

TYA OPERATION DELIVERY NETWORK MEETING MINUTES

Friday 30/03/23 3:00-5:00pm on Teams

Attendees: Daniel Stark (DS), Julie White (JW) Hilary Campbell (HC), Sarah Mettrick (SM), Robyn Hedge (RH), Georgia Thompson (GT), Lynn Mcnamee (LM), Rachel Wane (RW), Patricia Fisher (PF), Anne Thompson (AT), Nicola Balatoni (NB), Atchamamba Bobbill (AB), Emma Clarke (EC), Diana Greenfield (DG), Natalie Kisby (NK), Louise Ollivant (LO), Richard Feltwbower (RF), Jill Doherty (JD) Alex Chilvers (AC)

Apologies: Diane Hubber, Hillary Quinton, Liz Purnell, Nigel Beasley, Cathy Burton, Helen Greenwood, Claire Hall, Nicki Ingram, Daniel Swinson, Victoria McKay, Alun Windle.

Agenda Item	Notes	Actions
Welcome and Apologies	DS welcomed the group and introduced AC, new ODN Manager to the rest of the Network	
Notes from previous meeting	Notes from meeting 02/12/22 agreed by the group	
ODN Participation Tracker	An ongoing attendance tracker has been created to ensure the ODN meets service specification and MOU requirements. All network members are asked to provide a representative to all ODN meetings where possible.	See attached participation tracker
Matters arising	<p>Scoping of services</p> <p>Having a full and detailed understanding of all services for TYA with cancer. A template spreadsheet is available; however, the document doesn't fully reflect the service spec for TYA with cancer in its current draft form. Further work is to be done.</p> <p>ODN Website</p> <p>Development of a web domain is underway to populate key public facing information about the ODN and what we do. Negotiations are happening around payment, and this will be upcoming in the next few months.</p> <p>MOU</p> <p>Not yet complete for all Trusts. Bradford and Lincs/Goole outstanding.</p>	<p>Working group for Website content to be established</p> <p>AC to action</p>

<p>Service Update Slides including Clinical Governance</p>	<p>No new update service slides since the last meeting. DS is aware of the TYA ward not functioning at Sheffield Trust. RY commented around introducing the concept of days for newly diagnosed patients, once a month. This will be piloted over the coming weeks. DS commented this was a great way to deal with this situation and suggested if there is no sign of the ward re-opening, this should be escalated up through Trish and overall leadership group at Sheffield Trust.</p> <p>DS asked if there are any other high profile service challenges, complaints, or examples of quality of care. No updates from the group.</p>	
<p>Service improvement project updates</p>	<p>Research Accrual and related data</p> <p>RW shared difficulties in that finding out what happens at site level. Sheffield's system holds six months of retrospective data. No reliable way of doing this in Leeds without manually counting. RW feels the year of birth data may be the way to go as we are getting more of it; it should become more reliable.</p> <p>HC commented that CRNL are now asking sites to provide year of birth data and forms part of the performance operating framework.</p> <p>HC shared and explained the spreadsheet marked Cancer TYA Data 10/03/23. This does not hold BRIGHTLIGHT data and the cut off point is the middle of April. DS will make the Principal Investigator for BRIGHTLIGHT aware of the need to get the data uploaded by 21st April. HC mentioned BRIGHTLIGHT is closing permanently in March.</p> <p>DS updated around 25-30% of patients have been recruited into studies which is encouraging. DS talked about other studies opening in the coming months and highlighted overall progress is being made.</p> <p>WGS</p> <p>DS updated we are developing a smoother pathway. Updates from NB around contacting site MDT leads for awareness of eligibility and will update the ODN before leaving post.</p> <p>DS updated the group around aspirations/planned projects from NHSE relating to WGS plans.</p>	

