TYA CANCER CLINICAL NETWORK MEETING MINUTES

05/12/2023 3:00-5:00pm on Teams

Attendees:

Name	**Role**	**Organisation**
Sarah Mettrick (SM)	TYA Lead Nurse	Calderdale and Huddersfield NHS Foundation Trust
Natalie Kisby (NK)	Family Support Manager	Candlelighters
Rachel Cloke (RC)	TYA Lead Nurse	Doncaster and Bassetlaw NHS Foundation Trust
Claire Swift (CS)	TYA Lead Nurse	Hull University Teaching Hospitals NHS Trust
Iqtedar Muazzam (IM)	Consultant Medical Oncologist	Hull University Teaching Hospitals NHS Trust
Dan Stark (DS)	Consultant Medical Oncologist	Leeds Teaching Hospitals NHS Trust
Diane Hubber (DiHu)	TYA Lead Nurse	Leeds Teaching Hospitals NHS Trust
Jill Doherty (JD)	MDT and Project Co-ordinator	Leeds Teaching Hospitals NHS Trust
Shona Tutin (ST)	TYA CNS	Leeds Teaching Hospitals NHS Trust
Kevin Peters (KP)	Specialised Commissioner	NHS England
Hilary Campbell (HC)	Research Delivery Manager	NIHR
Rachel Wane (RW)	TYA Research Champion for Yorkshire and Humber	NIHR
Louise Ollivant (LO)	Haematology CNS	Rotherham NHS Foundation Trust
Dan Yeomanson (DY)	Consultant Paediatric Oncologist	Sheffield Children's NHS Foundation Trust
Angela Stephens (AS)	Late Effects CNS	Sheffield Teaching Hospitals NHS Trust
Liz Purnell (LP)	TYA Lead Nurse	Sheffield Teaching Hospitals NHS Trust
Robin Young (RY)	Consultant Medical Oncologist	Sheffield Teaching Hospitals NHS Trust
Tasha Morley (TM)	Genomic Nurse Practitioner	Sheffield Teaching Hospitals NHS Trust
Tricia Wyer (TW)	Teenage Cancer Trust MDT Co-ordinator & Service Administrator	Sheffield Teaching Hospitals NHS Trust
Georgia Thompson (GT)	Director of Cancer Services	South Yorkshire ICB
Gary Doig (GD)	Operations and Partnership Manager	Teenage Cancer Trust
Alex Chilvers (AC)	Network Manager	Y&H CTYACCN
Julie White (JW)	Lead Nurse	Y&H CTYACCN
Paddy Carley (PCa)	Data Co-ordinator	Y&H CTYACCN

Apologies:

Name	Role	Organisation
Claire Hall	Consultant Haematologist	Harrogate NHS Foundation Trust
Leanne Elder	Pharmacist	Leeds Teaching Hospitals NHS Trust
Richard Kelly	Consultant Haematologist	Leeds Teaching Hospitals NHS Trust
Cathy Burton	Consultant Haematologist	Leeds Teaching Hospitals Trust
Alastair Greystoke	Consultant Medical Oncologist	Newcastle upon Tyne NHS Foundation Trust
Diana Greenfield	Late Effects Consultant	Sheffield Teaching Hospitals NHS Trust
Nigel Beasley	Consultant ENT Surgeon	Sheffield Teaching Hospitals NHS Trust
Alun Windle	Chief Nurse	South Yorkshire ICB
Anne Thomson	Biobank Manager	Vivo Biobank
Lynn McNamee	Diagnostics Delivery Manager	West Yorkshire and Harrogate Cancer Alliance
Emma Clarke	CEO	Weston Park Charity
Nicky Bould	Senior Clinical Psychologist	York and Scarborough Teaching Hospitals NHS Trust

Item #	Minutes	Action
1	**Standard Business** **Welcome, Introductions and Apologies** DS welcomed the group and suggested those new to the meeting gave a brief introduction. GD and AS introduced themselves as Operations and Partnerships Manager for Teenage Cancer Trust and Late Effects CNS in Sheffield respectively. PCa received apologies which are noted above. **Declarations of Interest** No declarations of interest noted by the group. **ODN participation Tracker** DS stated the participation tracker will be updated from the engagement day and this meeting. He noted excellent engagement in general and growing engagement in work between meetings. Airedale, NLAG and Barnsley were highlighted as centres in which engagement could be improved. **ACTION.** **Notes from previous meeting** June meeting minutes were agreed by the group.	**a. PCa to update attendance tracker and send to all stakeholders**

