Yorkshire & Humber Children, Teenage & Young Adult Cancer Clinical Network

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

Wednesday 3rd December 15:00 - 17:00

Online Meeting

Attendees:

Name	Role	Organisation
Rachel Lyles (RL)	POSCU Lead Nurse	Airedale NHS Foundation Trust
Michelle Ratcliffe (MR)	Lead Cancer Nurse	Bradford Teaching Hospitals NHS Foundation Trust
Sarah Mettrick (SM)	DH TYA Lead Nurse	Calderdale and Huddersfield NHS Foundation Trust
Amanda Harland (AH)	DH TYA Lead Nurse	Harrogate NHS Foundation Trust
Iqtedar Muazzam (IM)	DH TYA Lead Clinician	Hull University Teaching Hospitals NHS Trust
Kirsty Gascoigne (KG)	DH TYA Lead Nurse	Hull University Teaching Hospitals NHS Trust
Diane Hubber (DHu)	TYA Lead Nurse	Leeds Teaching Hospitals NHS Trust/Y&H CTYACCN
Helen Richards (HR)	Network Lead Nurse	Leeds Teaching Hospitals NHS Trust/Y&H CTYACCN
Dan Stark (DS)	TYA Lead Clinician	Leeds Teaching Hospitals NHS Trust/Y&H CTYACCN
Paula Galbraith (PG)	DH TYA Lead Nurse	Mid Yorkshire Teaching NHS Trust
Kathryn Thornton (KT)	DH TYA Lead Clinician	Mid Yorkshire Teaching NHS Trust
Louise Ollivant (LO)	DH TYA Lead Nurse	Rotherham NHS Foundation Trust
Tricia Wyer (TW)	MDT Co-ordinator	Sheffield Teaching Hospitals NHS Trust
Liz Purnell (LP)	TYA Lead Nurse	Sheffield Teaching Hospitals NHS Trust/Y&H CTYACCN
Julia Dicks (JD)	Clinical Director	South Yorkshire and Bassetlaw Cancer Alliance
Anne Thomson (AT)	Biobank Manager	VIVO Biobank
Paddy Carley (PCa)	Data Co-ordinator	Y&H CTYACCN
Alex Chilvers (AC)	Network Manager	Y&H CTYACCN

Member Trusts	09/06/2025	02/09/2025	01/10/25 (Education Day)	03/12/2025
Leeds Teaching Hospitals NHS Trust	Yes	Yes	Yes	Yes
Sheffield Teaching Hospitals NHS Foundation Trust	Yes	Yes	Yes	Yes
Sheffield Children's Hospitals NHS Trust	Yes	Yes	Yes	No
Airedale NHS Foundation Trust	Yes	No	No	Yes
Calderdale and Huddersfield NHS Foundation Trust	No	Yes	No	Yes
Hull and East Yorkshire NHS Foundation Trust	No	No	Yes	Yes
York Teaching Hospital NHS Foundation Trust	Yes	Yes	Yes	No
Bradford Teaching Hospitals NHS Foundation Trust	Yes	Yes	No	Yes
Doncaster and Bassetlaw Teaching Hospitals NHS Foundation Trust	Yes	Yes	Yes	No
The Rotherham NHS Foundation Trust	Yes	Yes	No	Yes
Harrogate and District NHS Foundation Trust	No	Yes	Yes	Yes
Mid Yorkshire Teaching NHS Trust	No	Yes	No	Yes

Apologies:

Name	Role	Organisation
Caroline Salt	Macmillan Lead Cancer Nurse	Airedale NHS Foundation Trust
Jan Bunch	DH TYA Lead Nurse	Bradford Teaching Hospitals NHS Foundation Trust
Richard Kelly	Consultant Haematologist	Leeds Teaching Hospitals NHS Trust
Daniel Swinson	Consultant Medical Oncologist	Leeds Teaching Hospitals NHS Trust
Kelly Smith	Clinical Educator	Leeds Teaching Hospitals NHS Trust/Y&H CTYACCN

