



TYA CANCER CLINICAL NETWORK MEETING MINUTES

06/06/2024 3:00-5:00pm on Teams

Attendees:

Name	Role	Organisation
Patricia Dyminski (PD)	TYA Lead Nurse	Airedale NHS Foundation Trust
Holly Stanley (HS)	CNS	Airedale NHS Foundation Trust
Sarah Mettrick (SM)	TYA Lead Nurse	Calderdale and Huddersfield NHS Foundation Trust
Sylvia Feyler (SF)	TYA Lead Clinician	Calderdale and Huddersfield NHS Foundation Trust
Rachel Cloke (RC)	Lead Nurse	Doncaster and Bassetlaw NHS Foundation Trust
Dara Gibbons (DG)	Lead Nurse	Harrogate NHS Foundation Trust
Claire Swift (CS)	TYA Lead Nurse	Hull University Teaching Hospitals Trust
Diane Hubber (DHu)	TYA Lead Nurse	Leeds Teaching Hospitals NHS Trust /Y&H CTYACCN
Julie White (JW)	Lead Nurse	Leeds Teaching Hospitals NHS Trust /Y&H CTYACCN
Dan Stark (DS)	Consultant Medical Oncologist	Leeds Teaching Hospitals NHS Trust/ Y&H CTYACCN
Kevin Peters (KPe)	Service Commissioner	NHS England
Rachel Wane (RW)	TYA Research Champion for Yorkshire and Humber	NIHR
Hilary Campbell (HC)	Research Delivery Manager	NIHR
Louise Ollivant (LO)	Lead Nurse	Rotherham NHS Foundation Trust
Dan Yeomanson (DY)	Consultant Paediatric Oncologist	Sheffield Children's NHS Foundation Trust
Liz Purnell (LP)	TYA Lead Nurse	Sheffield Teaching Hospitals NHS Trust
Tricia Wyer (TW)	MDT and Service Administrator	Sheffield Teaching Hospitals NHS Trust

Georgia Thompson (GT)	Associate Director of Cancer Services	South Yorkshire ICB
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
Gillian Jackson (GJ)	Lead Nurse	York and Scarborough Teaching Hospitals NHS Trust

Apologies:

Name	Role	Organisation
Iqtedar Muazzam	TYA Lead Clinician	Hull University Teaching Hospitals Trust
Leanne Elder	Pharmacist	Leeds Teaching Hospitals NHS Trust
Danielle Ingham	Consultant Paediatric Oncologist	Leeds Teaching Hospitals NHS Trust
Alun Windle	Chief Nurse	Sheffield Teaching Hospitals NHS Trust
Nigel Beasley	Consultant ENT Surgeon	Sheffield Teaching Hospitals NHS Trust
Robin Young	Consultant Medical Oncologist	Sheffield Teaching Hospitals NHS Trust
Emma Clarke	CEO	Weston Park Charity
Nicky Bould	Senior Clinical Psychologist	York and Scarborough Teaching Hospitals NHS Trust
Muhammed Naveed	Consultant Haematologist	York and Scarborough Teaching Hospitals NHS Trust

Action log	Responsible person
Chase outstanding benchmarking document	AC/PC
Facilitate tech discussions between Designated Hospitals with Power BI tool	AC/PC/LO
DHu to contact AC regarding PPIE funding proposal	DHu/AC

