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

CHILDREN'S CANCER CLINICAL NETWORK MEETING MINUTES
10.07.24 1-3pm

Attendees:

Name	Role	Organisation
Rachel Lyles (RL)	POSCU Lead Nurse	Airedale NHS Foundation Trust
Rachel Wilkinson (RWi)	POSCU Lead Nurse	Calderdale and Huddersfield NHS Foundation Trust
Liz Higgs (LH)	POSCU Lead Clinician	Calderdale and Huddersfield NHS Foundation Trust
Natalie Kisby (NK)	Head of Family Support	Candlelighters
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
Julie White (JW)	Lead Nurse	CTYACCN / Leeds Teaching Hospitals NHS Trust
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
Jo Lyons (JL)	POSCU Lead Nurse	Hull University Teaching Hospitals NHS Trust
Danielle Ingham (DI)	Paediatric Oncologist	Leeds Teaching Hospitals NHS Trust
Rachel Harrison (RH)	Lead Research Nurse	Leeds Teaching Hospitals NHS Trust
Neil Shaw (NS)	Candlelighters Home Chemo and Bolus Chemo Closer to Home Project Lead	Leeds Teaching Hospitals NHS Trust
Michelle Kite (MK)	Matron	Leeds Teaching Hospitals NHS Trust
Alice Lewis (AL)	Oncology Outreach Nurse	Leeds Teaching Hospitals NHS Trust
Charlotte Mackrell (CM)	Oncology Outreach Nurse	Leeds Teaching Hospitals NHS Trust
Rachel Wane (RW)	TYA Research Champion for Yorkshire and Humber	NIHR
Saskia Roetschke (SR)	ST7 Oncology SPIN	Sheffield Children's NHS Foundation Trust
Deborah Rowley (DR)	Physiotherapist	Sheffield Children's NHS Foundation Trust
Alice Kay (AK)	Dietician	Sheffield Children's NHS Foundation Trust
Stacey Needham (SN)	Lead Nurse	York and Scarborough NHS Foundation Trust
Rebecca Proudfoot (RP)	POSCU Lead Clinician	York and Scarborough NHS Foundation Trust

Apologies:

Name	Role	Organisation
Gemma Williams	POSCU Lead Clinician	Airedale NHS Foundation Trust
Debbie Ibbotson	Children's Community Nurse	Harrogate and District NHS Foundation Trust
Vanessa Brown	Senior Matron CYP (Children and Young People)	Hull University Teaching Hospitals NHS Trust
Lisa Pearce	Business Manager	Hull University Teaching Hospitals NHS Trust
Ashwini Kotwal	POSCU Lead Clinician	Hull University Teaching Hospitals NHS Trust
Amy Ruffle	Consultant Paediatric Oncologist	Leeds Teaching Hospitals NHS Trust
Beki James	Consultant Paediatrician	Leeds Teaching Hospitals NHS Trust
Martin Elliott	Consultant Paediatric Oncologist	Leeds Teaching Hospitals NHS Trust
Bob Phillips	Consultant Paediatric Oncologist	Leeds Teaching Hospitals NHS Trust
Kevin Peters	Specialised Commissioner Cancer Programming	NHS England
Hilary Campbell	Research Delivery Manager	NIHR
Karen York	Children's Community Nurse	North Lincolnshire and Goole NHS Foundation Trust
Sara-Jane Goodwin	POSCU Lead Nurse	North Lincolnshire and Goole NHS Foundation Trust
Lynn McNamee	Diagnostics Lead	West Yorkshire & Humber Cancer Alliance
Louise Dolphin	Team Leader	YLvC

Action	Responsible person
RP to email JW with ENT referral concerns and she will expedite this.	RP
PCa to continue formal launch of the website (if all information is ready) and newsletter.	PCa
JW to check with Danielle Ingham regarding ALL guidelines	JW
JW and DR to meet regarding AHP data collection	JW/DR
RL to check with Gemma Williams to ascertain >16 outpatient issues.	RL
KPa/JW/LH to pick up deputy lead discussions in Calderdale.	KPa/JW/LH
HQ to share thoughts with the group on blood sampling equipment for POSCUs	HQ
JW to speak with day unit staff regarding late blood requests and line care	JW
DH to investigate TYA attendance at the York MDT meeting.	DH

