CHILDREN'S CANCER CLINICAL NETWORK MEETING MINUTES 17.01.24 1-3pm

Attendees:

Name	Role	Organisation
Rachel Lyles (RL)	POSCU Lead Nurse	Airedale NHS Foundation Trust
Gemma Williams	POSCU Lead Clinician	Airedale NHS Foundation Trust
(GW)		
Liz Higgs (LH)	POSCU Lead Clinician	Calderdale and Huddersfield NHS Foundation Trust
Natalie Kisby (NK)	Head of Family Support	Candlelighters
Jayne Lowther (JL)	Clinical Manager Community	City Health Care Partnership
	Children's Services	
Alex Chilvers (AC)	Network Manager	CTYACCN
Paddy Carley (PCa)	Data Co-ordinator	CTYACCN
Julie White (JW)	Lead Nurse	CTYACCN / Leeds Teaching Hospitals NHS Trust
Diane Hubber (DH)	TYA Lead Nurse	CTYACCN / Leeds Teaching Hospitals NHS Trust
Katharine Patrick	Lead Clinician	CTYACCN / Sheffield Children's NHS Foundation
(KPa)		Trust
Hilary Quinton	Lead Nurse for Haematology	CTYACCN / Sheffield Children's NHS Foundation
(HQ)	and Oncology	Trust
Liz Purnell (LP)	TYA Lead Nurse	CTYACCN / South Yorkshire, NLAG & North
		Derbyshire Teenage Cancer Trust
Debbie Ibbotson	Children's Community Nurse	Harrogate NHS Foundation Trust
(DI)		
Jo Lyons (JL)	POSCU Lead Nurse	Hull University Teaching Hospitals NHS Trust
Ashwini Kotwal	POSCU Lead Clinician	Hull University Teaching Hospitals NHS Trust
(AK)		
Vanessa Brown (VB)	Senior Matron CYP	Hull University Teaching Hospitals NHS Trust
Lisa Pearce (LPe)	Women's and Children's	Hull University Teaching Hospitals NHS Trust
,	Divisional General Manager	, , ,
Charlotte Mackrell	Children's Outreach Team	Leeds Teaching Hospitals NHS Trust
(CM)		
Jo Wood (JW)	Children's Outreach Team	Leeds Teaching Hospitals NHS Trust
Alice Lewis (AL)	Children's Outreach Team	Leeds Teaching Hospitals NHS Trust
Gabi Reynolds (GR)	Children's Outreach Team	Leeds Teaching Hospitals NHS Trust
Bola Badejoko (BB)	Registrar in Paediatric	Leeds Teaching Hospitals NHS Trust
	Oncology	
Karen Dyker (KD)	Consultant Clinical Oncologist	Leeds Teaching Hospitals NHS Trust
Danielle Ingham	Consultant Paediatric	Leeds Teaching Hospitals NHS Trust
(DIn)	Oncologist	
Michelle Kite (MK)	Matron	Leeds Teaching Hospitals NHS Trust
Jess Morgan (JM)	Senior Research Fellow in	Leeds Teaching Hospitals NHS Trust
· · · · · ·	Paediatric Oncology/Trust	
	Doctor	
Rachel Newby (RN)	Sister	Leeds Teaching Hospitals NHS Trust

Amy Ruffle (AR)	Consultant Paediatric	Leeds Teaching Hospitals NHS Trust
	Oncologist	
Debra Harris (DHa)	CCN Team Leader	Locala Health & Wellbeing covering North Kirklees
Kevin Peters (KPe)	Specialised Commissioner	NHS England
	Cancer Programming	
Rachel Wane (RW)	TYA Research Champion for	NIHR
	Yorkshire and Humber	
Sara-Jane Goodwin	POSCU Lead Nurse	North Lincolnshire and Goole NHS Foundation
(SJG)		Trust
Hassan Al-Moasseb	POSCU Lead Clinician	North Lincolnshire and Goole NHS Foundation
(HAM)		Trust
Lynn McNamee	Diagnostics Lead	West Yorkshire & Humber Cancer Alliance
(LM)		

