



Yorkshire & Humber Teenage Young Adult Cancer Clinical Network Meeting (previously known as Operational Delivery Network)

Tuesday 3rd December 2024 15:00 - 17:00

Online Meeting

Attendees:

Name	Role	Organisation
Sarah Mettrick (SM)	DH TYA Lead Nurse	Calderdale and Huddersfield NHS Foundation Trust
Rachel Cloke (RC)	DH TYA Lead Nurse	Doncaster and Bassetlaw NHS Foundation Trust
Ruth Medlock (RM)	TYA MDT Lead	Doncaster and Bassetlaw NHS Foundation Trust
Lesley Barnett (LB)	Head of Cancer Nursing	Doncaster and Bassetlaw NHS Foundation Trust
Dara Gibbons (DG)	DH Lead Nurse	Harrogate NHS Foundation Trust
James Wilson (JW)	DH TYA Lead Clinician	Harrogate NHS Foundation Trust
Claire Swift (CS)	DH TYA Lead Nurse	Hull University Teaching Hospitals Trust
Jill Doherty (JD)	TYA MDT co-ordinator	Leeds Teaching Hospitals NHS Trust
Kathleen O'Connor (KOC)	WGS Nurse	Leeds Teaching Hospitals NHS Trust
Diane Hubber (DHu)	TYA Lead Nurse	Leeds Teaching Hospitals NHS Trust/Y&H CTYACCN
Paula Galbraith (PG)	DH TYA Lead Nurse	Mid Yorkshire Teaching NHS Trust
Rachel Wane (RW)	TYA Research Champion for Yorkshire and Humber	NIHR
Hilary Campbell (HC)	Research Delivery Manager	NIHR
James Taylor (JT)	DH TYA Lead Clinician	Rotherham NHS Foundation Trust
Tricia Wyer (TW)	MDT and Service Administrator	Sheffield Teaching Hospitals NHS Trust
Robyn Hedge (RH)	TYA CNS	Sheffield Teaching Hospitals NHS Trust
Robin Young (RY)	TYA Lead Clinician	Sheffield Teaching Hospitals NHS Trust
Angela Stephens (AS)	Late Effects CNS	Sheffield Teaching Hospitals NHS Trust
Helen Trower (HT)	TYA Research Nurse	Sheffield Teaching Hospitals NHS Trust
Chris Capstick (CC)	Health Engagement Manager	Teenage Cancer Trust
Anne Thomson (AT)	Biobank Manager	VIVO Biobank
Paddy Carley (PCa)	Data Co-ordinator	Y&H CTYACCN
Alex Chilvers (AC)	Network Manager	Y&H CTYACCN

Apologies:

Name	Role	Organisation
Jan Bunch	TYA Lead Nurse	Bradford Teaching Hospitals NHS Foundation Trust
Iqtedar Muazzam	DH TYA Lead Clinician	Hull University Teaching Hospitals Trust
Dan Stark	TYA Lead Clinician	Leeds Teaching Hospitals NHS Trust
Danielle Brown	Pharmacist	Leeds Teaching Hospitals NHS Trust
Leanne Elder	Pharmacist	Leeds Teaching Hospitals NHS Trust
Nicki Ingram	Clinical Radiographer	Leeds Teaching Hospitals NHS Trust
Ruth Brown	CEO/Network Chair	Sheffield Children's NHS Foundation Trust/Y&H CTYACCN
Liz Purnell	TYA Lead Nurse	Sheffield Teaching Hospitals NHS Trust/Y&H CTYACCN
Lynn McNamee	Diagnostics Delivery Manager	West Yorkshire and Harrogate Cancer Alliance
Gillian Jackson	TYA Lead Nurse	York and Scarborough Teaching Hospitals NHS Trust
Nicky Bould	Senior Clinical Psychologist	York and Scarborough Teaching Hospitals NHS Trust

Actions:

Action	Responsible Person
DHu to send HNA to Mid Yorkshire.	DHu
DHu to forward contacts for over 18s Late Effects service in Leeds to AS.	DHu

