



**Meeting:** CYP Expert Advisory Group  
**Date:** 7 June 2018  
**Time:** 2pm – 4pm  
**Venue:** Evolve Business Centre, Houghton Le Spring  
**Present:**

Katherine Dawson, MacMillan Haematology Nurse Specialist, North Tees & Hartlepool	KD
Alison Featherstone, Northern Cancer Alliance Manager	AF
Gail Halliday Consultant Paediatric Oncologist, Newcastle Hospitals NHSFT	GH
Karen Hamlen, Teenage Cancer Trust Lead Nurse, Newcastle Hospitals NHS FT	KH
Lynn Hammal, Local Service Specialist, Specialised Commissioning	LHa
Laura Hope, NCA Programme Manager (LWBC)	LH
Toni Hunt, Regional Services Manager, Teenage Cancer Trust	TH
Lisa Jordan, Local Service Specialist, Specialised Commissioning	LJ
Emma Lethbridge, Consultant, Newcastle Hospitals NHS FT	EL
Jill Linton, TYA Designated Nurse, South Tees NHS FT	JL
Scott Marshall, Consultant, Sunderland	SM
Adrienne Moffett, Network Delivery Manager, Northern Cancer Alliance	AM

**Arrived at 2.45**

**In Attendance**

Claire Collard, Senior Administrator, NCA	CC
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**Apologies**

Simon Bailey, Consultant Pediatrics Oncologist, RVI	SB
Sandra Barlow, Nurse Specialist, Newcastle upon Tyne Hospitals NHS FT	SBar
Katie Elliott, GP lead, Cancer Alliance	KE
Gary McCoy, Social Work Team Leader, CLIC Sargent	GM
Michelle Mangan, Cancer Services Manager, Newcastle Hospitals NHS FT	MM
Nithya Natnavelu, Consultant, Gateshead	NN
Diane Plews, Consultant, South Tees	DP
Rod Skinner, Consultant, Newcastle	RS
Jane Stewart, Screening Manager, NHS England	JS
Maria Szubert, Consultant Haematologist, NTH	MS
Penny Williams, Research Delivery Manager	PW
NIHR Clinical Research Network North East and North Cumbria	
Linda Wintersgill, Information and Audit Manager, Northern Cancer Alliance	LW

## MINUTES

### 1. INTRODUCTION

#### 1.1 Welcome and Apologies

AF welcomed everyone to the meeting and introductions were made. Apologies as listed above. AF Congratulated Lisa Jordan on her new role as Regional Programme of Care Manager for Women and Children's in the North and thanked Lisa for all of the support she has provided to the group.

	Action	Enc

### **EAG Membership**

Simon Bailey Paediatric Consultant to be removed from the EAG.  
Gail Halliday to represent paediatrics.  
To be reviewed under terms of reference.

CC

### **1.2 Declaration of Conflict of Interest**

No declarations of conflict of interest were declared.

### **1.3 Minutes of the previous meeting 15.03.2018**

Attendees - Lisa Jordan to be removed from the minutes as she did not attend the meeting  
Section 1.4 to read "A meeting was held between the trust and CLIC Sargent".  
Following the amendments the group accepted the minutes as a true record.

CC

Enc 1

### **1.4 Matters arising**

- **Funding for fertility preservation**

Jane Stewart to be invited to September meeting.

- **TYA Long term follow up**

To be discussed at the September meeting

- **TYA Patient Feedback**

Patient and public voice involvement

AF explained to the group the on-going work carried out by the Cancer Alliance team regarding representation of the patient's voice at meetings. The Cancer Alliance Team are carrying out a wider piece of work involving all EAG's to outline a role descriptor.

## **2. AGENDA ITEMS – Paediatrics**

### **2.1 Service Specification**

All registered stakeholders had been sent a draft specification to review.

The Service Specification for Paediatrics was discussed.

Various comments were noted below:

- The number of POSCU recorded for the North of England. None were recorded as didn't meet level 1, 2 or 3.
- The formation of networks, who would lead and the role of the Cancer Alliance.
- Issues relating to the reduction of centres delivering

treatments, patients travelling for treatment and designated hospitals.

The group agreed that it would be more beneficial to see all specifications together as it is difficult to comment without all of the information. Timescales for the specifications to be released are vague.

The group agreed it would be useful to understand when the other specifications (paediatric radiotherapy and TYA) would be available in order to plan responses. Group asked LJ to enquire about timescales and report to chair. **LJ**

The group agreed to meet to discuss the specifications once available **ALL**

EL requested to review minutes prior to sending to the group. **CC**

### **3. AGENDA ITEMS – combined**

#### **3.1 Cancer Alliance Update**

AM provided an update to the meeting regarding the Cancer Alliance. The transformation funding has been confirmed for 18/19. The funding is connected to the region's 62 day standard performance. NCA are to receive 100 percent for Q1 and Q2. The funding for Q3 and Q4 will be agreed in September.

The CA team are currently focusing on optimal pathways for lung, prostate, lower GI and inter-provider transfers for upper GI.

AF attended the National Cancer Alliance meeting on Monday and received confirmation that there will be a role for the Cancer Alliance support team post March 2019. However, there was no confirmation regarding the transformation funding.

