North West
Teenage and Young Adult
Cancer Specialised Services
Clinical Network

North West Teenage and Young Adult Cancer Specialised Services Clinical Network

Annual Report 2024 - 25

Document Purpose	Annual Report
Title	North West Teenage and Young Adult Specialised Services Clinical Network Annual Report April 2024 – March 2025
Circulation	• North West Teenage and Young Adult SSCN Network Oversight Group • Greater Manchester Cancer Alliance • Cheshire and Merseyside Cancer Alliance • Lancashire and South Cumbria Cancer Alliance • ICSs/ICBs • NHSE/I, Specialised Commissioning • North West Teenage and Young Adult SSCN members
Description	Summary of the Network activity against the work programme and Teenage and Young Adult Service Specifications: Teenage and young adult cancer clinical network specification, TYA Principal Treatment Centres (TYA PTC) and TYA Designated Hospitals (TYA DH)
Contact	Rachael Hastwell Rachael.hastwell1@nhs.net

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Date	Version	Updated By	Update Reason
13/05/2025	1.0	Rachael Hastwell	Draft of document
04/06/2025	2.0	Rachael Hastwell / Laura Bayliff	Final version
06/06/2025	3.0	Rachael Hastwell	Review by Clinical Leads

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Introduction

This report outlines the activities and achievements of the TYA Network in 2024/2025 and looks ahead to 2025/2026.

Chair’s Foreword

The Teenage and Young Adult Network has made significant progress this year in strengthening cancer services for young people across the North West. Through continued collaboration with partners and providers, we have focused on building sustainable improvements aligned with the National Service Specification.

This year, our Network has made significant progress in delivering on its objectives, working to ensure that every young person with cancer across the North West has access to consistent, high-quality, age-appropriate care. Key achievements include expanding access to Whole Genome Sequencing (WGS), enhancing our education and workforce development through the introduction of bespoke TYA CCLG modules, and promoting multi-professional learning via poster presentations and regional study opportunities. We have also advanced our TYA Assurance process, with a strong focus on improving care pathways, supporting provider self-assessments, and strengthening data quality—driven by multi-professional collaboration and growing engagement across the wider TYA workforce.

We extend our sincere thanks to all providers and stakeholders for their dedication and input. Your continued efforts are driving meaningful improvements in outcomes and experiences for young people with cancer. Looking ahead, we remain committed to equitable service provision and to sharing learning across the TYA and Children’s networks both regionally and nationally. Together, we are shaping a future where every young person has access to consistent, high-quality cancer care.

Joan Spencer
Chief Executive - The Clatterbridge Cancer Centre / Chair of the TYA Network Oversight Group

Service

The Teenage and Young Adult Service Specification (2023) sets out the key objectives of the network.

The Network has **7 objectives**, these are:

TYA Clinical Network Specification (May 2023)
https://www.england.nhs.uk/wp-content/uploads/2023/05/service-spec-tya-ptc.pdf

Improve the experience of care. 1

Improve integration between different TYA cancer services within a geographical area ensuring collaboration and 2

Increase participation in clinical trials by improving data capture at the MDT level, in particular when patients offered trials do not enter the trial. 3

Improve the transition between Children's and TYA services and TYA and adult cancer services by setting up a joint TYA and CYP Transition taskforce to improve the transition between children's and TYA services. 5

Ensure there is no age gap between different services, particularly for 16–18-year-olds as they may transition between children's cancer services and adult services, such as psychology provision and fertility preservation 6

Embed genomic medicine within TYA cancer services 7

The Network's Key Achievements – a Snapshot

139 delegates attended a joint Children's and TYA conference in March 2025.

97% of respondents were somewhat satisfied or very satisfied with the joint Children's and TYA conference in March 2025.

6 multi professional TYA staff attended Global AYA Congress in Australia to share their knowledge and expertise.

100 young patients have completed AQA accredited education courses as part of The Christie PTC education programme The programme won an Innovation Award at Educate North.

3 providers (inc. clinicians and patient experience leads) took part in the Cancer Improvement Collaborative project The project was presented to the National Programme Team in London and won 'best poster' at the event.

40 complex TYA patients have been supported by a TYA Faster Diagnosis Clinical Nurse (TYAFD CNS) to date, a pilot funded by C&M Cancer Alliance.

2 centres now offer Vivo biobank for tissue banking. They are the first adult centres to open a Vivo biobank in the UK - 46 patients have been offered banking and 33 have registered to date.

9 experts showcased specialised TYA cancer care in a TYA education film.

85.6% Average compliance against the TYA Service Specification for 11 designated hospitals across the North West region. Compliance has increased by 8.8% since 2023.

13 providers across the North West region have worked with the Network to map TYA pathways to date.

Network Check List: Against section 7 of service specification Deliverables, Service Indicators and Outcomes:

Yes
Work In Progress
No

Indicator, Metric	Yes / No / In Progress	Issue or comment
There is an appropriate network management team in post with the skills to deliver the specification	Yes	There is a small permanent team plus fixed term project roles to support in the delivery of network objectives.
The network board meets at least three times per year, is quorate, and minutes actions and risks are recorded	Yes	The board is scheduled quarterly with minutes and risks recorded. Continued engagement in place with designated hospitals to ensure improved representation and action plans are presented.
As appropriate to the network spec, there are regular network specialist Multi-Disciplinary Team (MDT) meetings (or equivalent)	Yes	Weekly MDTs are held at both PTC's including representatives from DH's if patients are presenting.
There are IT facilities in place that enable communication across the network, supporting image transfer and remote participation in the MDT	Yes	Image transfer rarely required but can be facilitated – remote participation is facilitated.
There is an annual workplan agreed with the network's commissioners	Yes	Submitted annually.
There is an agreed plan for PPV engagement	Yes	There is PPV engagement as required.
There is an analysis of the service needs of the population served by the network, a gap analysis, and a plan, agreed with the network's commissioners to meet those needs	Yes	Assurance plan in place along with annual self- assessment across providers.
There are network agreed patient pathways, procedures, and protocols	In progress	Referral pathways to the TYA Regional MDTs are in place. The Network assurance group is reviewing network pathways.

There is an analysis of workforce requirements and a plan, agreed with network members to meet these requirements	In progress	TYA workforce sits predominately in the adult workforce. Education group oversight in place. The network plans to review its staffing model for services such as psychology provision across the region.
There are arrangements (for example passporting) that enable workforce flexibility between providers within the network	Yes	SACT passport in place.
There is an analysis of training needs, and an annual network training plan agreed with network members	In progress	The Education and Workforce committee oversees the training needs of the network with stakeholders across providers. TNA is under review and CCLG TYA training modules are in place/accessible.
There is an analysis of the networks data and information needs and a plan, agreed with network members to meet these requirements	In progress	Plans to develop regional Children's and TYA data dashboard. Discussions with PTCs to improve MDT data recording for national data quality.
There is a network agreed research strategy including access and participation in clinical trials	In progress	There is a Network research group established to identify key objectives. Audit being undertaken on trials uptake.
The annual workplan includes at least one quality improvement initiative	Yes	Ongoing CIC improvement project around late effects and ongoing initiatives planned.
An annual report is produced, summarising the work of the network and its outcomes. The report includes a financial statement	Yes	Submitted annually.
The network participates in the national network of networks	Yes	Attendance at National forums including CTYA National group.
The network data aligns to nationally agreed indicators and outcomes, for example as defined by a national transformation programme, or included in the service specification and delegated to network leadership.	Yes	All data held from annual self-assessments align with the TYA Service Specification. Data dashboard development to include national indicators.
The network's individual locally agreed annual workplan, has metrics and indicators for each element built in	Yes	Within the Terms of Reference for each working group.

Meet the Team

Joan Spencer

TYA Chair for Network Oversight Group

Chief Executive - Clatterbridge Cancer Centre

Hanna Simpson

TYA Network Nursing Lead (GM).

Chair for Education and Workforce & Transition Taskforce.

Member of WGS/TB.

Dr Anna Castleton

TYA Network Clinical Lead (GM).

Chair for TYA Assurance Group

Lead for TYA fertility preservation

Member of WGS /TB.

Rachael Hastwell

TYA Network Programme Manager.

Laura Bayliff

Project Manager for TYA- focused on Assurance, Trials and Data.

Aneta Murkova

Administrator for TYA Network

Dr Laura Elder

TYA Network Nursing Lead (C&M)

Co-chair of the TYA Research and Trials Taskforce

Member of WGS, Education and Assurance Committee.

Dr Nasim Ali

TYA Network Clinical Lead (C&M)

Chair for the TYA Research and Trials Task Force

Member of WGS / TB.

Dr Colin Thorbinson

TYA Consultant Lead (Alder Hey)

Member or Senior Leadership Team and Associated PTC lead.

