Yorkshire & Humber Children's Cancer Clinical Network Meeting (previously known as Operational Delivery Network)

Tuesday 10th January 2025 13:00 - 15:00

Online Meeting

Attendees:

Name	Role	Organisation
Rachel Lyles (RL)	POSCU Lead Nurse	Airedale NHS Foundation Trust
Gemma Williams (GW)	POSCU Lead Clinician	Airedale NHS Foundation Trust
Rachel Wilkinson (RW)	POSCU Lead Nurse	Calderdale and Huddersfield NHS Foundation Trust
Liz Higgs (LH)	POSCU Lead Clinician	Calderdale and Huddersfield NHS Foundation Trust
Jayne Lowther (JLo)	Clinical Manager Community Children's Services	City Health Care Partnership
Alex Chilvers (AC)	Network Manager	CTYACCN
Paddy Carley (PCa)	Data Co-ordinator	CTYACCN
Hilary Quinton (HQ)	Lead Nurse for Haematology and Oncology	CTYACCN / Sheffield Children's NHS Foundation Trust
Katharine Patrick (KPa)	Lead Clinician	CTYACCN / Sheffield Children's NHS Foundation Trust
Liz Purnell (LP)	TYA (Teenage and Young Adult) Lead Nurse	CTYACCN / South Yorkshire, NLAG & North Derbyshire Teenage Cancer Trust
Helen Richards (HR)	Network Lead Nurse	CTYACCN/ Leeds Teaching Hospitals NHS Trust
Diane Hubber (DHu)	TYA Lead Nurse	CTYACCN/ Leeds Teaching Hospitals NHS Trust
Lisa Pearce (LP)	Business Manager	Hull University Teaching Hospitals NHS Trust
Jo Lyons (JL)	POSCU Lead Nurse	Hull University Teaching Hospitals NHS Trust
Ashwini Kotwal (AK)	POSCU Lead Clinician	Hull University Teaching Hospitals NHS Trust
Trudi Cornforth (TC)	Oncology Outreach Nurse Specialist	Leeds Teaching Hospitals NHS Trust
Sally Morrison (SM)	Children's Cancer Outreach Nurse	Leeds Teaching Hospitals NHS Trust
Michelle Kite (MK)	Matron	Leeds Teaching Hospitals NHS Trust
Rachel Newby (RN)	CHODU Ward Manager	Leeds Teaching Hospitals NHS Trust
Vicky Holden (VH)	Lead Pharmacist	Leeds Teaching Hospitals NHS Trust
Karen Dyker (KD)	Consultant Clinical Oncologist	Leeds Teaching Hospitals NHS Trust
Hilary Campbell (HC)	Head of Research Delivery	NIHR
Rachel Wane (RWa)	TYA Research Champion for Yorkshire and Humber	NIHR
Deborah Rowley (DR)	Advanced Physiotherapist and AHP Workforce Lead	Sheffield Children's NHS Foundation Trust
Alice Kay (AK)	Dietician	Sheffield Children's NHS Foundation Trust

Lynn Mcnamee (LM)	Diagnostics Programme Lead	West Yorkshire and Harrogate Cancer Alliance
Oluwadamilola Bamigbade (OB)	POSCU Deputy Lead Clinician	York and Scarborough NHS Foundation Trust
Stacey Needham (SN)	Oncology Lead Nurse	York and Scarborough NHS Foundation Trust
Rebecca Proudfoot (RP)	POSCU Lead Clinician	York and Scarborough NHS Foundation Trust

Apologies:

Name	Role	Organisation
Natalie Kisby	Head of Family Support	Candlelighters
Julie White	Lead Nurse	CTYACCN / Leeds Teaching Hospitals NHS Trust
Dan Stark	TYA Network Lead	CTYACCN / Leeds Teaching Hospitals NHS Trust
Vanessa Brown	Senior Matron CYP (Children and Young People)	Hull University Teaching Hospitals NHS Trust
Beki James	Consultant Haematologist	Leeds Teaching Hospitals NHS Trust
Ruth Kirby	Business Manager	Leeds Teaching Hospitals NHS Trust
Karen York	Children's Community Nurse	North Lincolnshire and Goole NHS Foundation Trust
Umaima Aboushofa	POSCU Deputy Lead Clinician	North Lincolnshire and Goole NHS Foundation Trust

Action	Responsible person
KPa to check CCLG membership guidelines on service specification.	**KPa**
KPa to ask Danielle Ingham outside the meeting regarding ALL guidelines.	**KPa**
Network team to catch up with JW when she returns to see rationale for data spreadsheet and plan for the future.	**KPa/PCa/AC/JW**

Item	Minutes	Action
1. Standard business	**Welcome and Introductions** KPa welcomed the group and encouraged each member to introduce themselves in the chat. Helen Richards was introduced as the network Lead Nurse (7.5 hours per week) alongside her role as long-term follow up CNS. In JW's absence KPa encouraged queries to go to her or AC, with specific nursing questions to HQ and HR with the aforementioned copied in. **Minutes from previous meeting** Previous minutes were agreed by the group.	

