

NW Children's Cancer ODN

Annual Report 2023/24

Author: Davina Hartley Programme Manager





Contents

1.0 Introduction & Foreword	4
2.0 About Us	5
2.1 Meet the team	
2.2 The Network	
2.3 Provider Organisations	
3.0 Governance	9
3.1 Budget	
3.2 Risks	
3.3 Governance Structure	
4.0 Data Trends	10
4.1 National Data	
4.2 Regional Data	
5.0 Service Scoping and Self-Assessment Review	13
6.0 Achievements 2023/24	17
7.0 Key Priorities 2024/25	18
8.0 NHSE Transformation Programme	19
Appendix 1: Progress against workplan 2023/24	20
Appendix 2: Key Priorities 2024/25	23

1.0 Introduction & Foreword

This report provides a summary of the performance, the key developments, achievements and challenges that the North West Children's Cancer Operational Delivery Network (NWCCODN) has faced over the year 2023/24.

The NWCCODN is a relatively new network and has been developing rapidly over the 12 months from 1st April 2023 to the 31st March 2024 (the period this report covers). The network has grown as a team and the relationships with partner organisations across the region.

We have finalised our strategy document which sets a clear vision and mission for the network going forward and have worked hard to ensure that everyone working across the region within children's cancer services could input into this, in addition to, receiving parental input into this. We are also planning to develop an easy read version of the strategy to ensure accessibility.

We have developed working groups to start making progress on some of our aims and objectives and to begin to deliver our workplan (which you can find in the appendices). These include the Workforce and Education working group, Data and

Digital, and more recently Parent and Family Experience). We have had a fantastic response to these and have had really great engagement from across the region. Our focus for the coming year will be the development of the Equitable High Quality Care working group which will include how we look at delivering some treatment in the home and reduce travel time for children and their families.

We held the first regional children and TYA Cancer Conference in March 2024 which was sponsored by GM Cancer Alliance and are very proud of the response that this received. We are pleased that this will become an annual event with sponsorship from C&M Cancer Alliance agreed for 2025.

Data regarding children's cancer continues to be challenging in terms of accessing accurate real time data and accessing data in one central repository (as this does not exist). We are working with the NHSE Business Intelligence team to try and rectify this through the development of a regional children's cancer data dashboard. The data contained within this report is from national datasets including QGIS, the National Cancer registry and regional HES data.

Our strategic aims:

Access

Ensure equitable access to care for children with cancer across the North West

Quality

Ensure quality of care to children with cancer across the North West

Experience

Improve the experience of care for children with cancer across the North West

2.0 About Us

The North West Children’s Cancer Operational Delivery Network was established in October 2022. Our vision and mission statement can be seen here.

Vision:

“Continue to ensure that every child with cancer in the North West has access to world class, safe, high quality care & treatment, where, when and how it is required”

Mission Statement:

The aim of the NWCCODN is to work with all stakeholders to provide world class, safe, high quality care to all children with cancer across the North West Region, according to need. The focus is to provide system and service oversight, support training and education and share best practice to improve, where required, access, quality and the experience of cancer care across the region by working together to maintain standards for all.

