

Yorkshire & Humber Children, Teenage Young Adult Cancer Clinical Network Executive Board Meeting (previously known as Operational Delivery Network)

Wednesday 2nd April 12:00 - 13:00

Online Meeting

Name	Role
Dan Stark (DS)	TYA Lead Clinician
Diane Hubber (DHu)	TYA Lead Nurse
Alex Chilvers (AC)	Network Manager
Julie White (JW)	Network Lead Nurse
Liz Purnell (LP)	TYA Lead Nurse
Paddy Carley (PC)	Data Co-ordinator
Ruth Brown (RB)	Network Chair
Helen Richards (HR)	Network Lead Nurse

Action	Responsible Person
PC to arrange follow up meeting in Q2	PC
AC to contact PKJ/KPe regarding WGS issues and add to risk register	AC
AC to rework and circulate the workplan document with clear milestones, delegations and goals	AC
AC to continue conversations with Cancer Alliances and contact RB if needed for SYB Alliance contact	AC
PPIE lead to generate a proposal for patient representation on the Executive Board	HR/AC
AC to update TCT risk register with Sheffield and Hull roles and circulate the updated version	AC
HR to email out PPIE project plan to all members	HR

Item	Minutes	Action
1	<p>Welcome, Introductions and Apologies Apologies noted for Hilary Quinton, Katharine Patrick and Paul Kendrew-Jones.</p> <p>RB suggested sending out a pack of all relevant documents prior to the next meeting, increasing the duration to 90 minutes and meeting quarterly, rather than 6 monthly. ACTION.</p>	<p>PC to arrange follow up meeting in Q2</p>
2	<p>Declarations of Conflicts of Interest No declarations of conflicts of interest</p>	

<p>3</p>	<p>Minutes from previous Executive Board Meeting Previous minutes were agreed by the group as an accurate representation.</p> <p>RB noted all previous actions are to be discussed on the agenda.</p> <p>RB highlighted the news regarding NHSE, ICB and networks as occupying an unsettling space currently. She felt it was important to acknowledge that for those in associated roles. As announcements are made and changes move forward, this group may want to meet sooner than planned.</p>	
<p>4</p>	<p>Review and agree workplan 25/26 AC wished to organise the workplan in priority order and shared the working document. Benchmarking will be removed from the Children's side once the final report has been sent to NHSE, but the TYA benchmarking report is still outstanding. AC highlighted nursing training and education, care closer to home and PPIE as underway.</p> <p>RB suggested expanding the workplan with expectation of delivery including milestones.</p> <p>JW highlighted changes in resources may have implications. She wants to utilise the Clinical Educator (Kelly Smith) who starts 14th April 2025. She will work to compile the training and education strategy and JW wants to complete this prior to April 2026. This resource is wanted and required by shared care partners. Also, it may have a positive knock-on effect for the care closer to home projects (ambulatory / bolus chemotherapy). Specific milestones and timeframes will be clarified once KS starts in her role.</p> <p>DHu concurred with JW. TYA issues are slightly different to Children's but benchmarking highlighted a need for training and education support. She noted the lack of funding for WGS nurse role and queried if the workplan was achievable. She asked if Trusts could contact ICBs or Networks for extra funding. RB recommended investigating other areas of funding. Unfortunately, PKJ is unavailable today, but RB suggested seeking a view from him as Commissioner. All members concurred. AC will place on the risk register and contact PKJ to highlight issues since publication of the service specification and understand any funding options. ACTION.</p> <p>JW asked if the WGS nurse was fundamental to the service via escalating samples through the pathway. She queried if the genomics team may help with this process. LP noted biobanking is similar; how can centres expect to fulfil this without funding and staff. HR clarified JW's point. Prior to the WGS nurse being in post, the research team provided support in this capacity. Currently, they don't have capacity due to decreasing staffing levels. Thus, the service is not practical without a</p>	<p>AC to contact PKJ/KPe regarding WGS issues and add to risk register</p>

