



**North West
Teenage and Young Adult**
Cancer Specialised Services
Clinical Network

North West Teenage and Young Adult Cancer Specialised Services Clinical Network

Annual Report 2023-24

TYA

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Introduction

Welcome to our 2023-24 annual report for the NWTYA Network. It has been a busy year undertaking our Network wide service review, embedding our Whole Genomics Sequencing Working Group, and launching our Workforce and Education Group. Our workstreams are now fully operational and are working hard to deliver ambitious agendas. We are proud to share our progress in this report and look forward to our developments over the next 12 months.

Our Network began in April 2022 with the knowledge that every day in the UK, seven people aged 15-24 are diagnosed with cancer. The Teenage and Young Adult Cancer

Operational Delivery Network (TYA Network) is an NHS collaboration bringing providers, commissioners, patients, and other interested people together. Our purpose, with the NHS Long Term Plan commitments as a guide, is to improve the access, outcomes, and experience of Teenagers and Young Adults with Cancer.

Together, we've harnessed our expertise and set our Big Goal: that service users can always access the right care in the right place at the right time. We know that we will get closer to our Big Goal by improving the **Access**, **Outcomes**, and **Experience** of Teenagers and Young Adults with cancer.



About us

We are the largest TYA Network, proudly serving England's most densely populated region (excluding London), with 767,000 people aged 16-24. The TYA NETWORK's member NHS Trusts include three Principal Treatment Centres (PTC) and twelve Designated Hospital (DH) Trusts.

Our strong links with the North West Radiotherapy and Children and Young People Cancer Networks form a suite of specialist cancer Networks with possibilities to work together and make new connections.

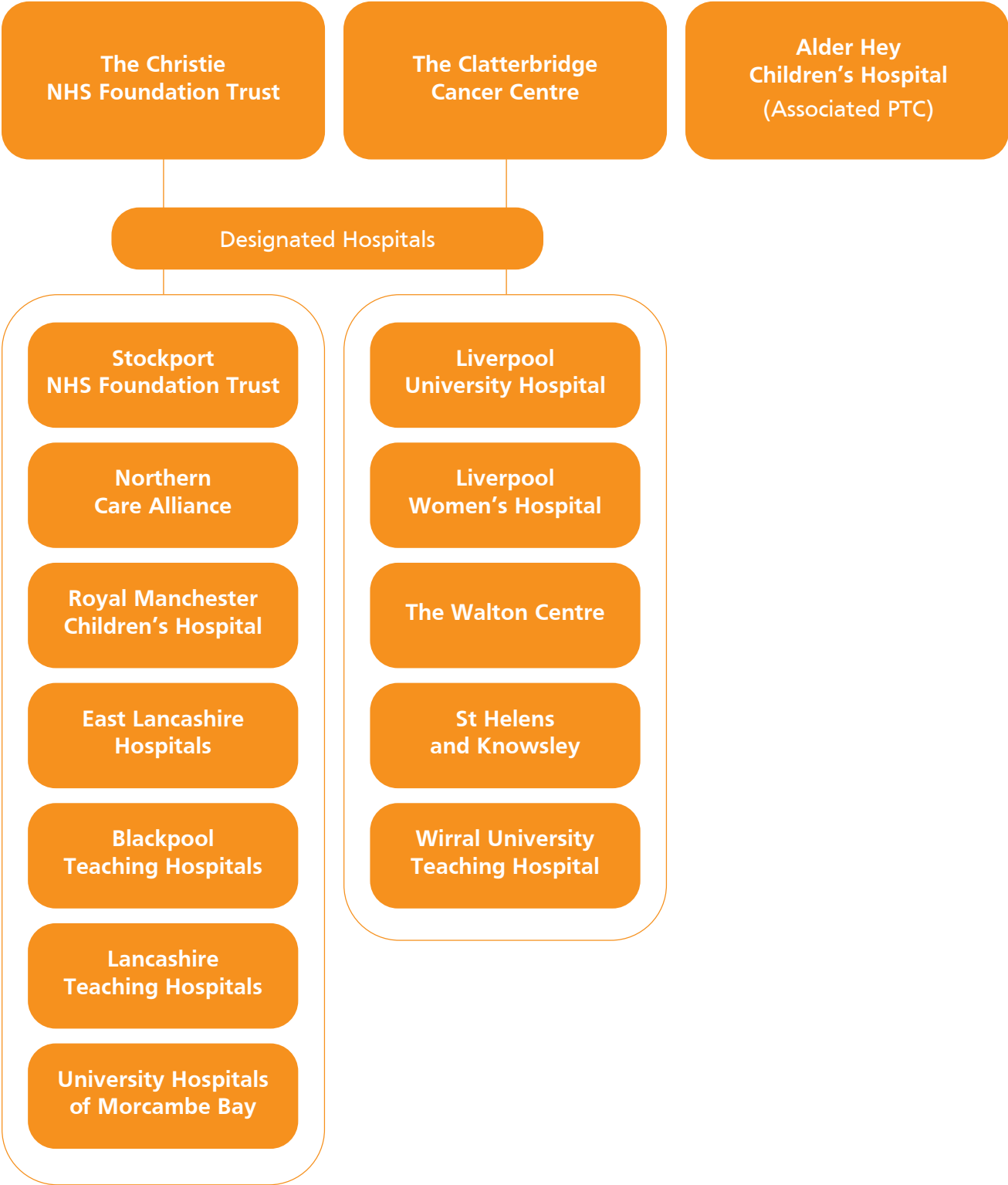
The care of people aged 16-24 with cancer is specialised; cancer is the leading medical cause of death, though the group accounts for less than 1% of all cancer diagnoses. The North