All POSCU and DGH representatives to email PCa/AC with suggestions for the Education Day	All

Item	Minutes	Action
1. Standard business	KPa welcomed the group and encouraged each member to introduce themselves in the chat. Previous minutes were agreed by the group. **High level pathways** KPa highlighted action points related to pathway work JW and Amy Ruffle had been undertaking. RP, Gemma Williams, and LH met and concluded Leeds pathways were not appropriate in POSCUs (Paediatric Oncology Shared Care Units). E.g., Lymphadenopathy is not referred to ENT (Ear, Nose and Throat). They did not believe area GPs should see this information as it may be confusing. JW emphasised this pathway is for Leeds GPs and noted it is not possible to have that detail for each POSCU in a generic pathway. JW wondered if each POSCU needed a separate referral pathway. RP is happy to follow CCLG guidelines. RP queried if GPs could refer directly to ENT for lymphadenopathy. She is worried genuine concerns are not being seen quickly by Mr Prasai in Leeds (some referrals are taking >2 weeks) - she wondered if this is because he is overwhelmed with GP referrals. JW stated they should be seen much sooner. On call oncologist stated RP needs to speak with ENT directly. JW is sending the high-level pathway to GP consortiums across the Yorkshire & Humber region to sense check. She noted some commonalties with work in Sheffield PTC (Principal Treatment Centre) by KPa. KPa feels it is important to note one size does not fit all. In Sheffield, the 2ww pathway being used primarily. After investigating, she noted GPs can access this easily and prefer this method and there is a co-ordinator managing referrals. It is key that all stakeholders are up to date and have bought in with regards to the pathways. She does not want misleading information on website that does not work in practice. JW is hoping to get this work signed off by the end of 2024. KPa noted NLAG have a good fast track system in place but practice within the other DHS is less certain.	**RP to email with concerns and JW will expedite this.**

	LH queried if this would allow GPs to refer direct to ENT. She noted Calderdale use a 2ww triage system. The recent audit showed over 95% of these were lymph nodes. GPs often are not reviewing patients and refer to paediatrics immediately. RP is worried about this. JW noted the service level agreement states best practice is for children to be seen at the PTC, which demonstrates challenges to be investigated with ENT services. KPa queried if a child is under the care of oncology, how quickly would ENT perform a biopsy. JW acknowledged they would not wait >2 weeks. KPa highlighted the need for second route with patients seen by a paediatrician. JL highlighted a long wait by a thyroid patient in Hull under the care of Leeds where the tumour recurred. KPa wondered if they were discussed in Leeds Oncology MDT. JW stated they were, but all thyroid cases are on adult pathways. She stated the importance of flagging worries to the team so they can help to expedite and garner detail. There is no paediatric equivalent in thyroid and delays are unacceptable. KPa noted the pathways are being finalised, but the group are identifying areas where concerns lie. She highlighted the usefulness of POSCU clinicians raising concerns. JW noted these examples are helpful, as the PTC may not be aware. Sue Picton and JW are presenting at the Leeds cancer board after peer review to highlight challenges. **Governance drug prescribing in palliative care** JW noted there is a different system in place in Sheffield. From Leeds PTC perspective, the need to be more robust and use documentation from each individual trust was highlighted. **Febrile neutropenia audit standardised template** Jess Morgan and Bola Badejoko are working on this project. They have circulated some documents asking for feedback locally. KPa added it would be useful to circulate to POSCU teams, so everyone is able to assess with the same criteria. **Attendance tracker** The attendance tracker was shared, and good attendance noted for each centre.	
2. Benchmarking update	All meetings have taken place and AC has been working on finalising the benchmarking document. KPa noted most were conducted in person but some meetings had to be hybrid. AC is producing a standardised report which will	