Item	Minutes	Action
1	<p>Welcome and Apologies DHu welcomed the group as chair and highlighted the apologies noted above.</p> <p>Declarations of Interest No declarations of interest noted.</p> <p>CCN participation tracker The tracker will be updated after the meeting, with any issues to be raised to the chair.</p> <p>Notes from the previous meeting Previous minutes agreed by the group.</p>	
2	Matters arising (not featured on the main agenda)	

	<p>Benchmarking update</p> <p>AC thanked the group for completing the self-assessment tool and reminded centres that the deadline to check the draft report is 9th December. AC will write an overarching report following this for NHSE which will show how the network is measuring against the service specification. Also, the work plan is developed from this report and will encompass issues which centres may need help with.</p> <p>She noted Hull and Harrogate benchmarking visits are both due in January 2025. All other centres have completed the benchmarking process.</p>	
<p>3</p>	<p>Service Update Slides including Clinical Governance</p> <p>Doncaster RC updated the group.</p> <p><i>Local service description</i> Lead TYA consultant - Dr R Medlock. Lead TYA Nurse - Rachel Cloke. Access to cubicle on ward 18 and on the Chatsfield suite day unit. DRI had a total of 8 TYA patients 2023-2024 (including 1 haematology patient).</p> <p><i>Service update</i> Close relationship with STH and Rotherham. Discussions with our local palliative care team after the TYA study day showed support and offers of donations to the TYA service in providing money for specific equipment. They are also looking at developing a garden for patients who may require a quiet reflection space. Plans underway to access Power BI to identify all TYA patients through DRI (like Rotherham's process).</p> <p><i>Multi professional workforce</i> Dr Medlock has taken over the TYA Lead role at DRI. Close working relationship with the lead and team at STH. To try and provide an equitable provision for TYA patients (see above).</p> <p><i>Referral pathways</i> Referral pathway via STH with no issues identified. No shared care pathway but looking at the team accessing Lorenzo or an updated online system</p> <p><i>Service specification requirements</i> Benchmarking completed, and no issues identified.</p> <p>DHu queried regarding Power BI. RC noted it is a system which enables staff to access data which can pick up TYA patients. RC is currently trying to get access. LB offered support with access to Power BI and highlighted the magnificent work RC is doing as Lead Nurse. DHu is happy to support with any upcoming projects. RC highlighted the support from Liz Purnell in Sheffield with training and attending CNS meetings.</p>	

Harrogate

DG updated the group.

Local service description

2023 - 5 TYA patients (2 melanomas, 1 leukaemia, 1 parotid, 1 testicular).

2024 - 6 so far (2 gynae, 1 bladder, 1 parotid, 2 lymphomas).

Most patients referred to the PTC (Leeds). Currently treating 2 lymphomas at HDFT.

Service update

Benchmarking visit is due January 2025.

Multi professional workforce

New Lead Clinician - Dr James Wilson (Consultant Haematologist).

Outgoing Lead Nurse in January 2025 (Dara Gibbons) awaiting recruitment as this post sits within the Lead Haematology CNS.

Referral pathways

No issues currently.

Not always able to offer a side room for TYA patients on SACT unit due to capacity issues. This will be picked up in the benchmarking visit.

Service specification requirements

Interviews for new Lead Nurse due mid-December.

Mid Yorkshire

PG updated the group.

Local service description

Provides diagnostics and some limited treatments depending on cancer type and presentation. All TYA patients are referred to LTHT for MDT. No designated TYA accommodation on any of the 3 hospital sites.

Haematology ward will accommodate in side rooms.

2023 - 14 TYA patients (10 first treatments, 5 local and 5 in Leeds, 4 subsequent treatment, 4 local SACT delivery).

2024 - 11 TYA to date (8 first treatments, 5 local and 3 in Leeds 3 subsequent treatments, all local surgery).

Service update

SOP to be updated in Q4.

Lead CNS and Lead Clinician in post (both from Haematology team).

Inpatient Haematology unit moved for major rework, resulting in lower bed numbers and fewer side rooms to accommodate patients.

