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

CHILDREN'S CANCER CLINICAL NETWORK MEETING MINUTES
17.04.24 1-3pm

Attendees:

Name	Role	Organisation
Gemma Williams (GW)	POSCU Lead Clinician	Airedale NHS Foundation Trust
Jayne Lowther (JL)	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
Liz Purnell (LP)	TYA Lead Nurse	CTYACCN / South Yorkshire, NLAG & North Derbyshire Teenage Cancer Trust
Debbie Ibbotson (DI)	Children's Community Nurse	Harrogate and District NHS Foundation Trust
Ashwini Kotwal (AK)	POSCU Lead Clinician	Hull University Teaching Hospitals NHS Trust
Bola Badejoko (BB)	Registrar in Paediatric Oncology	Leeds Teaching Hospitals NHS Trust
Michelle Kite (MK)	Matron	Leeds Teaching Hospitals NHS Trust
Jess Morgan (JM)	Senior Research Fellow in Paediatric Oncology/Trust Doctor	Leeds Teaching Hospitals NHS Trust
Vicky Holden (VH)	Pharmacist	Leeds Teaching Hospitals NHS Trust
Kate Hardy (KH)	Staff Nurse	Leeds Teaching Hospitals NHS Trust
Debra Harris (DHa)	CCN Team Leader	Locala Health & Wellbeing covering North Kirklees
Kevin Peters (KPe)	Specialised Commissioner Cancer Programming	NHS England
Rachel Wane (RW)	TYA Research Champion for Yorkshire and Humber	NIHR
Sara-Jane Goodwin (SJG)	POSCU Lead Nurse	North Lincolnshire and Goole NHS Foundation Trust
Deborah Rowley (DR)	Physiotherapist	Sheffield Children's NHS Foundation Trust
Alice Kay (AKa)	?	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
Phillipa Rawling	Deputy Lead Clinician	Airedale NHS Foundation Trust
Liz Higgs	POSCU Lead Clinician	Calderdale and Huddersfield NHS Foundation Trust
Jo Lyons	POSCU Lead Nurse	Hull University Teaching Hospitals NHS Trust
Vanessa Brown	Senior Matron CYP	Hull University Teaching Hospitals NHS Trust
Amy Ruffle	Consultant Paediatric Oncologist	Leeds Teaching Hospitals NHS Trust
Rachel Harrison	Lead Research Nurse	Leeds Teaching Hospitals NHS Trust
Beki James	Consultant Paediatrician	Leeds Teaching Hospitals NHS Trust
Hilary Campbell	Research Delivery Manager	NIHR
Karen York	Children's Community Nurse	North Lincolnshire and Goole NHS Foundation Trust
Lynn McNamee	Diagnostics Lead	West Yorkshire & Humber Cancer Alliance
Louise Dolphin	Team Leader	YLvC
Lisa Pearce	Business Manager	Hull University Teaching Hospitals NHS Trust

Item	Minutes	Action
1. Standard business	AC noted the network is obliged to ask of any declarations of interest at every meeting. All members may email AC directly with any queries. AC checked that all POSCUs had a representative present at the meeting. Previous minutes were agreed by the group. JW will pick up missing actions (examples of missing blood request) with Jo Lyons (JL) when she's back from annual leave in mid-May. AK noted 2 nursing staff are providing leave cover for JL. J Lo reported improvement in blood request issues between Leeds PTC and Hull. JW encouraged her to forward any issues if required.	
2. Benchmarking update	AC thanked everyone for their participation in the benchmarking process and highlighted the productive meetings taking place. She will produce a report on each centre with common themes, areas of improvement and timescales. The project is still in progress, but overall is very pleased with our networks progress and engagement. HQ clarified this is the benchmarking exercise for the Children's service, not TYA. AC is progressing with the TYA benchmarking process but no visits have taken place yet. JW stated this is a helpful exercise in gathering a baseline of our network and consolidating existing relationships.	