Julie White	Network Lead Nurse	Leeds Teaching Hospitals NHS Trust/Y&H CTYACCN
Jill Kenworthy	Lead Cancer Nurse	Mid Yorkshire Teaching NHS Trust
Rachel Wane	TYA Research Champion	NIHR
Jane Howcroft	Programme Performance Assurance Manager	South Yorkshire and Bassetlaw Cancer Alliance
Elaine McTavish	Health Engagement Manager	Teenage Cancer Trust
Lynn Mcnamee	Diagnostics Delivery Manager	West Yorkshire and Harrogate Cancer Alliance
Jason Pawluk	Managing Director	West Yorkshire and Harrogate Cancer Alliance
Hazel Rodgers	Professional and Clinical Lead - Nursing & AHP	West Yorkshire and Harrogate Cancer Alliance
Emma Clarke	CEO	Weston Park Charity

Item	Minutes	Action
1	**Welcome and Apologies** DS welcomed the group and encouraged new members to introduce themselves. Apologies are noted above. **Declarations of Interest** No declarations of interest noted. **CCN participation tracker** The tracker will be updated after the meeting, with any issues to be raised to the chair. DS noted help and support is available for anyone struggling with attendance. **Notes and actions from the previous meeting** Previous minutes agreed by the group. **Previous actions** • *Any centres interested in developing an automated diagnoses report to email PCa, DHu or AC.* DHu and KG had discussed this yesterday with KG to contact PCa for more information if required. • *DHu, DS, TW, LP, PCa to liaise regarding MDT attendance and timeliness of data transfer.* AC looked at patients with Hodgkin Lymphoma concerning TYA data transfer between HUTH and LTHT. She has included DHu and KG in email trail to give examples of specific issues. • *AC to email JB to check in regarding Bradford Lead Consultant role.*	

	MR noted this is no further forward as she hadn't received any responses yet. DS visited Bradford recently and the trust was willing but individual consultants were experiencing difficulties.	
2	**Matters arising (not featured on the main agenda)** **Teenage Cancer Trust (TCT) update** DS highlighted this as a sensitive issue. LP noted the health engagement manager is off currently with Elaine McTavish allocated to cover. DHu stated she is aware of this meeting and hopes to attend in the future. LP stated charities are struggling financially and TCT is looking at their structure and how they finance front line posts. There is uncertainty over how this will affect Yorkshire and Humber. DHu acknowledged the TYA service may need to approach trusts and designated hospitals for funding. LP noted there will be wider discussion over how much trusts are paid for services. DS stated this will take place at strategic and practical levels due to changes to funding. He acknowledged innovative ways of working will be needed to deliver excellent care. Whether funding is identified or not, both situations will need to accounted for. LP noted TCT is planning another congress in spring/early summer 2027.	
3	**Service Update Slides including Clinical Governance** **Designated Hospitals** **Harrogate** AH updated the group. *Local service description* • All TYA patients referred to Leeds MDT. • Local cancer MDT co-ordinators aware to inform Lead CNS of any new TYA patients. • Separate rooms offered and available on chemo day unit for TYA patients. • 5 TYA patients in last 10 months. *Service update* • SOP updated 2025. • Benchmarking visit in January 2025 with positive report. *Multi professional workforce* • TYA consultant James Wilson. • Lead TYA CNS Amanda Harland. *Referral pathways* • Good links with principal treatment centre. *Service Specification Requirements* • Not using TYA specific HNA. • Macmillan HNA used.	

Hull
KG updated the group.

Local service description

- 1 CNS and 1 YSC.
- Dr Muazzam - Lead Oncologist.
- Dr Bailey - Lead Haematologist.
- 4 bed TYA unit based on ward 33 which is also the Haematology ward.
- New patients since July 2025:
- Haematology - 3
- Skin - 1
- Brain - 3
- Germ cell - 3
- Sarcoma - 1
- Urology - 1
- Gynaecology - 1
- 5 of these patients are now cared for in Leeds and have shared care with us.

