannah Cottom	HC	Barts Health