	Declarations of Interest No declarations of interest noted. **Network Participation Tracker** KPa noted good engagement from all centres. **Previous actions** • RP is working with ENT regarding concerns noted in the previous meeting. • Network website officially launched at the Education Day 2024. • Questions regarding guidelines about managing new ALL patients. **ACTION:** KPa to ask Danielle Ingham outside the meeting. • AHP data collection is on hold while JW off. Previous emails received by DR and will be picked up in due course. • 16–18-year-old issues exist in Airedale; to be discussed later. • New Deputy Lead Clinician appointed in Calderdale & Huddersfield. There are plans in place to gain relevant experience in place and support is available from the trust. KPa previously sent over resources to aid training. • HQ shared blood sampling thoughts with SN, but will revisit this for other staff. • Day unit blood requests to be discussed later in the meeting. • DHu attended the TYA MDT in York this month and hopefully will attend more frequently and input into paperwork.	
2. Benchmarking update	KPa noted each centre in the network has been benchmarked against NHSE service specification using a traffic light system. Most visits took place in person, but some were hybrid based. All centres have received their reports and AC will forward them to the senior leadership team, clinical lead and lead cancer nurse so they are aware of the network's ask. Yorkshire & Humber's performance is very good overall. There are a few items which don't meet the service specification but the network will support centres with NSHE. AC noted the annual report is to be completed in the meantime between the next visits in 2027. LH queried regarding a standardised template. KPa stated the template will be discussed shortly. She noted possible updates to the service specification which may require	

	alterations. The aim is to collect data by the end of the financial year.	
3. Service Improvement Projects/ Workplan Update	**Website** The network launched the website at the recent education day. KPa asked whether staff are using it and for any suggestions. SN has put up posters on the ward at York and shown all staff with no complaints thus far. AK and JL will put posters on the ward at Hull. KPa highlighted there is no password protection so anyone is able to access guidance. She welcomed suggestions of other guidelines to add. **Annual report template feedback** KPa shared the latest version of the annual report template with a suggested completion date of March 2025. She welcomed any changes if the group felt aspects were difficult to complete. Clarifications alongside the document are as follows: • Workforce and training will be discussed in the following section regarding the spreadsheet. • Family feedback is often difficult to get and this could be performed every other year for example (making the rationale clear). • Serious incidents investigated by the trust should be included along with the agreed action plan • CCLG target guidelines will tie in with HQ's discussions later. DR queried regarding AHPs workforce training and whether centres have access to dietetics, physiotherapist, occupational therapists, SaLT, and play specialists. She suggested a yes or no format may be used. The topic was brought up at a recent CRG (clinical reference group) meeting and most are unaware what workforce is available. DR has access to hours available in the PTC but is unsure if POSCUs have the same AHP time. KPa suggested '*access to...'* may be a reasonable question to ask. SN feels for this to be useful locally, the data should cover the number of patients on active treatment locally during years 23/24. RP highlighted York collect data per calendar year for AGM and data is easily accessible. KPa acknowledged most POSCUs collect this data and the network is trying to standardise. Further additions may include; defining active treatment, specifying number of patients, and adding a palliative care section. LH asked for guidance on serious incident reporting. KPa noted each trust has a definition, which is escalated to the trust risk team and assessed with an RCA (root cause analysis). She noted this section may include other	

