

TYA OPERATION DELIVERY NETWORK MEETING MINUTES

Friday 02/12/2022 3:00-5:00pm on Teams

Attendees: Daniel Stark (DS), Hilary Campbell (HC), Hilary Quinton (HQ), Sarah Mettrick (SM), Robin Young (RY), Sylvia Feyler (SF), Elizabeth Purnell (EP), Georgia Thompson (GT), Lynn Mcnamee (LM), Kevin Peters (KP), Charlene Kent (CK), Mark Allcock (MA), James Taylor (JT), Rachel Wane (RW), Diane Hubber (DH), Martin Elliott (ME), Patricia Fisher (PF), Iqtedar Muazzam (IM), Kate Foley (KF), Rachel Cloke (RC), Freya Johnson-Smith (FJS), Egzone Muliqi-Begolli (EMB).

Apologies: Dan Yeomanson, Gary Doig, Nigel Beasley, Cathy Burton, Diane Greenfield, Claire Hall, Nick Morely, Louise Ollivant, Debbi Rowley, Nicky Bould, Nicola Balatoni, Emma Clarke, Leanne Elder, Gillian Jackson, Jill Doherty, Lucy Ward, Helen Greenwood.

Agenda Item	Notes	Actions
Welcome and Apologies	DS welcomed the group	
Notes from previous meeting	Notes from the 14/09/22 meeting 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>a. Lack of community nursing support for end-of-life care</p> <p>HQ noted an ongoing issue with gaps in end of life and palliative care for young people aged 16-18 at home. HQ highlighted that the Bluebell Wood Children's Hospice who provides care for young adult aged 19-20 is currently no longer offering clinical services.</p> <p>DH and EP confirmed that this is an issue for all regions. RY mention that adult services have been willing to take patients.</p>	

<p>Service Update Slides including Clinical Governance</p>	<p>The group agreed a clear pathway for these patients should be agreed and the appropriate training provided. This would require a scoping exercise and may form part of the larger Gaps in Care ODN Workstream.</p> <p>KP Noted that some work has already been done and will link the appropriate colleague to the ODN team.</p> <p>SM presented for Huddersfield and Calderdale J.T presented for Rotherham K.F presented for York</p> <p>DS thanked all for the updates and highlighted the importance of the engagement on the meeting, comparing with the slides from the last meeting there are still some Trusts who haven't sent any slides updates at all. Bradford, Airedale, Mid Yorkshire, and Barnsley.</p>	<p>KP to forward contact (Actioned)</p> <p>DH updated slides attached</p>
<p>Service improvement project updates</p> <p>Running</p>	<p>i. Research Accrual and related data</p> <p>RW commenced role of the TYA research champion. DS noted the work already been done by DR and that RW will be able to build on this work with the help of EMB, ODN Data Analyst. DS noted the importance of comprehensive data in the advancement of clinical trial accrual for TYA.</p> <p>ii. WGS</p> <p>DH updated in the absence of NB- Some good progress has been made on establishing the WGS current pathways and networks. NB from LTHT has been working closely with TM from Sheffield and linking both the TYA and Paediatric work. TM</p>	<p>EMB, FJS and RW meeting on the 16/01 to discuss data workstream. (Actioned)</p>

Running	<p>hopes to start on clinical pathways for both sarcoma and lymphoma from January. Good progress has been made on networking for haematology.</p> <p>Work is commencing with Hull. It will be excellent to hear about progress at other Acute Trusts with this core NHS activity for TYA with cancer.</p> <p>TM and NB to update further in 6 months with data.</p>	<p>TM and NB to update group on WGS. Workshop on WGS pragmatic implementation to be planned for away day?</p>
Running	<p>iii. Gaps in care</p> <p>DH is on the process of delivering project on the Gaps in care age 16-18. DS encouraged anyone who have experience of working with these cases to join DH and others in this project.</p> <p>iv. PPIE – DH and GD (TCT)</p> <p>DH updated the group on the workstream so far, a meeting was planned in October, however engagement was poor. Plans to arrange another meeting and work on engagement of TYA lived experience partners.</p> <p>EP expressed that it is positive to have two separate YAG meetings. One as a region and the other as an ODN and highlighted the importance of having a face-to-face meeting to get and know each other.</p> <p>DS mention Y&H ODN is in the process of creating a website and that could include a public facing space, were people can get in touch and find out more information about support on young people. DS encourage anyone who has any ideas for projects that can benefit Y&H ODN to get in touch with DS, FJS or EMB.</p>	<p>Working group met 16/01/23 with view to meet monthly to advance this programme of work.</p> <p>Working group for Website content to be established</p>
Running		