2	<u>**Matters arising (not featured on the main agenda)**</u> **ODN website update** AC stated the logo is in the process of being redesigned after feedback from the engagement day. AC feels it's important to engage with the group and act as part of a larger team; acknowledging it wasn't shared widely enough in the first instance. DS queried when a draft would be available. AC confirmed the logo will be shared by in January. **ACTION.** PCa stated feedback from the engagement day was helpful in populating written content for the website, and a meeting is being scheduled with the developers in January to continue the project. Following this, the steering group will test the website draft and offer feedback resulting in a final version and the editing functions handed over to the network admin team. DS asked which aspects of feedback were most helpful. PCa highlighted clarity over utilising existing patient facing content and streamlined access to guidelines. DS suggested the website may serve as a repository of clinical guidance, contact information and links to partner organisations such as charities and research groups. Offering a public facing part and a professional log in for technical documents may help encourage activity with the ODN. For example, new staff members may access the site via a professional log in which offers an overview of the ODN and its functions, and access to key documents on other systems. Within our joint care project, the ODN website ought to support that process. Having on the website identifiable resources for when services are managing cases that also have care elsewhere (e.g., Hull patient admitted acutely to Leeds). Info such as; who the key individuals are in each place and their contact details, links to key process paperwork (antibiotics, line care etc), links to the acute oncology services, etc. DS emphasised the importance of members contributing to developmental work and projects between meetings, which he feels will improve the enjoyment and productivity of the network. **Completion of all memoranda of understanding between ODN and each acute trust** AC highlighted Bradford and Doncaster signatures as still outstanding. RC represented DBFT in the meeting and informed Dr Bobbili is in the process of signing the MoU. DS suggested AC contact KP if she's struggling to find a representative in Bradford. KP concurred. **ACTION.**	**b. AC/PCa to share logo to group by 19/01/24** **c. Members to contact PCa if they wish to join the website steering group** **d. KP to chase with AC for Bradford contact**
3	<u>**Service Update Slides including Clinical Governance**</u> **Progress in keeping TYA services working well** DH highlighted the progress of work with Hull on shared care for 16–18-year-olds treated in Leeds and supported in Hull despite current	

pressures. She noted another meeting is planned in January. Currently, there is no clear process for ways of working together. This will hopefully be developed through this work; see later discussions over integrated care.

DS noted the interest of exploring this model throughout our network as a potential solution to the pressures of caring for young people. DS highlighted ensuring we have the right sets of opinions regarding care, reducing travel burden, access to research or trials and contributing biological data to tissue banks as key parameters to offer patients.

RW noted the appointment of a TYA research nurse for 2 days a week in Sheffield and another for 1 day a week in Leeds, promoting research and improving services closer to home. DS stated there is now an integration of some staff members, with the Leeds-based nurse recruiting to their own academic study and also locally open TYA clinical trials, whilst learning the specific features of the TYA NHS service alongside the importance of site-specific expertise for intervention trials.

Hull

CS provided Hull updates. The TYA unit is based on Haematology ward 33 within the Queen's Centre at Castle Hill Hospital and operates a close working relationship with Leeds. CS has been attending psychosocial meetings that focus on Hull patients (specifically the first Thursday of the month).

IAMS are now used for HNAs and Dr Muazzam is very supportive in TYA work alongside Dr Bozas and Dr Bailey (lead for TYA Haematology). Hull are recruiting patients in PROTECT and DS reminded the group all patients including relapses are suitable for this trial.

CS stated funding has been made available for HCP in Hull, supporting training on TYA cancer care, with support from the TYA lead nurse in Leeds.

As DiHu mentioned, the main issue involves improvements to shared care pathways for 16–18-year-olds. CS noted this is a small number of patients so hopefully we can overcome issues. The Hull Youth Support Worker is attending Paediatric MDTs and can support the younger patients through invitations to peer-group and educational events.

Leeds

Place of care:

DiHu provided Leeds updates. Leeds utilises Ward 33 (closed until Mid-Jan due to infection control) and Ward 24 with approximately 120 new young people per year.