2:1 Meet the Team



Davina Hartley
ODN Manager



Charlotte Lloyd
QI Lead Nurse



Katharine Field
Innovation Officer



Prof Bernadette Brennan
Clinical Lead & Deputy Chair



Dr Lisa Howell
Clinical Lead & Co Chair



Andrea Doherty
Commissioner & Co Chair

2.2 The Network

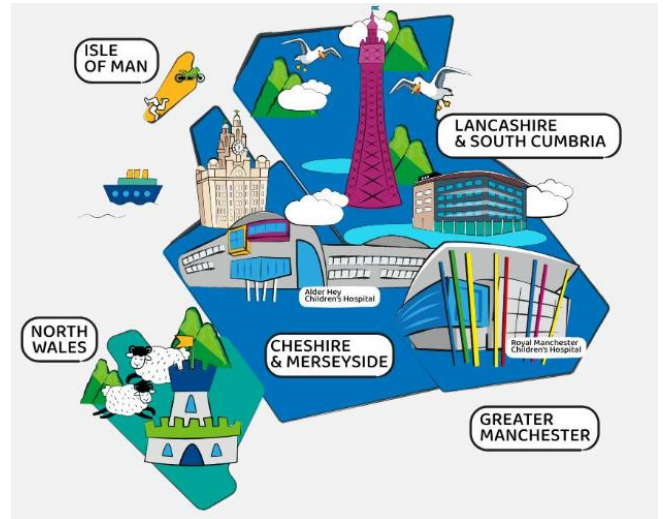
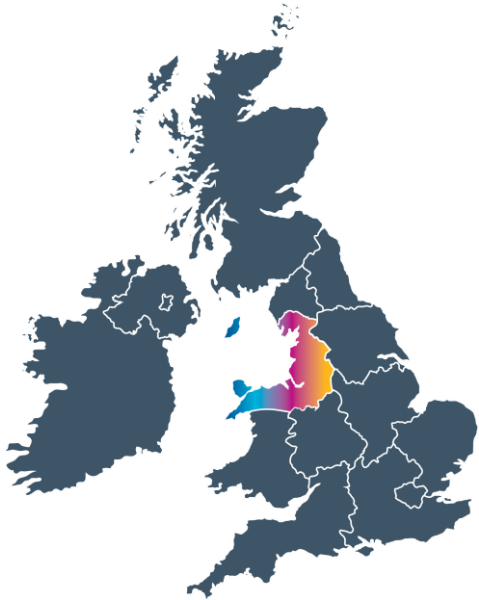


Diagram 1: Map of NW Region

The North West Children's Cancer ODN was set up in October 2022. the network is jointly hosted in a partnership arrangement between Royal Manchester Children's Hospital and Alder Hey Children's Hospital. The network aims to provide impartial clinical advice and expertise to all providers and commissioners across the North West of England (Cheshire and Mersey, Greater Manchester, Lancashire and South Cumbria), and the Isle of Man regarding cancer services for children up to the age of 16. The ODN focuses on supporting the coordination of cancer pathways between providers to ensure consistent, equitable access to specialist resources and expertise for children and young people across the North West of England. The North West Children's Cancer ODN serves a population of circa 7.3 million, of which, circa 1.5 million are children under the age of 16 years old. The network covers a geographical area of 14,165 km which is a mix of heavily populated urban areas and very contrasting remote rural areas which can make access to healthcare challenging for families. The Network also includes supra network POSCU's and patients from North Wales due to cross boundary travel and patient flows into one of our Principal Treatment Centres (PTC's) in addition to some families travelling from the Isle of Man to access treatment in our region. The geography that the network covers provides challenges for children accessing treatment from some areas due to the travel distances. For intense treatment appointments which may be on a weekly and sometimes daily basis, this can present a huge burden to families.

The North West region has high levels of deprivation in some areas, with 4 of the 5 *most* deprived local authorities in England being within the North West (Blackpool, Manchester, Liverpool and Knowsley). This presents challenges in access to care for some families and underserved communities.

2.3 Provider Organisations

Provider	Trust	Integrated care board (ICB)	Status
Alder Hey	Alder Hey Children's NHS FT	Cheshire & Merseyside ICB	Principal Treatment Centre
Countess of Chester	Countess of Chester NHS Foundation Trust	Cheshire & Merseyside ICB	Standard POSCU
Leighton	Mid Cheshire Hospital Foundation Trust	Cheshire & Merseyside ICB	Standard POSCU
Nobles Isle of Man	Manx Care, Isle of Man Government	IOM Health Board	Standard POSCU
Ysbyty Wrexham Maelor	North West Wales NHS Trust	North Wales Health Board	Standard POSCU*
Ysbyty Gwynedd	North West Wales NHS Trust	North Wales Health Board	Standard POSCU*
Ysbyty Glan Clwyd	North West Wales NHS Trust	North Wales Health Board	Standard POSCU*
Royal Manchester Children's	Manchester Foundation Trust	Greater Manchester ICB	Principal Treatment Centre
Royal Blackburn	East Lancashire Teaching Hospital Trust	Lancashire and South Cumbria ICB	Standard POSCU
Blackpool Victoria	Blackpool and East Lancashire Trust	Lancashire and South Cumbria ICB	Standard POSCU
Royal Preston	Lancashire Teaching Hospital	Lancashire and South Cumbria ICB	Standard POSCU
Royal Lancaster	University Hospitals of Morecambe Bay	Lancashire and South Cumbria ICB	Standard POSCU

In the North West region there are two Principal Treatment Centres (PTC's) for children with cancer, namely Alder Hey Childrens Hospital (AHCH) and Royal Manchester Childrens Hospital (RMCH). Alder Hey Children's Hospital is situated within the boundary of the Cheshire and Mersey ICB and is aligned with the Cheshire and Merseyside Cancer Alliance. Alder Hey currently has two standard POSCU's within England, 1 Standard POSCU in the Isle of Man and also offers shared care for patients in North Wales to the 3 standard supra network POSCU's.