The good news story – additional spend on Linacs with new machines in Newcastle and North Cumbria in 17/18.

AF reported the business case to combine working between Newcastle and Cumbria has progressed. Further work is to be carried out on the operational detail. AF reported a partnership board has been established between specialised commissioning the two Trusts and the CCG and is chaired by the Cancer Alliance.

#### **3.2 Terms of Reference**

Terms of reference have been previously circulated to the group for feedback.

The group requested changes to the Tor as follows:

**Enc 2**

## Membership

CLIC Sargent to be added into the core membership.

“TYA” to be amended to “TCT” representative.

To include “Paediatrics” and “TYA” from both – instead of rep from primary treatment centre.

AM  
AM

Minimum requirement for Quorum was discussed.

The group agreed to include specialised commissioning and some representation from the Cancer Alliance.

AM

Updated Terms of reference to be circulated with minutes

CC

The Terms of reference were formally agreed and signed off with an understanding that a further review would be required in line with the service specification when available.

### 3.3 Presentations from TYA Designated Units

AF reminded the group that there are processes in place for designation of services but no processes in place for de-designation and review. Therefore ALL services are being reviewed.

AF reported she had been asked to discuss designation at the Haematology EAG who advised that they would expect a TYA designated service to be 2b and above. The group discussed this recommendation.

LJ to discuss expected levels of designated services at the local governance group and will feedback.

LJ

- **Sunderland: Dr Scott Marshall**

Dr Scott Marshall delivered a presentation to the group on TYA Designated Service at Sunderland Royal Hospital.

Dr Scott Marshall gave an overview of:

- Site Specific Cancer sites designated for TYA age Group.
- TYA services at SRH
- Patient numbers at SRH in 2017
- Outcomes for patients
- ENT & urology Cancers
- MDT Database – second line treatment

Presenta  
tion

<p>The group discussed the presentation and suggested that the Head and Neck service may wish to offer TYA service alongside the current Thyroid designated service. SM to discuss with the team</p>	<p><b>SM</b></p>	
<p>The group requested some clarification on the current urology service as the designation was felt to be for testicular patients only with BEP being delivered at Newcastle.</p>	<p><b>AM/SM</b></p>	
<p>EL raised an issue regarding non-designated hospitals treating TYA patients. LJ to raise as a quality concern with specialised commissioning and local governance group. EL to provide details to LJ.</p>	<p><b>LJ / EL</b></p>	
<ul style="list-style-type: none"> <li>• <b>Gateshead: Dr Nithya Natnavelu</b> Did not attend but will be requested to present at the September meeting</li> </ul>	<p><b>AM</b></p>	
<p><b>3.4 EAG Discussion Paper</b> The group discussed the EAG paper which was circulated. AM briefed the group and gave an overview of the document.</p> <p>NCA offers to support two meetings per year for each EAG. One learn and share event and one business meeting.</p> <p>AM asked the group if they are happy to continue with what this offer?</p> <p>EL commented - yes but only if meeting is functional and have appropriate representatives at the meeting.</p> <p>The Service specification will drive future meetings.</p> <p>Group agreed to continue with current support from the CA.</p>		
<p><b>3.5 Action Log</b></p> <p>The Action log was circulated with previous minutes for comments. The group endorsed the action log at this meeting, once updates have been made. NCA Board have requested that only red actions be escalated.</p> <p>Point 1 – update – action to invite Steve Shields to attend meeting in September. – not red</p> <p>Point 2 – follow up pathways – Emma and Karen to present challenges at meeting in September – not red</p> <p>Point 3 – for next meeting Adrienne to email Penny to have data on clinical trial numbers.</p>	<p><b>AM</b></p>	<p><b>Attach</b></p>

### 3.6 LWBC Programme Update

Laura Hope delivered a presentation to the group on the LWBC programme.

Laura discussed the following areas:

- Aims and objectives of the LWBC Programme
- Survival and unmet needs of survivors
- Living with cancer and the consequences of treatment
- Recovery packages
- Holistic needs assessment
- Treatment Summary's
- Cancer Care Reviews
- Health and Well-being events
- Stratified follow-up
- Remote surveillance monitoring; and
- Future work

For further information and advice– contact LH at NCA.

[laura.hope1@nhs.net](mailto:laura.hope1@nhs.net)

The group acknowledged that this would be a big cultural shift for Primary Care.

The group requested Laura Hope to be invited to the September meeting – to give input on options on implementing LWBC agenda into to the TYA pathway.

LH

## 4. AGENDA ITEMS – TYA

### 4.1 TYA Referral and regional feedback to date

KH fed back to the group regarding TYA referral and regional feedback.

KH highlighted the current progress on a new video to promote the TYA service and what support is available. This is currently in draft format.

KH met with Amanda Walshe in North Tyneside to promote the service and will be attending future MDT meetings for skin.

AM suggested showing video at clinical leadership group.

KH – invited to present video at North Tyneside and Durham.

## 5. STANDING ITEMS

### 5.1 Any other business

None

### 5.2 Date of next meeting:

20 September 2018, 2.00-4.00, Evolve Business Centre

Contact

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