Prof Martin McCabe

Chair of WGS and Tumour Biobanking.

Board Member and Chair.

Funding Allocation

Role	WTE	Permanent/temp/ fixed secondment	Period
Network Manager	1.0	Permanent, core funding	n/a
Administration	0.5	Permanent, core funding	n/a
Clinical Lead x 2	0.5pa	Permanent, core funding	n/a
Nurse Lead x 2	2 hours per week	Permanent, core funding	n/a
Project Manager (Assurance and Data)	1.0	Secondment, Fixed term funding	October 2024-September 2025

Network Oversight Group

Core membership of the North West Teenage and Young Adult Network Oversight Group include: The Chair, Network Clinical Leads, cancer leads across providers, Cancer Alliance Representatives, Specialised Commissioner and a Programme Management team. Other Trust representatives are invited to attend meetings for specific agenda items and to provide comprehensive representation.

Governance and Management Structure

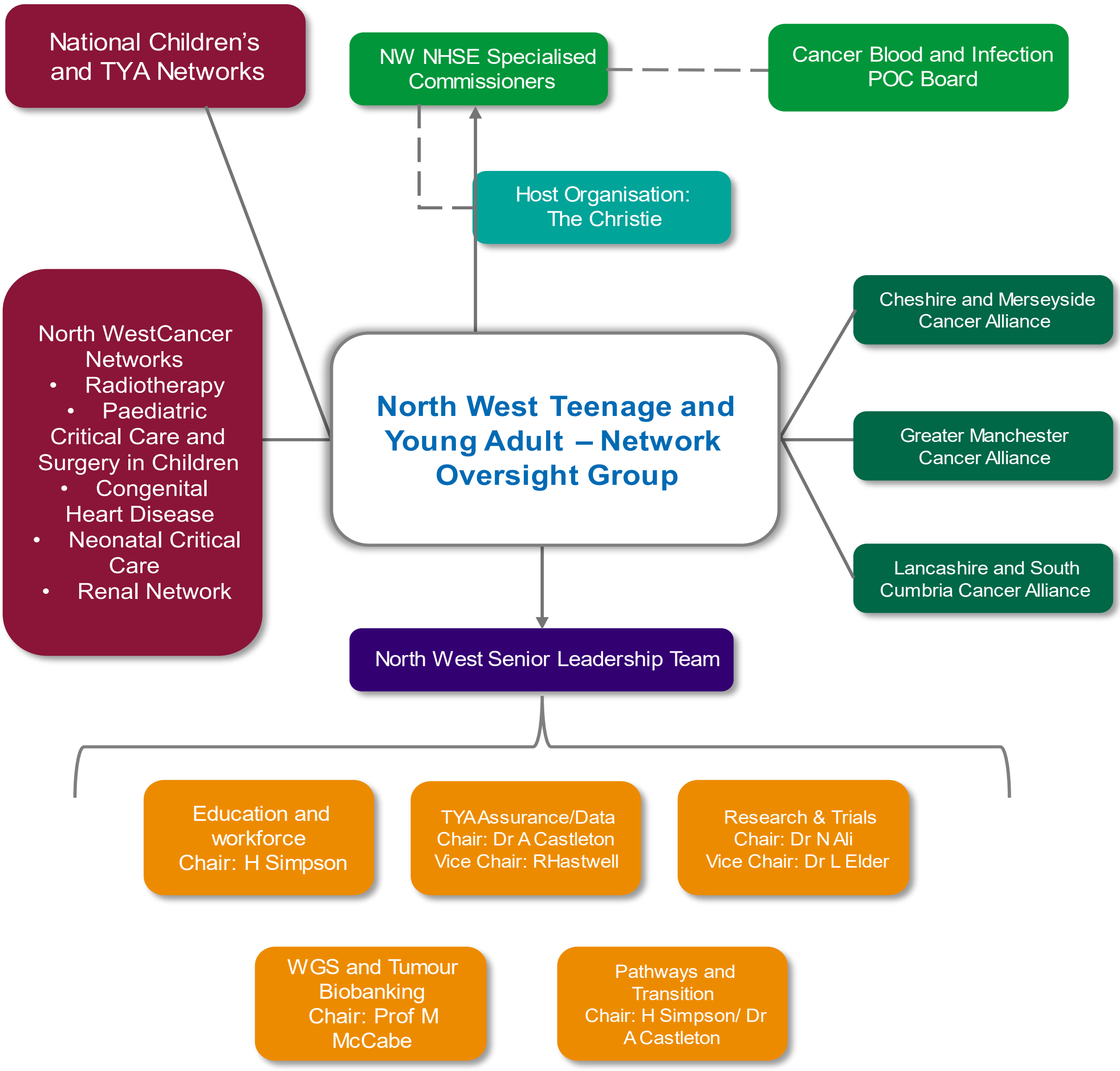
The Network Oversight Group (NOG) is accountable to the North West Specialised Commissioning Team for delivery of the Networks agreed programme. The NOG is independent of the host provider and provides direction and leadership to the Network team.

The Work Programme requires the approval of constituent providers, the Greater Manchester Cancer Alliance, Cheshire and Merseyside Cancer Alliance, Lancashire and South Cumbria Cancer Alliance, and Specialised Commissioning teams. The Work Programme is consistent with the requirements of the Teenage and Young Adult Specifications. The NOG board agree an annual work plan with the North West Specialised Commissioning Team. This includes clear deliverables and an agreed approach to monitoring delivery.

Provider organisations that deliver services within the network are collectively responsible for delivery of the Network functions in partnership with the host organisation. This includes sharing the risk for the continuance of the Networks functions and funding.

The Network’s Programme includes both national and locally agreed elements. The NOG supports the Network team in delivering the Programme. While the Network has a responsibility for improving quality, and supporting providers in achieving high quality care, individual providers remain contractually accountable for the quality of care that they provide to their patients.

Network Board Governance



National Children's and TYA Networks

NW NHSE Specialised Commissioners

Cancer Blood and Infection POC Board

Host Organisation: The Christie

North WestCancer Networks
- Radiotherapy
- Paediatric Critical Care and Surgery in Children
- Congenital Heart Disease
- Neonatal Critical Care
- Renal Network

North West Teenage and Young Adult – Network Oversight Group

Cheshire and Merseyside Cancer Alliance

Greater Manchester Cancer Alliance

Lancashire and South Cumbria Cancer Alliance

North West Senior Leadership Team

Education and workforce
Chair: H Simpson

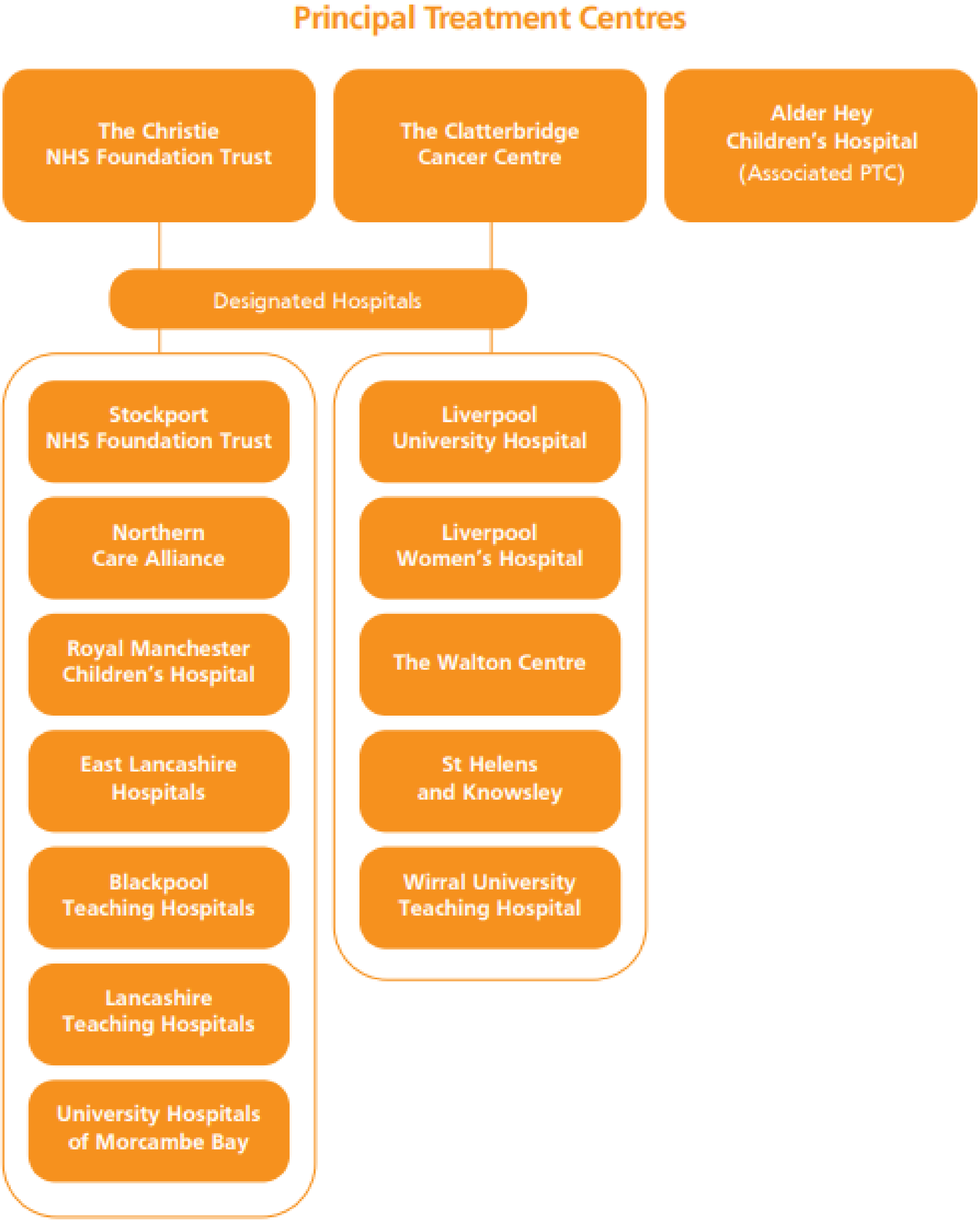
TYA Assurance/Data
Chair: Dr A Castleton
Vice Chair: RHastwell