Apologies:

Name	Role	Organisation
Suzanne Coulson	Clinical Educator	Leeds Teaching Hospitals NHS Trust
Philippa Rawling	Deputy Lead Clinician	Airedale NHS Foundation Trust
Hilary Campbell	Research Delivery	NIHR
	Manager	
Karen York	Children's Community	North Lincolnshire and Goole NHS Foundation
	CNS	Trust
Rebecca Proudfoot	POSCU Lead Clinician	York and Scarborough Teaching Hospitals NHS
		Foundation Trust

Item	Minutes	Action
1. Standard business	Welcome/Introductions/Apologies KPa welcomed the group and encouraged all members to introduce themselves in the chat and offer declarations of interest.	
	Minutes from previous meeting The minutes from the previous meeting were agreed with the action points to be discussed throughout the meeting.	
2. Benchmarking update	AC confirmed the ODN team had received all the documents back with the first visit planned for Hull and Sheffield on 18 th January 2024. Benchmarking visits for other POSCUs are in the process of being organised with dates TBC in March.	
	KPa reassured the group this is not a peer review exercise and the focus is on working collaboratively with the PTCs and POSCUs. KPa noted this process will uncover challenges and allow the ODN to support and drive through the change centres deem important; improving the service. KPa feels this will offer an oversight to the ODN of the strengths and gaps of our network and what work the	

KPa highlighted common themes (such as psychology
support) occurring for each centre on the benchmarking
documents.

3. Service Improvement Projects/workplan update

Website

PCa noted there is a meeting planned with the website developers on 29th January 2024 to finalise the content for the website. He stated the education day provided clarity on content and guidelines. Once the final draft is accepted, editing rights will be handed over to the ODN team.

KPa hopeful this will be a useful resource for all. She noted STH and LTH guidelines will be available without a password to negate out of hours access issues. The website will host standard and emergency referral processes and should help POSCU clinical teams and colleagues who are less familiar with oncology documentation.

KPa encouraged feedback from all members once the initial draft is available, and also once it's been in use for around 6 months.

Live dashboard

AC noted the dashboard has been procured and will be held by LTHT initially, utilising STH data in September 2024 once the new EPR is implemented. The data is collected from respective EPRs and cross referenced with Edge for trial accrual, negating the need for manual counting. AC stated this will help the network meet the 50% target set for trial participation. In addition, the dashboard may add other demographics and metrics which can support parallel projects, such as travel time and incidence data. AC highlighted this is still in the process of being built and will be showcased when ready.

KPa hopes the dashboard will offer a much more focused idea of the network's current status on a live basis. She noted a particular interest in whole genome sequencing and fertility preservation in paediatrics.

Training and Education

JW is in conversations with Lead Nurse for Education, who has a dual role with NHSE. She is in the process of identifying potential funding sources to support education and is linking in with ICBs and the CCLG digital platform. JW is committed to a strategy by the end of the year and keen for training opportunities in Yorkshire.

Care closer to home

JW noted the Bolus chemotherapy project had started in December which offers the opportunity to receive some chemotherapy in the home or at the local POSCU. The project lead has been in touch with community nurses and POSCUs to see where opportunities are and any challenges faced. This is a 2-year project and the lead is collecting the appropriate data informing the next steps.

Ambulatory chemotherapy

JM noted that the research papers have been submitted to CCLG and are awaiting a final outcome regarding funding. She stated service development discussions are in place with different potential funders, with an update hopefully available at the next ODN.

Virtual ward

JW highlighted the virtual ward as another development at LTH PTC. KPa stated this is relevant for LTH related POSCUs. JM is leading this project and explained it has been in place since October 2023 and funded to run until at least 2025. The virtual ward offers a place for patients to be discharged or have intensive monitoring at higher areas of concern e.g., ALL induction or Febrile Neutropoenia.