Royal Manchester Children's' Hospital is situated within the boundary of Greater Manchester ICB and is aligned with Greater Manchester Cancer Alliance. Royal Manchester PTC currently offers shared care for patients within Lancashire and South Cumbria ICB and has 4 standard POSCU's in Lancashire and South Cumbria and no POSCU's within Greater Manchester. All patients living within the Greater Manchester ICB boundary currently come directly to RMCH for all of their treatment.

3.0 Governance

3.1 Budget – Spend against income

The NWCCODN is funded by regional NHS England and has a budget of £170,000 for the year 1st April 2023 to the 31st March 2024, This is an increase of £12, 600 on the previous year.

We had additional £90,000 slippage from the previous year (2022/23) due to mid-year start up and mid-year recruitment to posts in the budget. Expenditure against the commissioned budget did not commence until October 2022. This enabled us to recruit to the post of a band 7 innovation officer role. However, due to recruitment delays internally within MFT this role was not commenced until September 2023 this has resulted in an underspend of £40,000 at the end of the financial year 23/24 to be carried into 24/25.

Under the terms of the commissioning agreement any slippage in the budget must be discussed with NHSE specialised commissioning to agree how these funds should be spent. NHSE agreed that any funding that was not allocated by 31st March 2024 could be repurposed into the next financial year (2024/25) to enable the funding to be ring fenced for children's cancer.

3.2 Risks

Top 3 risks for the network

No.	Area	Date Added	Risk &/or Issue	Description	Severity	Likelihood	Score	Mitigation
2	Timely Data Sharing	04/01/2023	Risk/ Issue	Live data is not available between PTC and shared care units. This can cause confusion to families, over reliance on parents for up to date information regarding child's care, prescriptions and interventions. Discharge summaries not readily available.	5	5	25	Interoperability discussions taking place to discuss possibilities regarding 'share to care' (C&M) and other platforms. Interim measures in place via email systems but these are not always effective. Interoperability Task & Finish Group.
3	Finance	04/01/2023	Risk	Risk of having underspend at end of financial year due to delays in recruitment of band 7 Innovation role. 1 year fixed term role/ secondment, not yet in post due to internal operational delays.	5	4	20	Chasing internal HR in the host organisation to try and speed process up. Escalate to senior management in host trust.
18	Workforce	03/11/2023	Risk	Fixed term contract for Innovation Project Officer role due to non recurrent funding is leading to uncertainty of staff and challenges in delivery of work plan. Risk of losing good staff members due to not being substantive roles.	4	5	20	Scoping funding opportunities to enable continuation of post. Escalation to NHSE due to the impact that the loss of this role would have on the Transformation Programme (PPI and Data) and Network capacity.

3.3 Governance Structure

The NWCCODN is governed by the Network Oversight Group (NOG). All North West provider Trusts of children’s cancer services form the working groups (sub groups) of the NWCCODN. Each working group will has representation from across the region relevant to its individual purpose. The working groups are accountable to the NWCCODN.

NWCCODN is accountable to the North West Paediatric Partnership Board and NHSE Specialised Commissioning. There

are terms of reference in place for the NOG identifying when the group will be quorate. The NOG is co-chaired by NHSE and one of the Network’s two clinical leads.

The NWCCODN host Trust is represented on the NOG by the Trust Medical Director. The Network has links with the regional Cancer Alliances and will be governed by the ICB’s following delegation when this occurs.

