



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

Thursday 6th March 15:00 - 17:00

Online Meeting

Attendees:

Name	Role	Organisation
Caroline Salt (CS)	Macmillan Lead Cancer Nurse	Airedale NHS Foundation Trust
Patricia Dyminski (PD)	DH TYA Lead Nurse	Airedale NHS Foundation Trust
Jan Bunch (JB)	DH TYA Lead Nurse	Bradford Teaching Hospitals 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
Natalie Kisby (NK)	Head of Family Support	Candlelighters
Rachel Cloke (RC)	DH TYA Lead Nurse	Doncaster and Bassetlaw NHS Foundation Trust
Tasha Dawson (TD)	Service Lead	Ella Dawson Foundation
Amanda Harland (AH)	DH TYA Lead Nurse	Harrogate NHS Foundation Trust
James Wilson (JW)	DH TYA Lead Clinician	Harrogate NHS Foundation 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
Helen Richards (HR)	Network Lead Nurse	Leeds Teaching Hospitals NHS Trust/Y&H CTYACCN
Kathryn Thornton (KT)	DH TYA Lead Consultant	Mid Yorkshire Teaching NHS Trust
Paul Kendrew-Jones (PKJ)	Specialised Commissioning	NHSE
Hilary Campbell (HC)	Research Delivery Manager	NIHR
Louise Ollivant (LO)	DH TYA Lead Nurse	Rotherham NHS Foundation Trust
Dan Yeomanson (DY)	Consultant Paediatric Oncologist	Sheffield Children's Foundation NHS Trust
Caroline Wiltshire (CW)	YSC	Sheffield Teaching Hospitals NHS Trust
Hannah Richardson (HR)	TYA CNS	Sheffield Teaching Hospitals NHS Trust
Robyn Hedge (RH)	TYA CNS	Sheffield Teaching Hospitals NHS Trust

Liz Purnell (LP)	TYA Lead Nurse	Sheffield Teaching Hospitals NHS Trust/Y&H CTYACCN
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
Ruth Medlock	TYA MDT Lead	Doncaster and Bassetlaw NHS Foundation Trust
Dan Stark	TYA Lead Clinician	Leeds Teaching Hospitals NHS Trust
Richard Kelly	Consultant Haematologist	Leeds Teaching Hospitals NHS Trust
Daniel Swinson	Consultant Medical Oncologist	Leeds Teaching Hospitals NHS Trust
Nicky Bould	Senior Clinical Psychologist	Leeds Teaching Hospitals NHS Trust
Paula Galbraith	DH TYA Lead Nurse	Mid Yorkshire Teaching NHS Trust
Rachel Wane	TYA Research Champion for Yorkshire and Humber	NIHR
Debbi Rowley	AHP Workforce Lead	Sheffield Children's Foundation NHS Trust
Ruth Brown	CEO/Network Chair	Sheffield Children's NHS Foundation Trust/Y&H CTYACCN
Diana Greenfield	TYA Late Effects Consultant	Sheffield Teaching Hospitals NHS Trust
Jemma Midgley	Youth Support Co-ordinator	Sheffield Teaching Hospitals NHS Trust
Robin Young	TYA Lead Clinician	Sheffield Teaching Hospitals NHS Trust
Chris Capstick	Health Engagement Manager	Teenage Cancer Trust
Emma Clarke	CEO	Weston Park Charity
Gill Jackson	DH TYA Lead Nurse	York and Scarborough Teaching Hospitals NHS Trust

Actions:

Action	Responsible Person
AC to add Hull nursing issues to risk register if applicable	AC
LP/AC to raise WGS issues at board meeting	LP/AC

Item	Minutes	Action
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<p>1</p>	<p>Welcome and Apologies LP welcomed the group as chair and highlighted the apologies noted above. She asked all new participants to introduce themselves.</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. AC noted most staffing gaps have been filled enabling higher participation in this meeting after the benchmarking exercise.</p> <p>Notes from the previous meeting Previous minutes agreed by the group.</p>	
<p>2</p>	<p>Matters arising (not featured on the main agenda)</p> <p>Benchmarking update AC stated draft reports have been written and sent out to centres for approval. She is currently writing a summary report for all centres across the region. Senior management will be contacted so they're aware of any issues or support needed.</p> <p>Teenage Cancer Trust (TCT) update Chris Capstick (Health Engagement Manager - TCT) sent apologies so LP updated the group. TCT has experienced financial difficulties which required changes to fundraising and operational models. As a result of this, there has been job cuts in LTHT, STH and HUTH for MDT staff and the chemotherapy nurse in HUTH.</p> <p>LP highlighted the work and value of the MDT staff and chemotherapy nurse and how they are a massive part of the TYA team. TCT are performing a scoping exercise and have 3 funding models to share with the trusts. However, trusts do not currently have the funding plan confirmed for MDT posts which is causing a lot of stress.</p> <p>LP is unsure what future staffing model looks like and this has been added to network risk register. AC noted trusts are meeting with TCT over the coming weeks to look at the impact of losing TCT funded posts. Discussions are ongoing with senior management teams as trusts need to know by September/October for budgeting purposes.</p>	
<p>3</p>	<p>Service Update Slides including Clinical Governance</p> <p>Bradford JB updated the group.</p> <p><i>Local service description</i> Vacancy for TYA lead as Haematology consultant is having issues with their job plan. JB asked if needs to be a haematologist. LP stated the lead</p>	