	show ongoing action points. KPa wants POSCUs to check and agree the report is accurate. If any alterations are required, please let the team know so they can amend.	
3. Service Improvement Projects/ Workplan Update	**Website** PCa shared the website link (Home | Yorkshire and Humber Children, Teenage and Young Adult Cancer Clinical Network (yorksctyacancer.nhs.uk)). JW hoped to develop a newsletter and formal launch to ensure the website is available to all stakeholders. KPa noted the ease of access for clinical guidelines which is good news for POSCUs and DGHs. She queried about a formal launch. PCa will work with AC/JW and others to organise this. JW wishes to utilise the Cancer Alliances and Integrated Care Board contacts for the launch. KPa noted it is important that the TYA group are happy with all the information on the website prior to launch. KPa queried whether the POSCUs and DGHs thought any other key guidelines would be useful to host on the website. RP noted there is currently no 'new diagnosis of ALL' guideline. She thought a version was developed by Amy Ruffle a few years ago and queried if there is one in Sheffield. KPa stated there is an 'investigating new patient' guideline which is PTC led and not currently on website. KPa is also in the process of developing 'managing mediastinal mass' and 'managing high white cell count.' JW thinks Danielle Ingham may have continued the ALL work and JW will pick this up from her. JW noted the Leeds Systemic Anti-Cancer Therapy policy has been reviewed with updates to come soon. KPa will investigate suspected new leukaemia guidelines in Sheffield. **Live dashboard** AC noted this will hopefully collect all incidences of cancer for ages 0-24 and influence network workstreams. She has been told by Leeds team that governance issues can be rectified so all staff can access the dashboard. RWa stated it will be useful for trials and research systems also. KPa noted the network team has spoken separately regarding children's metrics; mainly fertility preservation and whole genome sequencing (WGS) data. The numbers of children accepting fertility and WGS is available, but it is more difficult to work who did not accept this and why. There is a drive to improve WGS accrual rates nationally. However, most centres are not sure what their baseline is. She hoped the dashboard would help with this.	**PCa to continue formal launch of the website (if all information is ready) and newsletter** **JW to check with Danielle Ingham regarding ALL guidelines**

	Referral pathways See section 1.	
4. Radiotherapy Mutual Aid Update	Radiotherapy is being provided in Leeds besides total body irradiation for stem cell transplantation and palliative fractions. Staffing issues led to this changing. There are ongoing discussions at prominent levels between trusts and NHSE. It is acknowledged this is an interim solution and not a permanent solution. No more updates currently. JW noted communication between centres was a positive element taken from children and families accessing the service. However, accommodation was seen as an issue, but this seems to have settled. She hopes for an agreement on the plan going forward as it has been ongoing for 2 years. KPa feels it would be great to have HQ's family feedback as the patient voice is key to improvement at NHSE level. HQ noted recent questionnaire overload. Problems with accommodation noted previously. Some families using public transport had issues with the distance travelled.	
5. Workforce updates	**Lead Nurse role** JW has retired, returned, and reduced a day of her time as Lead Nurse. The replacement role is out to advert for a 2-year post with interviews taking place on the 6th of August. **Clinical educator** There is agreement to use last year's funding for a clinical educator role 0.6 WTE at band 7. This will be hosted by Leeds and the team is navigating issues with the systems in place. JW feels there is a need to support POSCU and children's community nursing teams around training and education and strategy for the network. She hopes for positive discussions with North West cancer network for a joint training approach. **POSCU updates** JW noted there is a requirement for oversight of workforce challenges and training compliance across the network. The team has developed a spreadsheet to replace the existing update slides. JW welcomed feedback from POSCU staff. Overall, this will help the network with annual reports and oversight. PCa shared the draft spreadsheet and will circulate after making alterations from feedback.	