Research & Trials
Chair: Dr N Ali
Vice Chair: Dr L Elder

WGS and Tumour Biobanking
Chair: Prof M McCabe

Pathways and Transition
Chair: H Simpson/ Dr A Castleton

TYA Providers in the North West



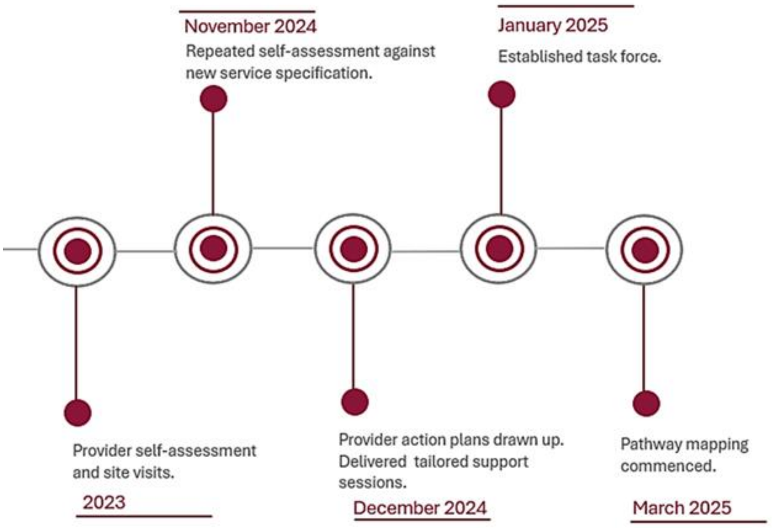
TYA Assurance Group

Aligned with recommendations from the NHS Long Term Plan, the NHS People Plan and other regional workforce strategies, the strategy around the Teenage and Young Adult assurance was developed to ensure ongoing review and support to the providers of cancer care in the north west.

The group continues to have focus of TYA Service Specification Compliance, developing action plans and oversight of designation of providers. Ensuring access to high quality care and to address health inequalities. The group includes key stakeholders across the regions 3 cancer alliances – Greater Manchester, Cheshire and Merseyside and Lancashire and South Cumbria. The Network continues to focus on improving the data collection at MDT and successfully launched a new MDT notification form across two Principal Treatment Centres at The Christie and Clatterbridge. This form helps to capture the holistic and psychosocial needs of teenagers and young adults and ensure equitable access to high quality care and research opportunity.

To further enhance the oversight of the network pathways and outcomes, the network reviewed the available data and agreed the key metrics required to develop a TYA regional dashboard. This is to improve reporting for national data sets such as COSD and the TYA Service Specifications but also to ensure ongoing quality improvement measures.

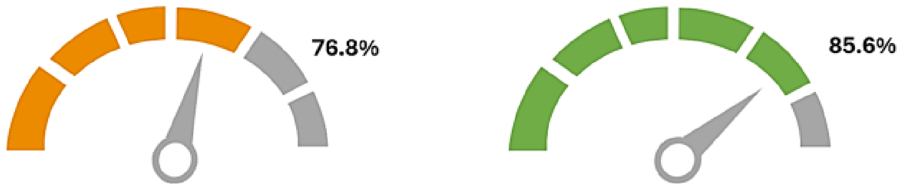
Our working group progress is shown in the diagram below.



TYA Service Specification Results 2024

13 of our providers returned their annual self-assessment to the network for analysis against the 2023 service specification. Each metric is then broken down into themes.

Designated Hospitals



2023 – Average Designated Hospital compliance

2024 – Average Designated Hospital compliance

1. Access to psychological support

DH Service specification metric: Do you refer patients to psychological support?

Overall compliance across all DH providers - 73%

2. Whole genome sequencing

DH Service specification metric: Ensure appropriate referral for Whole Genome Sequencing (WGS) for all eligible service users in line with Network agreed guidelines

Overall compliance across all DH providers - 46%

3. Tumour Banking

DH Service Specification metric: Ensure samples for tumour banking are sent in line with Network agreed pathways

Overall compliance across all DH providers – 64%

4. SACT provision prior to MDT discussion

DH Service Specification metric: Ensure that there are arrangements in place to support urgent SACT treatment prior to MDT discussion

Overall compliance across all DH providers – 90%

5. SACT competency

DH Service Specification metric: Ensure that SACT must only be prescribed by staff that have demonstrated their competency and are authorised and registered to prescribe SACT in the TYA DH

Overall compliance across all DH providers – 100%

6. Pre chemotherapy treatment assessment

DH Service specification metric: Undertake pre-chemotherapy treatment assessments for all service users to
ensure:
-Accurate pre-SACT assessment to enable variation from the service user's baseline to be detected;
-Pre-course and pre-cycle records meet all requirements of the relevant SACT; andhat the service user is confirmed to be fit to proceed and all precycle/course investigations are within the limits defined in the protocol

Overall compliance across all DH providers – 90%

7. Fertility preservation

DH Service Specification Metric: Offer fertility preservation to each young adult preparing to have treatment for cancer that is likely to result in fertility problems

Overall compliance across all DH providers – 64%

8. Sexual health advice

DH Service Specification Metric: Ensure that each young adult receives sexual health advice (including contraception) prior to treatment, if appropriate

Overall compliance across all DH providers – 90%

9. Pregnancy testing

DH Service Specification Metric: Ensure that all female service users of child-bearing age have a pregnancy test prior to initiation of SACT

Overall compliance across all DH providers – 90%

10. End of treatment summary

DH Service Specification Metric: Do you implement end of treatment summary for every patient?

Overall compliance across all DH providers – 64%

11. Transition

DH Service Specification Metric: Having a planned process of supporting young people to move into adult services

Overall compliance across all DH providers – 55%

12. Support groups and charities

DH Service Specification Metric: Facilitate patients to access to relevant service user support groups and charities

Overall compliance across all DH providers – 100%

13. Named key worker

DH Service Specification Metric: Named key worker

Overall compliance across all DH providers – 100%

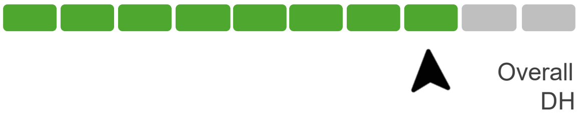
14. Holistic Needs Assessment (HNA)

DH Service Specification MetricPerform a TYA specific Holistic Needs Assessment (HNA) and provide these data to the TYA MDT

Overall compliance across all DH providers – 90%

15. COSD

DH Service Specification Metric: Regular data submissions on research participation are provided to the Cancer Outcomes and Services Dataset (COSD), NIHR and NHS England



Overall compliance across all DH providers – 82%

16. Emergency management

DH Service Specification Metric: Emergency management of patients with cancer (e.g. febrile neutropenia emergency treatment and inpatient supportive care (e.g. pain management and symptom control) (row 88)

Overall compliance across all DH providers – 100%

17. Outpatient support

DH Service Specification Metric: Outpatient supportive care and follow-up (includes: management of febrile neutropenia; management of symptom control (e.g. nausea,vomitting); central venous access and blood product support.

Overall compliance across all DH providers – 90%

18. Clinical trials

DH Service Specification Metric: Ensure that each young adult is offered an opportunity to participate in a clinical trial, where one (or more) is available and is clinically appropriate.

.

