



North Thames Teenager and Young Adult's Cancer Network

Coordinating Group (TYACNCG)

Date: **Monday 7th November 2016, 14:00 – 15:30**

Venue: **6th Floor East Meeting Room, 250 Euston Road.**

Chair: **Rachael Hough**

1. Welcome and introductions

RH welcomed members of the board, introductions were made.

2. Summary of progress and new structure and constitution

- RH stated that the group had not met for some time but was now being reinvigorated
- There are conversations taking place with NHS England to have commissioner representation
- RH outlined the previous governance structure and the group agreed that the structure should consist of a single board which would include representation from each trust and other relevant organisations such as CLIC Sargent and The Teenage Cancer Trust
- A nurse and consultant from each Trust will be invited to the board and can feedback to their colleagues

Meeting frequency and timings:

- The group agreed to meet every three months to start with as there is likely to be significant work associated with the national review of TYA and paediatric cancer services
- The time of the meeting (2pm-3.30pm) was the most suitable
- The day of the week is difficult to arrange to suit all but may alternate between Mondays and Thursdays

London Cancer and the National Cancer Vanguard

- HS outlined the changes in support structure for the group through *London Cancer* which has moved from UCLPartners to the UCLH Cancer Collaborative as part of the National Cancer Vanguard which also includes Royal Marsden Partners and The Christie in Manchester.
- The Vanguard has provided funding which allows more support for the group and other tumour pathway boards, and also includes workstreams of Early Diagnosis, The Centre for Cancer Outcomes and Living with and Beyond Cancer which will be relevant to the work of the group.

ACTION 1: HS to circulate information on the National Cancer Vanguard and *London Cancer*

3. Board work plan and education day

- LS outlined plans to hold a network wide or potentially pan-London education day for TYA cancer, likely to be held in March.
- LS asked for feedback from the group on whether this would be useful and what topics should be discussed.
- The group agreed that an education day would be helpful and made the following points:
 - Access to sperm storage and other fertility issues for men are a problem. This is also relevant to long term effects and has a significant psychological impact.
 - There is a lack of consistency in provision and commissioning of fertility services which is relevant for young women and men.
 - Melanie Davies and Lizzy Williams were suggested speakers.
 - It would be helpful to hear from commissioners about Sustainability and Transformation Plans (STPs) and about commissioning fertility services for TYA cancer patients.
- LS will circulate the draft agenda for the day and requested any further feedback on the agenda

ACTION 2: Draft plan for the education day to be circulated to the group.

4. Update on Trust Visits

- LS gave an update on Trust visits. LS has been compiling a directory of contact details and services at each Trust, including access to:
 - CLIC Sargent support
 - AOS
 - Social work
- LS received feedback on the TYA MDT, in particular regarding the option to dial in rather than send a form
- The group were in agreement about the value of dialling in, the benefits being:
 - Real time / direct feedback on the MDT outcome
 - Improve links with and understanding of TYA professionals and the support available
 - Reassuring for patient
- The difficulties are:
 - It can be difficult to dial in and present patients if you are not their key worker
 - There are problems being able to hear the conversation although videoconferencing is clearer
- LS also received feedback on the MDT forms as there are currently two, with an extra page seeming unnecessary. LS to check and revise form if needed so there is a single form.
- There can be problems feeding back MDT outcomes. Trusts to feed back to LS who the outcome needs to be sent to so that this can be included in the directory.
- Sometimes referring Trusts and the PTC double up and both give information packs
- LS fed back that TCT fund some TYA nurses in the community to support patients to make choices about treatment, through their treatment and post treatment. There may be funding for a TYA nurse in the North Thames network. LS will work with the board to deploy the resource. There has been very good feedback about the CLIC Sargent funded support.

ACTION 3: LS to check what information is required on TYA MDT form and amend if necessary
ACTION 4: Trusts to feed back to LS the contact details for who the MDT outcome should be communicated to.

5. Peer Review Update

- RH gave an update that Peer Review is likely to change and there are likely to be fewer standards with Trusts asked to self-report unless there are issues.
- There is uncertainty regarding the measures currently but there may be a review imminently.

6. TYA patients have superior survival if treated on a clinical trial

- RH presented data which demonstrated that:
 - Trial recruitment decreased with increasing age
 - Trial recruitment increased over time
 - Trial recruitment higher in those with a TYAC form
 - Survival significantly higher in those on trial
 - Mortality substantially higher in those not on trial
 - These data highlight the need to improve recruitment to clinical trials in TYA patients
- This is one of the aims of the board and RH invited members to nominate themselves to lead on research

7. National Cancer Patient Experience Survey – results for TYA Cancer Patients

- RH presented CPES data which showed that:
 - TYA patients are more likely to have multiple medical consultations prior to referral and diagnosis
 - The TYA group highlighted a number of additional areas of unmet need including better communication and more involvement in treatment decisions. TYA patients had a positive experience of research.
 - Patients treated within a PTC generally reported a significantly better experience of care compared to those treated in other hospitals
- It is difficult to look at the data at network level due to the small numbers of patients

8. Any other business

- The group discussed where patients are treated. Patients who are 19 years or older should be offered the choice between the PTC and a local TYA designated Trust. Patients under 19 years old should be treated at the PTC.
- The level of risk and patient choice should be considered and patient choice documented on the MDT form. The MDT should be reminded of the age of the patient at the meeting to support effective decision making.

9. Next Meeting

To be confirmed.

ACTION LOG

Action reference	Action	Owner	Date Due	Status
Nov-01	HS to circulate information on the National Cancer Vanguard and <i>London Cancer</i>	HS	Dec 2016	
Nov-02	Draft plan for the education day to be circulated to the group.	LS	Dec 2016	
Nov-03	LS to check what information is required on TYA MDT form and amend if necessary	LS	Dec 2016	Complete
Nov-04	Trusts to feed back to LS the contact details for who the MDT outcome should be communicated to.	Trusts	Dec 2016	

Attendees

Name	Trust/Organisation
Emma Chaplin	BTUH
Kizzy Parker	Chelsea and Westminster
Gill Read	Colchester / Mid Essex
Louise Soanes	UCLH
Michelle Vernon	CLIC Sargent
Rachael Hough	UCLH
Helen Saunders	London Cancer
Susan Mehta	UCLH
Cathryn Brock	Chelsea and Westminster
Wendy Ansek	Barts Health
Michelle Greenwood	Barts Health
Sinéad Cope	Charing Cross Hospital
Kate Williams	BHRUT
Elizabeth Kearey	BHRUT

Apologies

Name	Trust/Organisation
Katrina Maitland	Southend
Brendan McIntyre	TCT
Jasani Parag	BTUH
Anjelie Reyes	BTUH
Pauline Leonard	The Whittington
Laura Miles	Mount Vernon
Matt Riddleston	Mid Essex Hospital
Victoria Grandage	UCLH