

**CHILDREN'S OPERATIONAL DELIVERY NETWORK MEETING MINUTES**  
**18.10.23 1:00-3:00pm**

**Attendees:**

<b>Name</b>	<b>Role</b>	<b>Organisation</b>
Gemma Williams (GW)	Lead Clinician	Airedale NHS Foundation Trust
Rachel Lyles (RL)	Lead Nurse	Airedale NHS Foundation Trust
Rachel Wane (RW)	Lead Research Nurse	Bradford Teaching Hospitals NHS Foundation Trust/ National Institute for Health and Care Research
Gill Sharpe (GS)	Lead Clinician	Calderdale and Huddersfield NHS Foundation Trust
Rachel Wilkinson (RW)	Nurse	Calderdale and Huddersfield NHS Foundation Trust
Natalie Kisby (NK)	Head of Family Support	Candlelighters
Jayne Lowther (JLo)	Community Nurse	City Health Care Partnership
Alex Chilvers (AC)	Network Manager	CTYAC ODN
Julie White (JW)	Lead Nurse	CTYAC ODN/ Leeds Teaching Hospitals NHS Trust
Diane Hubber (DH)	TYA Lead Nurse	CTYAC ODN/ Leeds Teaching Hospitals NHS Trust
Katharine Patrick (KPa)	Lead Clinician	CTYAC ODN/ Sheffield Children's NHS Foundation Trust
Liz Purnell (LP)	TYA Lead Nurse	CTYAC ODN/ South Yorkshire, NLAG & North Derbyshire Teenage Cancer Trust
Lisa Pearce (LPe)	Business Manager	Hull University Teaching Hospitals NHS Trust
Ashwini Kotwal (AK)	Lead Clinician	Hull University Teaching Hospitals NHS Trust
Joanne Lyons (JL)	Lead Nurse	Hull University Teaching Hospitals NHS Trust
Michelle Kite (MK)	Matron	Leeds Teaching Hospitals NHS Trust
Danielle Ingham (DI)	Consultant Oncologist	Leeds Teaching Hospitals NHS Trust
Charlotte Mackrell (CM)	Oncology Outreach Nurse Specialist	Leeds Teaching Hospitals NHS Trust
Karen Dyker (KD)	Consultant Oncologist	Leeds Teaching Hospitals NHS Trust
Karen York (KY)	Lead Nurse	NLAG NHS Foundation Trust
Hassan Al-Moasseb (HAM)	Consultant Paediatrician	NLAG NHS Foundation Trust
Deborah Rowley (DR)	Physiotherapist	Sheffield Children's NHS Foundation Trust
Lynn McNamee (LM)	Diagnostics Delivery Manager	West Yorkshire and Harrogate Cancer Alliance
Louise Dolphin (LD)	Team Leader	Young Lives vs Cancer

**Apologies:**

<b>Name</b>	<b>Role</b>	<b>Organisation</b>
Liz Higgs	Consultant Paediatrician	Calderdale and Huddersfield Teaching Hospitals NHS Trust
Dan Stark	Lead Clinician	CTYACODN/Leeds Teaching Hospitals NHS Trust
Hilary Quinton	Lead Nurse	CTYACODN/Sheffield Children's NHS Foundation Trust

Trish Fisher	Clinical Director	SYB Cancer Alliance
Rebecca Proudfoot	Lead Clinician	York and Scarborough Teaching Hospitals NHS Trust

Item	Minutes	Action
<b>1. Welcome and apologies</b>	KP welcomed the group and encouraged participation from everyone by raising hands or speaking up.	
<b>2. Minutes from 19.07.23</b>	<p>The minutes and actions from 19.07.23 were agreed by the group.</p> <ul style="list-style-type: none"> <li>• AC and PC investigated chat functions for external members but unfortunately an NHS.net account is needed to access the chat.</li> <li>• NLAG have signed the MoU.</li> <li>• ODN education day has been moved from September to 21<sup>st</sup> November due to industrial action.</li> <li>• JW noted the Shared Care Agreement is awaiting sign off by Hull Teaching Hospitals NHS Trust and once completed this will support opening of the ALLTogether Trial at the Trust.</li> <li>• DR discussed access to physiotherapy for patients with long term needs. Children’s rehab pathways are already under review and DR is checking processes. ICB regional leads are covering this as a wider region.</li> </ul>	<b>AC/PC to add this as recurring agenda point</b>
<b>3. Yorkshire and Humber Children’s Cancer ODN</b>  <b>a. MOU - Network Members</b> <b>b. Work programme update</b>	<p><b>a. MOU – Network Members</b> AC stated the Calderdale and Huddersfield signature is outstanding due to an admin error. GS has arranged for this to be re-signed but unsure of timescale due to staff shortages.</p> <p><b>b. Work programme update</b></p> <p><b>Benchmarking</b> The Benchmarking exercise has been sent to the POSCUs with KP and KP a confirming availability for visits. AC reminded all that the documents are due to be returned by the end of October and offered the floor for any questions or concerns.</p> <p>GS queried whether this is a work in progress and if more guidance will be available after the meeting and visit. JW stated this should be viewed as a work in progress for the network. There is ongoing national work regarding guidelines and peer review with amendments to be made over time. Ideally, this promotes proactive discussion and support for individual trusts. KP a agreed with a constructive and supportive approach.</p>	

