



North Thames Children's Cancer Network Coordinating Group (CCNCG)

Date: **Wednesday 8th March 2017, 10:00 – 12:00**

Venue: **4th Floor East Meeting Room, 250 Euston Road.**

Chair: **Darren Hargrave**

1. Welcome and introductions

DH welcomed the group and introductions were made. DH introduced himself as co-chair. Michael Marsh is the commissioning co-chair but was on annual leave for this meeting.

2. Discussion on structure and terms of reference

DH outlined the background to the group. The initial intention was for the group to be a multidisciplinary task based board. The Pan-Thames review impacted the group significantly in the last year. This review was completed but not enacted and will not be enacted. This will now be enacted at a national level.

Going forward it was agreed that the network group should have representation from each Trust in the network. The Terms of Reference need to be revised to include all POSCU leads and some additional members. If POSCU leads can't attend then or example the lead nurse can attend.

Action 1: DH to circulate updated terms of reference.
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3. Update on Pan-Thames / National Review

As stated in item 2, the Pan-Thames review will not be enacted. Instead, the national CRG have an advisory role to commissioners in implementing a national review.

The national CRG and national review

DH presented slides on the national CRG on behalf of Dr Rachael Hough who is the chair. The paediatric CRG has been merged with the TYA CRG and now sits under cancer. There are now fewer people involved and there are large regions represented by individuals. The CRG has the remit to look at the full pathway including community care as part of a national review.

The national review may use data collected as part of the Pan-Thames review, but it is a new process. Key points discussed about the review were:

- The review is national but there is a high level of variation geographically in how services are organised so local networks will need to be engaged.
- The timeframes for this review is a year with implementation from November 2017.
- The work streams are:
 - 1: Defining incidence and current UK outcomes for CYP cancer (Chair: Martin McCabe)

- 2: Patient experience/holistic care – led by Clic Sargant and TCT (Co-chairs: Dara De Burca, Simon Fuller)
- 3: Paediatric cancer services - CCNCG/PTC/POSCU (Chair: James Nicholson)
- 4: TYA cancer services – TYACNCG/PTC/Designated Hospitals (Chair: Dan Stark)
- 5: Tumour banking/clinical trials (Chair: Darren Hargrave)
- 6: Follow up (Chair: Helen Jenkinson)
- 7: How do we assess quality of CYP cancer services in the future (Chair: Kathy Pritchard Jones)

The process for stakeholder engagement is yet to be confirmed by NHSE pending legal advice.

- DH suggested that this group should sign up as stakeholders to get communications about this review.
- Stakeholder engagement events will be carried out and are to be confirmed.
- There has not yet been agreement that the North and South Thames regions can come together to do some preparatory/parallel work to look at services in London. It is important that work isn't replicated.
- DH is not yet able to share documents discussed at the last meeting and is awaiting approval for this group to input into the CRG formally in addition to engagement events. DH expects to hear about this in the next week.
- The group were supportive of having a pan-Thames group meeting once the process is confirmed with every POSCU invited.
- It is not yet clear at what level the regional engagement will take place.

There was a discussion about data collection. Public Health England are collecting data from existing databases including from peer review and hospital databases. There were concerns about the accuracy of data reported from Trusts. It was agreed that it would be useful for this data to be examined at the next meeting.

Commissioners will also be looking at the commissioning of children's cancer services but there is no change in commissioning currently.

There was a discussion about IT enabling teams to work together more effectively.

There was consensus from the group that when comparing services nationally, it is important to talk about the characteristics of the services rather than just the designated level, as the definitions of levels of provision varied.

It was commented on that the CRG membership does not have a POSCU representative. The intention is for this to be covered as part of the engagement process.

Action 2: Members of the group to register Trust as stakeholders for the National Review. Individuals can also register. DH to send the link.

Action 3: DH to work with the South Thames region to set up a joint workshop

4. Pilot of online patient portal

- The complexity of existing systems was outlined. Some funding is available for a one pilot of a system called 'Patient Knows Best' (PKB).
- In this system the patient owns the data. A template has been developed with CRUK. There is an app version. There are 19 languages. The main use currently is elderly care but CRUK have piloted it with groups of cancer patients.
- DH outlined a presentation which will be circulated.
- There are already sites within our network which use this system. UCLH and GOSH are already using PKB and North West London Trusts have existing data sharing agreements. This has not yet been used for paediatric cancer.
- The pilot would help to test a system which would then inform a business case network wide for this system, or another one. There are various functionalities of the system that would need to be explored.
- To enable swift implementation and affordability it is proposed that the pilot includes Trusts where IT/IG approval has already been gained. The sites are: Hillingdon, St Mary's, Chelsea and Westminster, UCLH and GOSH. The cost for the pilot is £30,000 which includes training and use of the platform. This will also include the TYA group. It will be important to think about measuring the benefit. Some suggestions were looking at take up and a survey with users (staff and patients).