3. Service Improvement Projects/ Workplan Update	**Website** PCa showcased the website which has been made public now (https://yorksctyacancer.nhs.uk/). JW welcomed any feedback and suggestions regarding the website and is very grateful for the time taken. The network is investigating the launch process with colleagues (cancer alliances and GP consortiums). JM queried if the minutes and agendas from these meetings are in the public domain and if that was always the intention. JW noted discussions resulted in the consensus of an open and honest network with accessibility important. JM clarified the group should be aware that minutes are public and we should be mindful with our minute taking. **Live Dashboard** AC noted unfortunately the dashboard is not available yet. The network procured this initially to align with the TYA 50% trial accrual target and will link the EPR and EDGE to confirm whether patient has consented and enrolled in a trial. As STH is implementing a new EPR system soon the dashboard will be network wide after this process finishes. This will showcase incidence data alongside patient demographics which can link to other projects (patient travel burden for example). AK queried who will have access to data. AC is unsure if this will be accessible only on LTHT systems, but hoping to develop a link in which many people can view if governance allows. **High level referral pathways to Leeds PTC** JW has started work mapping out referrals to Leeds PTC. She noted the main challenges revolved around GPs referring straight into Leeds PTC, rather than to POSCUs. Amy Ruffle has performed a lot of background work over the last few months to demonstrate this and develop a pathway model. JW showcased the referral pathways in progress and asked for feedback from the relevant POSCUs. Some specific wording was changed including; 2ww to urgent suspected cancer to line up with NHSE guidelines. PCa sent the referral pathways work via email to the POSCU leads to feedback any thoughts. The group agreed that standardisation across the network would work well.	**Each POSCU lead to feedback thoughts on the referral pathway sent via email** **JW to share NY&H Cancer Alliance details with RP regarding GP referral changes**

4. Radiotherapy Mutual Aid Update	JW noted a number of high-level discussions ongoing with LTHT still providing mutual aid to STH. HQ concurred and clarified the discussions are taking place with STH who host Weston Park Hospital Radiotherapy services. KPe highlighted that a second meeting with relevant parties had taken place and there is a number of options for delivering the service. The Commissioners' aspiration is a single service delivered across two sites for Yorkshire, Humber and the wider area. They will formally respond to the options once the team have finalised the project. He noted they are making progress, but LTHT will continue to provide mutual aid for the time being. JW queried if there are any timeframes in place as colleagues and families are keen for updates. KPe stated there is no set timetable as the first draft of options appraisal is underway. He stated there is not a huge number of choices, only slight variations, but hopes it won't be much longer before this can be shared.	
5. Palliative Care Drugs and governance process within the Community	JW noted this agenda point was added after discussions with community nursing teams around the governance of auditing-controlled drugs in children's homes. She opened the floor for discussions regarding standardising this across the network. RW highlighted an example of a difficult situation with one family when a palliative drug box went to the home prior to use in hospital. CHNFT didn't have a log of the content of the box. However, RW noted once the drug administration process starts there is a stock control sheet in use. JLo stated a stock control sheet is only used when the drugs are being administered. The box sent from Leeds is the child's responsibility until in use by the CCN team. JLo understands that the drugs are property of the child and anything not in use will not be stock checked. She feels stock checks should be on an individual risk assessment basis. HQ wondered where the query came from so the network can aim for consistency. She confirmed that each family should be risk assessed and once the box is issued it becomes child's responsibility. SJG concurred, with the drugs labelled as patient owned, other than when using controlled drugs where daily stock checks are done. SJG would document the box is sealed and tagged before use which is standard practice in NLAG.	**JW to pick up the governance discussions outside the meeting and feedback when more information available**