West PTCs are leaders in TYA cancer care, including significant contributions to the 2016 Blueprint of Care, the gold standard care model, laying the groundwork for personalised care and new NHS Service Specifications.

Although TYA cancer prevalence in the North West is comparable to England, the region includes four of England's most deprived areas. We address our population's health challenges with a systems approach, engaging with the three Integrated Care Systems, Cancer Alliances, Genomic Medicine Services, and research groups. Working as a Network means leading the way to ensure everyone has access to TYA cancer services.

NHS Providers

Principal Treatment Centres



National statistics for TYA cancer

There are at least 88 different subtypes of young people's cancers. These can be put into 12 main groups. The picture below shows these groups and gives you an idea of how common they are.

The most common groups of young people's cancers in the UK are.

- Other malignant epithelial neoplasms and malignant melanomas (30% of cases)
- Lymphomas and reticuloendothelial neoplasms (20% of cases)
- Germ cell tumours, trophoblastic tumours, and neoplasms of gonads (16% of cases) (1997-2016)

Young people's cancer in the UK

Proportion of all young people's cancer cases by group

● ● ● Larger circles indicate more UK cases



Other carcinomas and melanomas



Lymphomas



Germ cell tumours



Brain and spinal tumours



Leukaemias



Soft tissue sarcomas



Bone tumours



Other tumours



Kidney tumours



Liver tumours



Neuroblastoma



Retinoblastoma
(very small number of cases)



Teenagers and
Young
Adults with
Cancer



CANCER
RESEARCH UK
for Children &
Young People



Together we are
beating cancer

Network governance

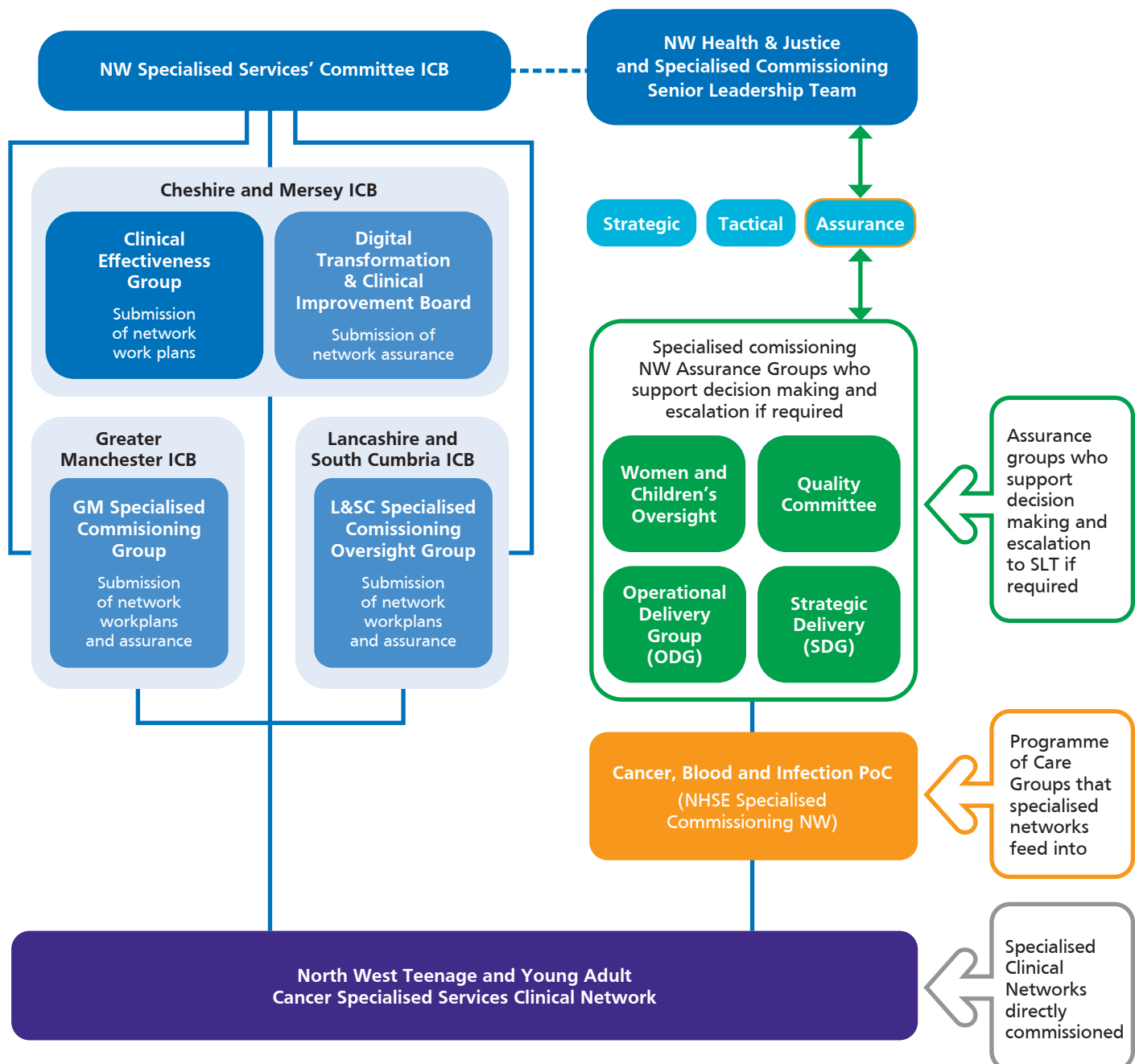
Governance responsibilities for the NWTYA Network are set by NHSE NW Specialised Commissioning via the Cancer Blood and Infection Programme of Care Board (PoC)