	<p>doesn't need to be a haematologist, but historically it has been that way. DY concurred. MR to pick discussions up in Bradford.</p> <p>Other teams in the trust are aware of the TYA service and are referring accordingly with support available from LTHT. Separate rooms are available on the ward, but the day unit is more difficult to negotiate separate space for TYAs.</p> <p><i>Service update</i> Lack of a clinical lead and an unsigned MoU are the current risks in Bradford. Bradford maintains a good working relationship with LTHT.</p> <p><i>Service specification requirements</i> There is no TYA specific eHNA in place. MR asked whether the TYA specific plan (IAMS) will work alongside the MyMacmillan system. DHu noted it cannot currently due to governance permissions in place. Due to questioning around TCT funding she is reluctant to make major changes. Once the funding position is clarified she will look to implement the IAMS system in all designated hospitals.</p> <p>Hull DHu raised the issue of Hull as a designated TYA service. As noted above, the chemotherapy nurse's funding from TCT has been withdrawn and HUTH are unable to fund the post. Alongside this, the TYA CNS is off on long-term sick leave. DHu suggested adding this to the network risk register. DHu is unclear what the plan is moving forward but sees keeping the chemotherapy nurse in post to backfill TYA CNS role as sensible.</p> <p>Mid Yorkshire KT updated the group.</p> <p><i>Local service description</i> 21 patient throughput in 2024/2025.</p> <p><i>Service update</i> TYA Lead Nurse updating SOP. Back on normal ward and up to capacity with side rooms.</p> <p><i>Multi professional workforce</i> TYA lead consultant and nurse relatively new to post.</p> <p><i>Referral pathways</i> Lead nurse is developing the shared care agreement for blood monitoring and line care transfusion requirements. Currently reviewing LTHT HNA and hoping to adopt locally.</p> <p><i>Service specification requirements</i> Arranging end of treatment visits which will hopefully be in place soon.</p>	<p>DHu to send out TYA specific IAMS assessment to all centres.</p> <p>AC to add Hull nursing issues to risk register if applicable.</p>
4	Service improvement project updates	

	<p>Research accrual AC stated staffing issues in informatics has resulted in delays of the dashboard as planned changes had not been passed on. Unfortunately, this has taken longer than anticipated and the final version is awaited pending governance regarding sharing data across the region. Ideally, all Designated Hospital and POSCU data will be included in the dashboard also.</p> <p>Whole Genome Sequencing LP stated there is currently no WGS team at STH. DY noted the service is offered at SCH but reporting is very slow. LP has escalated the lack of service at STH as an issue to TCT and the trust.</p> <p>DHu wishes to discuss this as a network as the genomics service is looking to establish without a nurse in post. Unfortunately, LTHT is unable to acquire further funding. She queried if it would be beneficial to ask commissioning for pathway co-ordinator or nurse funding.</p> <p>DY stated WGS is offered to most solid tumour as the lead oncology nurse has taken on the consent process and organises blood samples. This post is not funded and is additional to their job role. Haematology is also good at offering WGS; however, the complicating factor is often skin biopsy samples. LP noted this is a regional issue and should be raised at the network board meeting.</p> <p>Gaps in care LP highlighted the national issue concerning the 16-18-year-old gap. She is part of a Children's and Young People's Cancer Association (previously known as CCLG/TYAC) working group looking at issues and improvements to the system. If you wish to get involved with this work, please contact LP.</p> <p>Joint care DHu noted this project aims to oversee the challenges of offering chemotherapy treatments in designated hospitals with the PTC overseeing conditions such as sarcoma. Key issues faced include pharmacy delivery and prescriptions. Unfortunately, the nursing issues noted previously in Hull may make progress difficult.</p> <p>LP noted the GTD service (covering the north of England with patients in TYA age range) in STH raised issues with obtaining methotrexate for 16-year-olds. She suggested having a conversation with the nurse consultant as it is a commissioned service and only one between Yorkshire and London.</p> <p>DHu sees this as a good example to discuss in next joint care meeting. Often, trusts won't allow staff to deliver chemotherapy which wasn't prescribed in their trust due to governance issues. She queried whether this was replicated in designated hospitals across the region.</p>	<p>LP to raise WGS issues at the network board meeting</p>
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	<p>CS suspects Airedale wouldn't treat patients unless their prescription was made on ChemoCare. PD concurred as the prescription wouldn't be recognised within pharmacy. DHu will take this information back to the working group.</p> <p>LO suggested a live document on ChemoCare would work for treatment in Rotherham. DHu noted Hull use Aria which doesn't link effectively with ChemoCare.</p> <p>DY stated ensuring drug dosages are correct is vital. He noted some community nurses are trained to treat chemotherapy at home with a clear chain of collection in place. For this to work there needs to be a clear protocol to maintain correct drug doses are given. ChemoCare could be solved with remote access, or consultant requiring prescribing rights in a certain hospital covered by the Memorandum of Understanding or honorary contracts. Most centres are running the same system, but the ultimate solution is a single prescribing system across the network.</p> <p>PPIE PCa has shared HR's PowerPoint with all stakeholders. If anyone wishes to get involved with the PPIE work, please contact Helen Richards.</p>	
5	<p>Updates from other meetings</p> <p>Radiotherapy mutual aid PKJ noted specialised commissioning is in the final stages of securing non-recurrent funding for the STH - LTH mutual aid arrangement. The longer-term solution is still being investigated, but fragility in the north east and north west is adding to issues. There is a project team in place with a board meeting to follow later this month. He noted the importance of securing finances to continue mutual aid and will provide updates as the programme moves along.</p>	
6	<p>AOB LP raised TCT funding streams to PKJ from a specialised commissioning standpoint; he suggested speaking outside the meeting.</p> <p>DY expanded upon this and noted palliative care is historically funded by third sector financial support. However, this is often written into service specifications as requirement. In DY's opinion, services either need to be funded by NHSE or taken out of service specifications. Large parts of services are provided by third sector organisations who are now struggling to afford this.</p>	

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

- Monday 9th June 2025
- Tuesday 2nd September 2025

- Wednesday 3rd December 2025