

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

Wednesday 5th March 15:00 - 17:00

Online Meeting

Attendees:

Name	Role	Organisation
Jan Bunch (JB)	DH TYA Lead Nurse	Bradford Teaching Hospitals NHS Foundation Trust
Sarah Mettrick (SM)	DH TYA Lead Nurse	Calderdale and Huddersfield NHS Foundation Trust
Natalie Kisby (NK)	Head of Family Support	Candlelighters
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
Kelly Smith (KS)	Clinical Educator	Leeds Teaching Hospitals NHS Trust/Y&H CTYACCN
Julie White (JW)	Network Lead Nurse	Leeds Teaching Hospitals NHS Trust/Y&H CTYACCN
Rachel Wane (RW)	TYA Research Champion	NIHR
Louise Ollivant (LO)	DH TYA Lead Nurse	Rotherham NHS Foundation Trust
Angela Stephens (AS)	Late Effects CNS	Sheffield Teaching Hospitals NHS Trust
Jemma Midgley (JM)	Youth Support Co-ordinator	Sheffield Teaching Hospitals NHS Trust
Hannah Richardson (HR)	TYA CNS	Sheffield Teaching Hospitals NHS 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
Lauren Johnson-King (LJK)	Head of Health Engagement	Teenage Cancer Trust
Anne Thomson (AT)	Biobank Manager	VIVO Biobank
Lynn Mcnamee (LM)	Diagnostics Delivery Manager	West Yorkshire and Harrogate Cancer Alliance
Paddy Carley (PCa)	Data Co-ordinator	Y&H CTYACCN
Alex Chilvers (AC)	Network Manager	Y&H CTYACCN

Apologies:

Name	Role	Organisation
Michelle Ratcliffe	Lead Cancer Nurse	Bradford Teaching Hospitals NHS Foundation Trust
Rachel Cloke	DH TYA Lead Nurse	Doncaster and Bassetlaw Teaching Hospitals NHS Foundation Trust

Martin Elliott	Consultant Paediatric Haematologist	Leeds Teaching Hospitals NHS Trust
Richard Kelly	Consultant Haematologist	Leeds Teaching Hospitals NHS Trust
Daniel Swinson	Consultant Medical Oncologist	Leeds Teaching Hospitals NHS Trust
Dan Stark	TYA Lead Clinician	Leeds Teaching Hospitals NHS Trust/Y&H CTYACCN
Jill Kenworthy	Lead Cancer Nurse	Mid Yorkshire Teaching NHS Trust
Paula Galbraith	DH TYA Lead Nurse	Mid Yorkshire Teaching NHS Trust
Kathryn Thornton	DH TYA Lead Clinician	Mid Yorkshire Teaching NHS Trust
Dan Yeomanson	Consultant Oncologist	Sheffield Children's NHS Foundation Trust
Deborah Rowley	Advanced Physiotherapist	Sheffield Children's NHS Foundation Trust
Katharine Patrick	Consultant Paediatric Haematologist	Sheffield Children's NHS Foundation Trust
Elaine McTavish	Health Engagement Manager	Teenage Cancer Trust
Hazel Rodgers	Professional and Clinical Lead - Nursing & AHP	West Yorkshire and Harrogate Cancer Alliance
Emma Clarke	CEO	Weston Park Charity
Bev Barker	Team Manager	YLvC
Gill Jackson	DH TYA Lead Nurse	York and Scarborough Teaching Hospitals NHS Foundation Trust
Helen Richards	Network Lead Nurse	Leeds Teaching Hospitals NHS Trust/Y&H CTYACCN
Amanda Harland	DH TYA Lead Nurse	Harrogate NHS Foundation Trust

Item	Minutes	Action
1	<p>Welcome and Apologies LP welcomed the group as deputy chair and encouraged new members to introduce themselves. Apologies are noted above.</p> <p>Lauren Johnson-King introduced herself as Head of Engagement for Teenage Cancer Trust.</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. LP noted help and support is available for anyone struggling with attendance.</p>	

