

CHILDREN'S OPERATIONAL DELIVERY NETWORK MEETING MINUTES
19/07/23 1:00-3:00pm

Attendees:

Name	Role	Organisation
Rachel Wane (RW)	Lead Research Nurse	Bradford Teaching Hospitals NHS Foundation Trust/ National Institute for Health and Care Research
Liz Higgs (LH)	Consultant Paediatrician	Calderdale and Huddersfield NHS Foundation Trust
Rachel Wilkinson (RW)	Nurse	Calderdale and Huddersfield NHS Foundation Trust
Natalie Kisby (NK)	Head of Family Support	Candlelighters
Alex Chilvers (AC)	Programme Manager	CTYA ODN
Paddy Carley (PC)	Data Co-ordinator	CTYA ODN
Katharine Patrick (KP)	ODN Lead / Consultant Paediatric Haematologist	CTYA ODN / Sheffield Children's NHS Foundation Trust
Holly English (HE)	Children's Community Nurse	Harrogate and District NHS Foundation Trust
Ashwini Kotwal (AK)	Shared Care Consultant	Hull University Teaching Hospitals NHS Trust
Jo Lyons (JL)	Oncology Lead Nurse	Hull University Teaching Hospitals NHS Trust
Charlotte Mackrell (CM)	Oncology Outreach Nurse Specialist	Leeds Teaching Hospitals Trust
Claire-Anne Jobe (CJ)	Clinical Nurse Specialist	Leeds Teaching Hospitals Trust
Dianne Hubber (DH)	Lead Nurse	Leeds Teaching Hospitals Trust
Jess Morgan (JM)	Paediatric Oncology Trainee / Senior Research Fellow	Leeds Teaching Hospitals Trust / National Institute for Health and Care Research
Jo Wood (JW)	Oncology Outreach Nurse Specialist	Leeds Teaching Hospitals Trust
Rachel Newby (RN)	Day Unit	Leeds Teaching Hospitals Trust
Trudi Cornforth (TC)	Oncology Outreach Nurse Specialist	Leeds Teaching Hospitals Trust
Kevin Peters (KPe)	Specialised Commissioner	NHS England
Karen York (KY)	Oncology Lead Nurse	North Lincolnshire and Goole NHS Foundation Trust
Dan Yeomanson (DY)	Paediatric Oncologist	Sheffield Children's NHS Foundation Trust
Deborah Rowley (DR)	Physiotherapist	Sheffield Children's NHS Foundation Trust
Hilary Quinton (HQ)	Lead Nurse	Sheffield Children's NHS Foundation Trust
Liz Purnell (LP)	Lead Nurse	South Yorkshire, NLAG & North Derbyshire Teenage Cancer Trust
Fiona Stephenson (FS)	Deputy Director	West Yorkshire & Harrogate Cancer Alliance
Rebecca Proudfoot (RP)	Shared Care Consultant	York and Scarborough Teaching Hospital NHS Foundation Trust
Stacey Needham (SN)	Lead Nurse	York and Scarborough Teaching Hospital NHS Foundation Trust

Apologies:

Name	Role	Organisation
Gill Sharpe	Lead Clinician	Calderdale and Huddersfield NHS Foundation Trust
Julie White	Lead Nurse	CTYA ODN
Danielle Ingham	Consultant Paediatrician	Leeds Teaching Hospitals Trust
Karen Dyker	Consultant Oncologist	Leeds Teaching Hospitals Trust
Patricia Fisher	Clinical Director	South Yorkshire and Bassetlaw Cancer Alliance
Louise Dolphin	Team Leader	Young Lives vs Cancer