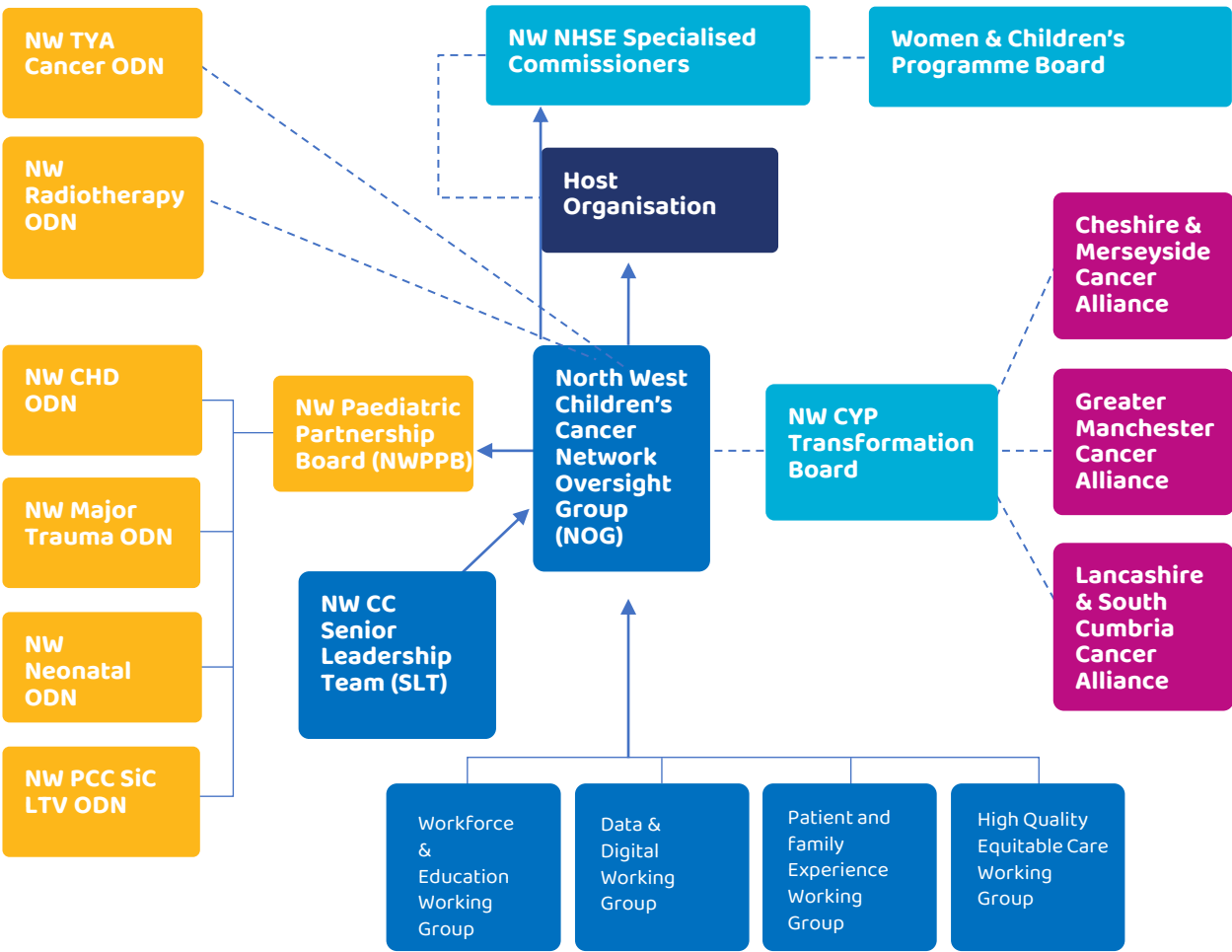


Diagram 2: Overarching governance structure

4.0 Data & Metrics

4.1 National Data*

Childhood cancer is rare there are around 1,800 new cases are diagnosed every year in the UK (in children aged 0-14 years). Childhood cancers account for less than 1% of all cancers in the UK. This means that around one child in 500 will develop some form of cancer by the age of 14 years. The numbers are higher for new diagnoses in boys than they are for girls (990 vs 840 respectively). Unfortunately, the incidence of childhood cancer is on the rise in the UK, increasing by 15% between 1993-1995 and 2015-2017. Some of this increase is thought to be due to improvements in diagnosis and registration Demographic Cohorts. For cancers in girls, age standardised (AS) incidence rates in the UK increased by 18% between 1993-1995 and 2015-2017 whereas for boys these rates increased by 13% between in the same period .

