

Meeting of the *London Cancer* CUP/MUO subgroup

Date: 26th September 2017, 15:00-16:00

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

Chair: **Ekaterini (Katia) Boleti**

1. Welcome and introductions and Minutes from last meeting

The team looked through the previous minutes.

- 2ww update; this is still a work in progress being led by ZG.
 - The national guidelines for GPs are complicated. The team discussed highlighting what is best for their own patients. The NICE guidance is for primary care not secondary care. GPs fast track patients into MDCs. The group discussed that abnormal imaging should be sent to MUO/CUP by the GP.
- Trials/biobanking;
 - JB explained that the PEACE study is going well. It is almost always patient lead. The patient's body can be retrieved up to 5 days after they are deceased as the DNA will still be good up until then. The trial aims to recruit 100 patients. They currently have 20-30 patients. The post mortem generates a lot of information as up to 100 blocks are able to be sequenced. The families aren't given the results generated by this, even if the primary is found. The group felt that families would be more likely to consent to their relative joining the study if they are given the results after. Patients are consented using the biobanking form. JB will send the form to the team. The completed form should be sent to Manuel Rodrigues. The Trust/hospital is obliged to send the block once requested. JB will circulate the entry criteria.
 - JB discussed Epi CUP; this study looks at the Epi-genome. A test has been developed to locate the primary. This is currently being conducted for free in Barcelona. The teams/hospitals here are required to send the block to Manuel Rodrigues and he will send it on to Barcelona. The results take 5 days to generate once it gets to Barcelona. The Biobanking form should be filled in for patient consent. SW to send a copy of the form to the team.
 - JB explained that there is a CRUK Accelerator bid for infrastructure not projects. Spain, Italy and UK have applied. The aim is to establish an infrastructure for running molecular on CUP. Expressions of interest have been sent.
 - StarTrk is a research study looking for the NTRK mutation. A pan London cancer treatment is likely to be licensed. However it takes a while for sample results to be generated.

ACTION:

- JB will send the biobanking consent form which can be used for PEACE study and the Epi CUP study. SW to send to the group.
- JB will circulate the entry criteria for the PEACE study

2. CUP event discussion; 21/11/17

- The CUP education event will take place 21st November 2017. Venue to be confirmed. This is a pan London event aiming to invite colleagues across London.
- The expected audience is anyone with an interest in CUP/MUO including GPs, radiologists, pathologists, clinicians and nurses. They should already have an understanding of CUP.

- KB has spoken to GP, Dr Martin Harris who has agreed to speak at the event. SW will contact Dr Harris to give information about the event.
- RG will be presenting the guidelines at the event briefly.
- Patient perspective; RG suggested a patient who may be happy to give a talk at the event. RG will contact her. The patient started on the CUP pathway then 2 years later she had a recurrence which found it was a gynae primary. JB has a patient who has been alive for years that could also be involved. It was suggested that Mr Chester could be asked to present, patient with metastatic renal cancer.
- CUP lead perspective; the group are aiming to possibly have someone from South London speak on this subject.
- The team recommended inviting radiologists and histologists to give a talk as they may have interesting cases.
- Palliative care perspective; DF to check whether he will be available to present or he will suggest alternative colleagues who could give a talk. The group suggested presenting the palliative care audit implemented at RFH. The team were able to make quicker treatment decisions therefore allowing patients to get to their preferred place of death. The current RFH House officer could possibly present these findings.
- PL suggested contacting Richard Wagland from Southampton as he does data interrogation and could present data at the event or at the next CUP group meeting.
- The group discussed getting sponsorship/funding for the event. JB mentioned contacting Rosetta Genomics, he will also send a list of companies to contact for sponsorship. This will allow the venue to be booked.

ACTION:

- SW will contact Dr Harris to give information about the event.
- RG to contact patient to talk at the event
- JB to contact patient to talk at the event
- DF to check whether he will be available to present or he will suggest alternative colleagues who could give a talk
- JB to send a list of companies to contact for sponsorship

3. AOB

- EK suggested teams to share their current CUP patient information. This will be added to the next agenda.
- JB queried whether the network should be doing audits. PL suggested the team to do an audit of true CUP percentages going through MDT. The group mentioned that there are audits at local level but none on a national level. A template should be created which also captures NHS numbers.
- The group discussed whether conducting a patient experience survey is feasible. The team felt that this could be done using the palliative care proformas.
- The 2ww audit will be added to the next meeting's agenda.
- Next meeting to be early next year

ACTION:

- CUP patient information to be added to next meeting's agenda
- 2ww audit to be added to next meeting's agenda

4. Next Meeting

To be confirmed

ACTION LOG

Action reference	Action	Owner	Date Due	Status
Sept01	JB to send the biobanking consent form which can be used for PEACE study and the Epi CUP study. SW to send to the group.	JB	13/10/17	
Sept02	JB will circulate the entry criteria for the PEACE study	JB	13/10/17	
Sept03	SW will contact Dr Harris to give information about the event.	SW	13/10/17	
Sept04	RG to contact patient to talk at the event	RG	13/10/17	
Sept05	JB to contact patient to talk at the event	JB	13/10/17	
Sept06	DF to check whether he will be available to present or he will suggest alternative colleagues who could give a talk	DF	13/10/17	
Sept07	JB to send a list of companies to contact for sponsorship	JB	06/10/17	
Sept08	CUP patient information to be added to next meeting's agenda	SW	-	
Sept09	2ww audit to be added to next meeting's agenda	SW	-	

Attendees

Name	Initials	Trust/Organisation
Emily Keen	EK	RFL
David Feuer	DF	Homerton
Emily Wang	EW	Homerton
Katia Boleti	KB	RFL
John Bridgewater	JB	UCL
Pauline Leonard	PL	Whittington
Sherrice Weekes	SW	<i>London Cancer</i>
Roopinder Gilmore	RG	RFL

Apologies

Name	Initials	Trust/Organisation
Chrissie O'Leary	CO	UCLH
Tanya Ahmad	TA	UCLH
Zara Gross	ZG	TCST
Nikolaos Diamantis	ND	Barts
Louise Dulley	LD	BHRUT
Mary Nolan	MN	BHRUT

Name	Initials	Trust/Organisation
Kate Earwicker	KE	Barts