TYA CANCER CLINICAL NETWORK MEETING MINUTES

06/03/2024 3:00-5:00pm on Teams

Attendees:

Name	Role	Organisation
Natalie Kisby (NK)	Head of Family Support	Candlelighters
Rachel Cloke (RC)	Lead Nurse	Doncaster and Bassetlaw NHS Foundation Trust
Dara Gibbons (DG)	Lead Nurse	Harrogate NHS Foundation Trust
Dan Stark (DS)	Consultant Medical Oncologist	Leeds Teaching Hospitals NHS Trust/ Y&H CTYACCN
Kevin Peters	Service Commissioner	NHS England
Rachel Wane (RW)	TYA Research Champion for Yorkshire and Humber	NIHR
Hilary Campbell (HC)	Research Delivery Manager	NIHR
Louise Ollivant (LO)	Lead Nurse	Rotherham NHS Foundation Trust
Liz Purnell (LP)	TYA Lead Nurse	Sheffield Teaching Hospitals NHS Trust
Angela Stephen (AS)	Late Effects CNS	Sheffield Teaching Hospitals NHS Trust
Tasha Morley (TM)	WGS Nurse Specialist	Sheffield Teaching Hospitals NHS Trust
Tricia Wyer (TW)	MDT and Service Administrator	Sheffield Teaching Hospitals NHS Trust
Robin Young (RY)	Consultant Medical Oncologist	Sheffield Teaching Hospitals NHS Trust
Sue Berry (SB)	Senior Quality Lead	South Yorkshire ICB
Anne Thomson (AT)	Biobank Manager	VIVO Biobank
Lynn McNamee (LM)	Diagnostics Delivery Manager	West Yorkshire and Harrogate Cancer Alliance
Paddy Carley (PCa)	Data Co-ordinator	Y&H CTYACCN
Alex Chilvers (AC)	Network Manager	Y&H CTYACCN
Muhammed Naveed (MN)	Consultant Haematologist	York and Scarborough Teaching Hospitals NHS Trust
Gillian Jackson (GJ)	Lead Nurse	York and Scarborough Teaching Hospitals NHS Trust

Apologies:

Name	Role	Organisation
Lucy Ward	CNS	Harrogate NHS Foundation Trust

Jill Doherty	MDT and Project Co-ordinator	Leeds Teaching Hospitals NHS Trust
Leanne Elder	Pharmacist	Leeds Teaching Hospitals NHS Trust
Julie White	ODN Lead Nurse	Leeds Teaching Hospitals NHS Trust/ Y&H CTYACCN
Alun Windle	Chief Nurse	Sheffield Teaching Hospitals NHS Trust
Nigel Beasley	Consultant ENT Surgeon	Sheffield Teaching Hospitals NHS Trust
Emma Clarke	CEO	Weston Park Charity
Nicky Bould	Senior Clinical Psychologist	York and Scarborough Teaching Hospitals NHS Trust

Action log	**Responsible person**
a. To share attendance issues with DS and AC (missing more than 3 meetings in a row)	PCa
b. Late effects discussion to be added to the agenda for the next TYA Network meeting	AC

Item	**Minutes**	**Action**
1	**Standard Business** **Welcome, Introductions and Apologies** DS welcomed the group and invited any new members to introduce themselves. MN and GJ introduced themselves as the TYA Lead Consultant and Nurse in York and Scarborough. PCa received apologies which are noted above. **Declarations of Interest** No declarations of interest noted. **ODN participation Tracker** DS noted the network looks at TYA oncology attendance for those working in the Designated Hospitals. He acknowledged this work doesn't come round at every hospital or trust regularly, but values input of all trusts. DS stated missing 3 or 4 meetings presents an issue to the network and service users, emphasising the impact of regular attendance. **ACTION.** PCa noted Airedale and Bradford had not sent a representative for the last 3 meetings. AC is aware of Harrogate's staffing changes and believes other trusts' issues will be picked up in the benchmarking process over coming months. Any attendance issues will be discussed with the service commissioner, network leads and manager. **Notes from previous meeting** DS noted most actions will be discussed throughout the meeting. AC noted Shamaila Anwar (NIHR) will hopefully present at the next meeting regarding the Year of Birth data. The group agreed the minutes were an accurate representation of the last meeting.	**a. PCa to share attendance issues with DS and AC (missing more than 3 meetings in a row)**