JM stated a form is sent to families via text which is filled in and subsequently checked by consultants for issues or concerns. Thus far, there has been 23 admissions, mostly from ALL pathways, but including Febrile Neutropoenia, Blinatumomab, post-transplant and bespoke patients who would've otherwise spent a lot of time in hospital.

JM noted a large group of patients are present on the virtual ward for a longer period of monitoring. She highlighted the POSCUs collaborative work regarding this, especially nursing teams offering blood support in the community and reviews taking place at local centres and communicated to the PTC. She stated the families seem grateful for this service.

However, admin and technology issues are adding to the workload. InHealthcare have been tasked to ease the process and provide a more user-friendly experience.

AK noted HUTH is small part of this project focusing on low-risk Febrile Neutropenic patients on antibiotics who qualify for early discharge. AK is worried about Bank Holiday disruption and issues with staff unfamiliar with oncology protocols. She has designed clerking sheets which automatically directs staff to pathways. AK queried

if there a way to ensure if a patient is discussed with LTH on call, to guarantee HUTH still conduct daily phone call.

GW implemented teaching sessions for junior doctors over the past week which brought about concerns that patients may slip through the safety net if not on LTH virtual ward.

GW has produced a flow chart for the patient led ward round on PPM, but is also concerned staff may not conduct phone calls every day as the situation doesn't arise often in Airedale. She queried if there was scope to put on the virtual ward in LTH.

JM noted there is capacity for 6 patients on the LTH virtual ward and LTH patients are already being turned away. Thus, JM cannot guarantee there will be space.

AR noted LTH may not have access to blood culture results if not an LTH patient. She emphasised not all Febrile children need daily phone calls, only the early discharge febrile neutropenic patients. She wants to ensure processes in place locally, but recognises this is hard.

She noted delegation may be difficult if some follow up is performed locally and some at PTC. In AR's opinion, care must be shared with POSCUs with staff phoning for advice when needed.

GW asked LTH staff to remind registrars that they need to conduct daily phone calls. AR will bring this up in the next management meeting.

JM emphasised the importance of a patient safety net. She highlighted phone calls are to stop the antibiotics, not to check on child's wellbeing. If child is unwell, the family should be calling POSCUs.

KPa queried whether this system mainly helped with early discharge or improving safety for high-risk patients who would have been at home anyway. JM stated mainly the later but some patients have been discharged earlier. Safety is generally improved, as occasionally information was missed when on the bottom of handover list. The virtual ward ensures each task is designated to a staff member.

JM stated ALL patients are going home slightly earlier, however there is small sample size. JM is collecting all data so a clearer picture should emerge over the coming months.

KPa stated discussions are underway regarding virtual wards in SCH, but not specifically catered Haematology and Oncology. HQ noted benchmarking the feasibility of a digital ward for all specialities is a large piece of work with data collection taking place before Christmas. HQ specified HaemOnc would be included as part of a wider trust virtual ward but would need to be assured of a robust safety net.

KPa noted the general paediatrics virtual ward wouldn't work with a specialised service. Hopefully, using the data from LTH, SCH could take forward plans for a virtual ward. KPa noted the same issues around ensuring outpatient febrile neutropaenia phone calls always happen, arising in the south of region, and acknowledged a formalised system would improve patient safety throughout.

JM stated in LTH there is other virtual wards for general paediatrics and NIV establishment at home. The latter in particular is quite novel and has improved pathways in the trust. KPa celebrated great examples of technology improving patient care.

4. Radiotherapy Mutual Aid update

KPa declared radiotherapy provided to SCH by STH had ceased due to the lead consultant taking maternity leave and the deputy consultant retiring. The intention was for this service to be repatriated to SCH. However, patients are still receiving radiotherapy in LTH, as the consultant who was due to return is now unable to. KPa noted ongoing discussions with relevant parties and will update when there is more information available.

