

Meeting of the NCEL Cancer Alliance Upper GI (OG) Pathway Board

Meeting held on Thursday 2nd July 2019, 6th Floor East Meeting Room, 250 Euston Road, London NW1 2PG

Chair: **Dip Mukherjee**

1. Welcome and introductions

- Introductions were made and apologies heard.
- Sally Thorpe and Nathalie Osborn were welcomed to the Board.

2. Minutes of last meeting and matters arising

- The minutes of the last meeting were agreed as an accurate record.

Matters arising

- The risk register had been created and was on the agenda as a stand-alone item.
- Dietetics working group – this work will be taken forward by the operational leads.
 - CC to send the summary of responses to LM.
- Pathway implementation – the 10 patient audit data had been collected and presented at the pathway event in June.
- SOP – not completed
- NCPES – CC to collate
- ITT audit – not yet collated
- 2ww referral data – this is still not separated into OG and HPB. The trusts have been asked to provide this data individually.
- CC to send audit data to LM.

ACTION:

- **CC to send summary of dietetics questionnaire responses to LM**
- **CC to collate NCPES data**
- **CC to send audit data to LM**

3. Update on the Cancer Collaborative

- Prof. Mike Richards carried out a governance review of the UCLH CC.
- As recommended its name has been changed to North Central and East London Cancer Alliance (NCELCA).
- NCEL will split into two alliances (NCL and NEL), aligned with integrated care systems (ICS) from April 2020.
- The pathway boards are being reviewed and they may be split into two and roles, responsibilities, membership and governance may change.
- It was queried whether accountability may change.
- DM will be interviewed on 4th July by PA Consulting who are conducting the review.

- Performance is likely to be a focus of the Boards in future and they should also remain clinical.
- DM asked the Board if there was anything they would like him to pass on to PA Consulting.
 - NO said that the membership should be looked at. She had not been invited to the meeting, but should have been.
 - DK felt that that it did not make sense to split the Board.
- DM clarified that the review is locally driven by Helen Saunders and Muntzer Mughal, but is mandated by NHSE.

ACTION:

- **CC to add NO to the Board distribution list.**

4. Faster diagnosis standard

- CC updated the Board on the cancer waiting times guidance for FDS.
 - All patients on an urgent cancer pathway will need to be told within 28 days whether or not they have cancer.
 - Patients can be told they do not have cancer by phone, email, letter as well as face to face, if that is agreed with them beforehand.
 - In cases of diagnostic uncertainty, patients will remain on the tracker unless interval scanning is arranged or the patient declines further diagnostic tests.
- NHSE is reviewing the waiting time standards which are currently monitored and input to this had been requested.

5. OG Pathway event

- DM updated the Board on the pathway event held on 4th June.
- The write up of this had been circulated prior to the meeting and will be sent to trusts with their individual outputs from the day.
- DH queried when and what will count as telling the patient that they do or do not have cancer.
- DM introduced draft guidelines for endoscopy units for implementing the new Faster Diagnosis Standard which he had produced with Michael Machesney, Director of the Colorectal Pathway Board.
- DK said that you can say someone does not have cancer from the tests that have been done, but they actually may have. He raised a concern that patients may be mismanaged to try to meet the pathway.
- DP said that patient anxiety levels are very high when they are on a suspected cancer pathway so the sooner they are given a diagnosis the better. It is most important to give the correct diagnosis, however, even if that takes a few days longer.
- DK asked whether being kept informed would ameliorate the anxiety.
- NO felt that the anxiety comes from not knowing if the cancer is treatable and that tests can be bundled together to speed up the process.
- It was noted that many patients do not know that they are on a cancer pathway.
- NO said that communication between patients and the hospital team was very important.
- DK suggested that things could be put in place to help, such as, communications and coordination of the pathway. Currently there are too many people involved in the pathway coordination and it becomes difficult to know where responsibilities lie.

ACTION:

- **CC to send event write-up and out-puts to trusts.**

6. Patient information leaflet

- The leaflet will be the communication/information for patients at the start of the pathway.
- It was agreed that the leaflet should now be sent to trusts for localisation and they can also adapt them if they wish.
- There was a discussion around patients being referred on multiple pathways. This happens quite frequently for upper and lower GI as referrers do not know which pathway the patient should be on.

ACTION:

- **CC to send the finalised leaflet to trusts.**

7. Risk register

- A risk register has been produced. This was circulated prior to the meeting.
- The risk register was updated by the Board at the meeting and will be recirculated.
- It was agreed that DM would write to PAH regarding the risk resulting from PAH having no upper GI dietitian.

ACTION:

- **CC to circulate the updated risk register.**
- **DM to write to PAH regarding the dietetics risk.**

8. Any other business

- There was none.

9. Date of next meeting

- Thursday, 17th October 2019, 16:00 – 17:30.

ACTION LOG

Action reference	Action	Owner	Date Due	Status
Oct 18-03	Develop an SOP for discharge communications.	DM/KD		In progress
Oct 18-06	Collate the OG responses from the NCPES for the next Board meeting	CC	15/1/2019	Carried over
Oct 18-08	Discuss undertaking an audit of ITT communications with KD.	DM/KD		In progress
Jan 19-02	Collate the NCPES data for OG and circulate to the Board.	CC	8/2/2019	Carried over
Jan 19-05	Ask the operational leads if they are able to provide OG 2ww referral data.	HS	16/1/2019	In progress
Apr19-01	Create a risk register for the OG Pathway Board and add a risk that PAH does not have a dietitian who	CC	28/6/2019	Complete

	sees OG cancer patients.			
Apr19-02	Send the summary of questionnaire responses to LM.	CC	26/4/2019	Complete
Apr19-03	Speak with Helen Saunders about the dietetic service provision in NCL.	LM		
Apr19-07	Meet with key people in each trust who will be delivering the pathway.	DM	31/5/2019	Closed
July19-01	Send summary of dietetics questionnaire responses to LM	CC	12/7/2019	Complete
July19-02	Send audit data to LM	CC	12/7/2019	Complete
July19-03	Add NO to the Board distribution list.	CC	5/7/2019	Complete
July19-04	Send event write-up and out-puts to trusts.	CC	5/7/2019	Complete
July19-05	Send the finalised patient leaflet to trusts.	CC	12/7/2019	Complete
July19-06	Circulate the updated risk register.	CC	12/7/2019	
July19-07	Write to PAH regarding the dietetics risk on the risk register	DM		

Attendees

Name	Trust/Organisation
Dip Mukherjee (chair)	NCEL Cancer Alliance
Caroline Cook	NCEL Cancer Alliance
David Khoo	BHRUT
Donna Hodge	RFH
Cate Simmons	PAH
Zenab Ahmad	BHRUT
Khaled Dawas	UCLH
Dave Pritchard	Patient representative
David Holden	Patient representative
Krupa Patel	UCLH
Sally Thorpe	UCLH
Nathalie Osborn	UCLH

Apologies

Name	Trust/Organisation
Nikolaos Diamantis	Barts Health
Jade O'Connell	UCLH
Brian Hill	Patient representative
Rosemary Phillips	PAH
Lucy McLaughlin	NCL STP