Currently, there is growing demand for day-case chemotherapy patients and reducing demand for in-patient beds, so DiHu is engaging in evidence-based work with the trust to improve experience of care.

The team is working with Ward 94 but with more structure they may be even more productive.

Patient engagement:
Patient feedback has helped challenge and improve patient experience on the ward.
The patient satisfaction survey is due to be sent out and the patient participation group launches 13th January and will hopefully see ~20 attendances.

Staffing:
The TYA Education Day in November gained positive feedback and plans are in place to develop an education package hosted on Moodle. Psychologist has been appointed for 2.5 sessions per week. Unfortunately, the community YSC post was withdrawn from TCT funding. Staff are able to offer peripatetic care, and see patients at Designated Hospitals but trying to maintain this service is challenging. Funding for an activity co-ordinator on Ward 33 should enable the Youth Support Co-ordinator to focus on specific Designated Hospital work and age-appropriate care. WGS nurse role is due for interview on 7th December. Regrettably, 2 YLvC Social Workers have recently left their roles resulting in referrals being prioritised and sent to the central team.

***Issues and challenges*:**
Education work is taking place on ICU for 16–18-year-olds. Late referrals of Thyroid and Melanoma patients result in lack of support from and engagement with the TYA service.
Plans to develop an electronic admissions diary with the J94 ward team due to be in place by February 2024.

Rotherham
LO provided Rotherham updates. 4 patients treated this year thus far. Lead TYA Consultant James Taylor and Lead TYA Nurse Louise Ollivant. LO has implemented a Power BI notification system set up to track all patient diagnoses via Infoflex. This negates reliance on other specialities to inform of diagnoses. No improvements to facilities. No referral issues or changes.

Sheffield
LP provided Sheffield updates. Currently, 64 new patients with 13 patients on diagnostic pathways. The regional study day was successful with plans for next year's underway. LP is investigating filming one of the workshops as part of mandatory training. Specific training on SIMS placement at Hallam University with YLvC is in place also.

TCU is closed this week, but overall is open on a more regular basis. Haematology patients are cared for in Ward O1 at RHH. This is an environment preferred by patients. New patient clinics are being trialled to improve peer support. Formalising end of treatment

	support with Youth Support Co-ordinators and psychologists which is being submitted as a presentation at the TYAC conference. ***Staffing:*** Staff appointments include: Tricia Wyer (TYA MDT Service Administrator) Hannah Richardson-Wood (Band 6 Nurse), Helen Trower (Research Nurse - funded by WPCC). Unfortunately, there is no funding available from TCT for YSC hours. Tasha Morley's (WGS nurse) funding is secure until end of March 2024 with updates to follow. **Complaints, service challenges, and examples of quality of care given.** DS raised the issue of WGS Nurse funding. DiHu noted Karen Henry (Lead Nurse LTHT) is looking into the possibility of developing a WGS team. TM stated STH may be taking on the funding responsibilities as Genomics England won't communicate plans until January or February. TM suggested an amalgamation of funds from various stakeholders to fund the WGS Nurse role. RY explained this is a grey area but suggested longer term expectation is that trusts will fund these roles. DS highlighted the same is true with technological or clinical innovations elsewhere. AS has noticed a gap in educational support for young people experiencing pain and fatigue post-treatment. She is investigating designated clinical offices to garner support for u25s to offer educational opportunities. In AS's opinion the Late Effects service is frustrating as acute service support ceases after a specific duration of survivorship. She hopes to implement support groups and therapeutics trips and breaks away for those suffering from post-treatment issues. DS queried if AS is connected with others experiencing similar issues. Note made to connect AS with other teams. **ACTION.** AS queried if the group knew of any Late Effects campaigns for key working and services for survivors. JW stated Leeds split their long term follow up services by 0-18 and 18+. She noted upcoming plans to look at pathways and support. Leeds provides key worker support to those with ongoing Late Effects needs but there is a limit to resources. Recent Candlelighters research echoes AS sentiments. In JW's opinion, end of treatment can feel isolating and lonely and feels Leeds can offer more. In the past, end of treatment days were offered but attendance declined. Eventually, JW hopes to nurture this by linking with primary and secondary care. LP suggested investigating Shine and Trekstock charities who are offering services for those finishing treatment and in Late Effects clinics. DS recently finished research involving the needs of Young People and Adolescents with cancer which highlighted mental health issues as a priority. In particular, developing the coping methods and psychological skills to withstand life's challenges. One of the	**e. ODN team to investigate connecting AS with teams focusing on education and support for those post-treatment.**