The NWTYA Network feeds into to three ICB areas, Cheshire and Mersey (C&M), Greater Manchester (GM) and Lancashire and South Cumbria (L&SC)

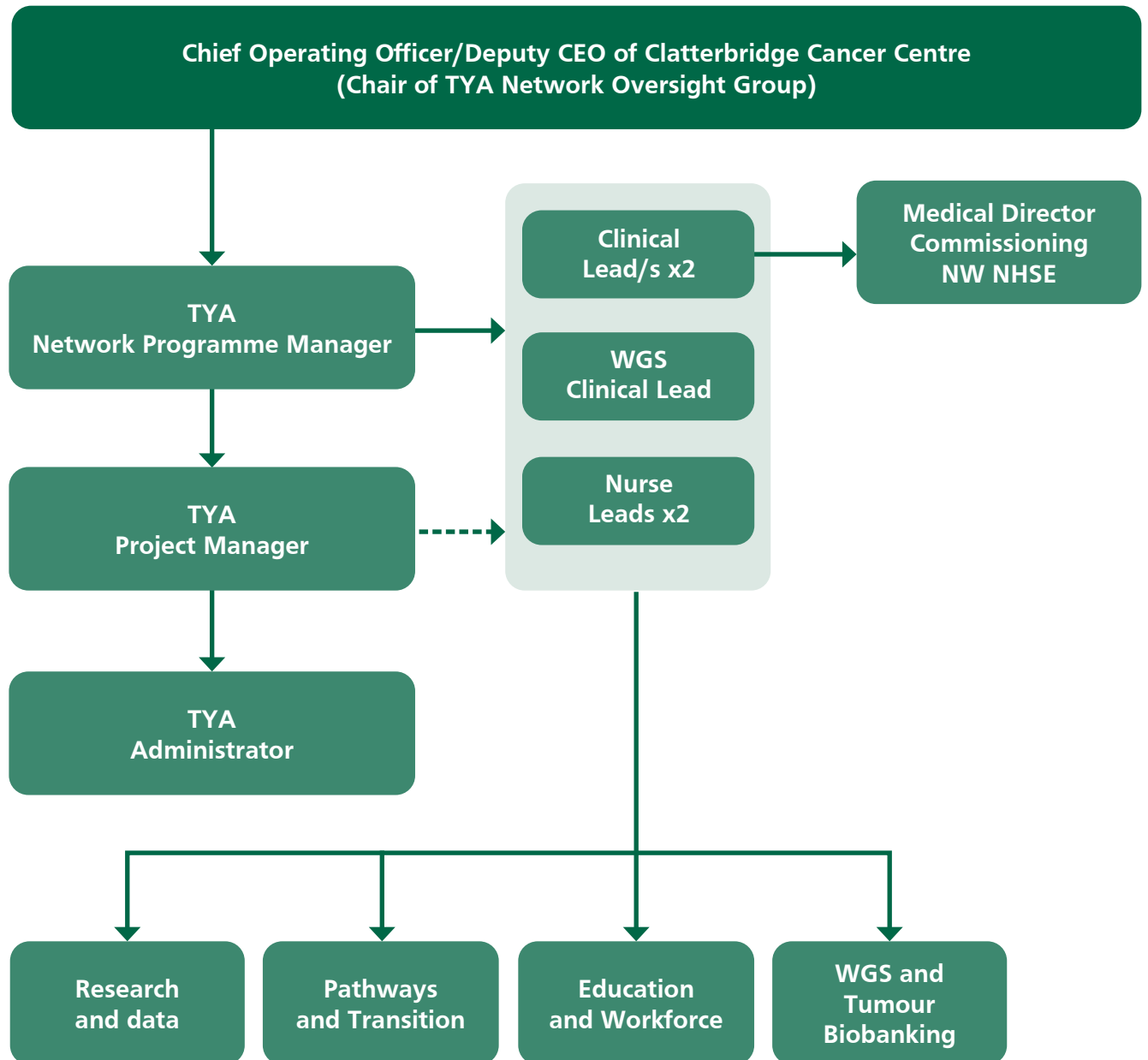
The TYA Network continues to seek support in the development of workplans and oversight assurance from Specialised Commissioning