2	**Matters arising (not featured on the main agenda)** **ODN website update** PCa stated the first draft of the website had been received and sent to the board and website working group. Feedback has been taken on board and relayed to the developers who will provide a new version in the coming weeks. From that point on, the upkeep of the website will be under network supervision. **Completion of all memoranda of understanding between ODN and each acute Trust** DS stated this is very important as it ensures an agreement for time to conduct this work. If staff are feeling unsupported, the MoU may be used to confirm the trusts are committed to TYA work, and share responsibility with individuals conducting the work. DS noted this may be escalated through commissioning if required. AC has escalated Bradford's MoU signature with commissioning, and Doncaster and Bassetlaw have queried some aspects of the MoU. DS highlighted a number of issues from Bradford, but understands they are keen to remain a Designated Hospital. **Benchmarking update** DS delineated this is the process of finding out how each Trust is engaging with delivering the commissioned services for TYA. The network is planning various meetings to have focused but informal conversations about what is working and how to improve the service. AC noted some Trusts are still awaiting response and there are some extensions in place currently. Provisional dates in April and May for site visits from the core network team will be organised pending diary commitments. AC has met with Harrogate and Hull and is happy to help other Trusts if required. DS hopes to take away examples of excellent practice which we can share amongst the group also. KPe added he believes this process has been very constructive in Paediatric settings and allows for a common understanding of issues and how Trusts can be supported by the network and commissioning. He hopes to replicate this in TYA process. AS queried what late effects services were available in the network for over 18s, and felt it would be very useful to engage with others. DS noted the TYA service specification mentions late effects, but there are different approaches at different organisations. He welcomed setting up a mutually supportive discussion with colleagues however. AS and LP are working closely on this and are very interested to see creative ideas from others. DS noted the late effects service in Leeds uses a risk stratified approach and is available to all service users up to 30th birthday. There are specific patient information documents copied to	**b. AC to add Late effects discussion to the agenda for the next TYA Network meeting**

	general practice and patients have an end of treatment conversation which is in a written form for full comprehension. DS stated there is not enough capacity to meet demand and different age ranges have different emphasis. AS stated she was keen to push the age group up to 40th birthday. **ACTION.**	
3	**Service Update Slides including Clinical Governance** **Progress in keeping TYA services working well** **Complaints, service challenges, and examples of quality of care given.** LP noted the TYA team in Sheffield had 3 posters accepted at the upcoming conference; • psychological support for TYA team members • mapping services end of provisions • bespoke TYA ready, steady, go AS is mapping the Late Effects service in Sheffield with case examples, so the team can edify potential issues are and how to expand the service. DS noted research actions and proposals are in place with adjustments for funding pressures from charities taken into consideration. The team is working hard to ensure age-appropriate facilities on L33 and J94 are open for day case and inpatient care; retaining a young person's atmosphere. Peer review submissions have been completed with a review scheduled in 3 weeks. DS is looking forward to conversations about improving the service at the PTC. Alongside this, the patient experience surveys are complete, also offering more feedback for improvements. Nursing groups are fully staffed; however, the senior nurse is away from work currently. Gentle challenges, as always in an organisation this size. AS and Robyn Hedge discussed the transgender cohort of patients and wants to clarify the pathway is correct, and service users are supported and included accordingly. DS stated it is important to raise these points, as other centres may find them useful and interesting.	
4	**Service improvement project updates** **Research Accrual, and related data (such as number of new diagnoses of TYA cancer) – Live dashboard for TYA data** AC noted a live dashboard is being created using LTHT and NIHR funds to support the target of 50% trial accrual by 2025 for TYA. EPRs and Year of Birth data will be brought together to house other demographics also (ag, ethnicity, referring hospital etc). The development team will be providing another draft before hopefully going live by the end of the month. AC is in discussions with CRN about Year of Birth data and waiting to cross reference this with the live dashboard. DS stated the Year of Birth data involves overlapping work resulting in age being estimated once patients enter an NIHR study; previously this was not a core function. Yorkshire and Humber were an early adopter of submitting	