Overall compliance across all DH providers – 90%

19. Decision making

DH Service Specification Metric: Do you ask patients if they agree for their parents or guardians to be involved in decisions they need to make?

Overall compliance across all DH providers – 64%

20. Pathology service access

DH Service Specification Metric: Ensure access to pathology services, in accordance with Network guidelines. This must include access to acute diagnostics services and clinical pathology opinion 24/7.

Overall compliance across all DH providers – 100%

Principal Treatment Centres

2023 – Average Principal Treatment Centre compliance

2024 – Average Principal Treatment Centre compliance

The Principal Treatment Centre results to date show positive progress across all metrics, indicating a continued upward trend. A full analysis will be presented at the upcoming TYA Assurance Group meeting prior to publication. While the overall themes remain consistent across all providers, several key areas have been identified for further improvement and are being actively addressed through targeted plans. These include:

- Enhancing whole genomic sequencing and tumour biobanking
- Improving access to psychological support
- Strengthening transitional care pathways
- Developing late effects services
- Embedding individualised care plans
- Increasing accuracy in COSD data reporting
- Ensuring timely referral to the MDT within 7 days

Both the PTC and Designated Hospital priorities are supported by specific actions within the network's 2025/26 work plan, to drive measurable improvement and ensure alignment with national standards.

TYA Assurance Group - Forward into 2025-26

1

The Network plans to continue its key focus on TYA assurance and data development to further improve quality and patient experience.

2

We will continue to focus on designation of centres via NHSE to improve the availability of SSQD data.

3

We will develop mechanisms for reporting against the National data set for TYA - working with NHSE BI/PTCs and providers to improve availability of data.

4

We will define pathways across the region, work with providers and cancer alliances to ensure population needs are met and shared care arrangements are in place between providers.

Workforce and Education

National Context

The NHS England Service Specification for Teenagers and Young Adults with Cancer (NHS England, 2023) outlines that TYA services must be delivered by professionals with “specialist knowledge, skills and competencies” relevant to adolescent and young adult care. The specification mandates that staff working within Principal Treatment Centres (PTCs) and Designated Hospitals (DHs) should have access to continuing professional development (CPD) and operate within clearly defined multidisciplinary teams.

This requirement reflects national standards for TYA services, which prioritise:

- Age-appropriate care informed by the developmental stage of young people.
- Psychosocial support embedded into care delivery.
- Seamless transition between paediatric and adult services, requiring workforce fluency across both systems.

The Importance of Education and Workforce in the TYA Cancer Network

A skilled, knowledgeable, and sustainably resourced workforce is foundational to delivering high-quality care for teenagers and young adults (TYA) with cancer. Across the UK, the National Cancer Programme recognises the unique clinical and psychosocial needs of this age group, which require a workforce trained not only in oncology but also in age-appropriate communication, safeguarding, transition, and holistic care.

Network Progress

This year TYA network developed tailored training content via CCLG modules accessible directly on the website https://learning.cclg.org.uk/

The Education and Workforce committee has also created specialist educational material via a TYA education film, showcasing the services within the Principal Treatment centre across our region. Shaped by health care professionals and leaders in TYA care this film will help raise awareness of the age specific care and holistic needs of TYA patients.

The film set to launch this year will be made available across our network.

The Network jointly hosted the TYA and Children’s Annual Conference for the second year running, funded by the Cheshire and Mersey Cancer alliance the event saw key speakers covering an exciting agenda. The day also saw patient and public voice representatives sharing their lived experience. This was an excellent showcase of all the work across the region and an opportunity for experts to collaborate on future projects.

Our programme supported study events and conference attendance – offering study and learning opportunities across the region.

The Global Adolescent and Young Adult Cancer Care Congress took place in Melbourne, Australia in December 2024. The Congress focused this year on ethics, equity, and emerging ideas, this was an opportunity to come together with members from across the AYA global population to explore the distinctive needs of young people with a cancer diagnosis. It was an opportunity to learn from international experts, share in current research and care practices alongside networking with a worldwide community that is focused on improving AYA patient experiences and outcomes.

Lindsey Griffiths:

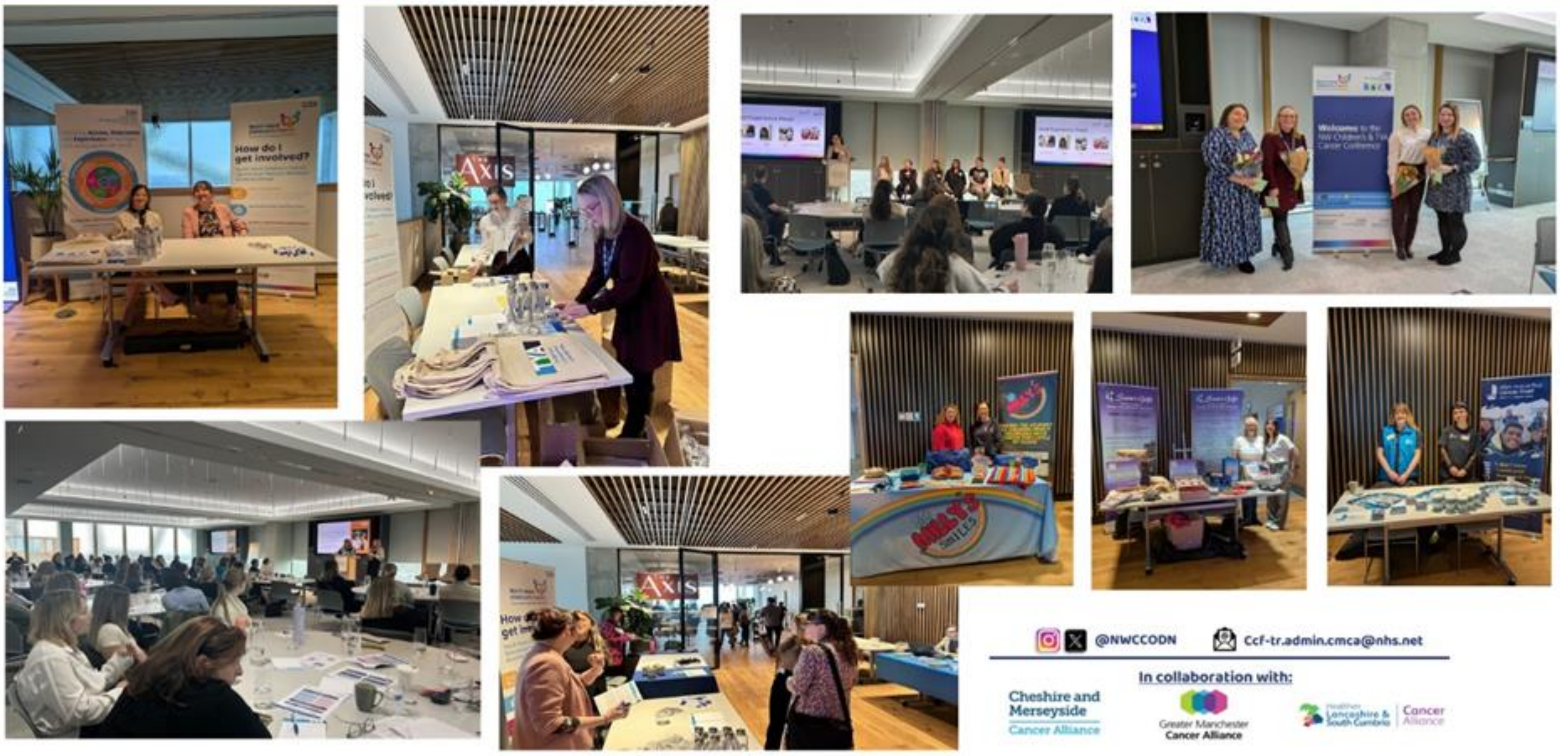
“I really enjoyed my experience of going to the AYA Global Congress. Whilst I have attended various conferences over the years, this was the first conference that I have attended in person focused solely on young people. It was very exciting to be in a space with so many people who are passionate about the care of the AYA population and to see and hear what is happening across the world, sharing experiences, ideas, current clinical practices and building relationships.”

The Christie PTC TYA team won a prestigious award at the Educate North Awards for Innovation earlier this year for their AQA accredited courses. This is the first TYA Centre in the UK to receive AQA Unit Award Scheme (UAS) accredited status. The Christie enabled access to over **17,500** online courses with more than **100** young patients successfully completing at least one course. This work was led by the teams Youth Coordinator Steve Harcourt (pictured below).

This work has led to the establishment of a pilot education and employment lead post for TYA's to offer bespoke support and opportunities for patients during and after completion of treatment.

These innovations respond directly to feedback from young people reinforcing the importance of education in improving care experience and outcomes.

