

TYA OPERATION DELIVERY NETWORK MEETING MINUTES

Wednesday 14/9/2022 3:00-5:00pm on Teams

Attendees: Dan Stark, Gary Doig, Freya Johnson-Smith, Elizabeth Purnell, James Taylor, Jill Doherty, Lynn Mcnamee, Nicola Balatoni, Julia Jessop, Dr Nicky Bould, Diane Hubber, Patricia Fisher, Sarah Mettrick, Natalie Kisby, Maddie Iredale, Egzone Muliqi-Begolli, Dr Dan Yeomanson, Clair Swift, Diana Greenfield, Dr Iqtedar Muazzam.

Apologies: Kevin Peters, Victoria Mckay, Tasha Morley, Debbi Rowley, Lucy Ward, Tricia Wyer, Keely Clawson, Clair Hall, Nigel Beasley, Sally Lane, Dr Robin Young.

Agenda Item	Notes	Actions
Welcome and Apologies	Daniel Stark (DS) welcomed the group	
Last meeting	DS asked for all future dates for the TYA ODN meeting in diaries now 2/12/22 1/3/23 All 3-5pm	DS and FJS to agree more dates for 2023
ODN Participation figure	DS noted that ongoing and robust attendance tracking will be vital to ensure the ODN meets service specification and MOU requirements. Therefore, is it important that all organisations provide a lead representative who contributes to the network at most meetings.	See attached participation tracker
Notes from previous meeting	Minutes from the 06/06 agreed by the group	
Matters arising	None, outside the main agenda	
Clinical governance issues in TYA cancer		
DH and PTS service updates	James Taylor (J.T) presented for Rotherham Liz Purnell (E.P) presented for STH DS enquired regarding commissioner involvement in the reopening of the TYA unit in STH. EP noted that commissioner is involved,	DH and PTS update slides attached

<p>Quality assurance routine metrics</p>	<p>and a meeting took place last week between KP and STH colleagues. Awaiting updates from KP EP noted that the Alliances were also aware of the issue.</p> <p>Harrogate shared updated service slides however representative weren't in attendance</p> <p>Diane Hubber (DH) updated slides from Leeds</p> <p>Claire Swift (CS) updated slides from Hull. CS noted concerns regarding service gaps between 16-18 years old</p>	<p>DH and CS to liaise and discuss with Paeds team</p>
<p>Service Improvement projects</p>	<p>DS informed the group that NHSE will release a list of mandatory performance metrics in TYA Cancer, defined by the clinical reference group (CRG). This will require all TYA services, both PTC and DH to report at an organisational level. The data collected will be shared through the ODN to understand service needs and outcomes at a Network level, celebrate success and support improving if there are places where that is required.</p>	
<p>Running projects</p>	<p>i. Research accrual and related data-FJS passed on a message from Debbie Rowley (DR). DR will be leaving the Research Accrual Champion post in October 2022. The post is currently out to advert via NIHR. DR shared that the first six months of data regarding accrual for Sheffield, Leeds and other DH's has been collected. This will be part of her finalised annual report.</p> <p>Hillary Campbell (HC) from NIHR noted that there were some candidates for the Research Accrual Champion post.</p> <p>HC and DS commended DR for her excellent work with the project as this was an extremely detailed and complex piece of work. DR has helped to provide our</p>	

	<p>baseline for accrual rates in TYA Y&H and understand the blockers to moving forward towards the 50% accrual rate target.</p> <p>DS noted the need for real time ongoing data collection as to age at accrual to research, from our DH's and PTC's, and the NIHR Edge database.</p> <p>HC noted some of the planned data collection projects that will hopefully assist in enhancing our understand of TYA research accrual.</p>	<p>EBM to liaise with HC to understand NIHR data collection.</p>
Running project	<p>ii. WGS and Tissue Banking- Nicola Balatoni (NB) mentioned that between our DH partners and the Leeds Genomic Hub there are no sample Trust transport pathways in place for WGS. This is an area NB will be developing. NB asked any colleagues interested in developing WGS pathways to please get in touch. NB also happy to answer any quires regarding WGS requirements for DH's.</p>	<p>FJS to circulate information re WGS on behalf of NB to DH contacts,</p>
Running project	<p>iii. Gaps in Care- DH has struggled to identify the key matrons to send questionnaire regarding data on gaps in care to date. However, some contacts have now been established and circulation of questionnaires will be completed in due course.</p>	<p>DH to circulate and update at next meeting.</p>
Running project	<p>iv. PPIE –DH, DR and Gary Doig (GD) have had some meetings on patient and public involvement and engagement for TYA in the Yorkshire region. An expression of interest form has been disseminated to patients, carers, and families across the region.</p> <p>Discussion of questions to work on with the PPIE group - One of the main questions is on research but the group is still working to establish key questions to ask our Young People.</p> <p>Please see ToR and safeguarding documents for colleagues to comment.</p>	<p>Documents attached with meeting invite and minutes.</p>

Planned project	i. Joint care- the network endeavours to offer care in the simplest most logical place we can provide optimal care. This is a workstream we endeavour to develop in due course.	
Planned project	ii. Patient travel burden- DS noted Professor Richard Feltbower and his team in Uni of Leeds has region-wide data to enable this piece of work. This data will help us to understand whether our current set up of DH's and PTC's is well matched to the distribution of our patients.	
Planned project	iii. The range of cancers and age-groups managed at each location - This aligns with data collection workstream.	

Updates from other meetings

Paediatrics cancer ODU

FJS mention that Katharine Patrick (KP) from Sheffield has now taken over as clinical lead for the children's cancer ODN.
Discussed mutual aid agreement between Sheffield and Leeds for paediatric radiotherapy is underway. Currently 5 patients at the Leeds hospital from Sheffield. Some issues noted re nursing capacity for RT GA patients, but this has been resolved.
Next meeting for Children's is 4th October 2-4pm

Other ODN's

Maddie Iredale-Cook (MIC) from Radiotherapy attended the meeting. The RT ODN is currently working through their annual work plan with a key focus on recruitment to clinical trials.

AOB	<p>FJS- The Memorandum of Understanding (MoU) needs to be reviewed and signed off by all of our DH Clinical Leads and their respective Service/ General Manager. FJS thanked the group as the majority are now signed off but there are still some hospitals outstanding.</p> <p>FJS will circulate reminders but please make contact if you believe you have not received a copy of the MoU and ToR for signing.</p>	
Dates for next meeting	<p>2/12/22 1/3/23</p> <p>All 3-5pm</p> <p>20/9/23 ODN Away day</p>	