	JW stated all medicine management teams seem to be echoing similar thoughts. She feels the query came from CCN team in similar situation to which RW mentioned. She acknowledged this needs risk assessment on an individual basis. In JW's experience there is a minority number of concerns regarding safety of drugs in a child's home. She noted this process highlighted for this team that there were no routine stock checks, and feels this needs to sit within each local trust, rather than PTC governance. JW asked for SN's opinion in York. SN noted York use local governance documents, which is not a perfect system as staff often don't see prescriptions at source. Sometimes Macmillan nurses go direct to GPs which results in SN being unaware of amounts of drugs ordered. VH noted she could perform a summary of the contents of palliative care box from PTC. However, she would have to look independently if additional drugs were supplied from community pharmacists. HQ aims for all stock to come from Sheffield and avoids using local GPs and Pharmacies; keeping control over stock. This means there is no confusion over how much has been ordered. However, she acknowledged more control is viable as there is only one POSCU working in collaboration. SJG concurred. She noted if for any reason there was a need for urgent controlled medication, this is delivered from the hospital pharmacy in Scunthorpe or Grimsby and taken over to the child's house. She stated this a rare occurrence and often the POONs team take the lead. JW wondered whether this could be an opportunity to involve and inform the GP. In HQ's opinion the information needed by the GP is surpassed by governance issues. SJG noted GPs are not cut out completely, they are informed and often perform visits to stay involved. VH highlighted the distance from the PTC for some patients results in accessibility issues, and feels if we get governance right shouldn't have to supply from PTC. JLo noted the CCN team in Hull always liaise with GPs as the distance to the PTC is too far. The CCN team is not on same systems as HUTH, and using this would result in the Lead Clinician writing all prescriptions. JLo highlighted	

	there has been no problems thus far and acknowledged the need for individual risk assessments.	
6. Network Lead Nurse Forum	JW noted there were no major updates. The CCLG annual meeting is taking place next week which will encompass the annual Lead Nurse meeting. LP noted that she is helping to set up a CCLG/TYAC affiliated working group looking at 16-18 gaps in care. LP welcomed all to join and to contact her with any queries. She will share more with this group when available.	
7. Service Risks/Issues - POSCU Update Slides	**Airedale** GW updated the group. *Service description* 4 patients on active treatment, 1 post-BMT. More oncology patients are being seen in follow up clinics and there is another link nurse on the ward now. Deputy Lead Nurse is TBC, which will hopefully be confirmed in time for the benchmarking visit. *Service update* Febrile Neutropenia audit (mid 2022-2023) undertaken by ST1 which is to be presented locally. Unfortunately, there were delays at all stages of the process with work to be done to improve. Looking to open ALL-Together trial but the research nurse has been seconded to another role. Awaiting further update. *Workforce* GW undertaking teaching for juniors with nurse update days in place. She also has a slot on a consultant training session. Recently, an established nurse has left, resulting in a lack of staff available to train. JW clarified there are funds within the Network to fund clinical educator hours and it is hoped this may be helpful to POSCU's moving forward. *Referral pathways* Febrile Neutropenia guideline includes AUS and practicalities which has gone out for further comment and will go through the documentation steering group in the next quarter. There are definite plans for over 16s to go to adult services. GW hasn't started looking at the feasibility of bolus chemotherapy, but is worried about keeping up competencies.	

	Service specification Family information leaflet with QR code is awaiting feedback. Lead Nurse doesn't have allocated time in her job plan and this is being discussed with workforce. JW is hoping to support with this element. She highlighted the commitment of the Airedale matron to have the ringfenced time for the Lead Nurse. GW is hoping the Lead Nurse can lead on some educational training for staff members. JW agreed and noted that the network is looking to appoint a clinical educator as a shared resource across the region. **Calderdale and Huddersfield** RW updated the group. *Service description* Caseload of 22 with 17 active on treatment (recent extra referral for TYA commencing active treatment). 3 off treatment and 2 in palliative care. 16–18-year-old inpatients remain under Leeds but may be admitted to the Paediatric ward. Inpatients follow the Febrile Neutropenia and blood product pathways. CCN team take care of blood support. Liz Higgs conducts long term follow ups. Link nurses from ward interested in attending the monthly MDTs. *Service update* Foundation training for nursing staff commenced in February 2024. Paediatrics registrar from Leeds introduced herself (Bola Badejoko) who is undertaking the shared care experience module 4. She is working with medical staff to develop the Febrile Neutropenia pathways and communication between PTC and patients. RW is also looking at patient feedback forms with a QR code and hoping this can be network wide in the future. LH is in contact about a Febrile Neutropenia audit tool and will update soon. *Workforce* Current vacancies: 4.4 WTE on the children ward and 1.4 WTE in CCN team.	