Moreover, we are aligning with the NHS Long Term Workforce Plan (NHS England, 2023), which emphasises the strategic development of the cancer workforce to meet rising demand and changing care models.



Education & Workforce - Forward into 2025-26

We have set out our key objectives to:

- Work with providers to promote TYA education initiatives
- Collaborate with the Whole Genomic Sequencing and Tumour Biobanking Committee on specific areas of focus

Whole Genomic Sequencing and Tumour Biobanking (WGS and TB)

National Context

The NHS Genomic Medicine Service (GMS), delivered in partnership with Genomic Laboratory Hubs (GLHs), is at the forefront of the UK's ambition to become a global leader in genomics. Whole genome sequencing (WGS) is now available for all children and young people with cancer through the NHS England Genomic Test Directory (2023), with the aim of improving diagnostic accuracy, prognostication, and therapeutic targeting.

The Service Specification for Teenagers and Young Adults with Cancer (NHS England, 2023) explicitly states that all eligible patients should be offered appropriate genomic testing, and that tumour and matched germline samples must be collected and processed according to national protocols. This includes participation in national research and data-sharing platforms such as:

- NHS-GMS WGS Cancer Programme
- National Cancer Registration and Analysis Service (NCRAS)
- Children's Cancer and Leukaemia Group (CCLG) Tissue Bank

The Importance of tissue Banking for Teenagers and Young Adults

Diagnostic clarity

TYA patients often present with rare, unusual, or histologically ambiguous tumours. Genomic sequencing helps refine diagnoses, particularly in sarcomas, central nervous system (CNS) tumours, and blood cancers—tumour types disproportionately represented in the TYA population.

Therapeutic benefit

WGS can uncover actionable mutations leading to targeted therapy or access to clinical trials. Data from the SMPaC pilot found that 15–20% of patients across paediatric and TYA cohorts had findings that changed clinical management (CRUK, 2022).

Network Progress

The Network undertook its initial audit in 2024 which concluded that **92** TYA Patients across the region had fresh/frozen tissue, however only **22** had WGS. This resulted in **76%** of missed opportunity. The working group focused on staff responsible for taking the biopsy, to further improve stakeholder engagement. There was challenge found with access the data as the audit spanned across multiple providers and had a missing volume of **13%** of the cases reviewed. The audit was presented at the Cheshire and Merseyside Cancer Alliance meeting in 2024 by our Clinical Pathway Project Manager and registered formally as a research audit in both The Christie and Clatterbridge Principal Treatment Centres.

The outputs from the audit supported in the development of SOPs for Haematology and Solid Tumour groups, as these disease groups had sufficient volumes to target staff groups.

Region / Pathway	Patients with Fresh / Frozen Tissue	Patients with WGS
CFT (GM, Cheshire & LSC)	68	14
CCC (Cheshire & Merseyside)	24	3
Bone Sarcoma (across regions)	10	5
TOTAL	**92**	**22**

Data showing fresh/frozen tissue by disease group / PTC

Whole Genomic Sequencing and Tumour Biobanking Forward into 2025-26

The network plans to continue to embed the Whole Genomic Sequencing and tumour biobanking objectives by:

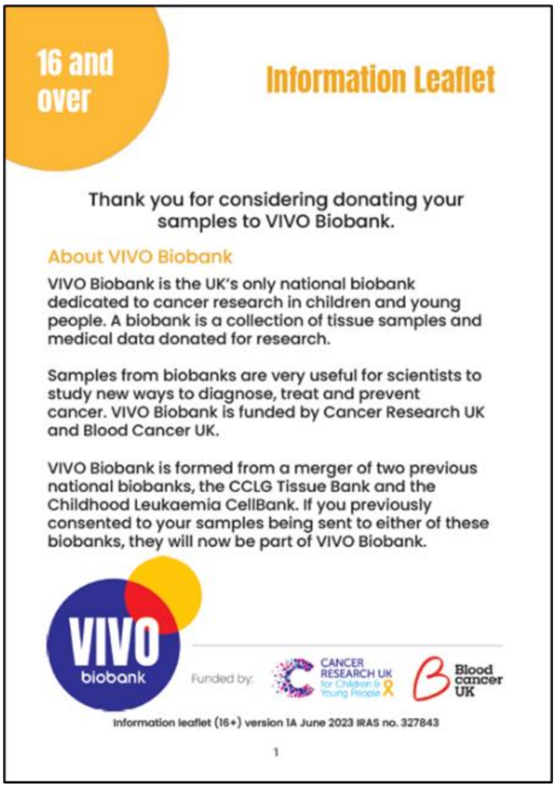
1. Plans to increase tissue banking for Designated Hospitals are being explored, reviewing options and required resources for network wide bio-banking.
2. Consider opportunities for Education- working with the Education Committee to improve education re WGS and TB.
3. Continuing to improve pathways by focusing on leukaemia, brain tumour and sarcomas and work with pathology departments in the largest Trusts for other histology's.

The Vivo Biobank is the UK's leading research resource dedicated to storing samples and data of cancers affecting children and young people, uniting researchers, medical professionals, patients, partners, donors, and charities – all with one goal in mind: to push the boundaries of research into childhood and youth cancers. VIVO Biobank is a collaboration between Cancer Research UK and Blood Cancer UK. For more information click the link **VIVO Biobank - Home**

We are proud to announce that The VIVO Biobank is now accessible from both The Clatterbridge Cancer Centre and The Christie NHS Foundation Trust—ensuring more young people in the North West can contribute to groundbreaking cancer research.

By participating in this national collection of samples, young patients have the opportunity to directly aid researchers in developing new treatments faster and deepening our understanding of cancers affecting young people. Samples may include blood, bone marrow, spinal fluid, or small pieces of tumours, all collected with full ethical oversight and patient consent of research teams.

This marks a huge step forward in providing young people with a voice in research and ensuring their experiences help shape better treatments for the future. By choosing to take part, young people play a vital role in shaping the future of cancer care. Their contributions will help researchers develop new treatments



16 and over

Information Leaflet

Thank you for considering donating your samples to VIVO Biobank.

About VIVO Biobank

VIVO Biobank is the UK's only national biobank dedicated to cancer research in children and young people. A biobank is a collection of tissue samples and medical data donated for research.

Samples from biobanks are very useful for scientists to study new ways to diagnose, treat and prevent cancer. VIVO Biobank is funded by Cancer Research UK and Blood Cancer UK.

VIVO Biobank is formed from a merger of two previous national biobanks, the CCLG Tissue Bank and the Childhood Leukaemia CellBank. If you previously consented to your samples being sent to either of these biobanks, they will now be part of VIVO Biobank.

Information leaflet (16+) version 1A June 2023 IRAS no. 327843

1

Research and Trials

Research and innovation are central to improving survival outcomes, treatment experiences, and quality of life for teenagers and young adults (TYA) with cancer. Historically underrepresented in cancer research, the TYA population requires tailored strategies to ensure equitable access to clinical trials and inclusion in cutting-edge developments.

National Context

The NHS England Service Specification for Teenagers and Young Adults with Cancer (2023) recognises that access to research and clinical trials is a core component of high-quality cancer care. It stipulates that Principal Treatment Centres (PTCs), and Designated Hospitals (DHs) must actively support TYA participation in trials, with appropriate governance and age-appropriate consent processes in place.

Despite this, recruitment to clinical trials for young people aged 13–24 has traditionally lagged behind paediatric and adult populations. The Cancer Research UK (CRUK) TYA Cancer Report (2020) highlighted barriers such as restrictive trial eligibility criteria, inconsistent clinician engagement, and insufficient research infrastructure tailored to this age group.

National initiatives such as the NIHR TYA Research Network, NCRI TYA and Germ Cell Tumour Group have sought to reverse this trend, advocating for:

- Greater cross-sector collaboration between paediatric and adult oncology researchers
- Embedding TYA representation in early-phase and translational studies
- Streamlining regulatory and ethical processes to suit younger participants.

Network Progress

This year the network launched a Trials and Research north west TYA group, which is focusing on the development of key objectives.
To date we have reviewed our two regional treatment centres uptake to trials.

The Christie uptake to trials for 2023-24 was at **95%** of those approached consented to trial, however, has shown a decline in the number of patients approached for trial when comparing to the previous 2 years. On review this looks to be due to a recording issue. The network is resolving this by including trials information in the MDT proforma that is supported by our data development work into 25-26. This will be overseen by the TYA Assurance Group.

At Clatterbridge Cancer Centre, patients were recruited wherever possible and referred elsewhere as needed. A review of the approach / consented figures is underway.

