

TYA OPERATION DELIVERY NETWORK MEETING MINUTES

Friday 06/06/23 3:00-5:00pm on Teams

Attendees: Idris Aurangzeb (IA), Sue Berry (SB), Atchamamba Bobbili (AB), Hilary Campbell (HC), Patrick Carley (PC), Alex Chilvers (AC), Gary Doig (GD), Jill Doherty (JD), Rachael Else (RE), Patricia Fisher (PF), Kate Foley (KF), Dara Gibbons (DG), Robyn Hedge (RH), Diane Hubber (DH), Helen Johnson (HJ), Lynn McNamee (LM), Tasha Morley (TM), Iqtedar Muazzam (IM), Louise Ollivant (LO), Catriona Parker (CP), Elizabeth Purnell (EP), Gaushiya Saiyad (GS), Dan Stark (DS), Claire Swift (CS), Kevin Peters (KP), Anne Thomson (AT), Shona Tutin (ST), Rachel Wane (RW), Lucy Ward (LW), Julie White (JW), Tricia Wyer (TW), Dan Yeomanson (DY), Robin Young (RY).

Apologies: Emma Clarke, Alun Windle.

Agenda Item	Notes	Actions
Welcome and Apologies	DS welcomed the group and introduced PC the new data co-ordinator for the CTYA ODN.	
Last Meeting	Notes from the previous meeting were agreed with an amendment made to the name of Dr Alzouebi on page 5 of the minutes.	PC actioned 06.06.23
Notes from Previous Meeting	<p>Expressions of interest regarding remaining funding within the ODN. DH noted research accrual data funding dependent on IAs presentation later in the meeting. HC reiterated this.</p> <p>JW stated we have the costing for the website and noted there is a further funding available for the branding and representation of the service. DS notified the group that expressions of interests for funding should go to AC with DS and EP to decide regarding the remaining budget over the next 3 working weeks (by 5pm BST 26 - 06-2023).</p> <p>Biobanking AC has circulated the poster from AT to the group.</p>	
Participation Tracker	Tracker is up to date from previous meetings and should be available in this slot for future meetings.	Please see attached attendance tracker

<p>Matters Arising</p>	<p>Website updates JW clarified GoDaddy confirmed as website builder. AC confirmed funding agreed for website. PC to take over from Egzone's work and organise website steering group. Links to Bristol and Nottingham ODNs to ensure joint learning and efficiencies between ODNs. Nottingham and Bristol website builds are still in the planning phase. Nottingham and Bristol sending over their documents. Katherine Patrick and JW ensuring children's pathway is as up to date as TYA. DS highlighted a need for a timeline and working document for the website.</p> <p>GD offered help and guidance from the North East ODN regarding branding for the ODN and website.</p> <p>Publication of service specifications for TYA ODN DS encouraged every member to read the service specifications. AC to compare service spec with workplan to ensure all objectives are met: key focus on WGS, tissue banking, research accrual, gaps in care, establishing pathways and education & workforce. Next we benchmark against this specification- therefore ensure benchmarking supported by documents that reflect the published specification. We are working from a Thames Valley ODN self-assessment spreadsheet, which must be reviewed by AC and updated where required by 5pm 30-06-2023. Then AC will share with Chair and deputy for confirmation. Then we schedule upon 'site visits', with completion in each partner provider trust of TYA cancer care, by 5pm GMT 29 December 2023. This enables us to offer specific network support in each location meeting their service specification. DS confirmed previously determined ODN priority order of 1. WGS 2. Research accrual 3. Gaps in care 4. Tissue banking for initial 12 months of work. Before we set further priorities the ODN, PTC and DH should self-benchmark. JW mentioned a piece of work in potential subjectivity in benchmarking tools. Manchester</p>	<p>PC, AC and JW to organise steering group, working document and timelines for website by 5pm BST 04/SEP/2023.</p> <p>GD and AC to liaise regarding branding.</p> <p>AC to organise site visits and ensure documents reflect service need.</p> <p>JW and AC to action</p>
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	<p>and Bristol shared details of guidance regarding this.</p> <p>KP queried service specifications regarding crossover care between ages of 17 and 19. ODN needs to be comfortable with any uncertainties emerging because of how we are choosing to structure our CTYA services in Y&H, and reflect services appropriately for our geography, services and patients.</p> <p>DS emphasised the importance of clear pathways describing what age ranges and which site-specific treatment and supportive services are provided by each acute provider trust. This can be specific and different in one acute provider from another, but there can be no 'gaps'.</p> <p>MoU Outstanding signatures from NLAG and Bradford. KP offered to raise contractually with the trusts.</p>	<p>AC to escalate</p>
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<p>Service Updates</p>	<p>Sheffield updates Robin Hedge joined as CNS. Interviews for band 6 TYA CNS role funded by TCT. New TYA MDT co-ordinator shortlisted. Ward staffing levels difficult but still open for planned chemotherapy. Discussions over rota to staff ward 24/7 with NHSE and senior management. TYA team developing nurse led education and training.</p> <p>TM introduced herself as WGS lead nurse in TYA North East and Yorkshire.</p> <p>HC queried date range targets for our TYA cancer incidence numbers; confirmed as January 1st – December 31st.</p> <p>RY confirmed new Sheffield Charity funding for TYA nurse (2 days per week) to help trial recruitment.</p> <p>KP noted TCU clarification after call with EP 07.06.23.</p> <p>PF stated issue regarding two separate TCUs and mentioned meeting regarding moving to a single TCU.</p> <p>Leeds updates DH identified ward 94 had a falling number of inpatients, due to increased use of ambulatory care and oral therapy protocols. Working with oncology BM and matrons to provide more daycase beds on the TYA unit to meet the contemporary need.</p> <p>Quality of Care – examples of good practice LO set up a Power BI which takes data directly from EPR in RDH.</p> <p>EP identified alert system for 18-25 years old once admitted as inpatient in STH, for notification of need for discussion at TYA MDT.</p> <p>CS and Hull TYA team have set up bereavement support walk.</p> <p>Service challenges DS asked if any service challenges or complaints in PTC or DH. No reply but emphasised importance of this as each centre will self-assess</p>	
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and openness about any challenges is constructive when support is available.