	There has been two in house training days for junior doctors in March. There is no deputy consultant resulting in a lack of cover for chemotherapy clinics. Thus, patients may need to attend Leeds PTC. *Service specification* CHNFT is a shared care enhanced level A. Although it does not conduct day case infusion chemotherapy. JW queried if there were any plans to appoint a deputy. RW noted LH is meeting with the medical director but nothing is imminent. **Hull** AK updated the group. *Service description* Standard level shared care centre with 25 on treatment. AK runs 5-year surveillance clinic with monthly MDTs. JL has designed Febrile Neutropenia flow chart which is being used on the wards for junior doctors. Efficient CCN team under the care of JLo which works well. Deputy consultant doesn't have enough time in job plan for cover. There are ongoing talks with management for deputy nurse to cover for JL. *Service update* Blood product requests from Leeds are improving overall. Service specification assessment is ongoing. Shared care agreement is awaiting signature from PTC lead clinician which JW has chased. Access to PPM is useful to upload results and see updates on patients. Leeds attendance at the monthly MDT has been chased and will improve moving forward. *Workforce* JL and AK lead on training with inductions happening 4-5 time per year. ST1 has taken on the Febrile Neutropenia audit. *Referral pathways* 16–18-year-old pathways have not progressed. This age range will attend the paediatric ward as a safety net.	

	JW wondered if there was anything the network could help with. AK is chasing up meetings with appropriate parties She hopes this will happen so the patients can utilise the facilities at Castle Hill, however agreement and governance needs to be in place. *Service specification* Ward staff training is working well. It is important to progress delivering chemotherapy but major management changes in the trust make this difficult currently. JW queried whether a standardised Febrile Neutropenia audit tool may be helpful. AK concurred. JM noted she has access to the national Febrile Neutropenia audit questions, but they may need adapting for POSCUs. JM suggested a working group come together to help benchmark and guide the audit in POSCUs. RP welcomed sharing her FN audit which has been used by GW also. HQ noted this is a great opportunity to have uniformity across the network. **NLAG** SJG updated the group. *Service description* Now part of the NHS Humber Health Partnership but still under the NLAG Trust (housing Scunthorpe and Grimsby). Total of 55 patients with 25 on treatment. Since January 3 patients have sadly passed away. Investigating a Febrile Neutropenia audit tool and highlighted the benefit of a network wide process. Noted Sheffield recently changed antibiotic regime for Febrile Neutropenia which NLAG has updated concurrently. Patient feedback QR code in place asking parents to give feedback on overall POSCU care. *Workforce* Junior workforce currently, working hard on training in collaboration with the nurse educator in Sheffield. 4 POSCU study days due over the year and positive feedback received so far. Training in place for CVAD and blood product support and ability to track staff competencies. *Referral pathways* Tertiary clinics available on web3 timeline gives a better overview as clinicians can see information from centres.	**BB to organise a meeting with POSCU leads and JM regarding FN audit**