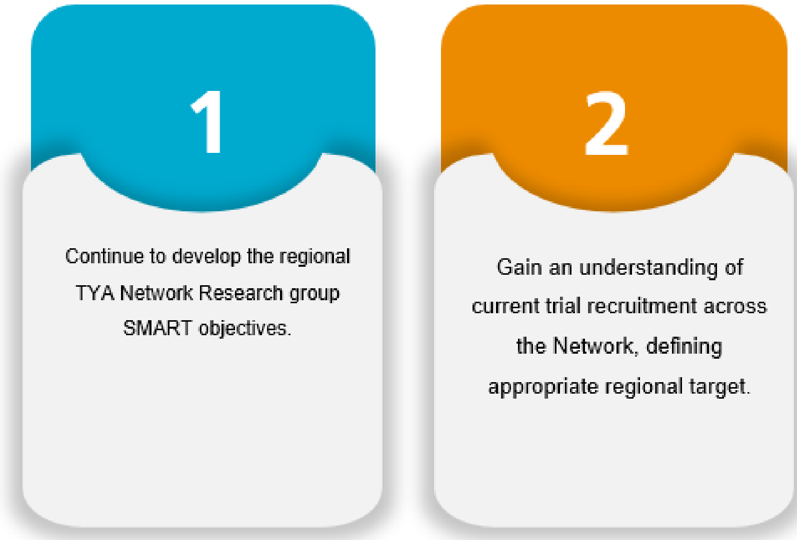
A working group was established in 2025 to oversee specific objectives for trials working in collaboration with national steering groups.

Year	Approached	Consented
2021/22	87	87
2022/23	66	65
2023/24	23	24

The Christie PTC held data

Research and Trials Forward into 2025-26

Our TYA network is committed to driving improvements in research access and visibility across all treatment sites. To achieve this, we continue to ensure close collaboration with NIHR Clinical Research Network, and by improving our monitoring and reporting of trial access by age, diagnosis, and site to identify inequalities and target improvement efforts. We have set out objectives to:



1 Continue to develop the regional TYA Network Research group SMART objectives.

2 Gain an understanding of current trial recruitment across the Network, defining appropriate regional target.

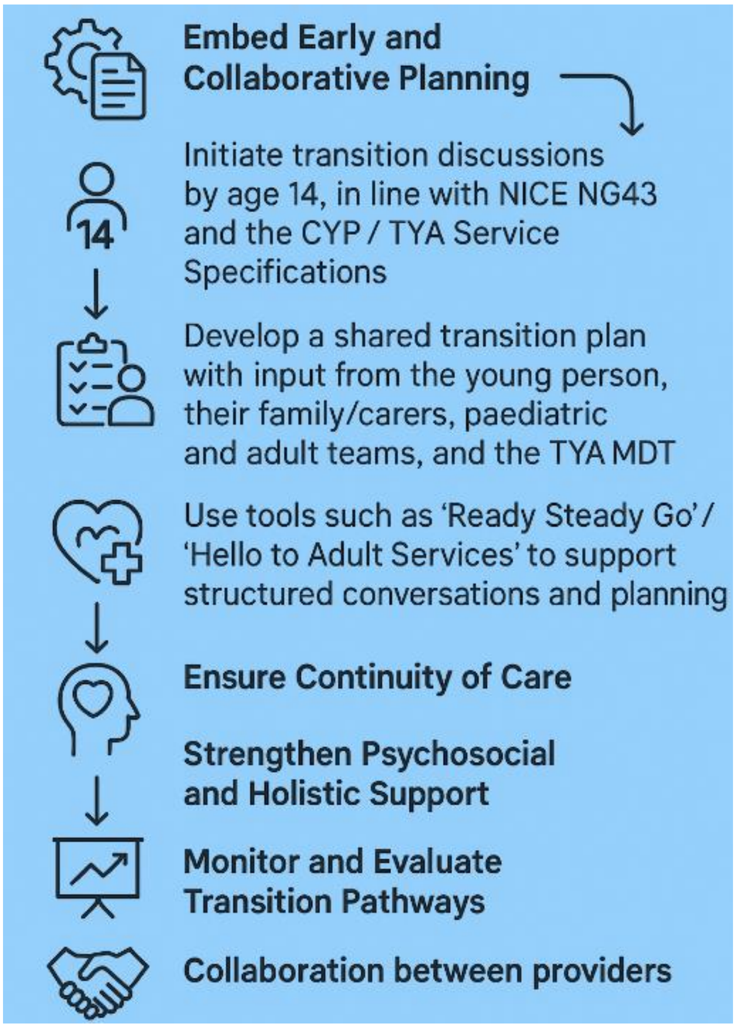
Pathways

Transition

Effective transition from paediatric or TYA-focused services to adult care is a critical phase for young people living with and beyond cancer. National guidance—including the NHS England TYA Service Specification (2023), NICE Guidance NG99 (2016) on transition, and NHS England's 'Ready Steady Go' framework—highlights the need for structured, person-centred transition processes that are responsive to the individual needs, developmental stage, and cancer experience of young people aged 13–24.

Despite increasing recognition of the importance of age-appropriate transition pathways, delivery remains variable across centres. National audits and reports (e.g. NCEPOD's Young People's Cancer Care and the Independent Cancer Taskforce Report) have consistently emphasised the gaps in continuity of care, psychological support, and holistic planning during this period. Poorly managed transitions can lead to disengagement, reduced treatment adherence, and worse clinical outcomes.

To align with national expectations and improve the experience and outcomes of young people transitioning to adult care, centres can focus on the following core areas:



Embed Early and Collaborative Planning

Initiate transition discussions by age 14, in line with NICE NG43 and the CYP / TYA Service Specifications

Develop a shared transition plan with input from the young person, their family/carers, paediatric and adult teams, and the TYA MDT

Use tools such as 'Ready Steady Go'/ 'Hello to Adult Services' to support structured conversations and planning

Ensure Continuity of Care

Strengthen Psychosocial and Holistic Support

Monitor and Evaluate Transition Pathways

Collaboration between providers

Transition Forward into 2025-26

A Transition task force was established in April 2025 with objectives to focus on children to TYA transition. The Children’s and TYA networks are leading this piece of work with initial focus of identifying existing pathways across our region. With Ready, Steady, go in place – the focus will be how we improve the transition experience for children as they transition to TYA care.

Additionally, the group will support designated hospitals objectives around TYA to adult transition for those without a clear pathway.

Fertility Preservation

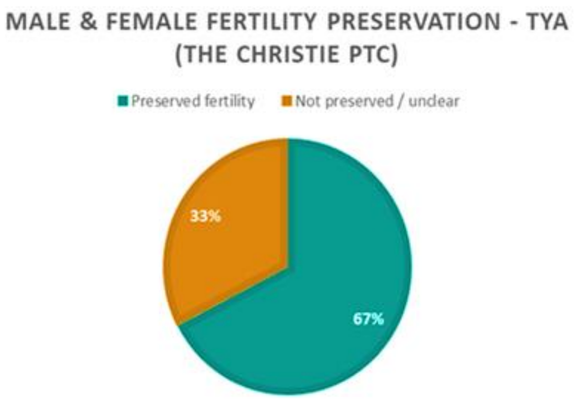
Fertility is a major concern for teenagers and young adults (TYA) diagnosed with cancer, yet access to timely fertility preservation services remains inconsistent across the UK. Cancer treatment can significantly impair fertility—impacting both short- and long-term reproductive health—making proactive, sensitive discussions and interventions essential.

National guidance, including the NHS England TYA Service Specification (2023) and NICE Quality Standard QS169 (2018), states that all patients of reproductive age must be offered fertility information and, where appropriate, preservation options before starting treatment. Despite this, the National Cancer Patient Experience Survey (NCPES) consistently finds that less than 50% of young people recall having a clear discussion about fertility impacts, and only a minority are referred for fertility preservation.

The Fertility Preservation Commissioning Policy from NHS England outlines that all cancer patients meeting clinical eligibility criteria should have equitable access to funded preservation, including sperm, egg, and ovarian tissue cryopreservation. However, service delivery is often limited by geography, funding arrangements, staff confidence, and lack of standardised referral pathways.

The TYA network undertook an audit to assess the initial offer of fertility preservation across Greater Manchester, Lancashire and South

Cumbria. This audit shows that **29** out of **89** TYA Patients (Male and Female) did not achieve fertility preservation over one year period **(33%).** Female split (23/37 – 62% not achieved). Male split (6/52 – 12% not achieved).