	<p>AK highlighted technical difficulties with the spreadsheet. Overall, the Benchmarking tool is helpful as ODN requirements can be flagged to management; highlighting the urgency of staffing issues for example. KPa confirmed the ODN can escalate issues with the trust.</p> <p>JL queried if the process needs signing off by management. KPa confirmed this is not a requirement.</p> <p>GW asked if evidence should be provided in a similar way to peer review exercises. KPa stated it would be useful to see key documents. JW emphasised this will help identify priority areas of focus i.e., updating of pathways, guidance etc.</p> <p><b>Website</b> JW stated meetings have taken place with the website developers. PCa has populated content with a focus on professional access. JW discussed whether an interactive session at the Education Day in November would be beneficial and offered the floor. GS suggested an interactive session will allow for constructive feedback.</p> <p><b>Workforce training and education</b> JW noted ICBs, Cancer Alliances and NHSE offer different funding streams with options for local and regional training. JW is looking at resources currently available and working on PTC development of a wider repository of modules on our platforms; offering complimentary training and not duplicating work. For example, NHSE run a training programme for CNS over 18-24 months. JW is investigating how can we replicate this in our ODN for various job roles. Preliminary discussions are underway with other ODNs to provide access on external training. Hopefully, a clear strategy will be in place by 2024 for all staff. JW suggested the Lead nurse meetings would be a good forum for this workstream.</p> <p><b>WGS nurse practitioner</b> No update regarding this role. Dan Stark and Diane Hubber to discuss in further detail. KPa noted patients can still access WGS but this is difficult without a dedicated nurse in post. Tasha Morley is the equivalent in Sheffield and has been working in paediatrics for the last 4 months which has been very helpful.</p> <p><b>Care closer to home</b> JW is meeting with shared care partners who are incredibly enthusiastic and positive. She highlighted GS for her work on this project and is updating the Leeds shared care agreements concurrently.</p>	<p><b>JW to send shared care agreements to Calderdale</b></p>
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	<p><b>Bolus chemotherapy</b> New starter is due in post early December as part of a 2-year project working with POSCUs to improve care closer to home. JW hopes as families receive care closer to home, confidence will grow in the service.</p> <p>JLo queried the job role and responsibility. JW confirmed it is a Candlelighters funded project for a dedicated resource to help deliver treatments locally and the community role will be backfilled.</p> <p>JL asked whether this is in an outpatient setting or at home. JW stated this is a work in progress. Feedback from families indicates a preference for home treatment.</p> <p>KPa acknowledged POSCUs will need to abide by enhanced POSCU regulations if treatments are to be delivered. Issue raised regarding prescribing chemotherapy infrequently which may not be safe practice. This could be done at the PTC, but all options are being discussed.</p> <p>Unfortunately, the ambulatory chemotherapy project bid with Leeds charities was unsuccessful. This is a priority nationally. The steering group is looking at other funding opportunities.</p>	
<p><b>4. Benchmarking feedback - POSCU queries and concerns</b></p>	<p>Please see section 2.</p>	
<p><b>5. Radiotherapy Mutual Aid Update</b></p>	<p>KPa updated the group. Sheffield based consultant was on maternity leave and subsequently off sick so the service was unable to deliver paediatric radiotherapy. The only exceptions were palliative single fraction and total irradiation for stem cell transplant. Diagnosis and initial treatment in took place in Sheffield but patients moved to Leeds for the majority of their treatment.</p> <p>This is unfortunately going to continue as the consultant is unable to return to work. There is a meeting in the next few days and KPa will update when this is available. HQ has undertaken feedback sessions with patients involved in the mutual aid process.</p>	<p><b>AC to ask HQ for feedback evaluation</b></p>
<p><b>6. NLAG pathway for suspected paediatric malignancy</b></p>	<p>KPa highlighted a number of patients who have been referred inappropriately in the region and suggested the pathway isn't clear enough for GPs from Sheffield PTC. KY stated the NLAG operational pathway is clear for GPs so further investigation is needed. She is speaking with an Obstetrics and Gynaecology matron who has worked on previous pathways and will update in due course.</p>	<p><b>KPa to contact Cancer Alliance/ICB</b></p> <p><b>KY to send NLAG 2ww form.</b></p>