<p>WGS nurse. RB suggested noting risks and mitigation but ensuring urgent action completed.</p> <p>AC raised the example of care closer to home project. Due to TCT cutting nursing funding it's become increasingly difficult to continue the project in Hull. DS had previously said the group needs to continue and hold the acute Trust to account. AC wants to pick out top priorities and focus on them. RB noted some priorities are large pieces of work and difficult to complete in 1 year, requiring delegation and articulation of job roles.</p> <p>DHu wished to look at 'quick wins' - care closer to home is a long-term project, whereas PPIE is crucial and achievable within 12-18 months with evidence. She suggested putting long-term goals lower on the priority list.</p> <p>JW noted the Board and Network doesn't yet have clearly defined strategies. Gaps in care are highlighted, but clinical pressures often take priority. She queried if the board is clear about its direction and stated a 5-year strategy may not be the most fruitful, with short-term goals easier.</p> <p>RB suggested collated deliverables and achievements from last year to see the value of the network and wishes to collate this in the annual report. AC noted the report is due to NHSE by the end of April.</p> <p>RB stated PPIE and nursing training and education appear most prioritised thus far and asked for a 3rd area to complete the work plan. AC is concurrently working on the Network Operational Policy, and alongside the benchmarking process with shared care agreements will remain on the workplan.</p> <p>JW noted the care closer to home projects (Children's and TYA) are always going to take a long time to enact change. She feels PTCs probably cannot continue on the same activity levels, and it is worth going to shared care partners for care closer to home. Keeping this topic on the workplan alongside others is useful. Training and education improvements may have knock on effect for TYA care in Designated Hospitals, for example.</p> <p>DS joined the meeting at this point. He noted under current pressures, keeping one medium term strategic project going (such as PPIE), one co-ordinated health care professional project (such as nursing training and education) and one project with a case study showing direct benefit for persons living with and through cancer would be sensible.</p> <p>DS expects NHSE or its equivalent to want an update of where the Network is at and what it has achieved. He suggested something where care is delivered with examples and outcomes; e.g., because of the network's project patient X received this experience of care because connections were enabled between hospital, centre or clinician.</p>	
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	<p>In summary, this shows the Network is focused on patient experience, looking after health care professionals and implementing a strategic and long-term vision. It is possible the education and care closer to home could combine into a single exercise if resources are short.</p> <p>RB stated this input was helpful and compliments the prior conversation. She suggested AC continue plans with benchmarking and creating the Network's Operational Policy. As discussed, nursing training and education, PPIE and care closer to home will comprise the high priority targets and AC will escalate WGS issues. Other aspects of the workplan will be reviewed in 6 months depending on how the aforementioned projects develop.</p> <p>DS asked if care closer to home is as useful in Sheffield Teaching Hospitals (STH) for TYA. LP stated staff visit patients, or they come to the PTC for chemotherapy. Haematology CDG is discussing home chemotherapy visits, but this may take a while. RB queried regarding virtual wards, but LP noted this is not available in STH currently.</p> <p>DS noted in Leeds Teaching Hospitals (LTH) patients not requiring ongoing care have access to a virtual ward. LTH has an aspiration to allow for treatment delivered at a hospital closer to patient's home, rather than <i>at</i> home.</p> <p>RB highlighted the 10-year hospital to community plan may see a shift in priorities also.</p> <p>AC to rework and circulate the document as above with clear milestones, delegations and goals. RB suggested AC uses annual report in April to update from there. ACTION.</p>	<p>AC to rework and circulate the workplan document with clear milestones, delegations and goals</p>
<p>5</p>	<p>Risks</p> <p>AC shared the relevant document and highlighted tabs for network issues and regional issues.</p> <p>The first issue highlighted the clinical educator funding. She asked if successes needed demonstrating firstly, with written papers for funding to come after. JW noted charities used to fund training partners for centres which was successful. The first tasks will include scoping, mapping and analysing strategy delivery. She is hoping at the 6-month stage all will have an understanding of the job role.</p> <p>RB queried if the risk rating of 25 for the clinical educator was appropriate. AC stated this applies for next year.</p> <p>AC highlighted patient representation on the board. Tasha Dawson (Ella Dawson Foundation) has shown interest to be a patient representative. HR has met with Tasha recently, whose sister was a TYA patient. She is the co-founder of the charity and is part of the Cancer Alliance board as a lived experience partner. She also sits on lots of steering groups and is</p>	