FutureNHS



TYA Network Structure



Meet the team

**Joan Spencer**

Chief Operating Officer
TYA Network Clinical Lead
GM

**The Clatterbridge Cancer
Centre NHS Foundation
Trust**

**Chair of The North West
Teenage and Young
Adult Cancer Operational
Delivery Network**

**Dr Anna Castleton**

Haematology Consultant
TYA Network Clinical Lead
for GM

**The Christie
NHS Foundation Trust**

**Dr Nasim Ali**

Medical Oncology
Consultant
TYA Network Clinical Lead
C&M

**The Clatterbridge Cancer
Centre NHS Foundation
Trust**

**Julia Charnock**

Specialised Commissioning
Service Specialist –
Cancer, Blood & Infection
Programme of Care (PoC)

**NHS England – North
West**

**Dr Colin Thorbinson**

Consultant
**Alder Hey Children's
NHS Foundation Trust**

**Hanna Simpson**

Lead Nurse for Teenagers &
Young Adults with Cancer,
Ambulatory Care and
Withington Unit

**The Christie
NHS Foundation Trust**

**Dr Laura Elder**

Lead Nurse for Teenagers &
Young Adults with Cancer

**The Clatterbridge Cancer
Centre NHS Foundation
Trust**

**Rachael Hastwell**

TYA Programme Manager
**The North West Teenage
and Young Adult Cancer
Operational Delivery
Network**

**Aneta Murkova**

Administration Assistant
**The Teenage and Young
Adult Operational Delivery
Network**

**Laura Bayliff**

TYA Project Manager (fixed
term)

**The North West Teenage
and Young Adult Cancer
Operational Delivery
Network**

**Peace Amaefule-Orie**

Clinical Pathway Project
Manager (fixed term)

**The Teenage and Young
Adult Operational Delivery
Network**

Comprehensive service review

Workstream Lead:

Dr Anna Castleton and Dr Nasim Ali

Aims

1. Improve the experience of care.
2. Improve the integration between different TYA cancer services within a geographical area.
3. Improve the transition between children's and TYA services and TYA and adult cancer services.
4. 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.

Highlights and Achievements of 2023-24 objectives

- Developed two self-assessment tools, one for Principal Treatment Centres and one for Designated Hospitals

- Hosted a clinically led webinar to share our plans with members and receive feedback.
- Visited nine member hospitals, meeting with cancer and organisation leaders to discuss the TYA Network, Draft Service Specifications and our goals.
- Received returns from 15 Trusts, with over 1,000 data points.
- Delivered the Network-level analysis, local analysis, and future plans to all Trusts.

Forward into 2024-25

The Network plans to continue to offer designated hospitals support following their self-assessment results, to undertake objective setting and quality improvement for providers.

The Network plans to review the assurance process that feeds into our Network Oversight Group.

TYA Service Specification

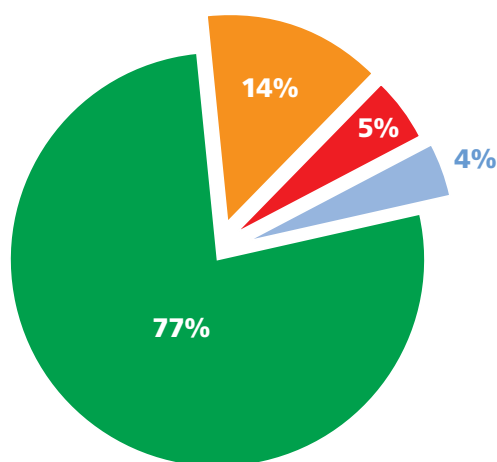
Summary of Service Specification Analysis work in 2023: results identified:

In Oct 2022 at the request of regional NHSE, the Network developed a Service Review workstream concurrently with the development of the Network to obtain a greater understanding of the current TYA Cancer provision across its providers. Each provider undertook a self-assessments exercise against the National TYA Service Specification (2019 version).