	relevant items. LH highlighted datix reports for minor items such as line infections. KPa stated these don't need to be included individually, but themes could be noted. HQ suggested the AHPs should link to those listed in service specification. KPa concurred. AK noted general paediatrics have access to AHPs, but there isn't designated oncology time. All POSCUs lack access to psychology services and this exercise would help in future planning at trust level. KPa delineated the easiest method is to capture accessibility and offer a free text box for views on availability. This ensures patients have access to services and if they are inadequate the network can escalate accordingly. GW wished to clarify if the deputy lead had to be a CCLG member. **ACTION** - KPa to check CCLG membership guidelines on service specification. RP feels it is hard to stipulate membership without funding. KPa noted this is useful data either way. She will aim to make modifications and send out for completion by the end of March.	
4. Radiotherapy Mutual Aid Update	Sheffield paediatric radiotherapy is unable to provide services with the exception of palliative fractions and stem cell TBI due to staffing issues. This has resulted in pressure on the Leeds service, particularly ward capacity and anaesthetics. There is high-level NHSE discussions ongoing but no updates since the last meeting. MK noted Leeds still have 8 beds closed and the additional patients are causing issues with capacity. There is only 1 part time nurse in radiotherapy which needs backfilling from the day unit. Despite this, patients have reported positive experiences.	
5. Workforce updates	**Clinical educator** Kelly Smith has been appointed to the clinical educator role and has a start date of 24th February 2025. She will be working across TYA and children's PTCs and POSCUs. KPa highlighted this exciting project and is interested to hear about gaps in service provision and where KS would be valuable.	
6. Network Lead Nurse Forum	Document in which HQ discusses updates is available here: This will clarify points and enable consistency in terminology. Kelly Smith, JW and HR will work training and education agreements for advanced levels across the network. JL queried whether POSCU ward staff caring for children with side effects need the same level of training. HQ clarified they don't need to be chemotherapy competent,	

	but must have an understanding of the topic covered through local study days. SN asked regarding renewal dates updates. HQ stated there has been no update, but registered nurses will be covered by RNMC good practice. There is mention of annual reaccreditation within SACT guidance and further work may be required across the network about what this means in practice. RW queried if everyone within the team requires advanced level training. HQ noted centres have struggled with workforce standards generally. She talked through staffing standards: For PTC and POSCU enhanced level B the inpatient facility must have 2 nurses on shift day and night who have successfully completed the foundation course, 1 advanced level course and are chemotherapy administration competent. The day unit must have 2 nurses who have successfully completed the foundation course, 1 level of advanced course and chemotherapy administration competent. For enhanced level A POSCUs the inpatient facility must have 2 nurses trained to foundation level - SACT competencies are not required, but a knowledge of managing side effects is. *HQ signposted to CCLG modules 4,5,6 and 7* for guidance. Day units must have 2 nurses trained to foundation level and chemotherapy administration competent. Standard level POSCUs inpatient must have 2 nurses trained at foundation level - SACT competencies are not required, but a knowledge of managing side effects is. Day units and clinics require 1 nurse on duty for each span of time the unit is open for supportive care who has completed foundation level training - SACT competencies are not required, but a knowledge of managing side effects is. HQ noted community training is not clear in the guidance decision and this should be discussed within the network. She stated it will depend on the proportion of case load which is oncology. GW queried regarding outpatient nurses and whether they require foundation training. HQ stated the decision is to be made within the network. KPa clarified that it depended on which patients were seen in outpatients. If patients seen in outpatients are off treatment then she	

	did not feel these training standard were relevant. Often, day case patients will go directly to the ward. GW confirmed on treatment patients go to the ward in Airedale. KPa noted the community nurses training will depend if they are giving SACT and the network needs to define how the standards apply in our region. JL noted outpatients has day case nurses who see patients on the ward so Hull would require 1 nurse, and she acknowledged most are trained to the required level. KPa sees the standards specifying training of outpatient nurses as aimed at a set up like Hull's rather than one where only off treatment patients are seen in outpatients. HQ clarified the standards are not always achievable, but each centre should be working towards them. RP sees this as unachievable for outpatients for York and Scarborough. HQ stated situations like this enable flagging in the annual report, monitoring and feedback. RP clarified all patients are off treatment. KPa feels this is not a priority given the challenges of training ward nurses. KPa asked how often the PTCs are achieving the targets. HQ estimated Sheffield at ~75% and noted it had been a challenge finding relevant cancer courses in the past, so the new definition is helpful. MK stated Leeds is at ~75% but new recruits mean this number will go down. Re-opening wards will affect this also. HQ shared the update spreadsheet with updated guidance. KPa clarified training levels are % of nurses meeting training levels. Updates for the compliance of staffing standards through daily rotas will be difficult. HQ asked how often the network needs to collect this data, and whether it could be done as part of the annual report. KPa asked if this data collection is feasible. GW added it will difficult, although mentioned it is possible to set parameters on specific rosters to see if standards aren't met. KPa wants data to be accurate and thinks it is important all centres are fulfilling the service specification, but doesn't want this to be onerous. **ACTION** - network team to catch up with JW when she returns to see rationale for this and plan for the future. MK noted training data is easy to collate, but training staffing compliance is more difficult. KPa noted	