The highest incidence rates for all children's cancers combined are in the under-fives for both sexes, with almost half (46%) of all cases in children being diagnosed in this age group (UK, 2015-2017), this pattern varies greatly by cancer type. Childhood cancer is the leading cause of death for children in the UK, however, in terms of mortality more than 8 in 10 (84%) children diagnosed with cancer in Great Britain survive their disease for five years or more. Cancer survival is similar for children whatever age they are diagnosed. Survival for children's cancers is improving and has more than doubled in the last 40 years in Great Britain. In the 1970s, more than a third of children diagnosed with cancer survived their disease beyond ten years, now it's over three-quarters. At least 15,000 more children have survived their cancer than would have done if survival had remained as it was in the 1970s. Survival rates vary considerably between different types of childhood cancer and by age and gender (figures quoted below are five-year rates):

- Childhood 5-year survival rate of retinoblastoma in England is 99%.
- Lymphomas have a high overall survival rate of 93%; within this, survival from Hodgkin lymphoma is 96%, and from non-Hodgkin lymphoma 90%
- Leukaemia has an overall survival rate of 88%; within this, acute lymphoblastic leukaemia (ALL), the most common form, has a survival rate of 90% and acute myeloid leukaemia (AML), 65%
- Brain tumours have an overall survival rate of 77%, but because they are one of the most common tumour types, they account for the highest number of deaths. There are a number of different types of brain tumours; some have a reasonably high survival rate whilst others still have a very poor outlook. Of the main childhood cancer types, neuroblastoma and bone tumours have the worst outlook. Childhood 5-year survival rates in England for neuroblastoma and bone tumours are 70% and 71% respectively. They have the worst survival outlook compared to other cancers.

Around 240 children in the UK, aged 0-14 years, lose their lives to cancer every year. Over the last decade, mortality rates for cancers in children have decreased by 21% in the UK. Rates in boys have decreased by 22%, and rates in girls have remained stable. Childhood cancer is however, still the leading cause of death for children in the UK.

4.2 Regional Data

There are several data sets required from our services to demonstrate activity and performance. These are collected via different sources from the treating centres. These include the 16 metrics included in the current service specification <https://www.nwchildrenscancerodn.nhs.uk/wp-content/uploads/2023/09/Childrens-Cancer-Services-PTC-Service-Specification-2021.pdf>. Several of these data items are collected through a quality framework dashboard. The results of these are included below. Others are collected from hospital episode data (HES) and from the cancer outcomes dataset (COSD)

In addition to the above metrics, each hospital supplies information monthly to NDRS (national cancer registry) via the **cancer outcomes service dataset (COSD)** on patient level information such as diagnosis and staging of disease. We also supply a monthly **SACT report** to detail chemotherapy treatments given, **cancer waiting times** data to show performance against current targets (28 day faster diagnosis, 31 and 62 days time to treatment targets) and take part in the annual **National under 16 Patient Experience Survey (U16CPES)**. Results from this are published on the U16 website; <https://www.under16cancerexperiencesurvey.co.uk/>. The NHS digital service provides a platform to view some of this activity data, known as the cancerstats2 platform <https://cancerstats.ndrs.nhs.uk>.

There may be other data collected by centres to demonstrate activity and map trends. There is a current project underway in the North West to develop a bespoke data dashboard to support services in activity mapping and for use in the current NHSE CYP Transformation project.

Within the region there is a higher proportion of Leukaemia prevalence in Greater Manchester area than seen nationally across all genders. Within Lancashire & South Cumbria malignant cancers excluding non-melanoma skin cancers has a higher prevalence than nationally, this is also seen within <16 year olds in Cheshire and Merseyside.

Approximately 35% of all paediatric inpatient cancer activity in the North West PTCs is seen in 5-10 year olds, with an increasing trend in lymphoid type cancer admissions. Lymphoid, hematopoietic, and related tissue accounts for one third of new cancer cases recorded in inpatient activity across the region. Chemotherapy and radiotherapy activity has remained at consistent levels since pre-Covid Overall inpatient activity average Length of Stay has increased since pre-Covid. There is significant variation across the region in waiting times to 2WW appointment. Across the region both PTCs have seen an increasing trend in the proportion of Non-CNS tumours patients remaining stable. Emergency readmission rates within 30 days at both PTC's are comparable to the Specialist Children's Hospitals average.

Both PTC's submit data to the SSQD, this is a national submission. See results on the next page for the year 23/24:

PTC04: Proportion of patients with leukaemia who progress or relapse.

Numerator: PTC04 * Denominator: PTC04 * Value: PTC04 %

Reason for non submission

Comment: PTC04

The number of patients who have progressed/relapsed in 2022/23 is 9. The number of new patients diagnosed with leukaemia in 2022/23 is 48. We do not have data systems to do Kaplan Meyer overall survival curves by determining relapses of patients diagnosed in a given year. Therefore this data presented may be inaccurate due to the denominator used.