Service update

- No dedicated TYA band 5 nurse. Ward 33 staff now have to manage all day case patients as well as inpatients. Staffing was a problem and communication seemed poor regarding the ward staff having to take on day case TYA patients.
- Example of a patient sent to adult chemotherapy day unit for blood products which caused a lot of anxiety.
- Building a good relationship with the ward sister and matron. Agreed that TYA patients just requiring blood test or line changes we will use adult services available. If patients require blood products or Chemotherapy, they will come to ward 33 into the TYA dayroom as a day case.
- TYA dayroom was being used for adult haematology ambulatory service. Concerns raised regarding this which has now been resolved.
- There have been 9 new starters on ward 33 who are all newly qualified. Plan for the staffing on ward 33 to have a dedicated TYA nurse although this has not yet happened due to training of the new staff.
- We have put in place 4 TYA link roles: 1 band 6, 1 band 5, 2 HCA to try and improve the communication regarding TYA patients between the team and the ward.

Multi professional workforce

- Plan to attend regional TYA cancer education day. Funding for Ward 33 TYA link roles and ward manager to attend.
- Planning started with Diane Hubber and education team to look at doing some local TYA study days with ward 33 staff.

Referral pathways

- Building a good relationship with LTHT team. Communicating well and shared care seems to be going well.
- Staffing in the office is very limited with just a CNS and YSC here. Sometimes there can be a delay in organising the blood appointments asked by PTC. Looking into ways we can improve this.
- Some struggle in attending some of the MDT meetings due to the lack of staff we have in our team and clashing commitments.

Service Specification Requirements

- PAF form to be completed at diagnosis. Not TYA specific.
- HNA form but not TYA specific.

DS and the group congratulated Charlene Kent on her recent 'outstanding care' award at the Humber and North Yorkshire Cancer Alliance ceremony.

Mid Yorkshire

PG updated the group.

Local service description

2024/25 patient throughput:

- Haematology - 5
- H&N - 1
- Lower GI - 2

Service update

- SOP gone through local governance. Query over divisional governance.
- TYA designated inbox for referrals and awareness for all tumour sites and what teams should consider when treating e.g., WGS and heads assessments.
- TYA intranet page underway for all tumour sites to refer to for guidance.

Multi professional workforce

- Clinical Lead - Kathryn Thornton - Consultant Haematologist.
- Lead TYA CNS - Paula Galbraith - Lead Haematology CNS.

Referral pathways

- All TYA patients currently referred to Leeds TYA MDT for care planning.
- Undergoing review of formal shared care agreement for local access to blood monitoring and line care transfusion requirements.

Service specification requirements

- TYA HNA - adopted HEADSS assessment form Leeds which is now in use at MYTT.
- EOT- still to roll out within speciality.

Rotherham
LO updated the group.

Local service description

- Diagnoses 24/11/24 - 23/11/25 - 4
- CML - 1
- Connective/ soft tissue - 1
- Malignant neoplasm - 1
- Carcinoma in situ of skin lower limb - 1

- Lead TYA Consultant Haematologist - James Taylor.
- Lead TYA Nurse - Louise Ollivant - Haematology CNS.
- TYA Link Nurse - Rachel Goodgrove - Haematology CNS.
- Access to Cubicle on Ward A7 Haematology Ward.
- Access to Cubicle on Ward A6 Chemotherapy Day Unit.

Service update

- PowerBI well embedded in practice to identify TYA patients aged 16-24 with a cancer diagnosis across the trust via Infoflex.

Multi professional workforce

- No issues - small numbers of patients.
- Continue to meet regularly with team at Sheffield PTC.

Referral pathways

- No issues identified.

Service specification requirements

- No changes to report.

PTCs

Leeds
DHu updated the group.