Item	Minutes	Action
1. Welcome and apologies	KP welcomed the group and introduced PC (data co-ordinator) and AC (programme manager). KP also stressed the importance of attendance from each centre. Issue raised with some attendees unable to access the chat without an NHS net account. Apologies noted above.	PC/AC to look at access
2. Minutes from 19.04.23	<ul style="list-style-type: none"> • NLAG signature on MoU still outstanding but being followed up by AC. • RT mutual aid feedback still underway with HQ. • JW organised a regional meeting for network lead nurse forum but awaiting a national meeting. • DH and JL working on a pathway regarding TYA representation at Hull MDT. • RW discussed a CVAD competency document being worked on in Calderdale. • Issue of community nurses giving patients on AllTogether-1 trial chemotherapy resolved and agreed as issued and prescribed by PTC. <p>Minutes agreed from the previous meeting.</p>	
3. Yorkshire and Humber Children's Cancer ODN a. MOU- Network Members b. Work programme update	<p>a. MoU NLAG still awaiting signature.</p> <p>b. Work Programme Update</p> <p>Whole Genome Sequencing The advert for the WGS CNS role has gone out to advert. Tasha Morley (WGS CNS Sheffield) is actively involved with Paediatric patients. In both PTCs WGS is the standard of care for Leukaemia patients, but more difficult with solid tumours. More children being offered WGS and progress being made due to CNS role. KP asked how much work is required for the WGS pathway. CM noted the research team will be best placed to answer but aren't present at this meeting.</p> <p>U16 Improving Experience of Care JW leading this project but no major update.</p>	AC to escalate

	<p>Care Closer to Home JM noted a proposal has been submitted to Leeds Hospitals Charity for the ambulatory care project but they have deferred this until September awaiting business case sign off. Also, the CCLG project will be funded with increased costings. KP noted agreement between Sheffield PTC and NLAG POSCU is moving forward.</p> <p>Workforce Development JW and HQ working on nurse education. KP noted there aren't many spaces left on the education day in September, with the agenda being formalised currently. Members to contact AC if they wish to attend.</p> <p>Network Data Collection KP noted that PC had mainly been working on TYA data collection. Sheffield and Leeds have different databases and trying to streamline this data collection for the Children's ODN should be a priority.</p> <p>PPIE KP wants to ensure the data we collect is relevant and useful to the ODN. No updates since the last meeting.</p> <p>Benchmarking Audit AC has Bristol's benchmarking documentation in preparation for a meeting with JW to ensure guidance is relevant to our ODN. This will be ready for roll out in September hopefully. KP clarified this is for each trust to benchmark themselves against NHS service specifications with guidance regarding compliance. DY queried if this is reported to our ODN or NHS England. AC confirmed this is to our ODN initially, with KPe noting eventually it will be to NHS England. FS stated dependent on the outcome of the assessment process, the ODN is welcome to share with Cancer Alliances as support and guidance may be available.</p> <p>ODN Website Correct method of payment for the website awaited. AC meeting with GoDaddy soon. PC has a draft email ready for the website working group participants. KP noted importance of guidelines being up to date with separate sections for Sheffield and Leeds PTCs planned.</p> <p>Shared Care Agreement KP stated JW keen to review all documents, streamline the process and create a consistent shared care agreement for POSCUs. This is a work in progress currently. Shared care agreement with Hull regarding R&D aspects of AllTogether-1 trial more urgent.</p>	<p>All members to contact AC if they wish to attend education day</p>
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<p>4. Radiotherapy Mutual Aid Update</p>	<p>KP stated at present Sheffield unable to provide paediatric RT on site with the exception of single fraction palliative RT or total body irradiation for bone marrow transplant. This is due to a lack of paediatric trained clinical oncologists. DY updated the group as the arrangement is being extended by 6 months. This requires a clinical oncologist working as before and paediatric specific training for a different staff member in Leeds with exact details to be arranged. DY and HQ expressed gratitude to Leeds for the help. KPe echoed DYs sentiments with a strengthening of relationship between the two teams and is confident of mutual aid stopping in March 2023. KP noted importance of feedback from patients organised by HQ.</p>	<p>HQ to continue mutual aid feedback</p>
<p>5. NLAG pathway for suspected paediatric malignancy</p>	<p>KP mentioned a few incidents regarding children with suspected malignancy seen in primary care referred to adult site-specific oncology MDT bypassing paediatric services. AK found patients as another consultant informed her and stated 16–18-year-olds also missing out on specific care. AK would like a written pathway to share with primary care and MDT colleagues.</p> <p>KP highlighted difficulty due to number of different pathways for GPs. KPe agreed with further guidance for GPs and especially for MDT leads. FS will contact Cancer Alliance and ICB counterparts to communicate this message to primary care. KY filled out Datix in NLAG and confirmed referrals weren't completed correctly in primary care.</p> <p>DY stated historically 2ww referrals were sent to be triaged by paediatric team and asked if the forms can be sent over for the wording to be considered.</p> <p>AK discussing with 2ww pathway team regarding clarity of referral wording for GPs. KP delineated that a clear pathway should be developed which can then be published at a locally accessible point.</p>	<p>FS to contact Cancer Alliance and ICB and obtain historic referrals</p> <p>KY to send DY/KP copy of 2ww form</p> <p>KY to look at publishing operational pathway on NLAG website</p>
<p>6. Education update</p>	<p>HQ focusing on planning on the away day and SACT chemotherapy passport. JW also working on education and training opportunities which feeds into the national CCLG directory of training and education; emphasising a multi-professional perspective.</p>	
<p>7. Network Lead Nurse Forum a. CCLG/RCN Update</p>	<p>HQ and KP spoke of the Lead Nurse Forum in the previous minutes section. JL noted this was a positive meeting with an action point of late blood results noted as improving. HQ noted consistency of issues in areas with concerted approach to progress this.</p>	