Fertility Preservation Forward into 2025-26

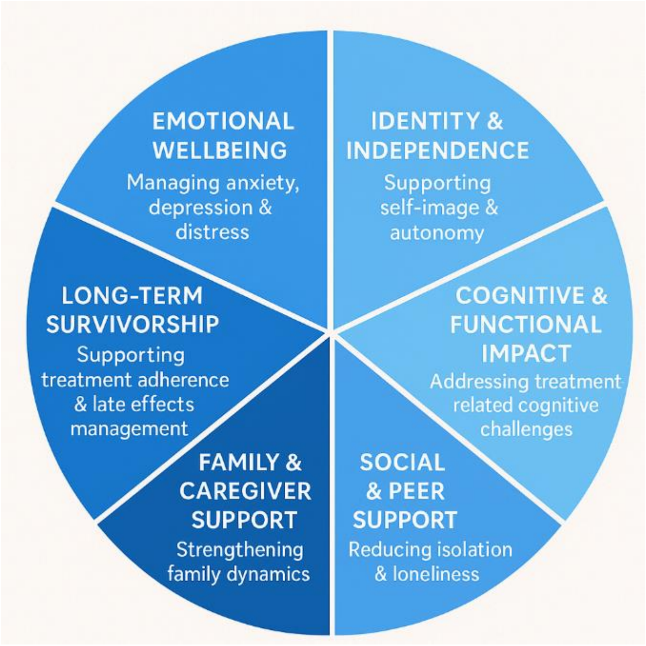
The North West networks review of fertility preservation access is being led by Dr Anna Castleton and Professor Vijay Sangar at The Christie along with fertility leads across the region. A business case is under development to initiate a Hub and Spoke model for the North West, in collaboration with NHS England aligned with national service specifications. This is being overseen by the TYA Assurance Group.

Psychology

TYA patients face distinct psychological challenges that require specialised care throughout their cancer journey. The NHS TYA Cancer Service Specification emphasises the integration of psychological support to improve outcomes and quality of life (NHS England, 2023).

Psychology Forward into 2025-26

The network will be focusing on undertaking a scoping exercise of the Psychology provision across the region. This will help understand the services offered to TYA patients and support in the development of any key objectives



Quality Improvement

The Cancer Improvement Collaborative 2024-25: NWTYA Late Effects Project

In October 2024 the Network initiated a regional project for the National Cancer Improvement Collaborative (Experience of Care), with its providers The Christie, the Clatterbridge Cancer Centre and Alder Hey.

The Cancer Experience of Care Improvement Collaborative brings together groups of cancer healthcare professionals and people with lived experience from different organisations to work in a structured way to improve services. Its aim is for each project team to use insight and feedback (e g Cancer Patient Experience Survey results) to improve the experience of care for cancer patients, their families, and unpaid carers. Project teams can make improvements based on what matters to people who use cancer services that align with local, regional, and national priorities.

[NHS England » Experience of care: Improvement collaboratives]

Cohort 6 had a focus on administration of care and asked for expressions of interest around improvements in this area.

The North West team met monthly to undertake a series of quality improvement methods to understand any gaps in administration of care. Each centre provided their late effects pathways, tools and resources and agreed a **SMART AIM:**

“To ensure all TYA Patients in the North West Network have access to an end of treatment summary and late effects information”.

A poster publication was shared at the Celebration event in May 2025 – images below from the event including a prize for the best poster.

Top – the project team Toni Derbyshire, After Cure Nurse Alder Hey, Laura Bayliff the TYA Network, Rachael Hastwell TYA Programme Manager, Dr Sindhu Retnabai, Speciality Doctor in TYA The Christie.

Left– Rachael Hastwell with Neil Churchill (Director for People and Communities) at NHS England.

The National Team at the Celebration event

Impact

The Project Team learned about variation within their own region and by collaboration have understood the gaps in the pathway. They are sharing resources, pathways and processes across providers to support and develop the service. The Project Team have used methodology to understand the issues and develop their key objectives. They continue to work with patient partners to develop improvements.

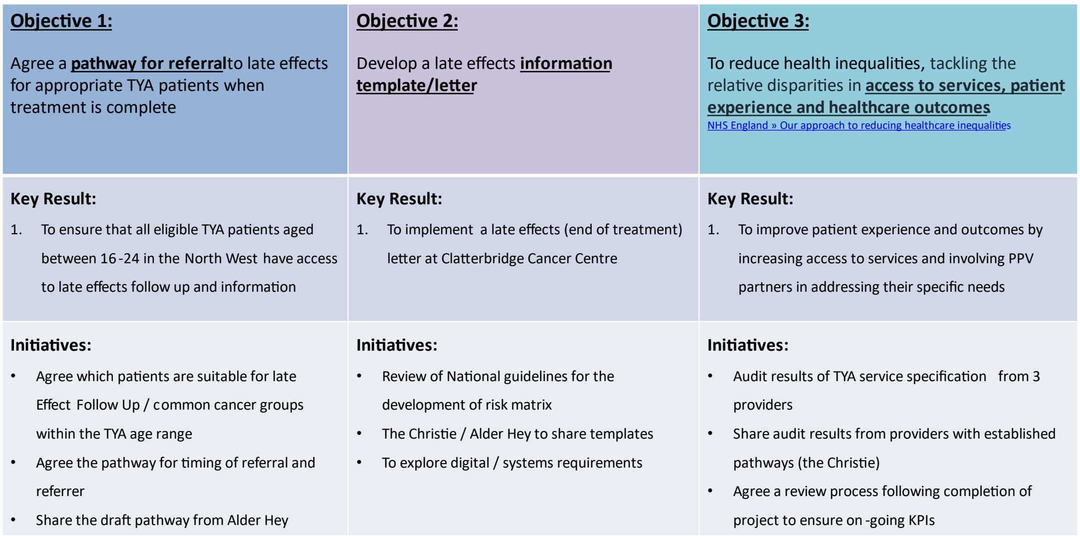
"The journey does not end at treatment completion" – ***Lived Experience Partner***

"The project reinforces why it's so important why everyone get the same service" – ***After Cure Nurse***

Next steps

The Project Team will meet in July 2025 to review progress against new pathway implementation. Additionally, there will be a 6-month review held in November with the National Cancer Improvement Collaborative team to discuss further actions and developments.

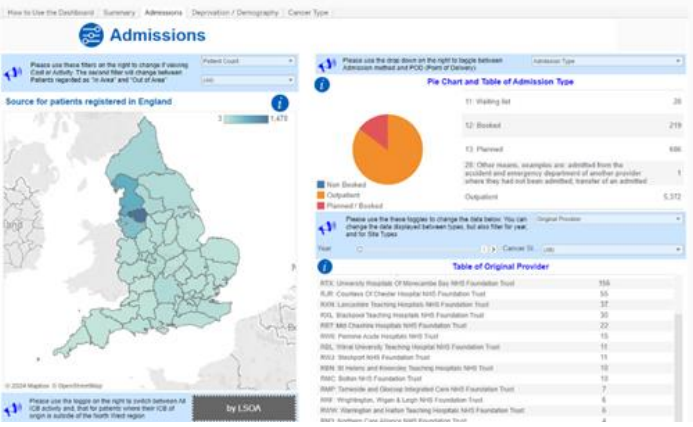
Objectives & Key Results Framework



Objective 1: Agree a **pathway for referral**to late effects for appropriate TYA patients when treatment is complete	**Objective 2:** Develop a late effects **information template/letter**	**Objective 3:** To reduce health inequalities, tackling the relative disparities in **access to services, patient experience and healthcare outcomes** NHS England » Our approach to reducing healthcare inequalities
Key Result: 1. To ensure that all eligible TYA patients aged between 16-24 in the North West have access to late effects follow up and information	**Key Result:** 1. To implement a late effects (end of treatment) letter at Clatterbridge Cancer Centre	**Key Result:** 1. To improve patient experience and outcomes by increasing access to services and involving PPV partners in addressing their specific needs
Initiatives: • Agree which patients are suitable for late Effect Follow Up / common cancer groups within the TYA age range • Agree the pathway for timing of referral and referrer • Share the draft pathway from Alder Hey	**Initiatives:** • Review of National guidelines for the development of risk matrix • The Christie / Alder Hey to share templates • To explore digital / systems requirements	**Initiatives:** • Audit results of TYA service specification from 3 providers • Share audit results from providers with established pathways (the Christie) • Agree a review process following completion of project to ensure on-going KPIs

Data Quality Improvement

Advancing Data-Driven Improvement through a Joint TYA and Children’s Network Data Dashboard



This year our network undertook a step towards integrated, equitable and intelligent cancer care by starting the development of a joint TYA and Children’s Cancer Network Dashboard.

Teenagers and young adults (TYA) often fall into gaps between paediatric and adult cancer systems, leading to fragmented data and inconsistencies in service access. A dashboard designed to bridge these systems offers the opportunity to capture a full patient journey, from referral and diagnosis through to treatment, recovery, and survivorship.

Serving all Designated Hospitals and Principal Treatment Centres across the region, this dashboard will enable multi-dimensional insights into care pathways, patient flow, outcomes, and regional variation.

This initiative aligns with NHS England’s Service Specification for TYA (2023), which outlines the requirement for regional data systems to support governance, equitable access, and quality improvement.