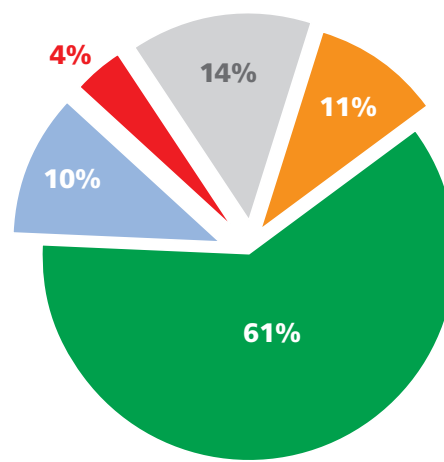
The Network results are shown below as a combined % of total 'Fully Met' or 'Not Applicable' to the standard.

Area	Red 'Not met'	Amber 'Partially met'	Green 'Fully met'	N/A	Blank	Total Green or N/A	%
Principal Treatment Centres (Combined)	26	69	372	19	0	391/486	80%
Designated Hospitals (combined)	24	69	373	62	84	435/612	71%

Overall Compliance
– 3 PTC's



Overall Compliance
– all designated facilities



■ Not Delivered
 ■ Partially Delivered
 ■ Being Delivered
 ■ Not Applicable
 ■ Blank

- In response to the 2023 gap analysis the Network has been working with its Principal Treatment Centres and Designated hospitals to improve compliance against the Teenagers and Young Adults Service Specification
- In October 2024 providers were issued with a revised self-assessment template based on the Service Specification published in May 2023, and is comparing year on year results
- The Network will continue working with its providers in 2025, to improve compliance against the Teenage and Young Adult Service Specification and support action plan development and assurance going forward



Themes identified from Principal Treatment Centres Self Assessments

The majority of the challenges were common to both The Christie and Clatterbridge Principal Treatment Centres. It was deemed appropriate to be considered as specific work-streams for the Network such as.

- Shared care arrangements
- Workforce/education
- Ensuring robust clinical governance arrangements between PTC and network
- MDT referral timelines
- Approaches to LE/survivorship

Many of the challenges are national (e.g. clinical trial access and embedding Whole Genomic Sequencing and Tumour Biobanking. These are featured in the Networks work programme.

Themes identified from Designated Hospital Self Assessments

- Results of indicators of KPIs – improved data
- Survivorship- comprehensive follow up planning
- Arrangements for transitional care
- Policies for holistic information and shared decision making
- Training and development
- Review of essential facilities
- *Trials uptake and Whole Genomic Sequencing and Tumour Biobanking- focus in the 2023 published specification.

****The Network developed the 2024-25 work plan based on key themes and continue to work with providers to collate and develop local action plans.***

Workforce and Education

Workstream Lead:

Hanna Simpson

Aims

1. Review of current Workforce and Education Provision
2. Stakeholder identification, including Patient and Public Voice
3. Generation and implementation of recommendations for Workforce and Education

Highlights and Achievements of 2023-24 objectives

- Sponsored over 40 places at relevant study days and events.
- Sponsored posters and attendance at the Global AYA Congress
- Collaborated with the Children and Young People's Network, becoming joint members of the Florence Nightingale Foundation Academy and offering access to all Registered Nurses and Allied Health Professionals in our Networks.

- Developed a working group with membership from across the Network to continue the work on Education and Workforce into 2024/25
- Held the first joint North West Children's and TYA Cancer Conference in 2024. The team welcomed 90 delegates from across the North West and further afield. 17 speakers delivered talks throughout the day and 10 exhibitor stalls raised awareness about local charities and organisations. The 2025 conference planning is underway.

Forward into 2024-25

The Network plans to continue to collaborate with the cancer alliance workforce programmes to develop co-ordinated approach to system level workforce planning and facilitate the provision of expertise to the development of appropriate training, education, and professional development opportunities.

The Network has offered funding to support 2 delegates the opportunity to attend the 6th AYA global congress (December 2024) in Australia.



The Whole Genome Sequencing and Tumour Bio Banking Working Group

Workstream Lead:

Professor Martin McCabe

Project Manager:

Peace Amaefule-Orie

Aims

The aim of the project is to embed genomic medicine and tumour biobanking into care pathways, making precise diagnosis and treatment plans, and inspiring future research to improve outcomes.

1. Pathway identification and process mapping
2. Review of current WGS and TB provision
3. Stakeholder identification, including Patient and Public Voice
4. First-level education and profile-raising activities
5. Generation and implementation of recommendations for WGS and TB pathways across the Network.

What is Genomic Sequencing?

Inside almost every cell of our body is a copy of the genome, made of DNA. The genome can be thought of as the instructions for running a cell. It tells the cell what kind of cell to be – is it a skin cell or a liver cell? It also has the instructions that tell the cell when to grow and divide, and when to die.

When a cell divides to become two cells, this genome is copied. Usually, our cells divide to make new cells in a controlled way. This is how our bodies grow and repair. Sometimes when our cells divide, mistakes happen when copying the genome. They are caused by natural processes in our cells, or just by chance.

The differences are called 'variants'. These might be a single letter. Or a string of letters may be in a different place or missing.