Member Trusts	09/06/2025	02/09/2025	01/10/25 (Education Day)	03/12/2025	05/03/2026
Leeds Teaching Hospitals NHS Trust	Yes	Yes	Yes	Yes	Yes
Sheffield Teaching Hospitals NHS Foundation Trust	Yes	Yes	Yes	Yes	Yes
Sheffield Children's Hospitals NHS Trust	Yes	Yes	Yes	No	No
Airedale NHS Foundation Trust	Yes	No	No	Yes	No
Calderdale and Huddersfield NHS Foundation Trust	No	Yes	No	Yes	Yes
Hull and East Yorkshire NHS Foundation Trust	No	No	Yes	Yes	Yes
York Teaching Hospital NHS Foundation Trust	Yes	Yes	Yes	No	No
Bradford Teaching Hospitals NHS Foundation Trust	Yes	Yes	No	Yes	Yes
Doncaster and Bassetlaw Teaching Hospitals NHS Foundation Trust	Yes	Yes	Yes	No	No
The Rotherham NHS Foundation Trust	Yes	Yes	No	Yes	Yes
Harrogate and District NHS Foundation Trust	No	Yes	Yes	Yes	No
Mid Yorkshire Teaching NHS Trust	No	Yes	No	Yes	No
<p>Notes and actions from the previous meeting Previous minutes agreed by the group.</p> <p>Previous actions N/A</p>					
2	<p>Matters arising (not featured on the main agenda)</p> <p>Teenage Cancer Trust (TCT) update LJK updated the group. She noted leadership changes internally with the CEO stepping down. Julie Worrall is acting as interim CEO, offering a period of stability whilst planning to recruit a permanent CEO.</p> <p>TCT is pleased to see plans to reflect calls recognising the needs of young people (trials and faster diagnosis, for example) in the national cancer plan. TCT spent a lot of time petitioning and advocating with MPs, supporting with the youth advisory group and working to ensure accountability and real change.</p> <p>Service delivery highlights include recent Royal Albert Hall gigs with the team working hard for a backstage experience. She noted positive press coverage around misinformation on sunbeds involving the BBC news health team.</p>				

	<p>2 age-appropriate health information booklets are being updated. ‘Your Diagnosis’ had the copy and design reworked involving front line staff and young people.</p> <p>Charity funded posts contracts for 2026 are being drafted and updated in the next week.</p>	
<p>3</p>	<p>Service Update Slides including Clinical Governance</p> <p>Bradford JB noted that Bradford is still struggling to appoint a clinical lead. New consultants have started and she is hoping they may take on the role. AC/DHu are available to support JB with any queries.</p> <p>Leeds DHu noted April is TYA cancer awareness month. If anyone has any promotion ideas, they can link in with the Lead Nurses.</p> <p>Sheffield RH is conducting a literature review of high intensity end of life care in AYAs. The conclusion being haematology cancers are at a significant disproportion and the least likely to have a DNACPR or palliative care input.</p>	
<p>4</p>	<p>Service improvement project updates</p> <p>Training and education KS and JW hosted a steering group in January and are looking at training options, noting there isn’t much for TYA currently. She is investigating options available to deliver at LTHT and STH PTCs and is contacting Designated Hospitals in South and West Yorkshire to meet in person. She is happy to take any questions over email: kelly.smith45@nhs.net</p> <p>Research accrual PC and RW shared their presentation, available here: 2025 Trial Accrual and Diagnosis data.pptx</p> <p>LP highlighted issues in research and difficulties in opening studies, especially qualitative ones. RW noted challenges about sites opening specific diagnoses trials; STRONG-AYA and PROTECT is disease and site specific. She noted a time lag between studies opening and diagnoses recognised as increasing.</p> <p>JW stated the importance of flagging mitigating factors, as it is easy to assume centres are not hitting targets. RW suggesting adding mitigating factors to the presentation. PC and RW will discuss this moving forward.</p> <p>LP noted the data doesn’t include instances of trials offered and declined by the patient. RW stated this is hard data to capture as LTHT crosses over different teams.</p>	

DHu is hoping to capture more data for 2026 with an updated spreadsheet. She suggested having a log of whether a trial was available for the patient or condition.