PTC08: Proportion of eligible patients aged 0-15 recruited to a nationally available trial

Numerator: PTC08 * Denominator: PTC08 * Value: PTC08 %

Reason for non submission

Comment: PTC08

PTC05: Proportion of patents with CNS tumours who progress or relapse.

Numerator: PTC05 * Denominator: PTC05 * Value: PTC05 %

Reason for non submission

Comment: PTC05

The number of patients who have progressed/relapsed in 2022/23 is 22. The number of new patients diagnosed with CNS tumour in 2022/23 is 50. We do not have data systems to do Kaplan Meyer overall survival curves by determining relapses of patients diagnosed in a given year. Therefore this data presented may be inaccurate due to the denominator used. Clearly the majority of the progressions are low grade gliomas, which would be expected.

All eligible patients were offered recruitment to trial but 8 declined

PTC09: Proportion of patients aged 0-15 completing treatment, who receive an end of treatment summary within 6 months of the end of treatment.

Numerator: PTC09 * Denominator: PTC09 * Value: PTC09 %

Reason for non submission

Comment: PTC09

PTC06: Proportion of patients with non-CNS tumours who progress or relapse.

Numerator: PTC06 * Denominator: PTC06 * Value: PTC06 %

Reason for non submission

Comment: PTC06

The number of patients who have progressed/relapsed in 2022/23 is 12. The number of new patients diagnosed with non-CNS tumour in 2022/23 is 69. We do not have data systems to do Kaplan Meyer overall survival curves by determining relapses of patients diagnosed in a given year. Therefore this data presented may be inaccurate due to the denominator used.

PTC16: Median time from onset of fever to administration of antibiotics in neutropenic fever in patients aged 0-15

Numerator: PTC16

Reason for non submission

Comment: PTC16 *

The median time from onset of fever to administration of antibiotics is 30 mins. Therefore your system will not allow us to record this value as you have requested in days.

PTC 1

PTC04: Proportion of patients with leukaemia who progress or relapse.

Numerator: PTC04 * Denominator: PTC04 * Value: PTC04 %

Reason for non submission

Comment: PTC04

PTC05: Proportion of patents with CNS tumours who progress or relapse.

Numerator: PTC05 * Denominator: PTC05 * Value: PTC05 %

Reason for non submission

Comment: PTC05

PTC06: Proportion of patients with non-CNS tumours who progress or relapse.

Numerator: PTC06 * Denominator: PTC06 * Value: PTC06 %

Reason for non submission

Comment: PTC06

PTC08: Proportion of eligible patients aged 0-15 recruited to a nationally available trial

Numerator: PTC08 * Denominator: PTC08 * Value: PTC08 %

Reason for non submission

Comment: PTC08

PTC09: Proportion of patients aged 0-15 completing treatment, who receive an end of treatment summary within 6 months of the end of treatment.

Numerator: PTC09 Denominator: PTC09 Value: PTC09 %

Reason for non submission

Comment: PTC09 *

Due to staffing issues in this area, the data we have is incomplete.

PTC16: Median time from onset of fever to administration of antibiotics in neutropenic fever in patients aged 0-15

Numerator: PTC16 *

Reason for non submission

Comment: PTC16

The median time in days is 0.02, but I am unable to submit data to two decimal places. This metric would be much better recorded in minutes. The median time in minutes is 31.

PTC 2

5.0 Service Scoping and Self-Assessment Review

A big project that our Quality Improvement Lead Nurse lead on this year was the regional benchmarking of all of our sites against the national service specification for children's cancer. A summary of the results from this can be seen on the next few pages.



Top 5 Areas of Regional Excellence

- Dedicated and commitment workforce with an above and beyond approach
- Engagement and participation of professionals within the newly formed NWCCODN
- Evident cross-organisational working of professionals
- Support Services and Charitable Sectors are fully integrated as valuable members providing essential support and provision to children, young people, immediate and extended families
- All Oncology patients have open access to POSCUs to ensure rapid review and interventions are completed within the expected timeframes. Compliance with the 'Golden Hour' treatment framework is monitored on an individual Trust basis