Whole genome sequencing will involve samples being taken, sent to a laboratory, run through a machine that 'reads' the DNA and a report will be returned to the clinical team with any relevant findings. As we share DNA with family, getting tested may have implications for other family members, so we may want to share that information with them and talk to them about what it might mean for them following the results.

Benefits of Genomic Sequencing

Results can provide information on:

- genes that have not previously been looked at through routine testing
- why a tumour or cancer developed
- what type of tumour or cancer the patient has and check that treatment is tailored to that cancer. There may be clinical trials looking for patients with specific genetic changes in their tumour
- how Whole Genome Sequencing results may be used in treatment planning for the future
- whether there is a gene presence which might increase the risk of developing other cancers in the future. This may lead to precautionary action or start screening for the cancer sooner
- whether other family members may have a greater risk of developing cancer and are able to get tested or start screening early

Information Resources

WGS for cancer patients

[genome-sequencing-cancer-patient-information.pdf \(england.nhs.uk\)](#)

Information for children and their parents

[whole-genome-sequencing-for-children-NHSE.pdf \(cclg.org.uk\)](#)

Information sheet for the National Genomic Research Library –

<https://files.genomicsengland.co.uk/documents/Genomic-Research-Patient-Information-v1.2-Dec-2020.pdf>

Highlights and Achievements of 2023-24 objectives

- Successfully appointed to the Clinical Pathway Project Manager post
- Established the WGS and TB Working Group
- Completed project brief and timelines.

- CPPM presented the project at cancer alliance meetings.
- Audit conducted and set to conclude in Q2.

Forward into 2024-25

An in-depth audit is currently underway across the Network and will enable us to develop and distribute best practice recommendations and map our typical diagnostic pathways.

Focused engagement sessions will be timetabled to enable us to improve stakeholder relationships and support our goal of embedding genomic medicine within TYA Cancer Services.

Programme management

Programme Manager:

Rachael Hastwell

Network Administrator:

Aneta Murkova

The NWTYA Network would like to thank Alistair Leslie-Dakers and Lucie McKie for their commitment in 2023-24 in supporting the delivery of the work plan and Network's objectives. A thank you also to Daniel Hutton from the North West Radiotherapy Network who provided support whilst recruitment was underway.

Workforce update

- **Programme Manager** – Rachael Hastwell started in post in June 2024. Rachael is establishing key relationships across the Network and Nationally, to help embed and progress the TYA strategic objectives. This is set to be an exciting year for the Network as we can focus on key areas of delivery within our programme.

- **Clinical Pathway Project Manager** – Peace Amaefule-Orie started in post in March 2024 and has a focus on embedding WGS and Tumour Bio-Banking. Driving the working group to ensure delivery against our work plan.
- **Administration Assistant** – Aneta Murkova joined in June 2024 and is supporting all aspects of administration across the Network. This role is key to the organisation of the Network office functions and will support the Senior Leadership Team in delivery.

Activities

- The end of year assurance report was submitted in June 2024 along with the development of the 2024-25 work plan.
- Recruitment is underway for the fixed term Project Manager along with workforce planning for the role.

Forward into 2024-25

The Programme Manager has set out to ensure that all activities align with the Network objectives. With the recruitment to the fixed term Project Manager this will enable specific focus on agreed project/s going forward.



NHS England Update

Specialised commissioning 2024/25 – next steps with delegation to integrated care boards

NHS England is the accountable commissioner for a portfolio of ~150 specialised services. The list of services is set by the Secretary of State for Health and Social Care through regulations.

Following Board consideration and decision in February 2023, commissioning responsibility for 59 specialised services has been delegated, since April 2023, to nine statutory joint committees formed between integrated care boards (ICBs) and NHS England Regions. These joint committees cover the entire population of England.

This important, yet deliberately cautious approach to achieving the benefits of integrated, population based commissioning

arrangements for specialised and non-specialised services was agreed by the Board as a transitional step towards delegating full commissioning responsibility for suitable specialised services to ICBs from April 2024.

NHS England will remain the accountable commissioner for the entire portfolio of specialised services and maintain responsibility for setting consistent national standards, services specifications and clinical access policies.

The benefit to our Network of commissioner engagement is to support the strategic decision making and governance of the Network.

NHS England » Specialised commissioning 2024/25 – next steps with delegation to integrated care boards



Welcome to our New Commissioner

We would like to welcome Julia Charnock as the newly appointed North West Commissioning Lead for Cancer, Blood and Infection Programme of Care (PoC). Julia started in the role in July 2024.

After two years as the Lead Programme Manager for Children & Young People's Mental Health Medium Term Fund Programme in the national Specialised Commissioning Team, Julia has returned to the North West to take up the role of Service Specialist for Cancer, Blood & Infection.

Julia has previously been part of the NHS North West Specialised Commissioning Team as the Service Specialist for Internal Medicine and prior to that, as Senior Supplier Manager in the Mental Health Team.