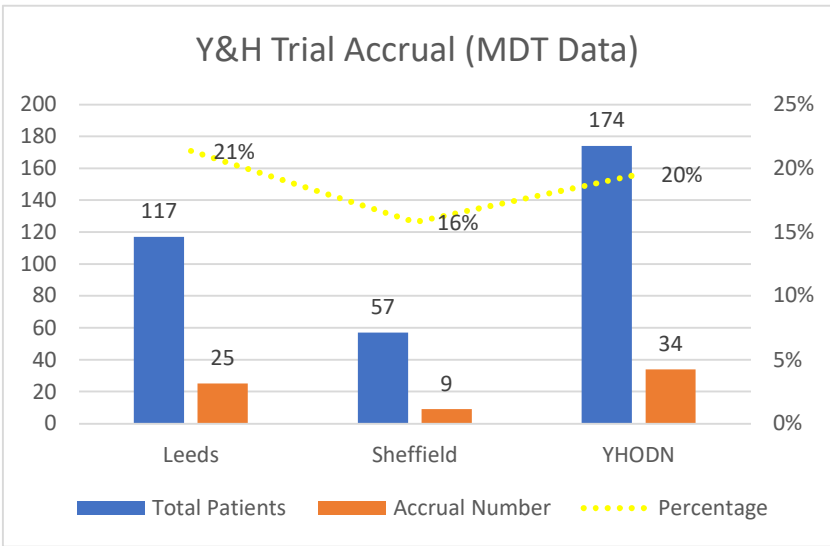
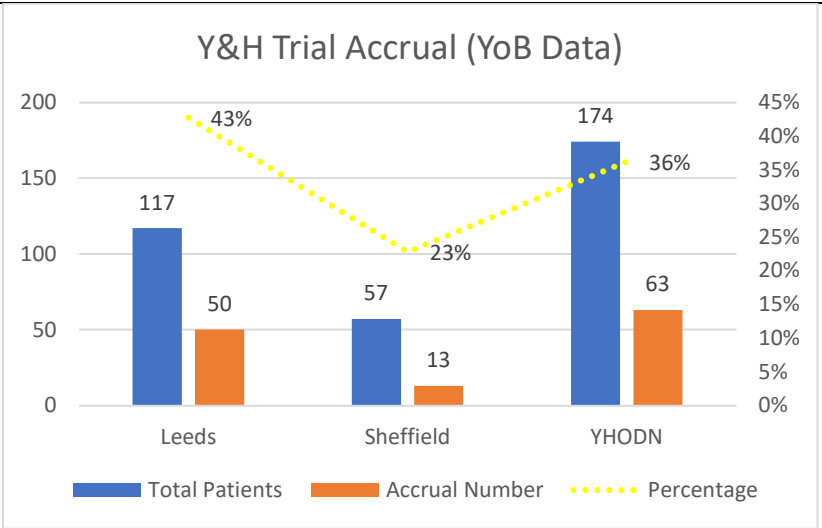
Item	Minutes	Action
1	<p>Standard Business</p> <p>Welcome, Introductions and Apologies DS introduced the group. Apologies noted above.</p> <p>Declarations of Interest No declarations of interest noted.</p>	

	<p>ODN participation Tracker Participation tracker shared with Airedale’s attendance today noted as a positive.</p> <p>Notes from previous meeting Minutes agreed from the previous meeting.</p> <p>Late effects discussion TYA late effects service across network has not been added as an agenda point yet, but if members wish for this to happen a working group could be developed. The network would need a group of people with this as a keen interest.</p> <p>JW noted Jess Morgan has been appointed recently as lead for late effects for 0–18-year-olds. She is investigating the pathway and will link in with adult side. DS stated Leeds offers services for those aged up to 30 treated with chemotherapy and/or radiotherapy. Michelle Kwok Williams is leading the state-of-the-art services.</p> <p>LP highlighted Angela Stephens and Diana Greenfield pick up TYA referrals in Sheffield. Diana Greenfield is looking into brain cancer patients missing referrals for late effects. DY clarified this gap is for surgery only neuro-oncology patients.</p> <p>DHu noted late effects services are changing and the network should focus on the benchmarking process for now, and to fully consider this after the acute services are in order. She suggested inviting the Late Effects service to speak at this meeting.</p> <p>DS asked the group for comments on TYA late effects managed close to home.</p> <p>CS noted this service is managed by <i>living with and beyond cancer</i> at Castle Hill Hospital. She will ask for more details and may arrange presentation or more information when required.</p> <p>DS suggested all members put details in the chat so AC/PC/AS may contact and set a time for summary, presentation and work which would be useful. The predominant goal for the network is to develop learning between services. DS noted more will be ascertained on the benchmarking visits in the coming weeks/months.</p> <p>LO noted all 19–24-year-olds in Rotherham are referred to the Sheffield service and DY highlighted Anna Jenkins is the LTFU lead in Sheffield. SM noted the service users in Calderdale and Huddersfield may access Leeds late effects service.</p>	
2	<p>Matters arising (not featured on the main agenda)</p> <p>ODN website update PCa shared the website and welcomed any thoughts and feedback. LP noted the minutes are public so the group should be weary of how</p>	