	<p>Gaps in care</p> <p>DS, LP and DH joined a meeting within the Palliative Care Network and start and finish groups relating to equity of provision in palliative care, including transition in palliative care and equitable provision of end-of-life care. DS updated the group with the detail.</p> <p>RH shared her concerns around patients with learning disabilities.</p> <p>PPIE - Patient and Public Voice</p> <p>DS updated the group - DH, LP and Gary from TCT are working on this and shared the ask to provide patient and public voice function for our ODN and work alongside Youth Support Coordinators to bring some of the patients and public voice people together. There is a request for us to provide strong candidates questions and to set up a patient and public voice meeting. One important question DS mentioned is how they viewed tissue bio-banking which needs to feature on this list.</p> <p>Data collection</p> <p>Egzone has been collecting data for incidences of TYA onset cancers. Now Egzone has moved on, this work will be picked once the new member is in post.</p> <p>Benchmarking</p> <p>DS requested between June and September the ODN team will commence benchmarking. Firstly, all provider organisations self-report how they are providing TYA services, and secondly, arrange meetings between members of the ODN group and services in individual locations for detail and context on TYA services in each provider organisations.</p> <p>Joint care</p> <p>DS updated we are to identify two organisations in our ODN, one Principal Treatment Centre and one Designated Hospital that would like to do some work together in providing joint care for individual TYA with cancer. DS suggested a small working group. RW is to be involved in these meetings. RH suggested Leeds and Hull are a good place to start in joint care due to good relationships. DS talked about software functions</p>	<p>To add to template agenda to discuss once the palliative care is underway</p> <p>AC to action</p> <p>AC to arrange meetings</p> <p>AC to arrange meeting</p>
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<p>Updates from other meetings</p>	<p>to centralise all key patient information, but this project will be discussed in time, most likely after our September meeting.</p> <p>Patient travel burden</p> <p>DH welcomed Richard Feltbower to the group. RF provided an update around the type of data that is available and asked the question of what the ODN want to see from this data and how far back we want it to go. DS made suggestions around what we want to see. AB questioned why Chesterfield is not a designated TYA centre. RH commented we are readdressing Chesterfield. RF felt a descriptive analysis start off would be the best, looking at all types of cancers. DS agreed and requested this information in the target age range of 16-24. DS is interested in long distance travel for patients who have had more than one hospital episode and how many are travelling short distances. From this information we will extract data for patients travelling past a DH to a PTC to identify inequitable distribution.</p> <p>DS welcomed all to join in this conversation in-between meetings and proposed a gentle development and outline proposal from now until the next meeting on 6th June.</p> <p>Paediatric Cancer ODN</p> <p>RH updated that Leeds and Sheffield are hosting a TYA study away day, which will rotate between Leeds and Sheffield. DS asked for contact details, should others want to express an interest in attending.</p> <p>PF updated for Paediatric and Radiotherapy ODN. A second Paediatric Radiation Oncologist will be soon joining the Paediatric MDT. Dr Al-Dubi is currently out of the country. A meeting is to be scheduled around how we filter patients back to Sheffield ready for treatment once Dr Alzouebi returns. No agreed date for return, however the situation will resolve itself.</p>	<p>Meetings to be arranged in May</p> <p>Send interest to Jill Doherty</p> <p>Meeting to be arranged</p>
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<p>Proposal of projects that may need funding</p> <p>AOB</p>	<p>Co-ordinating group for CYP cancer</p> <p>Update from DS from the Clinical Reference Group. For those who are interested in the structure of services across a region, there are a couple of papers in the public domain, one being the road map to integration (available on the NHSE website) and a paper on sectional specialist services (available in the NHS board papers on their meeting in February '23). Papers characterize the characteristics of services and how they are defined and commissioned.</p> <p>DS updated the group we did not utilise all available funds when setting up the Network due to upcoming projects. Three projects have been proposed which are Benchmarking our ODN work against another partner ODN, pilot of joint care between two sites and collating and contrasting referral pathways that are provided to primary and secondary care providers into specialist TYA cancer services. New project ideas are encouraged to be discussed with DS.</p> <p>AT raised the Biobanking process. For Leukaemia, there are no issues in banking immediately. AT requested an email to herself, and all relevant information will be sent. AT encouraged anyone to make contact who is interested in banking for patients. Recruitment is underway for the PPI group for TYA and if anyone is aware of anyone interested in joining from that age bracket, please get in touch with AT.</p>	 <p>AC to send out email with minutes</p> <p>AT to email AC PPI paper</p>
<p>Dates for next meeting</p>	<ul style="list-style-type: none"> • Tuesday 06/06/2023 • Wednesday 06/09/2023 • Tuesday 05/12/2023, each @ 3-5pm 	

	20th September 2023 CTYA Cancer ODN AWAY DAY Venue TBC	
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