

CHILDREN'S OPERATIONAL DELIVERY NETWORK MEETING MINUTES

Wednesday 19/04/2023 1:00-3:00pm


Attendees: Katharine Patrick (KP), Diane Hubber (DH), Julie White (JW), Joanne Lyons (JL), Patricia Fisher (PF), Debra Harris (DH), Theresa Bowen (TB), Rachel Wane (RW), Stacey Needham (SN), Hilary Quinton (HQ), Elizabeth Purnell (EP), Martin Elliott (ME), Ashwini Kotwal (AK), Holly English (HE), Deborah Rowley (DR), Alex Chlivers (AC), Gill Sharpe (GS), Sally Morrison (SM), Jess Morgan (JM), Charlotte Mackrell (CM), Hassan Al-Moasseb (HAM), Sara-Jane Goodwin (SJG), Jayne Lowther (JL),


Apologies: Kevin Peters, Michelle Kite, Vicky Holden, Liz Higgs, Sarah Hanson, lsanderson23@outlook.com, Nicola Seneviratne, Annabelle Oades, Vanessa Brown, Amy Porter, Dan Yeomanson, Louise Dolphin, Philippa Rawling.

Agenda Item	Notes	Actions
Welcome	KP welcomed the group.	
Minutes from last meeting	Minutes from 23/01/23 were reviewed and agreed by the group.	
Yorkshire and Humber Children's Cancer ODN	<p style="text-align: center;">a. MOU- Network Members</p> <p>KP updated on the MOU. Majority signed, however, Bradford and NLAG outstanding.</p> <p>KP mentioned ToR which will be re-circulated as soon as it has been signed by the host trust-Leeds.</p> <p style="text-align: center;">b. Work programme update</p> <p>There have been some delays in progress with the work plan due to the Network Manager change and other leave.</p> <p>Cancer Pathway Mapping:</p> <p>JW updated regarding the referral pathways, as part of the Cancer Collaborative. Mapping finalised and there is an understanding of the position. Plans are being made in</p>	<p>AC to send reminder email</p> <p>AC to organise and circulate</p>

	<p>terms of next steps for referrals coming into the Trust. JS met with ME, AP and JW to look at the referral process. Further work is to be completed on this pathway. Sheffield's system works well which will be looked into.</p> <p>Nursing Education:</p> <p>JW talked about resharing the questionnaire as further information is needed to better inform the development the Nursing Education Strategy for the Network. Considerations will include a potential Northern Region approach.</p> <p>Care Closer to home:</p> <p>JW has successfully secured funding for the Bolus chemotherapy project, with the intent of identifying a sustainable service delivery model moving forward. JW confirmed the bid has been submitted for ambulatory chemotherapy and will update once more is known.</p> <p>Whole Genome Sequencing:</p> <p>JW confirmed the nurse dedicated to WGS in Leeds will be leaving. KP confirmed WGS for leukaemia in Sheffield and Leeds is more established with patients being offered WGS and taking this up. KP highlighted difficulties in solid tumours, particularly when diagnosed on core biopsy due to limitations of tissue sample and complexities of the pathway. KP updated TM has approval to start paediatric record of discussion from next month. KP and TM are meeting tomorrow to relook at pathways. Turnaround times for Y&H for results are 3-6 months and it is recognised we are behind some other parts of the country, although overall KP feels progress is being made.</p> <p>ODN Website:</p> <p>KP mentioned the website domain. Funding has been agreed, and further updates will be provided at the next ODN Meeting. JW talked about what this may look like and welcomed any ideas.</p> <p>Benchmarking:</p> <p>JW talked about Benchmarking against national service specifications. JW is looking at standardising benchmarking across the region perhaps using templates from other ODNs</p>	<p>AC/JW to action and set up a working group in the coming months.</p> <p>AC/JW to set up meetings</p> <p>AC to meet with KP to move this forward</p> <p>AC/JW to arrange meetings</p>
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	<p>Shared Care Guidelines: KP highlighted Sheffield and Leeds have separate shared care guidelines and questioned whether we should have shared care guidelines for the region, Yorkshire & Humber given the general management is the same. KP welcomed thoughts but is hopeful we can get this agreed.</p> <p>Shared Care Agreements: JW mentioned the shared care agreements and advised these will be prioritised for review as they are dated. NLAG's will be reviewed during the process of formalising their POSCU status. York & Scarborough agreements will be joined and not separate.</p>	
Education update	<p>KP highlighted the Network Education day taking place on the 20/09/23. We have space for around 100 delegates and AC will send out a request for attendees. KP asked for suggested items for the agenda and JW asked for any suggestions re: format to ensure it is as engaging and valuable as possible.</p> <p>Nursing competency Workbooks: JL queried how far on we are with the workbook. JW confirmed Suzanne is looking into it and taking the lead on shared care.</p>	AC to circulate email to register interest for ask for items for agenda in May/June
Radiotherapy Mutual Aid Update	<p>KP mentioned the mutual aid between Leeds and Sheffield is continuing until around September 2023. Sheffield patients can then return to have treatment in their PTC when the paediatric radiotherapy consultant is expected to return from maternity leave. Of note, a second Paediatric Radiotherapy consultant has commenced in post and undertaking required training.</p> <p>JW highlighted the patient experience questionnaire and the low response rate, even with multiple reminders from the Radiotherapy team. KP will ask colleagues to prompt families to complete the questionnaire as their feedback is so important.</p>	HQ to action feedback from Sheffield families who have received RT in Leeds
Network Lead Nurse Forum	<p>CCLG/RCN Update JW updated she had received one response to the scheduling and format for the Lead Nurse Network meetings. JW will forward a virtual meeting date and this</p>	JW to send out a virtual meeting for 6 weeks' time