Running	<p>DH said they want to find the best way possible to engage with the young people and asked lead nursed if they could support with this.</p> <p>v. Data collection- The range of cancers and age-groups managed at each location</p> <p>DS explained the need for good quality local data to inform the range of care delivered across the region. This data will also be collected to understand research accrual rates. EMB mentioned to the group that work to collect this data has already started for newly diagnosed patients and thanked all DH's for their cooperation. There are still some DH's to submit date for all quarters so far</p>	<p>DH to follow up with Lead Nurses.</p> <p>EMB working with RW to expland collection to Research Accrual</p>
Planned	<p>vi. Benchmarking</p> <p>DS said not sure on the number of the organisation that did benchmarking last year. FJS and the ODN team will be working to establish PTC standards for the benchmarking process before full roll out to DH's.</p>	<p>EMB to organise benchmarking meeting (actioned)</p>
Planned	<p>i. Joint care</p> <p>D.S said from the middle of next year to think about creating a formal system for joint care.</p> <p>ii. Patient travel burden</p> <p>DS asked members to think about how far patient are traveling for their care and whether that can be improved. Some of the patient receive their clinical care in one hospital and some of it in another within a region or within a nation. DS added that one of goals on the service specification is to reduce travel where appropriate and have effective joint care in place. DS suggested a pilot plan could</p>	<p>Action – Agenda point with more time for next meeting.</p>

<p>Updates from other meetings</p> <p>Submission for costed project</p>	<p>consist of mapping across a few organisations to understand the current picture and how this can be improved.</p> <ul style="list-style-type: none"> a. Paediatric Cancer ODN b. Co-ordinating group for CYP cancer c. Other ODNs <p>KP updated for the Radiotherapy ODN. KP noted the challenges that Radiotherapy are currently experiencing. These issues are primarily workforce based. Addressing this will be part of the RT ODN workplan. KP mention mutual aid currently provided to SCH by LTHT. KP thanked LTH for the support considering their challenges with staff.</p> <p>DS mention away day which will be held on September 2023, DS highlighted that last years away day was a success and looking forward to meeting all face to face.</p> <p>HC welcomed Rachel Wayne who has been appointed on the role of TYA research champion.</p> <ul style="list-style-type: none"> • Year of Birth project <p>HC presented Year of Birth Project, this project is led by NIHR, collecting year of birth data. The project will move into a mandatory phase from April next year. A significant amount of data has been collected, however there are few Trusts outstanding.</p> <p>DS added when patients entered research, their year of birth wasn't something that was collected it</p>	<p>Action – Richard Feltbower or deputy to be invited to present at ODN away day, about how we can assess travel times data from the cancer register he works with</p> <p>Year of Birth slides attached</p>
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<p>proposals 2022-23</p> <p>AOB</p>	<p>is hoped this will lead to more data to work with overall. HC mention the brain app study which came out to all sites on 2021, will be resent. This is mainly suitable for LTH and STH/SCH. This app will have information about cancer symptoms and other information. Young people will be able to use the app to pick up if their condition is getting worse.</p> <p>NA</p>	
<p>Dates for next meeting</p>	<ul style="list-style-type: none"> • Wednesday 01/Mar/2023 • Tuesday 06/06/2023 • Wednesday 06/09/2023 • Tuesday 05/12/2023, each @ 3-5pm <p>20th September 2023 CTYA Cancer ODN AWAY DAY Venue TBC</p>	