HQ performed semi-structured interviews to gather thoughts from families who'd been treated in LTH to inform future mutual aid processes and lead improvement in centres. HQ noted consistent themes arising concerning the accommodation provided which the management team at SCH has been notified of.

JW devised an LTH questionnaire and provided opportunity for families to complete this with meticulous chasing up. However, she found this challenging due to the national trend of questionnaire fatigue. HQ concurred.

JW noted the themes fed back from SCH are echoed in LTH. JW highlighted communication between PTCs as a positive, with the planning and treatment process well received.

KPa queried whether the questionnaire was available as paper or electronic copy. JW stated both were available

	with multiple attempts to garner feedback. JW noted	
	conversations with Bob Phillips concerning dropping	
	completion rates in under 16 national cancer survey;	
	suggestions of a reset of normal of response rates and	
	fatigue of questionnaires post COVID.	
	KPa suggested text messages containing QR code forms	
	may improve response rates, but noted one can only	
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5 111 4 6 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1	encourage feedback to try and address major issues faced.	
5. NLAG pathway for	KPa noted patients from the NLAG region are sometimes	
suspected paediatric	referred to HUTH, which poses a significant problem as	
malignancy	HUTH POSCU refers to LTH, and NLAG to SCH, so patients	
	may be referred to the wrong PTC.	
	KPa noted this is part of a larger ODN project to	
	streamline referrals to flow from local practice, to general	
	paediatrician, to PTC. This requires collaboration and buy	
	in from local paediatricians to see patients urgently. KPa	
	stated this hasn't progressed as much as anticipated but	
	there is a strong desire from the team move this forward.	
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	AK informed the group a meeting between business	
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	managers, 2WW leads and secretaries had taken place in	
	HUTH. She believes the form should not visible, or should	
	contain disclaimer on it advising GPs to refer to local	
	paediatric unit rather than to HUTH. Multiple discussions	
	have taken place with GPs, but she admitted admin teams	
	may not know the processes. The merger of NLAG and	
	HUTH may lead to more confusion.	
	KPa accepted it is confusing for GPs as most adult cancer	
	pathways are through HUTH. SJG was unable to procure	SJG to obtain
	the NLAG 2WW but will continue the process.	NLAG 2ww
		pathway
	GW has progressed referral pathways in Airedale after	patitivay
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	conversations with the ICB clinical lead. She noted the	
	2WW pathway had been scrapped and replaced with 28	
	day faster diagnostic standard in accordance with NICE	
	guidelines v12.	
	GW is hoping to use CCLG guidance alongside ICB advice	
	to produce the Airedale referral. She noted the	
	Retinoblastoma pathway needed more work and GW is	
	organising discussions with the Bradford ophthalmologist.	
	GW queried if anyone else knew about 2WW changes.	
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	KPe highlighted a sweep of changes at the back end of last	
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	year with 9 cancer targets downsizing to 3. 2WW	
	reporting has been subsumed into FDS reporting but the	
	pathway still exists.	