	<p>KPa noted Sheffield are in the process of formalising pathways and guidance for POSCUs and GPs.</p> <p>JW mentioned Leeds PTC are in a similar position and working through challenges. This has been escalated to the management within the trust.</p> <p>AK aware that NLAG has different pathways for acute paediatrics resulting in incorrect referrals to Hull. Local meeting with business managers is planned to see if the form can be modified. Another issue was raised regarding Breast lump patients which is being discussed in tandem. AK is worried incorrect referrals are burdening patients with increased travel time.</p> <p>GW highlighted an issue informing GPs to refer to Bradford instead of Airedale. Attempts have been made to contact Primary Care ICB but no success yet. JW hoped for a dual approach with Cancer Centres and Cancer Alliances; reworking and streamlining systems.</p> <p>KPa stated we need to pick out children who need urgent referrals and address more mild symptoms via a different route.</p> <p>GS noted this has been discussed frequently, with DGHs all having slightly different systems for acute referrals and 2 week waits. Arranging common pathways which work for all is difficult.</p> <p>KPa mentioned the CCLG guidance is that children presenting in primary care with suspected malignancy should usually be referred urgently to a local general paediatrician who will then refer on to haem/oncology at the PTC if required after initial investigations. KPa asked if POSCUs have a rapid access clinic and how feasible it was for POSCUs to see these children within 48-72 hours if there was a high suspicion of malignancy.</p> <p>GS noted Calderdale have a 2ww triage system and patients are generally seen within a week. Most have minor illnesses and don't need to be seen urgently; urgent slots are often filled with patients displaying mild symptoms</p> <p>KPa emphasised this is not specific to NLAG region and widespread across the region.</p>	
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	<p>HAM discussed NLAG paediatric assessment unit. If the GP is concerned, they can ring the department and arrange assessment.</p> <p>AK suggested the admin processes in primary care led to incorrect referrals. HAM believes there is communication issues with primary care. KPa looking at this at PTC level and figuring out what requirements there are for urgent referrals.</p>	
<b>7. Education update</b>	The Education Day has been rescheduled for 21 <sup>st</sup> November. Please get in touch with AC if you wish to attend. The agenda will be sent out shortly.	<b>All members to contact AC if they wish to attend</b>
<b>8. Network Lead Nurse Forum</b> <b>a. CCLG/RCN update</b>	JW informed the group that the national ambulatory chemotherapy group is growing with key work streams being developed. The Career and Education framework for nurses working with CYP with cancer has led to some re-evaluation. Jeannette Hawkins (CCLG head of nursing) is retiring, and there will be a new incumbent soon. A working group to review appendix 3 from the service level agreement of nursing standards has been developed.	
<b>9. Service risks/Issues – POSCU Update Slides</b>	<p><b>Airedale</b></p> <p>GW updated the group. Airedale is a standard POSCU covering 700sq miles. 5 patients on treatment, 1 post BMT, 1 awaiting debulking surgery, 1 under monitoring ?LCH and 1 post-treatment.</p> <p>Dr Williams is the lead clinician with Dr Rawlings supporting as the deputy lead. GW emphasised she is happy to see follow up patients in Airedale. Rachel Lyles is the lead nurse with a ward nurse taking on the deputy role. Airedale is commencing with the ALL-together-1 trial and GW is liaising with the lead for the trial in Leeds to iron out some minor issues.</p> <p>During the ODN visit bolus chemotherapy was discussed and GW will meet with GS to see how Calderdale deliver this.</p> <p>91% of nurses are foundation trained, but 1/3 ward staff are non-compliant with CVAD training. Outreach training taking place with a Nursing E-roster set up to monitor compliance.</p> <p>GW is working to build links with adult colleagues in the trust. As mentioned earlier, GPs being advised to refer to Bradford is being investigated.</p> <p>Ongoing issues with access to psychology, allocated time for the lead nurse, oncology specific feedback and lack of</p>	<b>JW to inform Leeds team GW is happy to see follow up in Airedale</b>