	comparators noted was a well-supported cancer environment in comparison with those living with long term disabilities. GD noted the great work done by TCT co-ordinators delivering peer support to patients with lots of regional post-treatment activities which AS may link in with. **ACTION** AS highlighted her experience in paediatric oncology showcasing the potential gap in services for Late Effects patients. This is prevalent in university age group who may be struggling with lack of support available. Supporting the Late Effects service has allowed opportunities to investigate this and hopefully gain momentum.	**f. GD to link TCT support co-ordinators with AS.**
4	<u>**Service improvement project updates**</u> <u>**Running**</u> **Research Accrual, and related data (such as number of new diagnoses of TYA cancer) – Live dashboard for TYA data** AC is chasing the dashboard technical specification which is due by 08/12/23. According to the developers it is a simple process which once instigated will generate data immediately. DS stated the network is able to sign the payment off without an overall chair as resources had previously been identified. DS emphasised the importance ensuring this tool functions in a way which suits the group and highlighted links to RWs research work if built to the correct specifications. RW stated the Year of Birth project from NIHR will have a 2023 dataset by January giving an overall view of the network when combined with the incidence data compiled by PCa. DS highlighted the CRUK call for data science research in CTYA cancer to create resources closes 06/12/23. All applicants state they are providing a national accessibility. Our network, CRUK and NHSE acknowledge the national (NDRAS) cancer registry is not functioning to provide data analyses post-covid so other solutions are needed. CRUK have agreed to invest ~£5m over 4 years in innovative validated data systems to create a dataset with national reach. This might (depending which projects are funded) create a website with membership capabilities for accessing data via NHS trusts or region. This is an overarching plan over numerous years but there is an acknowledgement of understanding that CTYA cancer require robust data including research, planning and staffing. DS commented regarding the interest in the Year of Birth dataset. He suggested Shamaila Anwar present this at the network meeting 06/03/23. DS noted the vast nature of this work over the past 20 years as in previous years age was not a core field collected in the data set by NIHR, this has now been resolved. **ACTION**. **WGS – accrual and progress in local systems. Local and regional system pressures upon rate of improvement.**	**g. ODN team to contact Shamaila Anwar (NIHR) to arrange presentation at 06/03/23 network meeting**

DS highlighted TM’s ongoing work and the upcoming interview for the WGS Nurse role in Leeds. He emphasised difficulties in obtaining tissue in the correct form during the WGS process.

TM agreed with its complexities, especially in solid tumours as fresh tissue must come from a biopsy or resection (rather than just a blood test in haematology). The TYA patients tend to have specific pathological tumour types, influencing the need for WGS. Helen Trower is liaising with TM and patients who’ve had tumours removed at district hospitals. Storing the first piece of diagnostic tissue fresh as well as in formalin is greatly preferable, in each location in our ODN. If the patients have an initial biopsy or excision in the DH and no fresh tissue is stored, then even if (as sometimes) further removal of tumour (wider excision) is required it may not contain further tumour tissue.

DS emphasised WGS is not a complex process; patients need a blood test with a particular consent form, fresh tissue from the tumour, and a team member needs to ensure the correct individuals in the pathology labs are aware. Unfortunately, the paperwork is quite complicated and can be intimidating to consenting clinicians who do not do this regularly, within an otherwise uncomplicated process.

TM stated conversations with patients can take some consenters and patients up to 20 minutes, although quicker done by experienced staff. This is particularly demanding if close in time to a new diagnosis. TM is happy to liaise with other MDTs to help support the WGS process.

Leeds has instigated for sarcoma taking and storing fresh tissue at the primary resection, even if there is no detailed plan to use for WGS. This fresh tissue supports wider routine NHS work on contentious or rarer diagnoses. But as a consequence, this also enables Genomics England WGS conversations and discussions at a later date, when the emotional aspects of the diagnosis may be less and the trusting and supporting relationships may be stronger.