	this data to NIHR, thus having high levels of completeness compared with other areas of the country. Unfortunately, research accrual is shy of the 50% target which is highly relevant to our service. AT queried whether the dashboard can be used in future to show whether service users have accepted tissue banking. AT stated VIVO may send over the information directly to feed into the live dashboard. RW and HC have been working with AC to understand and provide an accurate account of the data comparing with Year of Birth and Ethnicity data. PCa shared the incidence and 7-day MDT dashboard taken from Sheffield and Leeds PTC data. This will be used as a comparison tool with the incidence data taken directly from the Trusts within the network. DS queried the process for collecting data. PCa confirmed this was done via the Caldicott Guardians and needed specific data sharing agreements. **WGS – accrual and progress in local systems. Local and regional system pressures upon rate of improvement.** DS noted the appointment process is underway for the Leeds based WGS nurse and highlighted TM's work in Sheffield. TM presented data from 2022-2023 collected from NGIS (where consent forms are submitted). She provided an overview of the paediatric and TYA WGS which can be accessed here: She noted some cases may be carried over from previous years, have possible differences due to waiting time on samples, and the occasional example disjointed care for 16–25-year-olds. DS queried how many samples were ongoing for 2023-2024. TM is interested to see how things progress over the next few years. DS highlighted some of 2023 specimens may still be in process. Unfortunately, problems with the systems and awaiting times are potential reasons some colleagues haven't embraced WGS. TM noted actionable information is still to be discussed and believes sample time will reduce over the coming years. DS stated the 2022 pathway was quite small and worked within 8-10 weeks. Unfortunately, in 2023 it took a lot longer due to increased workload. He expressed disappointment in the Leeds data, as most TYA are eligible and he believes WGS has a high value. WGS may shows biological variance relevant to management and can identify if family members are at risk, resulting in screening processes. DS stated lack of WGS may result in more cancers in future years. He noted in 2022 Leeds had capacity for supporting this pathway, but this came to an end, possibly resulting in lower take up.	

	TM reviewed some of TYA cases and often the resection size was too small and noted this may be a positive due to diseases being caught at an earlier stage. RY wondered whether there was any data on actionable mutation or germline findings, or whether WGS impacted the patient pathway, as it may help to advertise the service to colleagues. DS knows of patients who've benefitted, but doesn't have formal local data. From previous data, WGS is generally relevant to 1/5 patients. DS emphasised the importance of continuing TM's work to build for the future. **Gaps in care- Equity and transparency of service provision in each location (palliative care, referral to all relevant MDTs upon diagnosis, community nursing services, psychology, peer-group support)** DS noted there is a working group trying to improve 16-18 pathways and understand how reliable care after complications with cancer is implemented. DS noted issues include different services managing different groups, e.g., differing between organisations whether responsibility lays with children's or adult's services. Following on, it is not necessarily the same group in community services or surgical services. DS stated this becomes more complicated when one considers end of life care. This was a common theme from the network engagement day, with frequent reference to transition and palliative care. As a starting the point the group will look at diagnostics; who manages what, and where care is taken place? Who delivers treatments, acute events and deals with complications, supportive care, survivorship, late effects and end of life care? DS hopes the group will deliver a series of defined pathways for clinician, but recognises difficult aspects, with community services often differing to core cancer services. Alongside this, a mapping exercise will be undertaken to figure out responsibilities, building up a document which entails; a problem, a patient postcode and the responsible clinician. AS emphasised the work of adult community nurses in Bradford, with DS delineating the issues lie with integrated care and community services. DS welcomed others to join the group with the next meeting taking place in the coming weeks. **Joint care – A pilot of joint care between 2 sites (Leeds & Hull)** DS stated the group is hoping to set up a joint care pilot between Leeds and Hull. This would be for patients who receive complex care for an uncommon illness, but have needs for elements of care delivered near their home highly competently by expert teams.	

	The group is looking at how joined up and documented care is set up. Issues include; access to electronic patient records, links to pharmacy, administration teams, clinician and nursing. All of which provide the needs for treatment. The group will continue to meet to work through barriers to providing joint care. This project is making progress and moving forwards. **Planned** **Patient travel burden** Ds noted this needs to come either side of the joint care project to assess impact and ascertain the value of joint care; this will include quality of care and decreased travel burden for patients. This is in the planning stages with local epidemiologists in Leeds.	
5	**Updates from other meetings** **Radiotherapy mutual aid update** KPe noted discussions are ongoing, but there is a general agreement to provide a short-term service from Leeds for patients who would have previously gone to Sheffield. There is also general agreement that a single Yorkshire and Humber service delivered on more than one site may be more appropriate. He acknowledged it is important to recognise there is a small number of clinicians involved in the service and trying to get back to a position in Yorkshire and Humber with two consultants at two sites is unsustainable. DS agreed this sounds sensible if governance and technology put into place.	
6	**AOB** *Dates of next meetings – each 3-5pm (<u>all put in diaries now please</u>);* • Thursday 06/06/24 • Monday 02/09/24 • Tuesday 03/12/24	