Top 5 Areas of Improvement

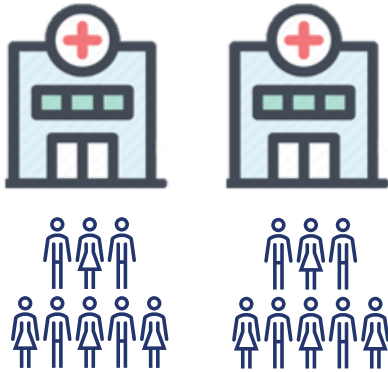
- Interoperability
- Access to Psychology Services
- Increased presence of Patient and Family Voice within Service Development and Forums
- Deep dive into the regional view of Children's Cancer Workforce and Training Needs Analysis
- Variation in Children's Community Nursing Team Provision and Palliative / EOL Care in certain parts of the ODN

Full regional report detailing the self assessment benchmarking process for our region against the NHSE Service Specification and all the results can be accessed via the members section of the NWCCODN website.

Provider Data

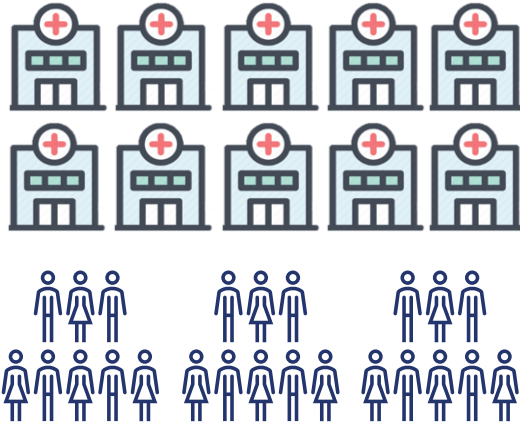
A spot-check of patient numbers across the region was undertaken during the site visits to POSCUs (April –June 2023) and average PTC patient numbers were obtained from Real World Health:

PTCs



300 to 400 new patients
diagnosed each year across the
two PTCs

POSCUs



148 active patients and 36 on surveillance

Facilities

Across the region there are the following facilities available to children being treated with cancer and their families:



302 inpatient beds



79 day case/assessment unit
beds/chairs



All of the PTCs and POSCUs
have beside parent
accommodation



6 outdoor play areas with
another 2 in development



All PTCs, POSCUs and Supra
network POSCUs have playrooms
There are also 8 sensory rooms

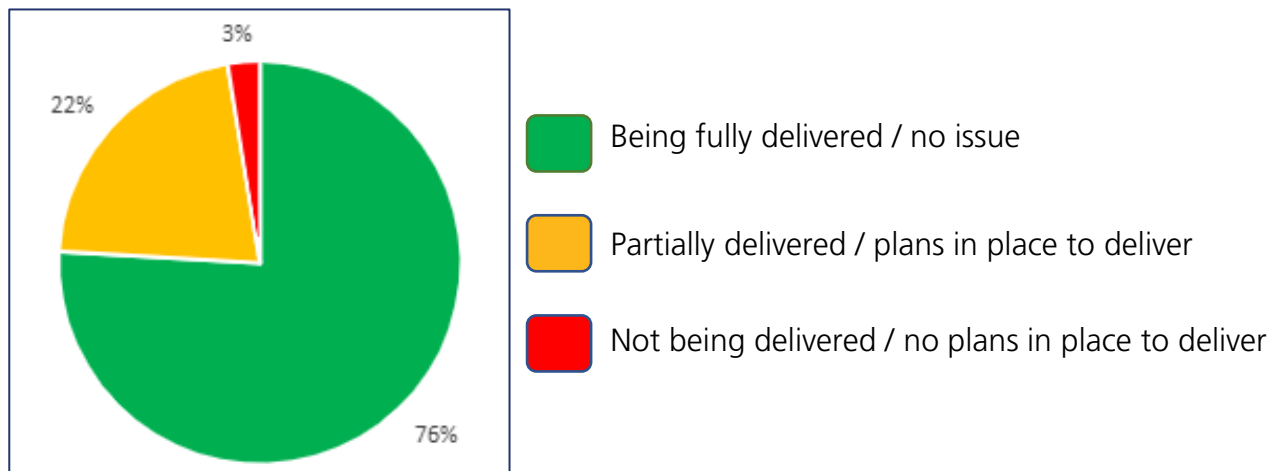


6 areas specifically
for teenage patients

Principal Treatment Centres

The pie chart demonstrates the combined PTCs results. From a regional perspective it demonstrates a compliance of 98% against the service specifications, with combined ratings of green and amber.