Later in the meeting, DH mentioned incomplete pathway for 16–18-year-olds having shared care between either Leeds or Sheffield and Hull. Originally raised in Children's ODN. No place of care (ward/clinic) accepting these patients in Hull. DS stated hopefully benchmarking work will quantify and help us understand why and the approach to take for this.

Service Improvement Project Updates

Presentation of TYA dashboard data by Idris Aurangzeb (Senior Information Manager, Research and Informatics) - TYA real time data dashboard for clinical research accrual.

Automate process of data linkage for all patients with an active cancer diagnosis in age range (15-24 inclusive) between (i) Leeds EPR ('PPM') and (ii) NIHR research data system (Edge). Both datasets hosted on a shared space; software is Power BI. DH noted challenges of going into individual records to see how many patients going into trial. Hopefully new dataset can offer these details.

Model can be duplicated (in principle) for other organisations if their EHR data is available.

DS confirmed funding may be required from ODN, but that is only appropriate if this proposal is a regional initiative. DS offered the floor to other hospitals to comment. RE (Data Manager in Sheffield). Also planning to integrate Edge and Power BI for TYA so interested in efficiencies from a joint project. RY questioned potential cost and whether the missed patients for research accrual and missed opportunities are a more important target and priority. DS stated linking this data to new cancer diagnoses is key so accrual is presented in real terms – can be against a denominator to identify missed opportunities. IA confirmed this will require input from respective hospitals R&I departments. Leeds collects an enhanced dataset for TYA patients. Once recruited in Edge it can link to the EPR.

DS offered AB the floor for Doncaster and Bassetlaw opinion but no reply. CW is working closely with research team and TYA trials offered in Hull. RE confirmed enhanced data collection taking place in Sheffield minus NHS number. HJ will put research department in Bradford touch with IA. LO happy to pass on Rotherham research department. IA confirmed costing is already in place for Leeds and will be arranged by IA liaising in detail with