	LPe clarified the withdrawal of 2WW standards is part of a wider piece of work dictating change to urgent cancer referral terminology. She noted the data requirements haven't changed yet with the first seen information still required. KPa noted Retinoblastoma, Thyroid and Bone pathways are very specific and she is trying to organise the corresponding referral pathways. AR has taken on the work in LTH concerning GP referral pathways. Previous referrals to oncologists on 2WW pathways were often not cancer. She believes this approach must be streamlined and is hoping to finalise with the speciality leads and JW in LTH. AR highlighted the gaps in TYA care, as patients with vague symptoms often end up with general paediatricians, or redirected from HUTH to LTH when referred to Haematology Oncology. This is a key piece of work in AR's opinion to ensure patients are accounted for across the network. KPa emphasised 16-18 patient pathways as an important challenge with a lot of work ongoing. She noted this is more straightforward in South Yorkshire for new patients only as there's a cut off for referrals at 16, whereas North and West Yorkshire occupy more of a problematic grey area.	KPa to send Retinoblastoma referral information to GW Interested parties for 16-18 working group to contact AC
	LP noted the TYA ODN has developed a working group for 16-18 pathways and if anyone is interested in joining, they may contact AC.	
6. Network Lead Nurse	CLG/RCN update	
Forum	Jeannette Hawkins (YLvC) is now part time and Jo Stark has been appointed to work alongside her as Chief Nurse. CCLG has focused on work around training and education with the first digital module and training suite online and available to members. JW noted the group hasn't met since last the network meeting.	
7. Service risks/Issues – POSCU Update Slides	Leeds PTC Service updates	
rosco opuate silues	JW noted a lot of work occurring regarding pathway	
	mapping and the reviewing of key documents to ensure the ODN website is fit for purpose. She also stated the benchmarking process highlighted out of date documents which LTH PTC is rectifying.	
	MK updated from an operational standpoint. There is a focus on IPC for the children's hospital as a whole. She's	Contact Michelle Kite if you wish to be linked to

aware that a lot of patients are seen at shared care and community partners and wishes to share learning and practices; ensuring patterns of care are uniform. E.g., there are pseudomonas learning processes to be shared across the network after work in LTH. Similarly, there is a CVAD group in place which is looking at practice across the hospital. Also, a side project concerning parental information and competencies, e.g., central line dressings as an aseptic procedure.

CVAD group meetings

MK noted ward L33 is closed for building works due to pseudomonas infection rates. Once L33 is reopened L31 will have to close which is affecting bed capacity and staff morale. MK believes it will be very challenging at that point and is working on a plan to negate this as much as possible.

Workforce

LTH is struggling with nursing vacancies, long term and short-term sickness which is replicated over the children's hospitals. MK is hopeful of all 3 wards being open once building works are completed.

JW concurred with SCHs struggles regarding skill mix, often having the least level of nurses on shift, coupled with a junior workforce and reduced beds. She noted staff are regularly putting in extra hours.

KPa queried if there was a lot of haematology oncology patients on other wards. MK stated staff are doing their best, but lack of side room capacity often results in the delay of a chemotherapy patients, resulting in a constant pressure to manage patients.

DI emphasised how important it is that patients attend shared care units for assessments, or if they're febrile. Due to capacity issues LTH need to use beds for treatments that can only be administered at PTCs. DI thanked all the POSCUs for their work and efforts regarding this.

JL and AK to share clerking proforma with the group

AK noted HUTHs inpatient issues which JL has taken the lead on by creating an inpatient clerking proforma. JL is willing to share this with the group for comments and reflection. AK noted this has been approved by governance in HUTH and feels it has improved communication with PTC.

Sheffield PTC

Service updates

HQ updated the group. She noted the biggest challenge is

delivering end of life and palliative care to a significant number of children, coupled with pressures from a busy period relating to transplant activity.

Turnover of staff has resulted in a less than ideal skill mix of nursing staff. The ward remains busy, but the majority of nursing staff are now trained on SACT passports, either as chemotherapy administrators or checkers.

Workforce

HQ stated opportunities are available in SCH for a POON outreach nurse in a development post, and a band 7 outreach nurse post awaiting advertisement.

KPa noted staffing numbers are better, with nursing up to establishment, despite periods of sickness. There is an ongoing plan with the education team to rectify the training issues.

Airedale

Service description Gemma Williams - Lead Clinician Rachel Lyles - Lead Nurse.

Currently there is 5 patients on active treatment (4 ALL and 1 Brain Tumour). GW and Mary Nightingale visited Calderdale to speak about Bolus Chemotherapy, this brought up potential issues with clinic space in paediatric outpatients. Also, maintaining competencies in giving chemotherapy due to low patient numbers.

Service updates

GW stated there was no parent information leaflet previously, which has been developed and is with families for feedback currently. Questionnaires are in draft format to garner more awareness of gaps in care. A junior doctor is conducting a febrile neutropenic audit concerning antibiotics administered in a timely manner.