	SN asked for clarity on nursing standards training compliance. The group concurred the spreadsheet looked easy to fill in otherwise. JW and HQ will clarify this from a PTC perspective. JW acknowledged the service level agreement nursing appendix is slightly dated. HQ stated the CCLG educators group looking at refreshing appendix 3 and investigating the training modules CCLG have launched. Currently, there is no consensus, but work is ongoing. DR feels the network should be highlighting other staffing problems. Recent AHP faculty meetings displayed problems with recruitment and having some knowledge around these vacancies would be useful. JW concurred. DR is happy to talk outside of meeting regarding data capture. HQ noted this data is not quantified in the standards and queried what the benchmark would be. DR noted there is benchmarking information about AHPs available in PTCs per bed. She suggested a separate spreadsheet showing vacancies and allowing support for inexperienced staff. JW feels it is frustrating the network does not have this in the service level agreement. KPa feels DR highlighted a valid point concerning data capture. Some data changes regularly, requiring 3 monthly updates whereas for others yearly capture would be sufficient. There is a balance between required information and onerous data capture. She notes clear guidelines for nurses, but AHP input is different between PTCs and POSCUs, so quantifying this information is difficult and more subjective. KPa suggested a different spreadsheet for PTC/POSCU and a column showing the network target.	**JW and DR to meet regarding AHP data collection**
6. Network Lead Nurse Forum	No updates from JW.	
7. Service Risks/Issues - POSCU Update Slides	**Sheffield PTC** HQ updated the group. Sheffield is currently in the process of changing the Febrile Neutropenia approach with regards to first line antibiotics. Staff are now able to give first doses. Also looking at exploring the virtual ward in further detail. Staffing is currently at full establishment, but establishment reviews are underway. Upcoming challenge with middle grade oncology doctors. Granted funding for an Anthony Nolan hospital play specialist which will improve child experience. Able to recruit an additional ANP from September. POON team not as challenged as previous months. Looking at taking more transplant patients activity due to Bristol's activity change. **Leeds PTC**	

	JW updated the group. Leeds has a 25% nursing vacancy rate when compared to existing nursing establishment, this is not optimal. 8 beds currently closed awaiting essential works which were paused due to financial issues. Junior workforce in place. Lead clinical educator has retired and their replacement is starting in a few months' time. Overall, under pressure and stretched but trying hard to mitigate pressures. Still pushing forward on ambulatory chemotherapy bid in collaboration with the cancer centre. Managing beds with ALLtogether trial. Virtual ward is helpful and is progressing well. Bids to sustain OWLS service submitted recently as this proved beneficial to families. **Airedale** RL updated the group. *Service description* Standard POSCU covering 700sq miles. **Key Team:** 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 (1 ALL, 1 brain, 1 LCH, 2 NHL); 3 surgery only - 1 post BMT, 2 recently completed treatment GW seeing follow-up patients in clinic *Service update* Febrile neutropenia audit completed and presented at audit meeting in June. Plan for improved direct access proformas to be implemented this month. Plan for simulation training. GW has contacted LTHT (Leeds Teaching Hospitals) to ask for changes to "script" for when patients are asked to attend local hospital ALLTogether trial. JW noted this is reminder to the PTC liaison with POSCU to inform of updates. Airedale have had SIV but not open yet. Enquiries from trial manager about source data form and delegation log which was easily resolved. EPR coming in September to Airedale. GW has contacted Calderdale (Bola) to obtain proforma for the Cerner computer system for Febrile neutropenia clerking. *Workforce*	