	<p>family leaflets. JL had success with Google Forms in Hull for surveys which could be replicated in other trusts.</p> <p><b>Calderdale</b>  GS updated the group. There are no major changes from the last update. Case load is relatively static and the Community team remain busy. There is a staffing issue with inpatient care (nursing and medical). An influx of new starters is resulting in an increased need for training. The Chemotherapy clinic is up to 4 patients per month and running smoothly.</p> <p>GS is retiring at the end of November, but no replacement is currently lined up. Liz Higgs is taking over as shared care lead in the interim. Neil Shaw (Macmillan nurse) is leaving soon but a replacement has been appointed. The new CCNT manager is proactive in helping with issues regarding staffing workload. Unfortunately, there is no MDT admin support.</p> <p>46% staff are foundation trained on the ward with work ongoing to support this. GS noted she has been invited to fewer end of treatment reviews.</p> <p><b>Hull</b>  JL updated the group. Shared care level 1 currently serving Hull and East Riding with 25 patients on treatment and 38 off treatment offering an inpatient service for febrile neutropenia. The Community team perform bloods at home and monthly MDTs take place. There is a vacancy for the deputy nurse role which will hopefully be filled across 2 days.</p> <p>Blood requests seem less timely after picking up recently. The Benchmarking process is complete and has been sent to AC. Shared care agreement is waiting to be signed by management. JL has access to PPM+ which is very helpful as blood test results can be uploaded.</p> <p>75% nurses on the medical ward are foundation trained with monthly training available. JL has set up a mandatory yearly update.</p> <p>JL is working in conjunction with DH to finalise the 16-18-year-old pathway. An agreement is in place for this age group to see paediatrics, but in the future, they will go to Castle Hill. AK confirmed ALLtogether-1 trial and 16-18 pathway are the priorities.</p> <p><b>Leeds – PTC</b></p>	<p><b>JW to investigate end of treatment reviews in Leeds</b></p>
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	<p>JW updated the group. There is an influx of new nurses but a 15% vacancy rate is still present. JW is pushing an education campaign to upskill as quick as possible.</p> <p>Due to ongoing work on ward 32 stem cell transplant has closed and relocated to the teenage unit (resulting in a reduction of capacity by 3). The team is struggling overall but additional resource is arriving from the trust.</p> <p>Radiotherapy mutual aid to Sheffield has hopefully resulted in positive experiences. Unfortunately, minimal feedback is available. Negative points were mainly focused on accommodation, but the radiotherapy process was positive overall.</p> <p>DI informed the group a new locum consultant has started in post focusing on leukaemia and transplant patients.</p> <p><b>NLAG</b> KY updated the group. Level 1 POSCU working with Sheffield ensuring the shared care agreement is functioning. Overall, 40 patients on treatment and 30 off treatment. Foundation and CVAD training days are being arranged currently with ad hoc sessions available.</p> <p>There is 2 band 6s on a shift who can access ports and plans in place to allow 6 hours a month to help the lead nurse duties. Meetings are being arranged with managers across the trust as current workloads are unmanageable.</p> <p>KPa is working on formalising agreements between trusts after the benchmarking exercise is completed.</p> <p><b>Sheffield – PTC</b> KPa updated the group. Lots of junior new starters with a varied skill set. Plan is in place for upskilling but it's leading to pressure on senior nurses. LP informed the group a senior band 6 has been appointed (2 days a week) and is starting imminently to help training and education.</p> <p><b>York and Scarborough</b> Rebecca Proudfoot was unable to make the meeting due to a ward emergency. GW deputised for the update slides.</p> <p>Staff grade is in post helping to deputise some the clinical lead's work. York has 15 on treatment and 6 off treatment. Scarborough has 10 on treatment, 0 off treatment.</p> <p>There is monthly MDTs organised and an emphasis on training regarding lymphadenopathy with the Head and</p>	<p><b>GW to send York Deputy details to AC to join ODN distribution list</b></p> <p><b>GW to liaise with Sue Picton</b></p>
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	<p>Neck teams. KPa and GW wondered if the new starter could contact Leeds PTC for training and protocols reviews.</p>	<p><b>regarding training</b></p>
<p><b>9. AOB</b></p>	<p>AK queried parking options for the Education Day in November which is readily available at the venue if you inform staff on arrival.</p> <p>KPa encouraged all members to feedback on whether the meetings are helpful and if any aspects could be changed to improve the experience and grow as a network.</p> <p>JW suggested an educational element to be brought into the meeting making topics relevant to all groups.</p> <p>JL queried how staff could access Leeds PTC training. JW confirmed everyone was welcome and is exploring external training. JW spoke of the training and education tab planned for the website which will capture the main events relevant to the ODN.</p> <p>JL noted the service specification states deputy leads must be trained to an external level. JW stated they've dropped the accreditation for external training. Leeds keen for external training to be accessible for all.</p>	
<p><b>10. Dates of next meetings</b></p>	<p>17/01/2024 17/04/2024 CTYA Cancer ODN EDUCATION/TRAINING DAY Venue: OEC Sheffield</p>	