	SJG conducting SACT training. **York** RP updated the group. *Service description* Standard Level POSCU with 16 patients on active treatment in York and 8 patients in Scarborough. Monthly MDTs. *Service update* No deputy currently. Staff grade who was interested is leaving unfortunately. New appointments in place who hopefully could lead on oncology in Scarborough. Lots of problems currently in Scarborough with the Febrile Neutropenia audit results very disappointing. This is not helped by a huge staff turnover increasing the difficulty of keeping competency levels in place. Regular teaching is offered but there is no designated time due to shift patterns. Parent user survey heralded good results. However, it is not possible to keep the monkey survey questions which is frustrating for future surveys. It took a long time to engage parents, all were from York and there were no recent diagnoses. Stacey Needham (Lead Nurse) is back from long term leave. *Workforce* Ongoing staff issues with a recent problem of personnel not available to access a porta Cath in Scarborough. There is good engagement with the MDT from Leeds but still not receiving full correspondence from PTC for new patients. *Referral pathways* ALL Together trial is up and running. Recent peer review was successful but issues regarding the standard of care in Scarborough were noted. M&M meetings also bringing up concerns regarding urgent referrals. RP queried whether lead consultants should have oversight of all referrals and if this is practical. Admin issues are causing worries. Unless GP states concerns for malignancy then RP feels the leads cannot have oversight. GW concurred and noted non-urgent referrals are placed in a waiting list.	

	AK noted Hull use the ERS system and urgent referrals are highlighted by secretaries to AK or the deputy on call who action the referrals. She feels the GPs must harbour some responsibility; if concerns persist then they should directly refer in via telephone. RP asked how to obtain PPM access. JL has access and knows how to request, when she is back from annual leave, she may assist AK and RP. AC can also support with this process. **Sheffield PTC** HQ updated the group. Inpatient ward manager has returned from maternity leave and there is a new day care ward manager in post. Biggest challenge faced is the current high-level of end-of-life palliative patients in the community. Sheffield is still without hospice support causing a big strain on POON team. For example, the team has been on call constantly since October 2023. There are some changes in the outreach team with Rachel Ducker retiring at the end of April. Vacancies within this team are resulting in difficulties with competencies and confidence regarding end-of-life care. Challenges with IT systems. Overall, the working environment remains stable. Established recruitment through Trust rotational programme. Sheffield achieved the Tessa Jowell accreditation recently. JW congratulated HQ on this great achievement. **Leeds PTC** JW updated the group. There remain significant challenges with 8 beds closed; 1/3 of the bed base. Progressing remedial works through estates but encountering a pause which is proving difficult. Currently 25% vacancy rates. Qualified nurses are coming through but there is still a significant junior workforce. This results in additional pressures on experienced staff and having the right staff with the right skills at the right time a challenge. Leeds is still providing mutual support to Sheffield for Radiotherapy. Exciting developments ahead with the	

	virtual ward, bolus chemotherapy and OWLS service (dedicated nurses supporting unplanned activity). Still pursuing ambulatory chemotherapy project funding. Considering pressures, it is positive that Leeds is still trying to move forward with service improvements. JM has been appointed locum consultant helping with solid tumour work, taking on long term follow up in June and looking at changes and developments for the service. She will come to network members for their thoughts on care closer to home when appropriate.	
8. Rehab Pathway for Children with Long-Term Needs	DR stated there has been no time to map the project yet. She is attending the SIOP rehab meeting in Turin next month learn from international peers and further defining what rehab means for childhood cancer patients. She will provide further updates when available. JW noted Leeds applied for Tessa Jowell accreditation but didn't achieve that, and the key component missing was a cohesive rehabilitation pathway and nursing establishment. Meetings are underway with the business team to see how to progress this. DR to look at this from a regional AHP perspective with regards to community services. She noted many issues with acute therapists and dieticians resulting in a disjointed pathway to community teams. JW stated this is consistently highlighted as a key gap in service provisions.	
9. Education Day 2024	JW is hoping for this to occur in Leeds October 2024. Feedback from last year's event provided ideas to explore, ensuring an interactive session to help and support POSCUs and CCN teams. JW is meeting with PTC educators and lead clinicians for discussions regarding the day's events. JM highlighted the need to avoid SIOP dates (October 17th - 20th 2024).	All members to send thoughts regarding Education Day to AC, JW or PC.
10. AOB	JW offered the floor for AOB. No other questions or points were noted.	
11. Dates of Next Meetings	• 10/07/2024 - 1-3pm • 02/10/2024 - 1-3pm	