Workforce

RL is undertaking GCP training and the lead pharmacist is investigating how she undertakes this also. GW is conducting junior doctor and nurse update sessions and has emailed all medical staff with AUS training.

Referral pathways

GW mentioned 2WW processes earlier in the meeting, and also hopes to build links with adult colleagues in the trust.

Service specification

GW noted psychology issues which are replicated across network. This has been added to the risk register for all paediatric patients. The lead nurse has no time in her job plan service improvements but this is in a consultation process. Monthly MDTs are underway which are well attended.

KPa noted compliance with guidelines and auditing this process is a functional way of understanding service. She queried if there were any issues the network may support with. GW stated most DGHs referral cut off is 18 leading to issues for 16–18-year-olds.

Bolus Chemotherapy discussions

She also noted a meeting with bolus chemotherapy project lead which is awaiting debrief with nurses in Airedale. KPa wondered if that was with the intention of becoming an enhanced level POSCU.

JW clarified that bolus chemotherapy on its own doesn't make the centre eligible for enhanced level A under the current service level agreement. She confirmed if the chemotherapy is prescribed within the PTC and verified and administered in the POSCU, the centre can be standard level, as shown in Calderdale. She stated the importance of maintaining competence for prescribing and delivering chemotherapy, as this may be done intermittently.

KPa queried if the chemotherapy is developed in the POSCU or PTC and wondered how the service specification relates to pharmacy protocols.

JW acknowledged she is still exploring this. Chemotherapy in Calderdale is made within their trust as the pharmacy service has been reviewed as part of the adult peer review where they showed compliance with the COSHH guidelines. Subsequently, there are viewed as compliant for children's services.

DI highlighted that her understanding is that Calderdale is an enhanced POSCU level A. However, within the requirements of the current service level agreement (NHSE 2021) they do not meet the requirements of this level and are therefore deemed a standard level POSCU. They are able to prescribe and make chemotherapy but oral chemotherapy maintenance is still undertaken at Leeds.

LH confirmed she approves regimens on ChemoCare and then it's made locally in aseptic pharmacy and delivered in outpatients.

JW queried if this is prescribed at PTC or POSCU. DI clarified ChemoCare v6 allows both trusts to view records. She noted Calderdale is responsible for the prescribing and approval but the overall treatment planning is undertaken at LTH PTC. This is different to the community administration of cytarabine done via bolus chemotherapy.

JW highlighted the LTH lead children's cancer pharmacist is currently investigating this, as there is lots of debate in England around this. She noted implications for POSCUs delivering the chemotherapy especially in South West. JW stated this is not unique to our area and its providing challenges over the country.

GW checked if she would be prescribing this in the bolus chemotherapy project. JW noted this is the subject of further discussion and agreement after updates from the national pharmacy team.

AR noted she spent 3 years working in a level 1 POSCU where clinics and flow sheets were taken from the PTC and prescribing and aseptics were done in DGH. In AR's opinion trusts need a vigorous process to ensure up to date flow sheets are readily available.

JL queried if any extra funding was available from commissioners for the delivery of vincristine and extra video clinics.

JW needs to check with KPe as part of his commissioning remit, but to her understanding, the business team at a trust will submit their business case to the commissioners regarding the resources needed to deliver this aspect of our service. AC concurred.

KPa believes the ODN should unpick everything before making major decisions. The service specification states enhanced level A POSCU is required for bolus chemotherapy, but this would also mean the centre is required to perform oral maintenance. KPa recognises the issues mentioned by JW in the South West, but highlighted the importance of following the service specification.

AK understands HUTH may need improvement in the service due to the high number of new patients if the

bolus chemotherapy project is to go ahead. She acknowledged a large undertaking of work with the extra clinics, prescription and administration of chemotherapy. This is further complicated by some nursing staff being under separate community governance.