Local service description

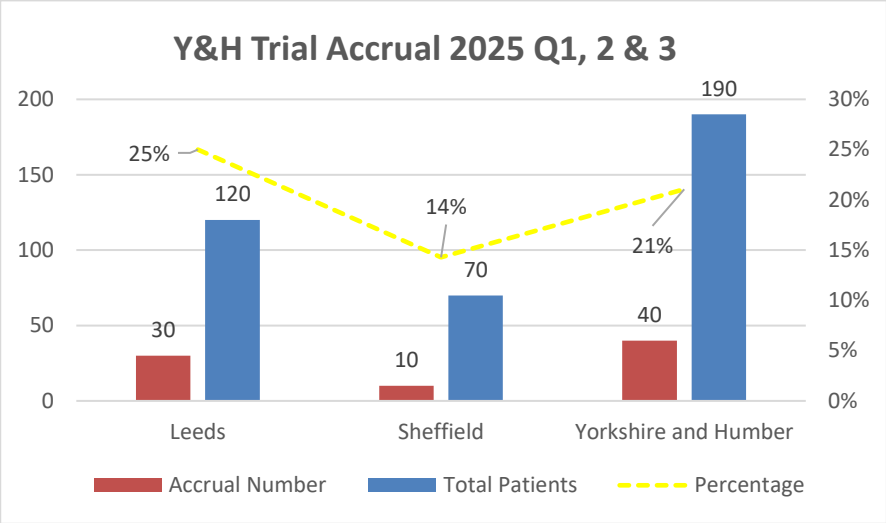
- One service covering two sites.
- Ward 33 covering 13-18.
- Ward 24 covering 18 - 25 including day case chemotherapy.
- Rise in numbers from an average of 130 a year to 175 in the last 12 months.
- Seen an increase in very rare diagnosis and standards ones with poorer prognosis due to unusual genetic changes.

Service update

- Ward 33 - 4 bed bay open for young people. Side rooms are bone marrow transplant unit. Works complete on BMT unit but staffing remains a restricting factor for reopening.

	• Ward 94 - recognition that day case treatment numbers are higher than inpatient numbers in the 18 -25 aged range. Work being done to evidence this with a possibility of increasing day case area and reducing inpatient bed numbers. • Youth support worker who covers 18 -25 now on secondment to March. Cover advert out now. • Ongoing work with Hull around supportive care for 16–18-year-olds. • Agreement to extend referral to long term follow up for cases such as Hodgkin's Lymphoma and Leukaemia who are treated in the adult service. • Looking at figures of young people in DHs aged 18-25 who would also be eligible to build a case and recommendation for referral on the back of service specification guidance. Funding discussion at cancer alliance and ICB may be require. • Blood tests closer to home being looked at with DHs to see how LTHT can facilitate this. *Multi professional workforce* • Psychologist on maternity leave with cover in October. Waiting list for psychology support is 18 weeks. Utilising Ella Dawson foundation. • Planning for regional education day with Sheffield. This was delayed due to the issues around funding reductions and not knowing impact on post holders who would be providing teaching. Due to proximity to ODN education day plans to arrange for March or April to give two education opportunities 6 months apart through the year. *Referral pathways* • Hull shared care pathway for 16–18-year-olds work on going. • Joint care programme success means Leeds can see Hull tests and investigations on ICE saving considerable CNS time and improving patient experience. • Local blood tests pre-treatment experiencing some challenges to have these done due to GP not doing bloods for patients for secondary or tertiary care. • Discussions have begun with Bradford if there is a way of having bloods be taken at locally at their trust when there is no named consultant. If solution found other designated trust will be approached. **Sheffield** LP updated the group. *Local service description* • January to November 2025: 62 new patients, 8 relapsed • SCH - 13 - 16-year-olds • WPH - 16 - 25-year-olds - Oncology • RHH - 16 - 25-year-olds - Haematology	