8. Service risks/Issues – POSCU Update Slides

Calderdale and Huddersfield

LH and RW presented the update slides.

- 28 patients discussed on the MDT (22 on treatment, 6 off treatment).
- Gill Sharpe is retiring so there will be a replacement lead consultant.
- Lots of staffing changes (senior managers, admin staff and newly qualified nursing staff in September).
- Chemo clinic is working well at new premises.
- New community nurse trained who is able to cover RW.
- KP queried whether GS' retirement will affect the service. LH stated inpatient work may be a struggle as she is community based but the clinics and MDTs will be covered.
- Training dates in place with clinical educators. CVAD competency document implemented for nursing staff.

Harrogate

KP presented the update slides.

- Not a POSCU but a small DGH.
- Similar issues throughout the network with staffing and backfilling.

Hull

JL presented the update slides.

- Usually have ~25 children on treatment but due to influx around June/July this has raised to 30.
- Benign Haematology has 28 active patients on treatment.
- Survey regarding ward or assessment unit for febrile patients was undertaken with the ward favoured due to comfort and waiting times.
- Support available from TCT for patients ages 13+.
- More notice for bloods from community nurses which is improving service.
- Yearly mandatory update training in place with 75% staff attending foundation training.
- Debate over thyroid pathway as to whether place of treatment should be Hull or Leeds. KP queried involvement of paediatric service in Leeds. AK clarified that patient was seen in paediatric MDT eventually. Thyroid pathway allows for surgery without paediatric involvement. Simone Wilkins is looking at this pathway.
- DH also looking into 16-18 pathway. AK noted that this is an issue in Hull. New patients are not being referred from A&E to paediatrics. AK working with local colleagues to delineate a pathway. DH noted