	<p>minutes are taken and what's taken offline and discussed privately. DS concurred. DS confirmed the website hosts the network aims and objectives.</p> <p>Completion of all memoranda of understanding between ODN and each acute Trust</p> <p>Benchmarking update The network is looking to understand services on offer throughout the area and what is being delivered by each centre. Service development and work being done to achieve quality care will also form a key element and further developed over a number of visits happening over July. The vast majority of centres have returned the reports which makes the visits helpful and more useful.</p> <p>Peer review Leeds received their full report this week. LP noted Sheffield are awaiting a final report, with 2 serious concerns (access to critical care and the trust investment support, which the trust must reply to by the 14th June). None of the concerns relate to quality of care.</p> <p>DS noted Leeds had 1 serious concern regarding ward space, but progress has been made on this. This concerned the availability on nurses recruited to post. Leeds is still maintaining service quality despite this.</p>	<p>AC/PC to chase remaining benchmarking spreadsheet</p>
<p>3</p>	<p>Service Update Slides including Clinical Governance Progress in keeping TYA services working well</p> <p>Sheffield <i>Local service description</i> 2023 - 68 new patients, 5 non-cancers and 4 relapses referred to the TYA service. 2024 - 42 new patients to date not including 4 recurrences. SCH - 13–16-year-olds. WPH - 16–25-year-olds - Oncology. RHH - 16–25-year-olds - Haematology.</p> <p><i>Service update</i> Peer reviewed on 18th April 2024 awaiting final report. Some positive feedback but 2 serious concerns raised: Link bridge from WPH to ICU and lack of support to TYA team from STH exec team.</p> <p><i>Multi professional workforce</i> No WGS CNS in post. Continue to support Paediatric and Adult Student Nurses on placement. Part of the Junior Doctor Induction at WPH, student nurse programme at SHU and new nurse starter day for Haematology and Oncology staff in STH.</p> <p><i>Referral pathways</i> Highly commended for the Lisa Thaxter award at CCLG for team psychology poster. Came 3rd in the STH nursing and midwifery conference poster awards. Currently in the process of having 2 pieces of work published.</p>	

	<p>Live share point for policies and documents shared with research teams in local hospitals. Plans to work with DY on the Children’s side. This could be linked to the network website. Users would need an NHS.net account so would be for professionals only. DS suggested this could publicise research portfolios. RW agreed but would be mindful of updates and contact points. LP noted there is responsible people at all stages.</p> <p>Hull CS noted the amount of work done with DHu for the Hull and Leeds shared care protocol for 16- to 18-year-olds. She highlighted a recent successful meeting and will press on with plans to develop the previous protocol and update accordingly.</p> <p>Rotherham LO noted a Power BI workbook has been developed so to inform CNS teams of TYA diagnoses from different specialities. This ensures every service user is offered the same care. DH congratulated LO and queried who set the system up. LO noted the cancer team at RGH did and it is now used to identify all new diagnoses and helps the trust target for Holistic Needs Assessments. Every CNS has access to this so each may identify any missing facets of care.</p> <p>DS suggested linking in with Rotherham tech team to see if this can be replicated throughout other trusts. LO happy to put people in touch. PD and GJ expressed an interest in utilising this tool at Airedale and York respectively.</p> <p>York <i>Local service description</i> York is the designated hospital for TYA patients with Scarborough patients attending York, Hull or Leeds for treatment. Level 1 and 2 service available for haematology and level 1 for oncology. Ward 31 has 5 side rooms available and the outpatient room has a designated side room also.</p> <p><i>Service update</i> SOP updated 2024. Change over to the Somerset Cancer Register has affected data collection of number of patients and diagnosis. Data for 2024 is pending.</p> <p><i>Multi professional workforce</i> Lead Consultant - Dr Muhammad Naveed, Haematologist (previously Dr Kate Foley and Dr Bond retired May 2022). Lead Nurse Gillian Jackson. Capacity issues continue both in OP and IP facilities.</p> <p><i>Referral pathways</i> Patient s referred into Leeds TYA service and continue to work with all CNS teams to support this. SOP update 2024. Significant staffing issues and vacancies in both medical and nursing which has impacting</p>	<p>Facilitate tech discussions between DHs with Power BI tool</p>
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	<p>attendance at various meetings. TV and console kindly donated by TYA charity pre COVID.</p> <p><i>Service specification requirements</i> Plan for ENHA in all cancer areas and EOT summaries.</p> <p>DS noted the Oncology and Haematology links are strong between York and Leeds. GJ stated good links exist with CNS and medical teams. DS asked if there were any areas the network could help with. GJ wondered whether training and education could be offered for staff, and help with documentation of EHNA and EOT summaries.</p> <p>DHu asked if this was a time constraint issue. GJ confirmed this and noted the service was being offered by CNS, and some Band 4 nurses taking on this role now. GJ stated she is still clinically based and would like more staff to enable a step back. Often clinic time runs out, but hopefully benchmarking allows discussions with management to improvement. DHu suggested having a chat to see if any support could be offered. LP and DHu concurred that this is a problem nationwide.</p> <p>Complaints, service challenges, and examples of quality of care given.</p> <p>DS offered conversations offline for any challenges faced to see if the network can help facilitate changes.</p> <p>DHu noted the 16-18 shared care gap in Hull. She believes the working documents are in place to form an agreement with Castle Hill Hospital. If this can't be progressed will be brought back to this meeting. This will be moved forward over the next few weeks.</p> <p>DS noted this is an organisational problem over many centres. On occasion, neither adults nor children services will see a patient and this is replicated over the country. Important to address this issue.</p>	
<p>4</p>	<p>Service improvement project updates</p> <p>Research Accrual, and related data (such as number of new diagnoses of TYA cancer) – Live dashboard for TYA data PCa shared the data from Year of Birth and MDT staff. Showcased the differences between the datasets with a particular focus on the PROTECT study in Leeds.</p>	



DS important to note the methodology counts trial entries, not individual patients. NHSE call next week to decide which methodology which be used moving forward.