	<p>helpful for PPIE work. RB doesn't believe this group can make a decision currently and needs to look at the Terms of Reference (ToR) prior.</p> <p>AC added the risk relates to the lack of Cancer Alliance input, with recent peer review showing a gap in the escalation process. She noted the mitigation of a Cancer Alliance representative and LP communicating outside this meeting.</p> <p>JW sees the above as two separate issues. The first issue is regarding escalation and the challenges across the network. The second issue is within Children's and TYA; does this group need representation on the executive board. AC has contacted Cancer Alliances and they are interested in contributing, providing it was within their remit.</p> <p>RB suggested taking this as an action and to have conversations outside this meeting. She noted her own links with SYB Cancer Alliance. As the priority for the patient representative is PPIE, RB suggested whoever's leading the project come up with a proposal. ACTION.</p> <p>AC highlighted the regional issues concerning Teenage Cancer Trust, with a meeting taking place this afternoon. As the network has an underspend of £28,699, she queried whether this could be used as partial funding for TCT roles.</p> <p>DS provided an overview for those not directly involved. TCT is a national charity and for around 25 years have made significant investments in enhancing staff and holding political influence. Post-covid charitable reductions in funding is resulting in a reduction of NHS posts and redeployment.</p> <p>DHu noted the posts lost are within Hull and Leeds PTC so this may not benefit the whole of the network. DS feels this might have a substantial negative impact over the network in a wider context. Utilising the underspend to buy back small parts of staff time could be viable. He suggested exploring delivering priority projects by buying back time from staff. AC confirmed the underspend must be spent by March 2026.</p> <p>DHu stated the meeting today won't confirm any decisions made. DS noted there are currently 3 or 4 ways in which TCT may continue. AC to circulate the updated risk register. ACTION.</p>	<p>AC to continue conversations with Cancer Alliances and contact RB if needed for SYB Alliance contact</p> <p>PPIE lead to generate a proposal for patient representation on the Executive Board</p> <p>AC to update TCT risk register with Sheffield and Hull roles and circulated updated version</p>
<p>6</p>	<p>ODN Governance</p> <p>MoU sign-off AC stated Bradford had signed the MoU last week meaning every centre is compliant.</p> <p>Review/update of Terms of Reference and Memorandum of Understanding Not discussed due to time constraints.</p>	

	<p>Review of ODN Board representation Partially covered during the risk register item on the agenda. To continue at the next Board meeting.</p>	
7	<p>Updates</p> <p>Mutual Aid PKJ was unable to attend but provided an update via email.</p> <p><i>Specialised Commissioning have now secured additional funding for 2025/26 for LTH to continue to provide mutual aid in light of STH no longer being in a position to reinstate their service.</i></p> <p><i>We have met as a project board this week (including Newcastle) to develop an appropriate model for the future of paediatric radiotherapy services in the NEY. This included looking at RRT, TBI, palliative care and transplantation services.</i></p> <p><i>Will update the group further when we meet next.</i></p> <p>Education Day AC noted the venue has been chosen with a date to follow shortly.</p> <p>Dashboard and Data Collection AC noted the dashboard is still under development due to staffing issues in informatics. She has asked if it can be used as a work in progress, but informatics denied this for now.</p> <p>PPIE Project update HR is keen to get agreement from all board members regarding her project plan and will send out an email following the meeting.</p>	<p>HR to email out PPIE project plan to all members</p>
8	<p>AOB No other business noted.</p>	