Lack of robust referral and monitoring process for all current patients.

Multi professional workforce

Lead Clinician - Kathryn Thornton (new in post).

Lead CNS - Paula Galbraith (new in post) - PG would be interested in any TYA specific formal training.

MDT coordinator - Katherine French.

<p><i>Referral pathways</i> All TYA patients are referred into the Leeds MDT for information and access to holistic support. MYTT to adopt Leeds HNA. Referral form used tumour site wide and uploaded to PPM electronic notes system.</p> <p><i>Service specification requirements</i> TYA Specific HNA or EOT summaries not completed currently. Will adopt Leeds HNA and develop the use of EOT within the speciality.</p> <p>DHu queried if referral issues were to do with other cancers besides Haematology. PG noted there may be another database but is unsure if there is a robust referral process. DHu suggested CNS meetings and visits and noted the benchmarking process suggested more education programs. The Network Clinical Educator role will be due in post in January to support education.</p> <p>AS queried if SOPs can be shared to adapt to each centre's needs. DHu asked if this was a SOP for caring for young people. Unfortunately, no other Designated Hospitals had any up-to-date processes. DHu feels this would be good project to work with as a network after benchmarking discussions.</p> <p>Rotherham JT updated the group. <i>Local service description</i> 2024 - 5 TYA patients. Lead TYA Consultant Haematologist - James Taylor. Lead TYA Nurse - Louise Ollivant Haematology CNS. Access to Cubicle on Ward A7 Haematology Ward. Access to Cubicle on Ward A6 Chemotherapy Day Unit.</p> <p><i>Service update</i> Power BI well embedded in practice to identify TYA patients aged 16-24 with a cancer diagnosis across the trust via Infoflex.</p> <p><i>Multi professional workforce</i> Rachel Goodgrove (Haematology CNS - TYA Link Nurse) attended the recent TYA Day which was especially useful and will help deputising for LO.</p> <p><i>Referral pathways</i> No issues identified.</p> <p><i>Service specification requirements</i> Benchmarking completed, and no changes identified.</p> <p>DHu queried if Power BI was available in all regions. LB noted it is the system in which Cancer Alliances send out data to centres. DHu noted this could help alleviate some referral issues in Mid Yorkshire, for</p>	<p>a. DHu to send HNA to Mid Yorkshire.</p>
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example. CC highlighted it is a Microsoft Package and IT, or procurement should be able to help. TW stated STH were unable to use Power BI.

Hull

CS updated the group.

Local service description

4 beds unit with 2 cubicles.

Dr Muazzam - TYA Lead.

Dr Bailey - Lead Haematologist.

CNS, Staff Nurses, and YSC.

~30 patients treated per year. Historically, Hull took patients up to age 30 but had to stop this due capacity issues. Current bed capacity issues.

Operational policy means TYA have priority, but capacity at the Queens Centre negating this. CS is unsure what the TYA service can do regarding this.

Service update

Very good working relationship with Leeds PTC. Attending psychosocial MDTs and using IAMs. No issues finding patients with regular CNS meetings in place and hearing about patients prior to diagnosis which is great.

Multi professional workforce

Looking at implementing the ACCEND framework. Interested in hosting a TYA study day. Spoke to management about more clinical supervision which will be provided by psychological services. Young palliative patients recently diagnosed. Support not formalised currently. Lots of patients diagnosed with incurable cancers and more deaths than previous years.

Referral pathways

Working with network team to improve pathways for chemotherapy joint care and looking at sharing information on systems. Need to finalise a date for the benchmarking process. DHu noted different challenges to other Designated Hospitals due to bed capacity.

Late Effects

AS updated the group. She queried regarding challenges for access to bloods for telephone appointments. Disease fatigue often happens when coming for face-to-face appointments. Patients often emerge with late effects symptoms, and she is looking for creative ways to access local bloods.

RH stated most centres use ICE so staff can use an open net request with "sample later." STH's remit covers South Yorkshire and NLAG, and LTHT's covers the West Yorkshire area. DHu noted the challenge is often identifying blood rooms. AS will feed this information back to the late effects group.