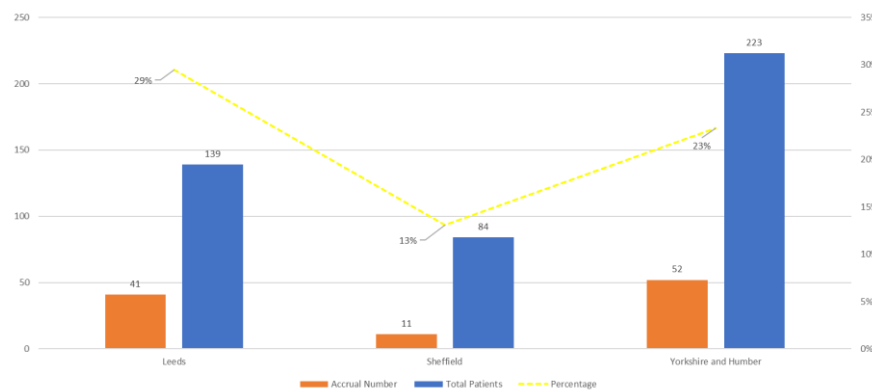


Fig. 1 2025 trial accrual data

Whole Genome Sequencing

AC noted the recent workforce review has changed, with the WYAAT pathology programme now conducting the genomics review. WGS is mandated by the service specification but there is only a small resource to help.

LP noted WGS is included in the cancer plan so it is not solely a TYA issue and will impact the entire pathway. STH PTC is struggling as it requires executive level buy in.

DHu noted the HUTH pathologists don't have funding in their job plan for WGS. The only solution to Designated Hospitals taking on WGS is performing all biopsies in PTCs.

LP noted Paediatrics has standardised pathways of care and adult brain services has lab buy in. JW asked if biopsies done in Designated Hospitals could be forwarded to PTC for WGS assessment. LP highlighted the need for fresh samples at the right time.

JW stated WGS is more embedded in Paediatrics as the CNS helped with pathway development. LP highlighted the TYA pathway is more disparate with most cancers seen and biopsied locally before referred to the PTC.

DHu noted an incident with a tongue cancer biopsied locally at BRI which was unable to facilitate WGS. JW suggested opening funding opportunities to support development. DHu noted the small number of patients means it is difficult to get buy in. She suggested using examples of other hospitals across the country to raise awareness.

Joint care

AC noted EHRs and pharmacy systems interacting is the most difficult aspect of the project. The Yorkshire and Humber Shared Care Record team presented at the previous meeting. The team is working to see if it is possible view information from pharmacy prescribing systems. She stated

DHu, AC & LP to meet to discuss ways of approaching WGS with Designated Hospitals

	<p>outcomes from this project will be transferred to the other parts of the region in time. She has a lodged a bid with the Cancer Alliances for specific funding. The next meeting is due 16th April and the work forms part of the cancer plan, service specification and cancer alliance objectives.</p> <p>PPIE HR was unable to attend the meeting but gave a written update.</p> <ul style="list-style-type: none"> • She will be sending out the posters and business card bundles to POSCU's ASAP. These will contain the QR code 'what would make your day better?' link. • She is continuing to collate feedback from patients and families. • She has contacted Bev Barker, Patient Representative to welcome her on board and start discussions about what her role will look like. She welcomes any thoughts on this from the TYA team. • She is in the process of writing an SOP/protocol for "PPIE - Business as Usual" to be implemented in the future, in case Network funding is cut and/or her job no longer exists. <p>LP welcomed ideas on how to disseminate the information and encouraged members to contact Helen Richards (helen.richards12@nhs.net) for more information.</p>	
5	<p>Updates from other meetings</p> <p>Radiotherapy mutual aid LP noted unfortunately NHSE were not present at this meeting to update. HR asked whether a 16-year-old would need to go to LTHT for Radiotherapy treatment. LP suggested checking with the consultant firstly.</p>	
6	<p>AOB AT reminded the group of the joint CCLG & TYAC event which VIVO biobank has a stall at. DHu noted the TYA regional study day is on the 21st April with tickets still available.</p>	

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

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