TM had been previously quoted £200 for a pathologist to process a sample and to obtain freezer and database space in Sheffield. She noted Newcastle do have the capacity due to upgraded facilities.

DS queried with RY if Sheffield are keeping fresh tissue routinely in sarcoma diagnostics. RY stated unfortunately there isn’t freezer space in pathology. He noted a number of patients where WGS is sought when they present with metastatic disease. Here simple needle-core biopsy for diagnosis may yield insufficient tissue for WGS, unless there are system changes to take further cores, both to make NHS complex and rarer diagnoses easier, and also to support WGS.

IM queried if we can keep tissue and whether this affects the quality of the test; WGS is not investigating proteins which tend to degrade, so this process may continue.

IM highlighted value from our ODN collaborative approaches with 2 WGS over the last 4 months in young breast cancer patients. This has led to treatment options where previously there was none, in a clinical trial. It has also identified the need to do this more, so that the technical pathways become slicker and more effective.

DS often explains to patients this is a state-of-the-art science, and may fail, so its important clinicians don't raise undue expectations. IM commented there is often a 3-6 months' timescale to receive GE WGS results. Consequently, DS highlighted the need to not rely on WGS for early management decisions (but have histopathology locally able to complete specific routine adjunctive tests in real time, using FISH or other techniques in cancers with well-established molecular changes. DS supports NHS policy in that WGS should be considered for all young people, with new processes required to ensure that for those less frequent cases and smaller numbers presenting to Designated Hospitals. He noted charities are promoting this and hopefully engaging with more patients.

DS noted the Vivo Biobank email has been shared with all members (enquiries@vivobiobank.org). DS highlighted this research will answer our unanswered questions about cancers (e.g., Why did this patient get more severe side effects that that one? Why did this treatment not work? Is this cancer caused by what I have done in the past?) and help to develop new & kinder treatments. He noted fresh tissue is welcome, but isn't necessary for Vivo biobank. Samples can be from blocks, blood or some bodily fluids. Funding for Vivo biobank has been increased and what was previously only a paediatric endeavour is not extended to TYA. The service is local to our ODN, currently based both in Newcastle and York. DS noted that within the Service specification, the chance to take part in the biobank should be offered as an informed choice to every TYA at a new diagnosis. DS reminded people that when in the past cancer outcomes have been revolutionised the key has usually been cancer tissue going to the best research labs; improving outcomes for young people.

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)
DiHu noted this was discussed as part of the network engagement day and pathways were noted as an ongoing challenge for stakeholders. LP identified the specific challenges (in transition and palliative care themes) from the Slido responses in the engagement day. DS is confident focussing upon one of these will be a key piece of work and wider improvements will come from this even if the work is sensibly focussed initially. The more collaboration, guidance and

documentation is readily available for clinicians, the better. He noted the 16–18-year-old pathway work, which can be an issue of

- rules and regulations regarding patient care (which ward can take which age of patient). DS spoke of research in European hospitals where, for example, the world expert is an adult physician or paediatrician and the counter group isn’t a specialist. If the patient is a day over or under the age limitation, they will not receive the care from the expert.
- staff skill sets (even if the ward is permitted to take them, can the staff manage them well) and
- professional confidence (do staff feel the need for more support managing TYA even when they are trained).
- DS noted emotions often affect decision making in these stressful circumstances, but the need for flexibility in accepting cases, and breadth in assessing of patients’ needs and how they’re met are vital aspects.
- AS highlighted palliative care quality can often depend sadly upon whether a young person interacts and engages well with adults. Ideally services would be able to manage young people well, whatever the patient maturity or skill-set is. DiHu stated the challenges faced include patients wanting to stay locally, where geographically the only availability is adult palliative care in community services and in hospices. ST worked on similar project previously which the group can build on.

DiHu provided an example of a patient requiring a community nurse when they were week under 18 and no one would oversee their care as the rules/criteria determining who was to provide the care were not clear and hence could not be met. DiHu believes building links and offering flexibility is important to avoid situations like this.

DS hoped for a common-sense approach in this work, to identifying skills, time and expertise to improve patient care.