	recommended staffing levels are very difficult to achieve and often not possible at PTCs or POSCUs.	
7. Service Risks/Issues - POSCU Update Slides	**Sheffield PTC** HQ updated the group. SCH are progressing the virtual ward in haematology oncology. First pathways are febrile neutropenia, general monitoring and ambulatory chemotherapy (part of the national ambulatory chemotherapy project). 24/7 nurse led modulation laser treatment has been a major success, training more nurses and benefitting patients. Acuity is high with transplant activity, as unlike other centres, there is integrated facilities. Fully recruited currently, previous issues with skill mix but this has settled now. Transplant CNS team is down 1 WTE due to maternity leave which is causing pressures. SCH is due JACIE inspection this week. There has been a flurry of complex diagnosis patients recently. Currently without inpatient hospice care as Bluebell Wood is gradually reintroducing services (1 patient is receiving end of life care on the ward). Care and management of 16–18-year-olds remains challenging and LP is leading the CCLG/TYAC working group. SCH is looking to recruit a 3rd transplant consultant. **Leeds PTC** MK updated the group. LTHT is feeling the strain of new diagnoses with bed capacity and nursing numbers causing issues. Building works have been completed on 2 wards with regulations in progress for L31. Awaiting a business case to be agreed for increase in nursing establishment. Tessa Jowell centre for excellence provided information that Leeds is 15/15 PTCs for staffing options. Recruitment will hopefully start soon. Research team has jobs out to advert as Kelly Smith is moving to the network education role. New band 7 clinical educator doesn't have haematology oncology experience, but has ICU experience and increasing competencies. KS is reviewing foundation training. Medical and pharmacy roles have started in post for ambulatory chemotherapy. The planned nurse appointment unfortunately has gone out to advert again. Proud mention to OWLS (Oncology Haematology Walk-in Liaison Service) who tele triage and offer acute patients' assessment. Approval granted to hire 6.5 WTE for a 24/7 service. Streamlining of chemotherapy pathways underway.	

	Airedale GW updated the group. *Service description* Standard POSCU covering 700sq miles. Dr Gemma Williams (lead clinician), Rachel Lyles (lead nurse), Dr Philippa Rawling (deputy clinician), deputy lead nurse TBC, link nurses to ward (Jess Cook and Aidan Aubrey) Currently on monthly MDT list: - 5 on active treatment (2 ALL, 1 brain, 1 neuroblastoma, 1 LCH) - 1 post BMT - 1 aplastic anaemia - Recently off treatment: 3 lymphoma treatment, 2 brain GW seeing follow-up patients in clinic. *Service update* Febrile neutropenia audit currently ongoing for 2023-2024. Monthly MDT meetings continue as well as continued attendance at ODN meetings. Direct access proformas in use as well as family information leaflets. ALLTogether-1 continuing care site open since July 2024. Research nurse appointed during paediatric nurse secondment. Dr Williams on maternity leave from end of February to beginning of December 2025. Advertised for locum, doing dedicated oncology follow-up clinic in February 2025. Working with Leeds for new off treatment patients. Dr Williams gave presentation on shared care centres to POET conference in November 2024. *Workforce* Dr Williams continues to have a slot at medical inductions and nurse update days. Holds an oncology teaching session for junior medical staff every 10 weeks. Also doing consultant induction. Multidisciplinary Simulation morning held 15th January covering febrile neutropenia. *Referral pathways* Dr Williams has updated the care of the febrile neutropenic child guideline which has been ratified Airedale take up to age 18 on the ward. Between 16-18 years outpatients currently tricky, but GW seeing the fast-track referrals in clinic and this will continue. Need to look at neck lumps pathway – neck lumps guideline being drafted at present. *Service specification requirements* Assessment against service specification has been completed. Issues highlighted:	