DH to complete minutes from 16-18 pathway meeting

	<p>Julie Watson's work is on hold due to absence. This is not unique to Hull and is an issue throughout network. KP stated differences in shared care between POSCU and PCT agreements. New agreements should be clear for 16-18 years old.</p> <ul style="list-style-type: none"> Hull not being informed of discharges from Leeds and finding out from parents. KP queried whether this was being addressed with Leeds. JW has been working on this. KP questioned how many patients with febrile neutropenia for example would go to Hull rather than Leeds. JL confirmed all but the high-risk patients stay in Hull. <p>North Lincolnshire and Goole KY updated the group.</p> <ul style="list-style-type: none"> Large trust in size ~40 patients: Scunthorpe (8 active, 16 non-active) and Grimsby (14 active, 24 inactive). Good discussions regarding formalising POSCU status MoU signature being chased by KY. POSCU specific training days in conjunction with Sheffield Lead Nurse. CVAD training with Band 5 and 6 nurses in Grimsby. Management changes but highlighted need to keep service in spotlight. Need to improve pathway as noted previously. Acute services review as AK mentioned previously is in the background. KP highlighted POSCU shared care agreement not in place for inpatients, but this is being worked on to allow for care closer to home. <p>Leeds DH updated the group.</p> <ul style="list-style-type: none"> Issues regarding staffing. Ward 33 is still temporarily closed with the transplant unit there currently. <p>Sheffield HQ updated the group.</p> <ul style="list-style-type: none"> Work with NLAG ongoing, thanks to KY for her hospitality. Service remains busy with some issues regarding sickness and maternity leave. Ensuring patients for RT in Leeds are transitioned appropriately and managing patient and parent expectations. 	
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	<ul style="list-style-type: none"> • KP noted inexperience of nurses managing oncological diagnoses putting pressure on senior members of staff. Similar messages throughout the network. <p>York and Scarborough RP presented the update slides.</p> <ul style="list-style-type: none"> • Less patients than the other groups but numbers are quite fluctuant. • Deputy Lead Oncologist (based in Scarborough) has left with no replacement available. New staff grades employed soon with the hope that one may take on some of their tasks. • Parent user survey developed and currently underway. • AllTogether-1 trial being set up. • RP Teaching at paediatric and H&N MDT with clinical governance and GPs on referral pathways. • SN noted community nurse educator is critical in prioritising oncology training for nurses. Ward liaison has been named and due for attendance at MDT. • KP queried whether patients are still attending SGH and if this affecting patient care. RP confirmed this isn't affecting patients with the only difference in long term follow up. AK noted she is happy to take follow up in Hull for patients if closer to home. • Similar issues of communication with ward discharges from Leeds. 	
<p>9. AOB a. Community physio & OT services for patients with complex needs following completion of cancer therapy.</p>	<p>Community physio & OT services for patients with complex needs following completion of cancer therapy.</p> <p>DR noted when significant rehab is required on discharge it's often a postcode lottery on how much input patients receive in the community. KPe is aware and the head of CRG informed also. This is a nationwide issue not just within our network.</p> <p>Sheffield is dealing with this by submitting individual funding requests (which are being approved) but this is time consuming. KP asked whether this was the same with patients with acquired brain injuries. DR noted this is across the board with diagnoses. KP stated IFRs become difficult as when there is multiple, they say it should be a cohort funding application.</p> <p>KPe confirmed this is common regarding funding. There are proposals around neuro rehabilitation but unsure of scope. South Yorkshire commissioners looking at adults</p>	<p>DR to look at referral pathways with centres</p>

	<p>and trying to include paediatrics as there are similar themes with adults and children. Questions may be asked regarding IFR being approved consistently as it could be part of the overall budget.</p> <p>DR queried if all centres have referral pathways to physiotherapists and if they are fully trained. AK confirmed no pathway in Hull making it complicated for the patients. DR asked regarding non-neuro patients. AK confirmed no pain team in Hull with patients going to Leeds.</p> <p>DR noted congruent supportive care pathways (physiotherapy, psychology, SaLT, dietetics) is something we should be looking at. KP agreed with this and asked for York's input. RP stated there is no defined pathways but no issues with physios seeing patients. RW mentioned the life limiting caseload which enables access to quicker routes to referral.</p> <p>AK stated that physiotherapy is available at Hull. DR queried regarding the pathways available. KP highlighted that an informal physio forum could be useful. DR suggested this could be a sub-section on the website.</p> <p>KP offered the floor for any other business. Nothing noted. KP highlighted importance of finishing the benchmarking work and finalising the website working group. This should be useful and informative and volunteers are welcome if anyone wishes.</p> <p>KP also provided a reminder for the education day in September.</p>	
<p>10. Dates of next meetings</p>	<p>18/10/2023 17/01/2024 17/04/2024 All 1-3pm 20th September 2023 CTYA Cancer ODN AWAY DAY Venue OEC Sheffield</p>	