	Dr Williams continues to have a slot at medical inductions and nurse update days and holds an oncology teaching session for junior medical staff every 10 weeks. Needs consultant update on AUS/LR-FN. *Referral pathways* Dr Williams has updated the care of the febrile neutropenic child guideline. AIredale take up to age 18 on the ward. There are now plans for patients >16 to be referred to adult outpatients (rather than paediatrics) if required. DH queried the details of 16+ going to adults. RL discretion of the consultant to decide feasibility of outpatient destination. DH stated this is like issues in Hull which could become confusing. Not started properly looking at feasibility of bolus chemotherapy. *Service specification* Assessment against service specification has been completed. Issues highlighted: No access to psychology locally which is on risk register for Paediatrics in general at AGH. Lead nurse does not have allocated time in her job plan - this has been raised but no updates. QR code has been sent to families to obtain feedback – no feedback available yet. Family information leaflets have been written about our service and will be circulated shortly. Febrile neutropenia audit has been completed. **Calderdale and Huddersfield** *Service description* Caseload of 18 oncology children and 1 TYA (16 on active treatment, 2 off treatment and 1 new patient). Deliver inpatient care on the Febrile Neutropenia pathway and supported care with blood products Work closely with CCNT with line cares, bloods, low dose cytarabines. Follow-up clinics led by Dr Higgs. Monthly MDTs running. **Key Team:** Dr Liz Higgs – Paediatric Consultant (Lead) Rachel Wilkinson – Children's Oncology Lead Nurse Marie Beeson – Children's Community Nurse (Deputy) *Service update* Decreased Chemo clinic numbers, now 2 patients a month. Appointed a children's ward link nurse who is enthusiastic to be involved in oncology.	**RL to check with Gemma Williams to ascertain >16 outpatient issues.**

	Unable to deliver Foundation Training for nursing staff due to capacity at Calderdale. Dr Badejoko (Paediatric Registrar, Children's Ward) is working with medical staff around educational needs. Developed a patient feedback QR code and tick box for paediatric oncology and CCNT. Febrile Neutropenia audit to be performed. *Workforce* Nursing vacancies on the Children's ward – 2.2 WTE (from September 2024) Vacancies on Children's community nursing team – 0.6 WTE (B5) 0.6 WTE (B3). New B6 0.7 WTE (starting from September 2024) No capacity to provide further Foundation Training dates for nursing staff at present. No deputy consultant which has been added to the trust risk register. LH has emailed Sue Picton to understand what training is required for chemo care for an existing consultant to take on role. No consultants in posts who have much oncology experience. This means chemo clinic patients will go to Leeds and any fast-track referrals would go to the consultant of the week in lead consultant absence. KPa noted the difference between supportive care and responsibility for delivering chemotherapy. There is a need to be careful over who has responsibility for delivering chemotherapy. She suggested talking about this outside of this meeting. LH noted the ALL trial may affect future numbers of patients on chemotherapy. Any advice would be particularly useful. JW noted the deputy lead needs some tertiary experience. Issues resolved around chemo care access for lead pharmacist. *Service specification* Shared Care (Enhanced Level A). Not conducting day case infusional chemotherapy. No Deputy Paediatric Consultant - this is on the Trust risk register. **Hull** JL updated the group. *Service description* POSCU for Hull and East Riding. Caseload of ~26 on treatment oncology children. Lots of children in the end of treatment (EOT) follow up clinic. 1 CVAD flush post EOT. Separate Community Nursing service (CHCP).	**KPa/JW/LH to pick up deputy lead discussions in Calderdale**.

	Service update New Febrile Neutropenia Proforma in use which is more in depth. Nurse Deputy added but no allocated job hours currently. Investigating an MDT admin support appointment. MDT Action plan underway. Started annual report. Need to do patient survey. Thought there would be a generic one from Leeds but unsure if this were ever done. Febrile neutropenia audit completed. Ashwini Kotwal taking on Neurooncological follow up soon. *Workforce* 17/25 staff members now have done the foundation study day on woodland ward. 12/16 on the assessment unit. 8/11 on PHDU. Sessions on every month now for foundation day. Community nursing update date session arranged for August. Updates for junior doctors and registrars in August also. *Referral pathways* TYA pathway work looking at age 16-18yrs is continuing. DH hopes to add Castle Hill into the existing agreement with Hull Royal Infirmary. No TYA input in MDT. Happy to discuss TYA patients early in the meeting so they do not need to stay for the full meeting. *Service specification* ALLtogether trial is still awaiting the signed version from LGI to give to research/audit team at HRI. JW will remind Sue Picton to sign. **NLAG** There was no representative from NLAG present. **York** RP updated the group. *Service description* Level 1 shared care Currently on MDT list: York - 12 on active treatment, 4 off. Maintenance therapy for ALL a sizeable proportion of this. Scarborough - 9 on active, 0 off. Online Monthly MDTs with good attendance. *Service update*	