AK noted business managers will want to know what positive elements this project is bringing to the trust. Her plan is to undertake an initial meeting with project lead and key people in the trust. She emphasised the need for more time in her job plan to conduct this as she doesn't want an unsafe service.

DI stated it's important to clarify the difference between chemotherapy delivered at home with PTC staff, and delivering chemotherapy in a POSCU. She noted care closer to home is very important to reduce travel burden on patients and highlighted this project differs to becoming an enhanced level A POSCU due to the number of new patients for example.

Calderdale

Service description
Liz Higgs - Lead Clinician
Rachel Wilkinson - Lead Nurse
Marie Beeson - Children's Community Nurse - Deputy
Lead

There is 26 Oncology patients currently (18 on treatment, 8 off treatment) as part of the standard level POSCU care with a monthly MDT. There is a Chemotherapy clinic every Wednesday with 4 patients on monthly Vincristine and 3 slots available for fast-track GP referrals.

Service updates

LH has taken over from Gill Sharpe after her retirement meaning there is no deputy lead currently. The new Children's oncology outreach nurse Alice Lewis is in post. RW updated regarding CCNT. She noted a new paediatric matron, children's ward manager and clinical educator, but a loss of admin staff resulting in new roles adapting to change.

RW is in talks with a member of staff who is willing to undertake training to administer vinca-alkaloid chemotherapy. Unfortunately, there is no MDT admin and a high turnover of staff of children's ward. Expressions of interest have been sent for an oncology link nurse role on the ward for MDTs.

Workforce

RW has arranged foundation training for nursing staff in February 2024 and is liaising with clinical educators in LTH. She noted a planned education session with junior doctors after issues with inpatients which could be developed into a rolling programme.

Referral pathways

LH highlighted the 3 slots on fast-track pathways which often see patients with enlarged lymph nodes which have reduced by the time they're seen. She noted inpatient issues regarding blood product support requiring meetings with ward staff. LH hopes to start implementing service improvements and audits once she is settled in the role. She noted the good communication between POSCU lead and LTH PTC.

KPa highlighted the need for a deputy to meet the service specification and suggested talks with the trust regarding this. KPa noted the benchmarking will also help this process.

Hull

Service description

JL updated the group. HUTH is a standard level POSCU covering Hull and East Riding. There are 22 patients on treatment, 1 off treatment and a large number on follow up. JL noted 28 patients on follow up in benign haematology also.

Service updates

JL noted a new family survey is being developed on google forms as the uptake was positive previously. The febrile neutropoenia proforma has been agreed by governance after adapting from Leeds and Southampton.

There is no deputy nurse in post, but JL is in discussions to try and rectify this. The ODN benchmarking meeting is taking place this week and JL has met with the bolus chemotherapy lead recently; more formal meetings are needed with all relevant stakeholders concerning funding and staffing.

When a new child is diagnosed, JL sends the CCLG guidance on referrals to the GP. She hopes over time all GPs will have access to this guidance.

Workforce

JL stated there has been no MDT support from LTH for the last 3 months. There is also a key worker off sick which has made attendance difficult. JL has PPM access and able

JL and JLo to give examples of missing blood requests to JW to unpick the reasons and understand processes to obtain patient updates directly. Unfortunately, late blood requests from LTH have led to patients missing necessary tests.

JL is continuing foundation training every 3 months with a mandatory update every month. She also trains junior doctors when they start in post.

JL highlighted the lack of admin support for MDT.

Referral pathways

HUTH thyroid pathway is still being investigated. There is a TYA service meeting booked due to issues with 16–18-year-old pathways. There had been difficulties in A&E with this age group and services not taking responsibility. Patients to be seen by paediatrics until further notice.

Service specification

The ALLTogether trial is waiting for the shared care agreement to be signed off in LTH by lead clinician Sue Picton.

KPa queried if late requests for bloods were being reported to LTH. JL noted she delineates this frequently, and acknowledged improvement after the last ODN, but noted this is lapsing again due to admin changes.