	can be agreed at this time.	
Patient and Public Involvement	KP is keen to push this forward in the ODN and there will be a platform on the website to facilitate this. Keen to hear ideas on how we can best involve families and the information we need to help shape our service improvements. JL and JM shared their ideas. JW updated on key charity partners, who do a lot of engagement work and the possibility of using their engagement events to obtain feedback on families experiences. JW and KP stated the need to identify the key questions we want answering as a Network. JW confirmed that Nationally there is a sense of questionnaire fatigue, illustrated in the downward trend of response rates across all surveys.	JW/AC/KP to take this forward
Service risk/ Issues- POSCU update slides	<p>JL presented slides from Hull</p> <p>Caseload smaller than normal. Monthly MDT going ok, however TYA service not currently present and the community team would value their input. POSCU activity around 3-5 inpatients each month. Palliative care meetings have started with Consultants in Leeds which is working well. Lots of senior members of staff have left, leaving a predominately junior workforce. No psychology service available in Hull, therefore reliant on the PTC service.</p> <p>JL has taken over training for internal staff and community team. This is now formalised and on the training matrix as a mandatory requirement.</p> <p>JL raised there has been inconsistent advice around Febrile Neutropenia. Bob Phillips sent over posters to help clear this up.</p> <p>Ongoing issue is last minute requests for blood tests and cytarabine. This was raised at MDT and a plan is being discussed. Referrals have been problematic to the CCNT in particular those discharged from the PTC in-patient wards with a nursing need. JL and MK have been working on a resolution.</p> <p>AK added she has been providing weekly scenario-based teaching for junior doctors weekly with regards to the supportive management of children during their cancer journey. JL commented that learning around safety of medications had been identified from a recent Datix and changes implemented.</p> <p>DH queried with JL that the TYA service is not attending meetings. AK confirmed the PTC TYA team are not attending their MDT meetings and would really appreciate</p>	<p>Slides attached</p>  <p>Update Slide Hull.pptx</p> <p>DH to progress - JL to forward DH</p>