	Dr Bamigbade (Dami), has joined as deputy lead in Scarborough. She is not oncology trained but enthusiastic about taking on the role. *Workforce* Good engagement with MDT, except for Scarborough ward nurse. *Referral pathways* AllTogether1 trial set up & running **Bloods request issues** Last minute requests for bloods from Leeds and increased requests for finger prick bloods are issues currently. Nurses are struggling to do these and often clot when done in the community. There is not the ward capacity to do this as it requires a cubicle being free, which is not feasible on a small ward. SN noted on the ALLtogether trial, central line is taken out quicker, whereas it is often more practical to keep in. Children are promised finger pricks so generally do not want peripheral venepuncture. SN noted that central lines have infection concerns also. York has issues with patient spread; some live a long distance from hospital due to the large rural area. She is working with biochemistry team on clotting, but it is not easy. HQ noted similar issues with distance in NLAG. She highlighted a successful project done a few years ago teaching parents to perform finger pricks, resulting in less impact on CCN and POON teams. Parents can take samples to a local hospital or GP practice. This has been rolled out for select groups steadily and is another tool to alleviate issues. JLo stated similar issues in Hull CCN, but with higher case numbers. Monday and Tuesday can be busy with lots of full blood counts required. Hull use port catheters and central lines. Sheffield expected a finger prick for a joint patient which is an example of clotting consuming CCN time. SN has been researching lancets as the Bradford team have a special tool for jaundice patients. She will update with any positive outcomes. HQ noted support staff in the day care unit took a business case to procurement for devices which helped influence their case.	**HQ to share thoughts with the group on blood sampling equipment for POSCUs**

	RL noted Airedale perform finger pricks often but feels a change in the labs has reduced clotting. KPa queried if full blood counts or biochemistry samples were clotting. The clot must be forming at the time the bloods is taken, and it should not be a major problem sitting in bottle for the journey time. JLo noted technique is important, and she is disseminating information to the team to ensure everyone is performing bloods correctly. KPa highlighted late requests from Leeds and wondered if this is being addressed. RP has spoken about this at MDT, but the CCN team is struggling with this for all patients. JW queried whether there are similar issues elsewhere. JL stated it is similar in Hull. She is trying to pre-plan for Leukaemia patients, but it is difficult with other diagnoses. Emails sent late from Leeds are not picked up until the next day. Capacity is low for rural areas. JW wondered if there was a clinical reason for this. RL noted in general there is late requests, making it difficult overall. Often a parent phones prior to the requests. RL asked about ensuring line care and dressings are also done. JW thanked the teams for all their hard work. RP noted a lack of engagement from TYA in MDT.	**JW to speak with day unit staff regarding late blood requests and line care** **DH to investigate TYA attendance at the York MDT meeting.**
8. Rehab Pathway for Children with Long-Term Needs	KPa will contact DR outside of the meeting. She is unsure if this is something the cancer network can help with.	
9. Education Day 2024	22nd October in Leeds. KPa asked each representative from POSCUs and DGHs for one topic they wish would like to see discussed at the education day. JL suggested diet related changes for children with cancer as often the guidance is unclear. KPa noted the transplant nurses have conducted some work on this topic and there are different rules in different areas. Many are not evidence based. She feels some common-sense guidelines would be beneficial.	**All POSCU and DGH representatives to email PCa/AC with suggestions for the Education Day**
10. AOB	KPa highlighted educational resources on the website focusing on junior doctor education. She hoped for volunteers to conduct recorded education topics on supportive care. There would need to be governance reviews in place but feels this would be a great resource for POSCUs and PTCs. LP highlighted the CCLG and TYAC 16-18 working group. This is a national project which anyone is welcome to join by emailing LP directly.	

11. Dates of Next Meetings	• Education Day - 22nd October 2024 - Horizon Leeds • 15th January 2025 1-3pm • 23rd April 2025 1-3pm • 16th July 2025 – 1 –3pm • 8th October 2025 1-3pm	