Risk Register

AC noted the network risk register is currently being worked up. TYA peer review acknowledged this wasn't in place. DHu highlighted a risk

	<p>affecting Leeds; fertility preservation is not offering egg storage for 16–18-year-olds. Currently, Leeds is looking at alternatives. DHu is investigating service agreements and funding for this process. AC highlighted concerns can be raised to the network group.</p>	
<p>4</p>	<p>Service improvement project updates</p> <p>Research accrual DHu noted various challenges around the TYA trials dashboard due to staff changes in informatics. AC is hoping for more updates soon.</p> <p>Whole Genome Sequencing KOC updated the group. DHu highlighted some disparity across the region as STH has no WGS nurse in post. KOC is further developing pathways from previous postholder and looking for any issues, pitfalls, and solutions for the process. She is working closely with the labs to identify how systems work, as there had been issues with booking in samples. Pathways will go live on the intranet in the new year and offer an overview of electronic documents and education links.</p> <p>KOC noted the need for fresh tissue samples. She is due to talk with surgeons to negate any potential communication issues. She is looking for paediatric neuro-oncology patients to see if any have been missed between postholders. Any other backlog issues are also being worked through. Plans to link in with tumour site teams to offer education, support and improve access to testing.</p> <p>DHu noted the benchmarking process showed some centres are offering WGS, and others not. Anyone is welcome to contact KOC for more information on WGS. RY queried regarding the model in Leeds, is KOC doing most of the administration in the pathways. KOC noted she is for 0–25-year-olds and all sarcoma patients, whilst also linking in with gynae nurses and helping their patient pathway process. She noted each site-specific team will be doing this rather than TYA team, but she needs to embed the pathway first.</p> <p>DHu noted it’s important to put roles into place; teams knew what to do before but didn’t have capacity - evidence that we need the nursing post. KOC attends the GTAB (Genomic Tumour Advisory Board) meeting and this week there was no clinicians. Fortunately, the WGS Nurse was able to provide clinical history.</p> <p>Gaps in care TYAC and CCLG is running a project led by Liz Purnell with panels of Designated Hospitals. Key issues to be identified at a meeting in January and work is ongoing with updates to come.</p> <p>Joint care This is a project looking at chemotherapy given in local Designated Hospitals, starting with Hull. Meetings have been taking place and</p>	

	<p>pathway examples drawn up with the next meeting taking place 10th December.</p> <p>PPIE Helen Richards has taken on 7.5 hours of Julie White's time as Network Lead Nurse and is specifically looking at PPIE for Children's and TYA services. Meetings are in the calendar with stakeholders with updates and feedback to come at the next meeting.</p>	
5	<p>Updates from other meetings Radiotherapy mutual aid LTHT is still offering mutual aid with no updates currently.</p>	
6	<p>AOB RH highlighted the recent TYA Study Day in Sheffield garnering positive feedback, with emphasis on the young person's panel being successful. DHu highlighted a similar experience for the Network Education Day.</p> <p>DHu noted that Kelly Smith has been appointed as the new Clinical Educator for the network (part time). She starts in January and hopes to offer in-house education sessions.</p> <p>AS queried if anyone wishes to link in for age gaps in late effects services. She wishes for more educational opportunities, online tutorials, and networking. DHu highlighted TCT's monthly webinars which are open to anyone working with young people on treatment.</p> <p>AT reminded the group that VIVO biobank is open to all for information and help. The contact details are available at: https://vivobiobank.org/</p> <p>CS noted at the CNS meeting last week the ACCEND framework was discussed. LB implemented ACCEND in Doncaster and is happy to help regarding this.</p>	<p>b. DHu to forward contacts for over 18s Late Effects service in Leeds to AS</p>

Dates of next meetings – each 3-5pm (all put in diaries now please);

- Thursday 6th March 2025
- Monday 9th June 2025
- Tuesday 2nd September 2025
- Wednesday 3rd December 2025