	<p>ODN members from other hospitals to prepare a regional proposal. DS stated IA to provide one page document with aims, objectives and costs project proposal by pm BST 14-07-2023.</p> <p>WGS Transition of WGS post in Leeds due to Nicky Balatoni leaving. Confirmation of funding informally received but not yet 'tracked down' in LTHT management systems (DH chasing).</p> <p>TM offered to prepare report on progress with WGS in the North East and Yorkshire for the next meeting (20-09-2023).TM highlighted difficulty in capturing data as often have surgery (therefore tissue taken and decisions made) before clinical teams doing surgery are aware of mandate for fresh tissue for WGS for TYA cases.</p> <p>DS specified WGS suitable for all TYA patients eligible. Correct approach is to store fresh tissue and decide later about sending to Genomics England and VIVO biobank when patient later comes to TYA MDT and services.</p> <p>Vivo Biobank AT explained she can help with meeting tissue bank side of service specification for all centres. Work to satisfy ethics committee but all consent forms available. Please contact Vivo directly with any queries. DS specified we are mandated to offer tissue banking to all TYA patients in all locations.</p> <p>TM queried which samples Vivo take. AT confirmed Vivo take all samples whether the patient is on a trial or not.</p> <p>Gaps in Care DS commented on work ongoing with palliative care that DH and EP are part of- this work is still being developed.</p> <p>DS noted more prompt referrals to TYA MDT are now mandated by the service specification; Now 7 days rather than 14 days. Work therefore needed with PTC MDT co-ordinators and partner trusts to see how the pathway is working.</p>	<p>TM to send report to AC</p> <p>AC to distribute Vivo email address</p> <p>TM to liaise with AT outside the meeting</p> <p>PC to liaise with MDT co-ordinators by 28-07-23 to gather</p>
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	<p>Patient and Public Voice DH attempted to get representatives for PPI engagement but currently not progressing because we don't have specific areas for this work for TYA. Hopefully along with website one of the first pieces of work.</p> <p>DS noted VIVO biobank is asking questions of its own PPI group – We should take their questions and ask them of our PPI group. That will help Y&H design its own pathways to VIVO and GE and help VIVO design their own work as well. AT happy to amend ethics agreement for their research to include involving the Y&H TYA PPIE group.</p> <p>RH suggested educational TikToks for patients. DS suggested this comes from patients rather than staff. JW mentioned CCLG are reviewing information and resources particularly videos as a learning resource.</p> <p>Data Collection DS noted we need to understand in real time patients managed at each location. Ask on a 6 monthly basis all identifiable details of all TYA patients diagnosed with cancer. Caldicott guardians have previously agreed to allow specific data from various hospitals to be submitted to Leeds data team under a routine NHS care quality audit. In this case that data would go to PC as our ODN data manager.</p> <p>Benchmarking Discussed on page 2.</p> <p>Joint Care DS introduced Joint Care (consisting of joint treatment and joint supportive care) from the service specification. BRIGHTLIGHT study confirmed those receiving care in 2 acute providers had the worst experience overall. This care was largely haphazard, through for example ambulance services taking patients to different trusts, or patient flows at geographical watersheds being unpredictable, or patient dissatisfaction with care in one hospital and</p>	<p>preliminary data</p> <p>AT, DH and GD to liaise regarding PPI work in Y&H by 28-07-23.</p> <p>JW and AC to discuss questions for PPI group on website</p> <p>PC to organise permissions from Caldicott guardians in writing for data collection.</p>
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	<p>moving to another, or patients having very complex care requiring a hyper-specialised provider, or patients relocating geographically and having management delays and problems (for example). BRIGHTLIGHT data was interpreted by the NHSE CYP Clinical Reference Group in 2019 as requiring the devising and implementing of structured joint care, to improve communication and actively manage inevitable haphazard patient flows by better networking and clinical information flows. Clinical information and care delivered and outcomes need to be transferred between joint providers in 'real time' as determined by clinical urgency.</p> <p>DS suggested (as he had proposed in outline in March 2023) an exemplar project between Leeds and Hull. Commence paper-based about how this would work, based upon reviewing previous patient's HCP contacts and pathways as they functioned, and identify all stakeholders in the work and all themes in the work. DS clarified this is an exemplar project which other trusts could use going forward.</p> <p>DS introduced IM (TYA lead in Hull). IM noted good relationship between Leeds and Hull, but this is not structured. DS noted CW and DH interested in this piece of work with a duration of 6-9 months. Examples included; RH noting line flushing policies differ between these trusts. Staff unsure of reasons behind this and this affects patients.</p> <p>RY mentioned clarity on planned joint care treatment pathways and unplanned/acute setting to ensure correct exchange of information is available.</p> <p>Patient Travel Burden Richard Feltbower holds the data for this topic DS hopeful to develop a project with RF to benchmark patients travel times and costs, in order to have a baseline for one impact of developing joint care (above) by minimising travel as a result.</p>	<p>AC to organise a meeting between Hull and Leeds colleagues for this project.</p> <p>AC to organise meeting with RF during September</p>
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Updates From Other Meetings	No updates from other paediatric meetings or ODNs.	
Submissions For Project Proposals 22-23	<ul style="list-style-type: none"> • Potential extra costs for website branding. • Data on trial accrual. • Proposals for pilot of joint care between two sites. • Benchmarking ODN against partner ODN. • Collating and contrasting referral pathways for review. <p>Any other to be sent to AC for review by DS and EP by 5pm BST 26 -06-2023. Then these are to be passed to the overarching steering groups for arbitration between meetings.</p> <p>No further funds are identified currently or proposed for leadership of ODN, places of care, or barriers to research costs (other than the project mentioned).</p>	
AOB	Nothing noted.	
Dates for next meeting	<ul style="list-style-type: none"> • Wednesday 06/09/2023 – cancelled due to CTYA away day • 20th September 2023 CTYA Cancer ODN AWAY DAY Venue TBC • • Tuesday 05/12/2023, each @ 3-5pm • Wednesday 06/03/24 • Thursday 06/06/24 • Monday 02/09/24 • Tuesday 03/12/24 	