Patient and Public Voice – Diane/ Gary – specific projects to complete with the PPIE group

DiHu and LP are establishing this across the region including young people in designated hospitals and using the basis from the group formed last year. Funding from TCT for a peer support event is available and there are plans for an event in January to communicate with young people and decide how they wish to be involved. DiHu suggested a shared regional event including Sheffield and Designated Hospitals every three months. Payment and recognition for young people was highlighted by DiHu and she wishes to look at network funding to help offer incentives for participants. Similar projects at Royal Marsden Hospital have shown slow uptake but extremely worthwhile. DS noted all members of network must feel included and offer support and encouragement for young people to participate.

	Data collection - The range of cancers and age-groups managed at each location PCa stated there are agreements in place with Caldicott Guardians for data sharing in Bradford, Calderdale and Huddersfield, Harrogate and Hull. Conversations are underway regarding data sharing with Doncaster, Mid Yorkshire, Rotherham and NLAG. Airedale isn't engaging from a data perspective but this will be investigated further. **ACTION.** DS thanked the network members for the progress being made on the range projects being undertaken by the network, and encouraged members who are not as active (yet) in our projects to feel confident to take part. **Planned** **Benchmarking process** AC noted some centres may have received emails from KP already. AC has contacted all lead clinicians and nurses at Designated Hospitals. The benchmarking spreadsheet outlines the service specification and offers solutions to problems centres are facing. DS stated this is an information gathering exercise where everyone should be clear and open to gather factual information of what services we offer. Research accrual, WGS, early referrals to regional MDTs and HNAs are some examples of sections within the benchmarking exercise and this will begin early 2024. AC will be sending out the benchmarking exercise and supporting documents over the next week. DS noted this could be done as an informal visit also. **Joint care – A pilot of joint care between 2 sites (Leeds & Hull)** This entails working together as a network and utilising systems and staffing to offer the best care in the best place, each time, for each patient. The network wants to develop piece of work to embed this in our structure. **Patient travel burden** DS highlighted Richard Feltbower and the Yorkshire Specialist Register for Cancer in Children and Young people who offered to deliver work illustrating patient travel times at a high quality. See https://ysrccyp.org.uk/ This outstanding regional project uses robust data extracted from many sources about patient care and outcomes. DS feels any excess in budget towards year end could provide useful baseline data regarding travel burdens. **ACTION.**	**h. AC and PCa to chase contact at Airedale** **j. AC to conduct budget review end of Jan 2024 - if unspent budget contact all involved (RF, ODN board) to identify a way of providing a current travel report for CTYA across Y&H CCN.**
5	**Updates from other meetings** **Radiotherapy mutual aid update**	

	JW noted Leeds have been providing RT mutual aid for last 14 months but there's been a request from Sheffield to extend this to March 2024. She stated Sheffield are committed to repatriate this service but Leeds have highlighted the operational challenges facing the trust. Currently, Leeds is awaiting a finalised plan from Sheffield. KP noted the meeting to confirm this process has been delayed by a week and will update in the future. DY stated SCHT is contributing to the options appraisal papers which will be fed back to the working group. DY feels this is not as relevant to the TYA network as over 16s can be treated as Weston Park Hospital. DS feels this is still of interest as under 16s are treated as part of TYA service in Leeds.	
6	**AOB** IM highlighted providing the best care for patients close to home who are unable to travel and ways of building robust procedures. He queried if PTCs could monitor process when a patient is under the care of the Designated Hospital team. DS noted the project being built between Leeds and Hull will hopefully meet this need. DS acknowledged outcomes have been difficult for patients choosing not to travel to centres with a wider knowledge base. He highlighted patients want all things - the best care in the world at their home location with family around them. As providers, we must be open and clear outcomes of treatment can be compromised by having treatment in centres with a lesser range of experts. Although in some cases reviewing case notes and communicating over the phone can help, this cannot fully compare to assessing a patient in person. PTCs such as Leeds have the same challenges when explaining the need to travel to London or Manchester to seek expertise they don't have. Often when the pros and cons are honestly explained, young patients see the advantages of having key decisions made in the very best place, backed up by local care supporting that once the key decisions are in place. DS stated we can mitigate these outcomes, but patients need informed discussion. *Dates of next meetings – each 3-5pm (all put in diaries now please);* • Wednesday 06/03/24 • Thursday 06/06/24 • Monday 02/09/24 • Tuesday 03/12/24	