AR queried the plan for delivering bolus chemotherapy and its impact on HUTH. JW noted the plan is for the project lead to do this in the short term with a view of exploring options for local community children's nurses and/or lead nurse to take forward in the future.

Currently, children with solid tumours are eligible to receive bolus chemotherapy in the home. It is hoped in the future children requiring bolus chemotherapy as part of their leukaemia treatment will be eligible also.

JW explained the outreach model is presently available to a limited group, and while the project has scope to extend out, but it can't be sustained across the region as an outreach model. The team is looking at other options of delivery through CCN or POSCU teams, thus the governance arrangements are to be confirmed.

JW had previously spoke to day unit about blood requests but multiple changes within the admin team is making these clear processes problematic. Patients on trials dictate a different time frame and LTH wishes to give as much notice as possible due to effects on caseload and plan activity in HUTH.

JL noted some children on maintenance guidelines missed appointments. She has to wait for clinic staff to book bloods, but often finds parents ringing asking for appointment which requires JL to intervene.

DI noted the immense amount of planning in leukaemia pathway. She will plan discussions to alleviate this in the next leukaemia meeting

JLo noted she's started plotting blood tests in the oncology MDT tracking. She stated some maintenance patients are receiving duplicate emails with differing dates which is adding to the confusion. She noted if HUTH knew of the maintenance patients, then it's easier to plot bloods.

NLAG

Service description
SJG updated the group.
Dr Hassan Al-Moasseb - Paediatric Consultant
Dr Umaima Aboushofa - Paediatric Consultant (Deputy)
Karen York - Lead POSCU Nurse (DPoW)
Sara-Jane Goodwin - Lead POSCU (Scunthorpe)

SJG noted 2 main hospitals (DPoW and Scunthorpe) with an MDT caseload of 21 on treatment, 12 off treatment and end of life care for 2 children. NLAG are also providing bereavement support for 1 family. There is a monthly MDT with good attendance and input from SCH. Patients are discussed on treatment every month and off treatment for 6 months with the POSCU nurses supporting families as long as required.

Service updates

Tertiary clinic letters can be uploaded onto WebV timeline which enables SCH letters to be viewed also. SJG is in process of completing a SACT training passport.

The benchmarking process has been completed with a follow up meeting to be arranged in March. POSCU nurses and Dr Al-Moasseb attended education day which was very beneficial.

However, there is no psychology support directly in NLAG as it is provided by SCH. Sometimes, families mention they'd like this service closer to home. SJH noted some risks related to junior staffing and ensuring competence levels are up to requirements on each shift.

Workforce

	SJG highlighted 4 POSCU study days organised for 2024 facilitated by lead nurse and SCH to cover CVAD, blood transfusion and febrile neutropoenia protocol. There is CVAD buddy days and mandatory training due every 2 years. Referral pathways Within NLAG operational policy there is a clear pathway for referrals to tertiary centre. Issues seem to arise for some GP 2WWs. NLAG advocate urgent patients come to assessment unit to be referred to the tertiary centre after investigations. KPa acknowledged the workload in Grimsby and Scunthorpe over the last few months. She highlighted the work completed to formalise governance of inpatient care and is awaiting updated shared care agreements to reflect this.	
	York Apologies noted for Rebecca Proudfoot. KPa highlighted that there is no replacement lead clinician at Scarborough after Gemma Williams departure. The POSCU lead nurse is also off on long term sickness. JW and Sue Picton have scheduled a meeting to see if the network can support the trust with shared care.	
8. Education Day update	KPa felt the education day was a success after being rearranged due to industrial action. The next education day is planned for October 2024. KPa hoped members of the group would contribute ideas and welcomed suggestions.	
9. AOB	KPa offered the floor to the group. No other business noted. She also welcomed any suggestions on the organisation and flow of the meeting.	
10. Dates of next meetings	All 1-3pm 17/04/2024 10/07/2024 02/10/2024	