



## North Thames Teenager and Young Adult's Cancer Network Coordinating Group (TYACNCG) Annual Report 2016-17

### Introduction

The North Thames TYA Cancer Network serves a population of 8.36 million people across North Central and East London, Essex, Mount Vernon and North West London.

TYA cancer services are delivered through the Principal Treatment Centre (PTC), situated at University College London Hospital (UCLH), and 11

partner TYA designated Hospitals:

- Barking Havering and Redbridge University NHS Trust
- Barts Health NHS Trust (for Barts and the Royal London)
- Royal Free Hampstead Hospital NHS Trust (Skin, HPB, NET and renal cancers only)
- Whittington Health NHS Trust (shared care only)
- Chelsea & Westminster Hospital NHS Trust (HIV and skin only)
- Imperial Healthcare Hospitals NHS Trust
- Southend University Hospital NHS Trust
- Colchester Hospital University NHS Trust
- Mid Essex Hospitals Trust
- Basildon and Thurrock University Hospital NHS Trust (Shared Care only)
- Mount Vernon Cancer Centre / East & North Hertfordshire NHS Trust (Lister hospital)



Dr Rachel Hough, TYACNCG Chair



Dr Louise Soanes, TYACNCG Lead Nurse

All patients aged up to 18 years are treated at the PTC and patients aged 19-24 years chose between care at the PTC or care closer to home in their nearest TYA designated hospital.

The TYACNCG led by Dr Rachael Hough (Chair) and Dr Louise Soanes (Lead Nurse) is responsible for driving improvement across the whole care pathway in a specific cancer type. The Board's membership includes multi-disciplinary representation from cancer professionals across the region and active participation from primary care and from patients.

The role of each pathway board is to understand any variation in practice and set standards that take advantage of planning whole pathways of cancer care for a large population. This drive to improve cancer care for patients covers an integrated care pathway that extends from presentation and diagnosis through to palliative care and living with and beyond cancer. Disease specific pathways for TYA patients across the network are operational and all patients have access to the TYA MDT, based at the PTC. For 2016/7, a total of 268 new patients and 143 follow-up patients were discussed in the MDT, with 72 new patients being presented by the designated trusts.

## Achievements this year

2016/17 has seen the TYACNCG become part of the newly formed UCLH Cancer Collaborative, part of the national Cancer Vanguard as part of the New Care Models programme of NHS England.

This year we have had a focus on network governance, updating patient pathways and patient experience.

Our key achievements have been:

- Updating the membership and constitution of the Board including site visits across the network
- Organising a pan-London TYA Cancer Education Event to be held in June 2017
- Updating referral pathways for Brain and Spine, Eye Cancer, Gynaecology, Leukaemia, Lymphoma, Skin and Proton Beam Therapy
- Drafting a TYA patient experience survey
- Improved care across the network is indicated by 100% TYA patients discussed in the TYA MDT across the network now have an identified key worker and 83% of patients were recruited to a clinical trial if a trial was available

## Patient representation

Our patient representatives have moved on to either university or full time employment. With the re-establishment of the patient involvement team, we are looking forward to welcoming new representatives in the coming year.

## Future plans

In 2017/18 we will have a focus on linking into the work on the National CYP CRG on service reconfiguration, post treatment and recovery, and understanding patient outcomes. Our work plan is outlined below.

No	Objective	Owner	By
1	Pathway improvement <ul style="list-style-type: none"><li>- Update and complete written pathway including the transfer from acute to late effects</li><li>- Define generic transition pathway from acute to long term follow up</li><li>- Submitting a bid to TCT for additional outreach posts to support young people in their local environment.</li></ul>	LS  SM/VG  LS	March 2018
2	Improve patient experience <ul style="list-style-type: none"><li>- Conduct patient satisfaction survey</li><li>- Understand and address gaps in roll out of improved patient information and gain feedback</li></ul>	LS	August 2017
3	Improve research and access to clinical trials	BC	March 2018
4	Develop a collection of metrics to understand the current position and progress for care of TYA in the network working with the International Consortium for Health Outcomes Measurement (ICHOM)	RH	March 2018
5	Recovery <ul style="list-style-type: none"><li>• Introduce treatment summaries for all survivors of teenage and young adult cancer as they transfer to long-term follow-up</li></ul>	VG/SM	March 2018

	<ul style="list-style-type: none"> <li>• Invite young people to be core members of a late effects steering group to inform future development of the service</li> <li>• Introduce an annual late effects event based on the patient satisfaction feedback following the pilot event in 2016</li> <li>• Introduce a transition event for all young people transferring to the late effects service from Great Ormond Street Hospital and Royal Marsden Hospital</li> <li>• Introduce a discharge to self-management information pack</li> </ul>		
6	Early diagnosis: undertake audit of two week wait referrals	RH	March 2018

## Acknowledgements

We would like to thank all the members of the North Thames Teenager and Young Adult's Cancer Network Coordinating Group for contributing their time to Board meetings and projects outside the meeting.