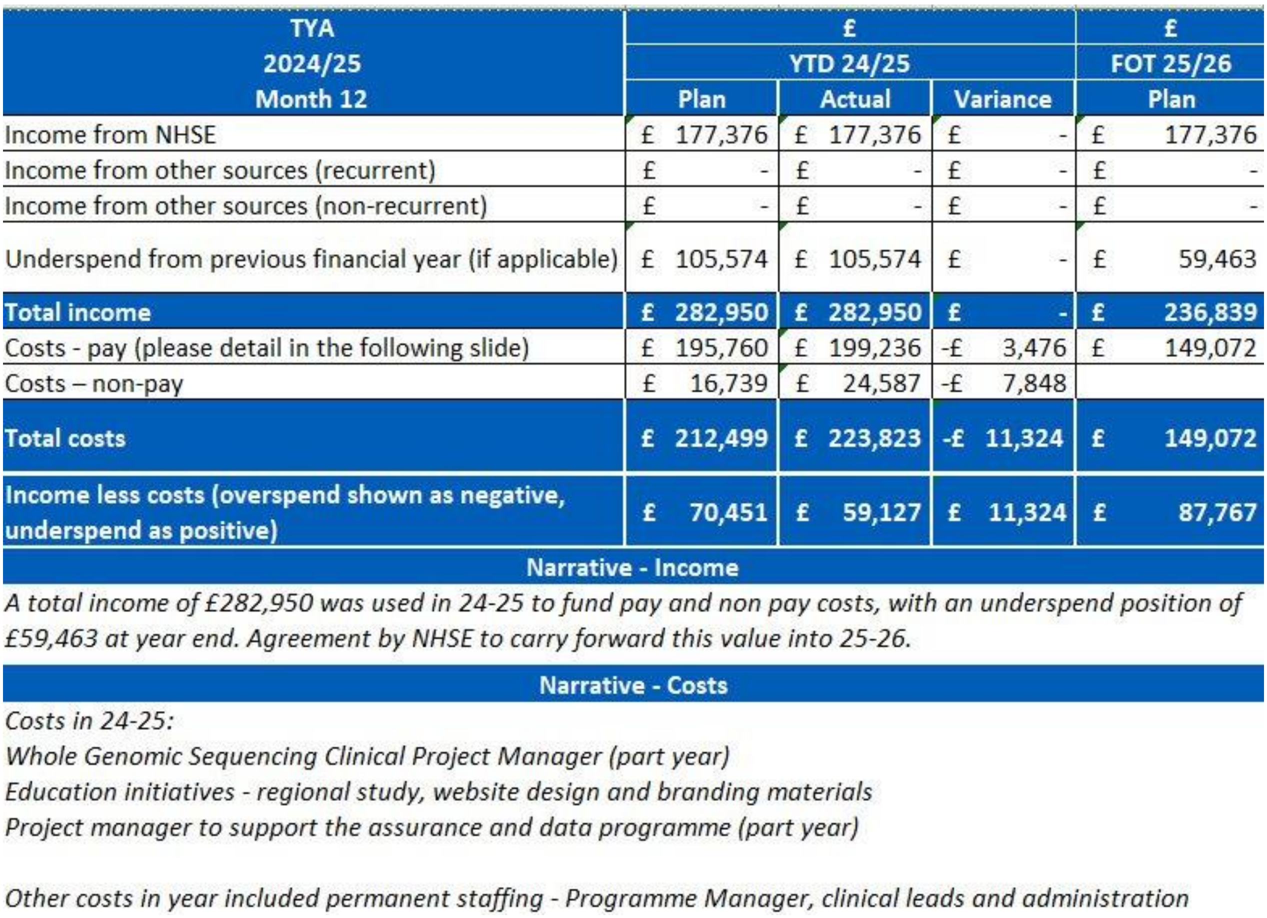
Developed by the North West Children’s Network via the Programme of Care Board, the networks have collaborated to design a bespoke TYA section of the dashboard to further improve the quality of data for patients in this age group. The work will continue to drive forward improvements for patient outcomes and experience.

The dashboard represents not only a technical achievement but a cultural shift towards shared intelligence and collaborative improvement. It is a key pillar in delivering the NHS vision for personalised, integrated cancer care.

Finance Summary

The primary income for the Teenage and Young Adult network is the core funding received from NHS England North West Specialised Commissioning. This year the network had an agreed underspend carried forward to the value of **£105,774**. The allocation of funding is detailed in our financial summary below.

The network's budget allocation is overseen by the Network Oversight Group to ensure that all spending is strategically aligned with the network's key objectives. This collaborative approach helps prioritise funding in areas that directly support service development, improve quality of care, and promote equitable access for young people across the region. Resources are directed toward initiatives such as education, data improvement, and pathway enhancements, ensuring that financial decisions are both purposeful and impactful.



TYA	**£**			**£**
2024/25	**YTD 24/25**			**FOT 25/26**
Month 12	**Plan**	**Actual**	**Variance**	**Plan**
Income from NHSE	£ 177,376	£ 177,376	£ -	£ 177,376
Income from other sources (recurrent)	£ -	£ -	£ -	£ -
Income from other sources (non-recurrent)	£ -	£ -	£ -	£ -
Underspend from previous financial year (if applicable)	£ 105,574	£ 105,574	£ -	£ 59,463
Total income	**£ 282,950**	**£ 282,950**	**£ -**	**£ 236,839**
Costs - pay (please detail in the following slide)	£ 195,760	£ 199,236	-£ 3,476	£ 149,072
Costs – non-pay	£ 16,739	£ 24,587	-£ 7,848	
Total costs	**£ 212,499**	**£ 223,823**	**-£ 11,324**	**£ 149,072**
Income less costs (overspend shown as negative, underspend as positive)	**£ 70,451**	**£ 59,127**	**£ 11,324**	**£ 87,767**

Narrative - Income

A total income of £282,950 was used in 24-25 to fund pay and non pay costs, with an underspend position of £59,463 at year end. Agreement by NHSE to carry forward this value into 25-26.

Narrative - Costs

Costs in 24-25:
Whole Genomic Sequencing Clinical Project Manager (part year)
Education initiatives - regional study, website design and branding materials
Project manager to support the assurance and data programme (part year)

Other costs in year included permanent staffing - Programme Manager, clinical leads and administration

Work Plan on a page – 2025-26

Description	Strategic objectives
Whole Genomic Sequencing and Tumour Biobanking	• Focus on leukaemia, brain tumours, and sarcomas; engage pathology teams in major Trusts for other histologies • Roll out tissue banking to Designated Hospitals (DHs) • Scope required resources for network-wide biobanking • Collaborate with the Education Committee to improve understanding of Whole Genome Sequencing (WGS) and Tumour Biobanking (TB)
Research and Trials	• Establish a regional TYA Research Group with clear Terms of Reference and SMART objectives • Map current trial recruitment activity and define an appropriate regional recruitment target
Development of transitional pathways	• Improve pathways with a Standard Operating Procedure (SOP) • Collaborate with the North West Children's Network to support transition
Fertility Preservation Pathway	• Ensure consistent access to fertility preservation pathways across the network
Review TYA provider compliance against National Service Specification/s	• Support the designation of centres through NHSE to enhance access to SSQD data • Develop mechanisms for reporting against the National TYA Data Set • Work with NHSE BI teams, Principal Treatment Centres and providers to improve data visibility • Continue regional pathway mapping to identify gaps and ensure population needs are met.
Patient and Public voice Involvement	• Involve Patient and Public Voice (PPV) representatives in all key workstreams
Education and Workforce	• Promote TYA-specific education opportunities across providers • Collaborate with the WGS & TB Committee on shared education and workforce priorities.

Network Summary

This year, the network has continued to strengthen its collaborative approach, driving improvements in the quality, equity, and visibility of care for young people with cancer. Providers across the region have played a vital role in supporting service delivery and innovation. Our quarterly network meetings have enabled teams to connect, share learning, and enhance the experience of care for teenagers and young adults.

We've seen increased engagement across clinical teams and patient representatives, particularly through the Children's and TYA Conference and the involvement of public voice representatives in shaping our national Cancer Improvement Collaborative project. This has helped sustain momentum and ensure our priorities remain focused on the specific needs of our patients.

A major focus this year has been mapping TYA care pathways across providers. With strong engagement from Trusts, clinicians, and cancer alliances, this region-wide exercise is nearing completion and will be strengthened by the development of a dedicated TYA data dashboard in collaboration with the North West Children's Network. This will help identify variation and target improvements more effectively.

Our work remains aligned with the TYA National Service Specification and local priorities, ensuring we adopt best practice with focus on the NHS long term plan, specifically improving the experience of care, tackling inequalities, and driving innovation and efficiency across the region.

Thank you to everyone who has contributed to another impactful year for the network.

Rachael Hastwell

TYA Network Programme Manager

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