<p>Service risk/ Issues- POSCU update slides</p>	<p>their support. DH advised representation will be provided. DH talked about a query around the age range and consultants at Castle Hill will only take patients at age 19+, therefore there is a gap in local service provision in Hull. DH to set up an MDT meeting to discuss further.</p> <p>GS presented Calderdale slides</p> <p>GS talked about changes. The chemotherapy clinic has now moved to their community hub. Families are happy in this new vibrant environment. Initial challenges from the pharmacy perspective have now been resolved. Main issues are around the inpatient service, which is short staffed, experiencing loss of more senior staff members. Compliance with two nurses per shift who are trained to foundation level is proving a challenge. Plans are being made to move training forward to support this issue.</p> <p>Central line infections have been an issue with ongoing investigations inhouse.</p> <p>No new problems with referral pathways, however, there is on-going improvement work as the potential risks remain around diagnosis and treatment delays.</p> <p>RW commented training is the biggest challenge and KP agreed the challenges are the same across the region. KP queried training needs, in particular around central lines and asked if there is a role between both PTC's for nurses to access learning. JW and HQ confirmed the PTC's have always offered CCNT to visit PTC's for training purposes; however this was not possible during the pandemic. KP asked if there are capacity issues in one PCT's, whether the other could offer mutual aid. JW/HQ will explore further.</p> <p>SN commented this is encouraged in York, however, this does prove difficult to release staff for such training.</p> <p>SN updated for York and Scarborough</p> <p>Apologised for not getting around to completing the slides. 24 patients on active treatment, 8 inactive. They are losing a consultant in Scarborough with no succession plan. RP will cover cross site. SN has been given one day a month, dedicated time to fulfil the lead nurse role. Training has improved since having a clinical educator one day per week and is specific to Children's Cancer. Children's cancer training has been added to the Matrix and is updated once a year as part of their mandatory training. Last minute requests from Leeds remains an issue, however, this is being addressed. SN requested TYA</p>	<p>MDT link</p> <p>Slide attached</p>  <p>Update slide Calderdale.pptx</p> <p>HC to action</p>
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	<p>service is available for support in York. Continuation of the work programme and yearly report which informs quality standard compliance. Biggest issue is knowledge in relation to the ALLtogether trial and that cytarabine's are not to be delivered if the trial isn't open at their POSCU. SN queried if patients could continue to receive cytarabine.</p> <p>JW confirmed this has been raised nationally and raised with the trial centre. DI is asking questions to clarify the situation. JW is hopeful of a workaround but is unclear at this point.</p> <p>Various members of the group felt they didn't know where they stood in terms of giving Cytarabine. KP confirmed this has been raised nationally and there will be national guidance being issued. AK suggests emailing DI for further clarity. KP agreed.</p> <p>TC asked JL and JL to stay on after the meeting to discuss what can be done.</p> <p>SJG updated from NLAG</p> <p>They are caring for 40 patients across sites. 23 on treatment and 17 off-treatment. Confirmed they are working closely with community nursing teams to provide support at home and have a red flag system in place for children and teenagers who attend their A&E services.</p> <p>SJG echo's what everyone else is reporting. Challenges are that they don't always receive clinic letters with updates for children that have been seen in Sheffield. Discussions are happening with Sheffield to resolve this. Training days are continuing with the aid of the Sheffield team, two planned for July and September. Due to training, only one staff member can administer chemotherapy and she does do the home cytarabine. CPD training also goes onto the Matrix. No major issues.</p> <p>HQ presented Sheffield PTC update</p> <p>There is nothing specific from Sheffield, however echo's issues which others are reporting around training and junior work force in the clinical areas. Clinical Educator is currently absent for a protected period which is causing delays but no major challenges. Some changes will be happening in the paediatric outreach team shortly due to retirement. One post has been advertised and possibly another post in 6 months.</p>	<p>JW to flag with DI and KP will email DI</p>
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	<p>JW Updated on Leeds PTC.</p> <p>Staffing and skill mix proving a challenge in not only registered nursing but admin staff. The Teenage Unit had been shut for a period time, it is now open, however it is housing the SCT Unit (4 beds), which is closed due to staffing and requirement for essential works. Currently, the PTC has 4 beds closed.</p>	
<p>AOB</p>	<p>Whole Genome Sequencing</p> <p>ME updated Nicola has put the pathways in place and there is still a long way to go. Turnaround time is proving an issue. KP commented the analysis is taking some time and this is recognised and is being worked on nationally. KP queried the funding for Nicola's post. ME is of the view the post will be re-advertised and the work will continue to move forward.</p> <p>DR wanted to highlight she is now the AHP representative on the NHSE CRG and will add items to the agenda as needed and feedback from her meetings.</p> <p>KP commented she wants to make these meetings as useful as possible. If there are any suggestions on reformatting them, please let us know.</p> <p>KP confirmed she will contact DI re cytarabine.</p>	
<p>Dates of next meetings</p>	<p>19/07/2023 18/10/2023 All 1-3pm</p> <p>20th of September 2023 CTYA Cancer Away Day- venue OEC in Sheffield</p>	