Julia maintains her nursing registration as a Specialist Practitioner in District Nursing and has worked in a number of nursing roles in Provider Trusts across the North West. Before joining the team, Julia was Programme Manager for the Maternity and Children's Strategic Clinical Network, and had previously led work programmes and projects for both Greater Manchester and the North West Coast Strategic Clinical Networks, covering the Lancashire & Cumbria area.

In her role as the regional Privacy & Dignity Lead, Julia successfully implemented a national policy directive to Eliminate Mixed Sex Accommodation across Lancashire & South Cumbria. She also worked extensively with clinicians across the North West to develop key Primary Care Standards for Managing Asthma in Children & Young People.



Julia Charnock

North West Commissioning
Lead for Cancer, Blood and
Infection Programme of Care
(PoC)

With both a clinical and commissioning background and experience of PRINCE2 and MSP methodologies her successes include programme and project management around; Medium Term Funding for CYP Mental Health, Perinatal Mental Health inpatient & community services, Maternity, Children & Young People services, Stroke, CVD and COPD, along with guideline development and service improvement/redesign.

Working with stakeholders in Lancashire & South Cumbria, Julia's work with the Better Birth Team supporting the transformation of Maternity Services included the development of the Local Maternity System and the development of Perinatal Mental Health Services, including the new PNMH Mother & Baby Unit, Perinatal Specialist Community mental health team and workforce development.

Finance – Spend Against Income 2023-24

The TYA Network received **£158,291** of funding from NHS England in 2023-24. It was agreed that **£43,173** underspend would carry forward into 2023-24 giving a total budget of **£201,464**.

TYA – 2023/24	2023/24		
Month 12	Plan	Actual	Variance
Income from NHSE	£158,291	£158,291	£0
Income from other sources (recurrent)			£0
Income from other sources (non-recurrent)			£0
Underspend from previous FY	£43,173	£43,173	£0
Total Income	£201,464	£201,464	£0
Costs – Pay	£142,784	£88,062	£54,722
Costs – Non-pay	£15,507	£16,001	-£494
Underspend from previous FY	£43,173	£43,173	£0
Total Costs	£158,291	£104,063	£54,228
Income less costs (overspend shown as negative, underspend as positive)	£43,173	£97,401	£54,228

Narrative – Income

Funding for 12 month B7 in place to deliver Whole Genomic Sequencing and Tumour BioBanking from Feb 2024 from 22-23 underspend

Narrative – Costs

Pay – underspend due to ODN Vacancies in year
Non-pay – small spend on computer hardware and course provision

Underspend carried forward as Provision

(105,574)

- The Network invested in a Clinical Project Pathway Manager for the Whole Genome Sequencing and Tumour Biobanking Project for 1 year. This was agreed in 2023-24 from underspend monies and commenced Feb 2024.
- The TYA Network intends to grow additional sources of income. Continued collaboration with NHS England is crucial for budget setting and future investment.
- In 2023-24 the end of year position resulted in a further £105,574 underspend, primarily due to vacancies. This was agreed to be carried forward into the financial year of 2024-25 for further investment for a project management role to support the Network objectives.

TYA Network Workplan 2024-25

TYA Summary Workplan 2024-25

Research Data and Service Review

Improve the data capture at MDT level, in particular when patients offered trials do not enter the trial – by re-designing a Network MDT notification Form

Scope and develop the metrics for the TYA regional dashboard

Establish timelines for referral to MDT by audit

Audit current awareness/uptake to trials for TYA (vs baseline audit) and any areas of focus

Review role of the TYA research nurse

Set up annual mechanisms for feedback by setting up a timetable for designated hospitals (virtual session) with local action planning to support alignment with service specification and peer support

Assurance process to be set up feeding into Network Oversight Group

Review metric requirements for NHS England TYA dashboard to ensure compliance across (NHSE) for COSD data submission

Research Data and Service Review

Conduct and audit of available education initiatives for TYA staff across the North West

Conduct a training needs analysis (TNA) for TYA services across the North West

Develop an education programme across the North West with available Education initiatives

Generate recommendations for Education and Workforce across the Network

Plan and hold a regional annual conference (Joint CYP and TYA) in March 2025

Develop ODN Education platforms and material (Website/conference banners/TYA foundation video)

Transition and Pathways

Set up a TYA and Children's transition taskforce

Audit the transition pathway – focusing on patients aged >16 in children's centres

Develop a joint regional paediatric to TYA transition pathway document

Review psychology provision arrangements across the Network for 16–18-year-olds

Review fertility preservation pathways across the North West, ensuring patients who are eligible have access to ovarian tissue retrieval (Hub and Spoke model)

Transition and Pathways

Clinical Pathway Project Manager to conduct the WGS and TB Project

Complete and publish an audit of current WGS and TB working practices across the North West