Inefficiencies in PROTECT study wasn't regarding approaching patients, it was being informed in a timely manner of outcomes. This shouldn't detract from the headline trial accrual figure of 36% for the network which is very encouraging. RW concurred.

WGS – accrual and progress in local systems. Local and regional system pressures upon rate of improvement.

DY noted WGS for 13–16-year-olds is being offered to most service users with no resource available. Previously refused to do this without resource, but any would be appreciated and more efficient.

LP noted Tasha Morley has left her post but Robyn Hedge (CNS) is keen to hire someone to perform WGS biobanking. This is on the agenda for a meeting with STH executive team. STH can't offer to the TYA service, but children's going well.

DS attends WGS results panels with others in Yorkshire, Humber & North East. Leeds is particularly lacking in this group. DS noted a small resource returning imminently which will help develop the service. Clinician process with histopathology is laborious.

LP TYR website has been signed off by the developers and will contain all the contact details for staff for young people. This will also be a resource for the network website when available.

DHu WGS nurse will be starting in post next week. Karen Henry (Lead Nurse LHTT) is hoping to embed WGS in Leeds and wondered whether the role could this be a pathway co-ordinator, rather than a nurse; reducing costs for trust.

DY noted the major difference is that fresh tissue samples are available on site. There is a different challenge in adult services where biopsies are often taken elsewhere. Discussions are needed with surgeons to ensure they're fully informed.

DHu noted the stopping point in Hull concerned the pathology team capacity. CS concurred, with WGS not currently taking place in Hull.

AT stated the biobanking process is simpler and can be blood, rather than tissue. VIVO provide tubes and postage materials with a minimal cost to the trust. This doesn't need to involve the labs if a liquid sample is taken. She highlighted pathology samples are great, but can be collected after what's left from clinical sample.

DS spoke of a cancer vaccine developed in Melanoma patients. Best estimate of vaccine efficacy is halving the chance of metastatic disease. He feels it would be a major shame to miss out on this.

HC is part of the new CVLP launch pad open for samples and storage of tissue samples. Hull is opening a Colorectal study and vaccine development which will hopefully improve cancer studies in the North. DS highlighted the need for a good pathway in place for our patients. HC noted sometimes northern sites are not selected by the external companies, and acknowledged more work is needed.

Gaps in care- Equity and transparency of service provision in each location (palliative care, referral to all relevant MDTs upon diagnosis, community nursing services, psychology, peer-group support)

DS noted a working group set up and the benchmarking process will go over this in more detail. Hoping for further updates at the next network meeting.

Joint care – A pilot of joint care between 2 sites (Leeds & Hull)

DS noted this involves delivering elements of care in the right location with competently skilled staff. TYA services lacking in communication of care. DS feels a joint care system would be beneficial with Leeds and Hull engaging in conversations regarding what communication tools are

	<p>needed and how pharmacy can be utilised. Cancer Alliance representatives joined the last meeting which was helpful. This group will be used to overcome challenges and roll out strategies across the network.</p>	
5	<p>Updates from other meetings</p> <p>Radiotherapy mutual aid update DY noted a longer-term solution has not been reached, but a clinical pathway in place currently.</p>	
6	<p>AOB</p> <p>AC reminded the group of the network education on 22nd October. Encouraged members to get in touch with suggestions of content, speakers and to book a place.</p> <p>DHu noted the patient participation and involvement group funded by TCT met in March. One crucial point mentioned was remunerations and refreshments at events. She wondered if funding is available for this across the region.</p> <p>DS queried if the group is aspiring to do this as a network; it is more quorate but more complicated if so. DHu noted initial plans included groups across Yorkshire which Designated Hospital patients can access. The same questions will be asked and fed back to the main group. Hopes to establish funding. DS noted this needs to speak to a network wide solution.</p> <p>LP feels it is hard to put PPIE in place with no structure around it. Recent survey sent out to 13-25 to improve care in STH. Hopes to incentivise this as other centres.</p> <p><i>Dates of next meetings – each 3-5pm (all put in diaries now please);</i></p> <ul style="list-style-type: none"> • Monday 02/09/24 • Tuesday 03/12/24 	<p>DHu to contact AC regarding PPIE funding proposal</p>