	Service update • Awaiting discussion between TCT and STH re final funding model. *Multi professional workforce* *TYA Staffing:* • No WGS CNS • TYA Research Nurse in post, 1 day per week. • 1 YSC on long term sickness *Research:* • Vivo Biobank is open across both Haem onc and Solid tumours. • Reached target for Young Survivors of Cancer • Recruited patients across 4 different studies • TYA Research nurse attended UKONS with a poster on the work she has been doing *Education:* • Regional study day with Leeds planned for April 2026 • Part of the Junior Doctor Induction at WPH. • Part of the student nurse programme at Hallam University. • Part of the new nurse starter day for Haematology and Oncology. • Part of the SCH induction day • Continue to offer education to CNS teams across the region • Presented at the annual Paediatric Palliative Care conference *Referral pathways* • No Changes • Achievements: • Set up a National group looking at the gaps in care for 16–18-year-olds • Shortlisted for Nursing Times Award • Involved with developing a UK version of Voicing My Choices (palliative care tool to promote discussions) • Working with SCH and St Lukes Hospice developing a Palliative care transition simulation course (covering all illnesses but includes 2 cancer specific scenarios)	
4	**Service improvement project updates** **Training and education** Julie White provided a written update: *"we're scoping provision provided by other PTCs to identify what may be helpful to develop locally and mapping options of how we may deliver Training and Education across the network. We are planning a steering group meeting for early in the New Year to discuss all of this and agree what may work best moving forward."* **Research accrual** PC shared the TYA trial accrual data for Q1-3 2025. This has been cross-referenced with local MDT data and confirmed with research teams.	



Whole Genome Sequencing
AC noted previous roles have been cut due funding issues. She has been informed a workforce review led by the LTHT Lead Cancer Nurse will take place but initial plans show genomics will be included in current roles. There is a lot of work involved and DS looks forward to developing this business case as a region.

Biobanking
AT noted LTHT is still regularly banking but there are some issues with solid tumour collection. VIVO is opening at Royal Hallamshire Hospital in Sheffield and visiting Hull in hopes of opening there. She emphasised VIVO provide all the tools for banking and welcomed staff to contact her.

AT noted haematology and solid samples are taken frozen and FFPE and VIVO is in regular contact with pathologists. DS stated this is a very well organised and run research endeavour which is minimally invasive. He noted those receiving care closer to home can contribute to cancer care improvements and new treatments arise from this research.

16-18 pathway
DHu noted work is ongoing between LTHT and HUTH which is contributing to national work. LP noted good representation in the national work from this region. She highlighted 3 working streams nationally:

1 - Palliative and end of life care group (co-chaired by Robyn Hedge) writing best practice guidance on supporting young people.

2 - Transition group looking at appropriate guidelines patient and parent voices involved.

3 - Genomics group who have sent out a survey to pathology labs asking what is offered currently.

DS suggested this is removed from the regular agenda.

Joint care

	DS noted the joint care between HUTH and LTHT has moved forward but EHR relationships have proven challenging. Biochemistry and histology results are more available in Humber which is helpful for blood work locally. Radiology is able to be delivered locally with reports provided after working on a proof of principle. DS hopes for an alternative to signing in to separate systems as an end point. **PPIE** HR introduced herself and gave a brief overview of the network PPIE project. She noted plans to raise the profile of the network by using social media. QR codes have been developed to direct patients to the website form 'what will make your day better?'. She encouraged all the group to share as widely as possible with qualitative and quantitative data needed. HR has undertaken a lot of scoping work with various forms of PPIE already taking place. She wants to draw on themes and keep the patient voice at the heart of what the network does as a continuous project. HR has developed a person specification for a charitable representative to sit on the board and integrate patient voices. DHu highlighted valuable answers can be gained from this but asked if there were any issues in designated hospitals due to lower throughput. HR asked if it work better to send directly to patients. KG highlighted a new patient information pack in HUTH which PPIE details may be added to. DS noted discussions about engaging local charities as part of this project. HR is keen to cover TYA and children's age ranges so intends to approach YLvC first and open to other charities after.	
5	**Updates from other meetings** **Radiotherapy mutual aid** AC and JD noted a deadline of 18th December and a meeting will be scheduled once all models are explored. Specialised commissioning is able to update if required.	
6	**AOB** No other business noted.	

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

- 5th March 2026
- 8th June 2026
- 8th September 2026
- 9th December 2026