	- No access to psychology locally – is on risk register for Paediatrics in general at AGH. - Lead nurse does not have allocated time in her job plan - TBD. - No feedback available yet from families. GW doesn't see patients acutely in Airedale. The lead clinician replacing her won't have oncology experience unfortunately. KPa to discuss with GW any ways the network can help once she goes on maternity leave. KPa noted issues are felt universally across network and added the simulation training sounded very interesting. **Calderdale and Huddersfield** RW updated the group. *Service description* POSCU covering Calderdale & Huddersfield. Caseload of 20 oncology children and 3 TYA (15 on active treatment, 2 off treatment and 6 new patients). Inpatient febrile neutropenia pathway and blood products. CCNT line cares, bloods and low-dose cytarabines. Follow-up clinics under Dr Higgs and monthly MDs. Dr Liz Higgs (lead clinician), Dr Julie Nicholson (deputy lead), Rachel Wilkinson (lead nurse) and Marie Beeson (deputy lead nurse). *Service update* Chemo clinic with 1 patient a month and children's ward link nurse working well. Unable to deliver foundation training for nursing staff due to capacity. There has been clarity regarding this today - plans to discuss with the new clinical educator. Febrile neutropenic audit in process. Registrar started this but moved to Bradford. RW and LH plan to finish this. Deputy nurse recently passed university level course. **Hull (now Humber Health Partnership incorporating NLAG)** JL updated the group. *Service description* POSCU unit covering Hull and East Riding Caseload of ~31 on treatment oncology children and lots in EOT follow up clinic. 1 CVAD flush post EOT. 2023-2024 Summary: 14 New patients, 2 Palliative, 2 Relapses and 4 Deaths. Separate Community Children's Nursing service (CHCP) managed by JLo. *Service update* Febrile neutropenia proforma has not been used.	

	Nurse Deputy has been highlighted but not active due to staffing in POPD. Need to complete a patient survey. Community nursing report getting late bloods requests again. *Workforce* Lead nurse is starting a non-medical prescribing course. 17/25 staff members now have done the foundation study day on woodland ward, 12/16 on the assessment unit and, 8/11 on PHDU. Sessions taking place monthly for foundation day and sessions delivered to Airedale staff. *Referral pathways* Started to use shared care pathway at CHH for TYA patients. *Service specification requirements* AllTogether-1 Trial site registration form filled in and officially registered. MK has asked the Leeds day unit to perform an audit of all the blood request to consider why late requests are occurring. JLo noted the community monthly MDT enables her to plot when bloods will be requested and she tries to contact Leeds. She queried if there was a better solution as it's difficult to do last minute visits in for non-local patients. MK wishes to wait and see what the audit shows. She suggested trialling a blood hub for patients to save nurse travelling time. SN noted this is a great idea, but wouldn't work in York due to lack of space. AK highlighted the febrile neutropenia audit completed by a trainee who is now on maternity leave. The proforma is not being used, but Hull are still compliant with guidelines. Currently lacking on Leeds pathway regarding early discharge and phone calls, improvements have been made over time however. Hull's main issue is lacking a deputy nurse. Sharing the benchmarking document with managers will hopefully help this. Ongoing psychology access an issue also. **NLAG** No one present from NLAG. **York** RP updated the group. 2 new patients in York, and 2 new patients in Scarborough. Yearly febrile neutropenia audit taking place at the start of the year. Recent patient survey completed, which KPa suggesting re-doing in 3 years. Signed up to AllTogether-1 trial, but unfortunately a	

	recent patient didn't consent. Overall good MDT attendance and no major issues. 76% of ward nurses are foundation trained. SN has no time allocated as lead nurse and has taken on another role also. She is developing a business case for further funding. Link nurse has been recruited and is attending MDTs. CCN has recruited a full-time band 5 nurse. Unfortunately, the patient end of treatment meeting is often organised late. GW suggested contacting secretaries and Macmillan nurse try and arrange diaries as she has similar issues. AK concurred, she emails colleagues and copies link nurses in.	
8. Education Day 2024/2025	KPa felt the Education Day was a great success and the network received a lot of positive feedback. She suggested all attendees write to AC/PCa with any issues which may be improved upon for the next year. AC provided an overview of the feedback garnered: • 77 attendees & 54 responses (70% response rate). • Ways to improve: more study days, presentation slides sent out sooner, more advertisement for day and breakout rooms, promote nurses' voices, on-site parking. • Actions: send the date out quicker this year and arrange speakers earlier. Feedback was overwhelmingly positive, with speakers seen as uplifting and the day being a good opportunity to network. Suggested topics to cover this year: • Febrile neutropenia, network project updates, patient experience in clinical trial, psychology and late effects. DHu suggested a presentation from OWLS team in LTHT, or the how the new virtual ward in children's service is working. HQ added this could be done as a joint presentation with SCH. KPa noted feedback is useful but often difficult to find a venue which suits everyone's needs.	
10. AOB	HQ highlighted the CCLG meeting in Birmingham (24-25th March 2025) as good networking opportunity. Dammy Bamigbade introduced herself as Deputy Lead Clinician in York & Scarborough and will email KPa for resources to help in her role.	

11. Dates of Next Meetings	• 23rd April 2025 - 1-3pm • 16th July 2025 - 1-3pm • 8th October 2025 - 1-3pm	