Map the typical diagnostic pathway

Develop and distribute improvement and best practice recommendations

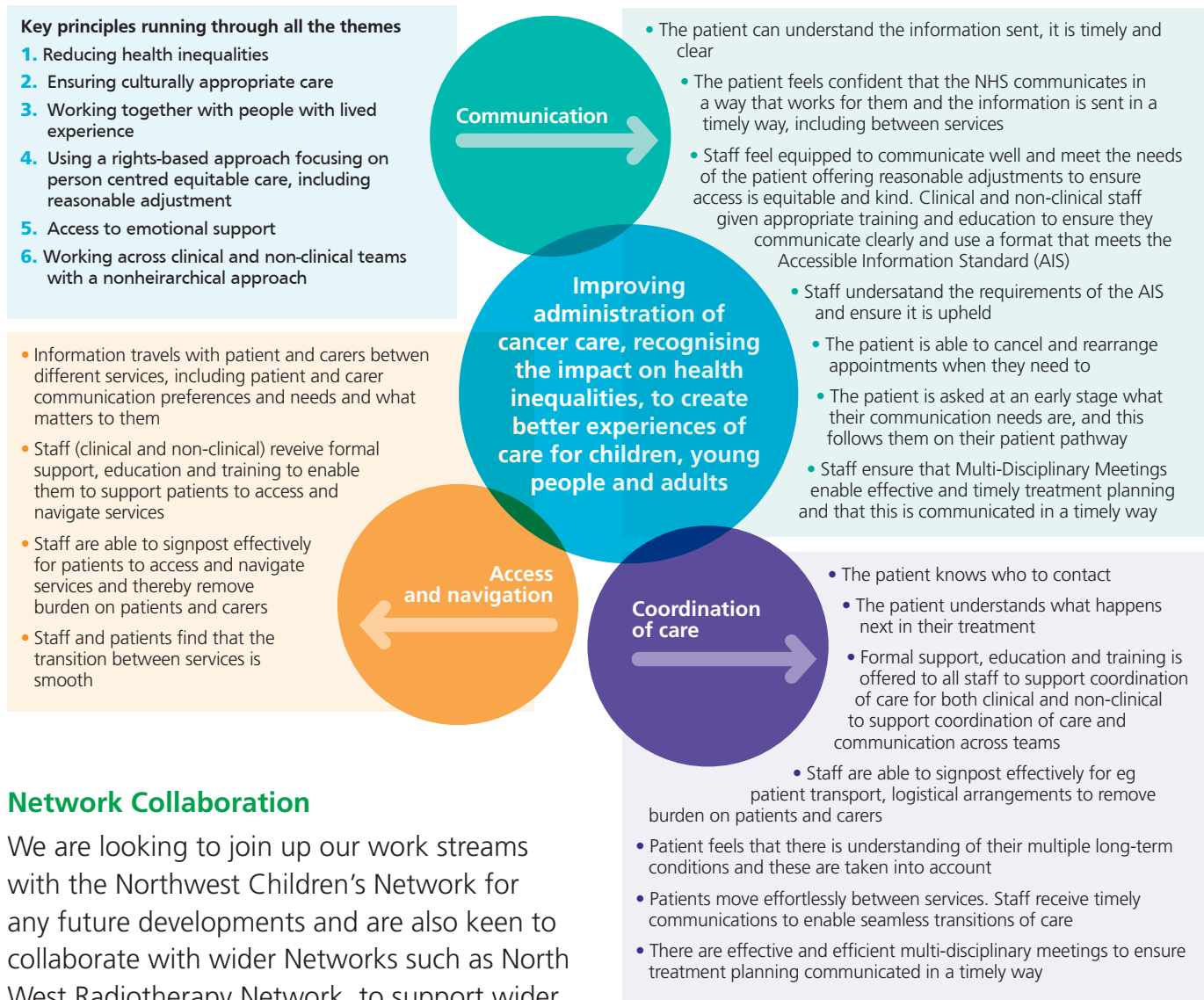
Form strong stakeholder relationships and engagement

Other exciting initiatives for 2024-25

Cancer Improvement Collaboration

The Network is leading a project around improving the administration of care. Launching in Autumn 2024 with the aims of improving late effects information for TYA patients. This will link with National priorities and be supported by the Cancer Alliances and NHSE.

Improving experience of care through administration of care: Themes



Network Collaboration

We are looking to join up our work streams with the Northwest Children's Network for any future developments and are also keen to collaborate with wider Networks such as North West Radiotherapy Network, to support wider transformation initiatives.

Teenage and Young Adults Rapid Diagnostic Service

The Cheshire and Mersey Cancer Alliance have piloted the Teenage and Young Adults Rapid Diagnostic Service within two of its hospitals. The Christie PTC would like to be considered for any future development, working across our 3 cancer alliances. We await project feedback to establish the next steps and feasibility.



The Right Care
in the Right Place
at the Right Time

Thank you

Thank you to our host organisation, The Christie NHS Foundation Trust, The Clatterbridge Cancer Centre NHS Foundation Trust for executive leadership, and associated Principal Treatment Centre Alder Hey Children's NHS Foundation Trust.

We look forward to working with you and new contributors as we continue our exciting plans into 2024-25.