



North Thames Teenager and Young Adult's Cancer Network Coordinating Group (TYACNCG) Annual Report 2017-18

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 Rachael Hough, TYACNCG Chair, Consultant Haematologist at UCLH



Dr Louise Soanes, TYACNCG Lead Nurse, Nurse Consultant at UCLH

All patients aged up to and including 18 years are treated at the PTC and patients aged 19-24 years are offered a choice 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 for all cancer types. The Board's membership includes multi-disciplinary representation from cancer professionals across the region.

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.

Achievements this year

In 2017/18, 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
- Holding a successful pan-London TYA Cancer Education Event in June 2017.
- Introduced a transition event for all young people transferring to the late effects service from Great Ormond Street Hospital and Royal Marsden Hospital.

Patient representation

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

Future plans

In 2018/19 we will have a focus on linking into the work on the National CYP CRG on service reconfiguration, post treatment transition and recovery, and understanding patient outcomes. Our work plan is outlined below.

No	Objective	Owner	By
1	Pathway improvement - Update and complete written pathway including the transfer from acute to late effects. - Submitting a bid to TCT for additional outreach posts to support young people in their local environment.	LS	March 2019
2	Improve patient experience - Conduct patient satisfaction survey. - Understand and address gaps in roll out of improved patient information and gain feedback.	LS	March 2019
3	Improve research and access to clinical trials - Engage with appropriate partners to develop platforms to link patient teams with studies that may be relevant to their patients care - Develop metrics to monitor patients are being appropriately screened and entered on to clinical trials.	BC	March 2019
4	Develop a collection of metrics to understand current position and progress for care of TYA in the network working with international partners, the International Consortium for Health Outcomes Measurement (ICHOM)	RH	March 2019
5	Recovery - Introduce treatment summaries for all survivors of teenage and young adult cancer as they transfer to long-term follow up - Invite young people to be core members of a late effects steering group to inform future development of the service - Introduce an annual late effects event based on the patient satisfaction feedback following the pilot event in 2016	VG/SM	August 2018

	- Introduce a discharge to self-management information pack		
6	Early diagnosis - Undertake audit of two week wait referrals	RH	August 2018
7	Engaging with the national service review - Hold an engagement event - Register as a stakeholder for the CYP CRG - Provide feedback on the new TYA cancer service specifications when circulated for feedback	RH	March 2019

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.