Next steps are to form a group from Trusts who are participating in the pilot but also to include people from other Trusts with a view to taking this forward with findings from the pilot. PKB would be invited to this meeting. Members of the group to contact HS if they would like to be part of the group.

Action 4: Members of the group to contact HS if they would like to be part of the group.

5. Audit of 2ww proforma

LR gave an update.

- In the previous meeting LR raised issues with the new pan-London 2ww referral forms.
- An audit is being carried out on the last 50 referrals to look at whether the correct forms are being used, filled out correctly and the correct process is being followed.
- LR asked members of the group if they would like to be involved to get in contact.

The group were very supportive of this process.

The process of a paediatrician reviewing children's referrals was discussed. Most POSCUs currently do this.

Action 5: Members of the group to contact LR if they would like to take part in the 2ww audit - lynn.riley2@nhs.net

6. Pilot of phone MDT (PTC/POSCU)

AL presented an idea for a phone MDT. Barts Health have a monthly phone MDT lasting an hour, discussing 3-4 patients. This helps to reduce ad hoc phone calls for advice to centres.

AL suggested that it would be helpful for POSCUs to have a link consultant at the PTC.

A virtual MDT was felt to be helpful for complex patients. There are examples where this has worked well and the group discussed other models:

- Clinics being carried out at POSCUs were also carried out in the past
- Some POSCU staff carry out clinics at PTCs
- Some joint meetings are carried out already

The importance of regular contact was emphasised.

LR added that she is presenting at a study day on how to make shared care really work. LR is going to carry out a survey to explore this. This will include palliative care and will be separate for medical and nursing.

AL to work with a PTC colleague to put together a pilot.

Action 6: LR to circulate survey on shared care to board members

Action 7: AL to work with a PTC colleague to pilot a phone MDT

7. Discussion of work plan 2017

DH outlined the current work plan:

- Engagement with CRG/national work
- Pilot of online patient portal
- 2ww audit
- Pilot of POSCU communications

The board were in agreement.

8. AOB

The next meeting will be held on the 2nd May.

ACTION LOG

Action reference	Action	Owner	Date Due	Status
Dec-04	POSCU leads to suggest people to join the Parent Council and to put them in touch with Claire Gallon: Claire@gallonmail.co.uk.	POSCU leads	31/1/17	
Mar-01	DH to circulate updated terms of reference, constitution and governance	DH	2/5/17	
Mar-02	Members of the group to register Trust as stakeholders for the National Review. Individuals can also register. DH to send the link.	All	2/5/17	
Mar-03	DH to work with the South Thames region to set up a joint workshop	DH	2/5/17	

Mar-04	Members of the group to contact HS if they would like to be part of the PKB group	All	2/5/17	
Mar-05	Members of the group to contact LR if they would like to take part in the 2ww audit - lynn.riley2@nhs.net	All	2/5/17	
Mar-06	LR to circulate survey on shared care to board members	LR	2/5/17	
Mar-07	AL to work with a PTC colleague to pilot a phone MDT	AL	2/5/17	

Attendees

Name	Trust/Organisation
Darren Hargrave (co-chair)	GOSH
Fiona Hikmet	PAH
Michelle Vernon	CLIC Sargent
Kirsty McKeon	Whipp's Cross
Anthony Michalski	GOSH/UCLH
Helen Saunders (minutes)	London Cancer
Lynne Riley	Barnet/Royal Free
Julie Baylis	GOSH
Mary Foo-Caballeo	PTC lead cancer nurse GOSH/UCLH
Marc Arca	Imperial
Zoe Berger	GOSH
Richa Ajitsaria	Hillingdon
Andrea Simmons	Barts Health
Andrea Leigh	Barts Health
Gopa Sen	Whittington
Helen Speight	Whittington

Apologies

Name	Trust/Organisation
Michael Marsh (co-chair)	NHS England
Jo Davison	Hillingdon
Ranjith Joseph	
Rachael Hough	UCLH