

Meeting of the *London Cancer CUP/MUO Subgroup*

Date: Tuesday 30th January 2018, 15:00-16:30

Venue: 6th floor east, 250 Euston Road, London, NW1 2PG

Chair: Roopinder Gillmore

1. Welcome and introductions and Minutes from last meeting

- Introductions were made and apologies heard.
- The team went through the previous minutes;
 - **ZG gave an update on TCST work;**
 - They are currently working with Multi-Disciplinary Clinics (MDCs) on how to standardise MUO referral pathways.
 - The clinical lead is Lance Saker. Working on GPs having direct access to diagnostics. They are working to produce a paper which will be presented to the cancer commissioning board in a couple of months which will highlight what the gold standard should be. This is pan London.
 - The team discussed that some GPs have direct access to diagnostics but need to be sure what the next step in the pathway is if an abnormality is reported. They need to know whether they should refer to an MDC MDT or to a tumour site specific service.
 - DF felt that there is a definite need for imaging prior to referral.
 - The group wanted the name of ZG's update on the previous minutes to be changed. The 2ww referral which was being looked into a long time ago, is different to what is being discussed now.
 - **Epicup; Update from JB;** Experience is that the service is not running sufficiently well to be clinically useful, so do not use. However they are still keen to support a "research" meeting in the UK.
 - **CUP event;** the team looked at the summary from the feedback received at the CUP event which took place November 2017. The group felt the GP perspective was insightful and it was felt that linking with colleagues outside of London would be very useful at a future event.
 - **The previous minutes were signed off**

2. Trust specific patient information

- EK was keen to know what is happening regarding patient information across the network, what the services are using and when the information is being given to patients. EK is currently working on the patient information she will be giving to patients.
- The team looked at Barts Health's patient information leaflet provided by KE. This was based on the initial RFH leaflet. KE mentioned that it is a little out of date as some people listed in the contact details have now left the service. EK brought along the RFH leaflet.
- The team discussed having two leaflets; one for MUO patients who are under investigation and the other for true CUP patients.
- The team discussed giving patients an information pack. It was felt that this could overwhelm patients.
- KE discussed her experiences of conducting a patient experience survey that took place a few years ago at Barts. They only received two responses, as many patients had been too sick to complete. The team discussed the difficulties with discussing true CUP patients due to their poor prognosis. Only a tiny

percent of MUOs turn out to be true CUPs. The team also discussed the difficulties in getting patients to review and sign off the leaflet, as only a few patients will be well enough to be involved. It was felt that the MUO's who receive a benign diagnosis or don't become true CUPs will have a different view of the service.

- KE put the Barts information through a cancer patient panel which wasn't specific to CUP patients.
- The team discussed how difficult it is to know when to give all the information. LD felt that it helps patients know who to contact and the team members involved in their care.
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- TN shared NMUH's patient information leaflet. It was felt that these leaflets could be used as templates for everyone else to base theirs on. The team felt that it would be good to standardise what is being given to patients across the network.
- ZG suggested involving John Symons from CUP charity to help find patients to sign off information. .
- ZG explained that they have standardised patient information for primary care. They could possibly look into standardising the MUO/CUP patient information in the network. ZG is on the pan London working group where they could create the leaflets.

3. Clinical trials

- **Acute Oncology Clinical Trials day;** PL has been involved in the organising of this event; it is an NCRI gap in research portfolio. There will be a dragon's den session near the end of the day. PL would like anyone who is interested in the event to send her an email. The event will take place 7th March 2018, 10am-4pm at Sadlers Wells. Event outcome to be discussed at the next CUP meeting.
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ACTION:

- To send email to PL if interested in attending NCRI event
- Outcome of NCRI event to be discussed at the next CUP meeting.

4. Audits

- NMUH have recently conducted an audit (July-December 2017) looking at the number of referrals received and what was the outcome.
- DF explained that hospitals handle referrals differently. LD explained that tumour sites only accept patients with specific but different criteria to one another.
- The group discussed the types of audits that could be undertaken; could look at numbers of patients referred to CUP / MUO services,
- The team agreed to conduct an audit of the number of referrals to the CUP / MUO MDT and outcome of referrals for CUP/MUO patients. This audit will start in the financial year (1st April 2018) for 3 months.
- PL discussed the need to look into the coding that is used in hospitals as the coders can tend to make mistakes.

ACTION:

- The team agreed to conduct an audit of the number of referrals to the CUP MDT and outcome of referrals for CUP/MUO patients. This audit will start in the financial year (1st April 2018) for 3 months.

5. AOB

Discussion points:

- The team discussed Holistic Needs Assessments (HNAs) and how each service was completing them. All in agreement that eHNA's should be done by CUP teams for true CUP patients. The eHNA should be done within 6 weeks of diagnosis so is often done by the tumour specific team. But that it is often challenging to know when to do it. KE explained that she only sees inpatients and therefore does not complete them with outpatients. TN confirmed that they are doing HNA's at North Middlesex. EK is starting to do this. Macmillan eHNA system will have data from the whole country but CUP patients share a category with UGI and Brain so it may be difficult to draw findings from this.
- TN raised how radiology alert systems work across the network. The group explained that a button can be pressed which allows autotext to come up. EK and PL to share information and protocol with TN regarding alerts in radiology reports.

ACTION:

- EK and PL to share information and protocol with TN regarding alerts in radiology reports.

6. Next Meeting

Tuesday 24th April 2018, 3pm-4pm, 6th Floor East meeting room, 250 Euston Road, London NW1 2PG

ACTION LOG

Action reference	Action	Owner	Date Due	Status
Jan01	To send email to PL if interested in attending NCRI event	ALL	01/03/18	
Jan02	Outcome of NCRI event to be discussed at the next CUP meeting.	PL	24/04/18	
Jan03	The team agreed to conduct an audit of the number of referrals to the CUP MDT and outcome of referrals for CUP/MUO patients. This audit will start in the financial year (1 st April 2018) for 3 months.	ALL	01/04/18	
Jan04	EK and PL to share information and protocol with TN regarding alerts in radiology reports.	EK/PL	01/03/18	

Attendees

Name	Initials	Trust/Organisation
Roopinder Gillmore	RG	RFH
Zara Gross	ZG	TCST
Becky Driscoll	BD	UCLH CC
Emily Wang	EW	Homerton
Kate Earwicker	KE	Barts Health
Pauline Leonard	PL	Whittington
Tony Ndlovu	TN	NMUH
Emily Keen	EK	RFH

Name	Initials	Trust/Organisation
David Feuer	DF	Homerton
Louise Dulley	LD	BHRUT

Apologies

Name	Initials	Trust/Organisation
Mary Nolan	MN	BHRUT
John Bridgewater	JB	UCLH
Stephanie O'Neill	SO	UCLH
Katia Boleti	KB	RFH
Thomas Smith	TS	RFH
Girija Anand	GA	NMUH
Kellie O'Riordan	KO	RFH
Ursula McGovern	UM	RFH
Tanya Ahmad	TA	UCLH