Further analysis of the findings highlights a 25% margin for improvement when focusing on the amber and red ratings; partially delivering and not delivering RAG ratings.



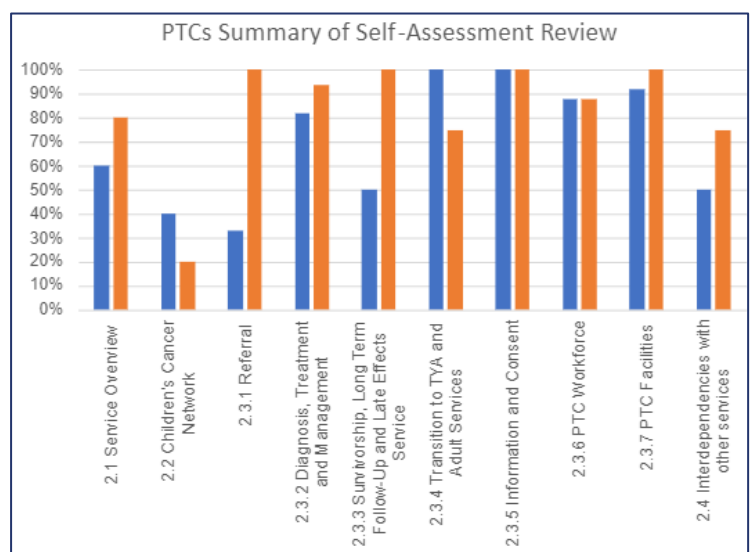
The results were analysed per section of standards. This is shown in the bar charts below; each colour represents a PTC.

PTCs similarly above 80% Compliance with Standards

- 2.3.2 Diagnosis, Treatment and Management
- 2.3.5 Information and Consent
- 2.3.6 PTC Workforce
- 2.3.7 PTC Facilities

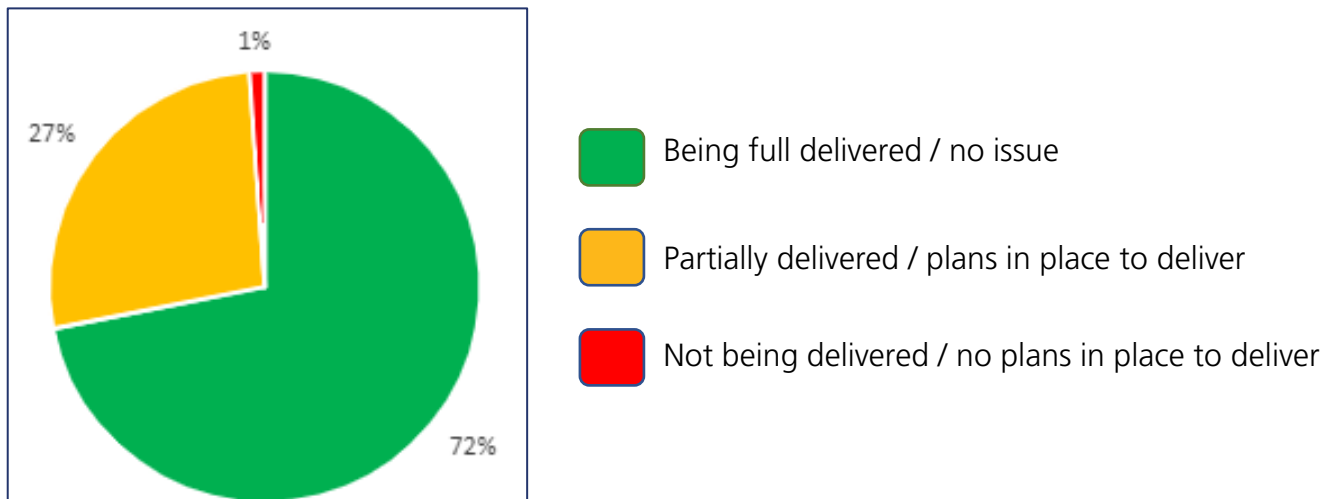
Areas of improvement and focus:

- 2.1 Service Overview
- 2.2 Children's Cancer Network
- 2.3.1 Referral
- 2.3.3 Survivorship, Long Term Follow-Up and Late Effects Service
- 2.3.4 Transition
- 2.4 Interdependencies



Paediatric Oncology Shared Care Units

Collation of POSCUs findings (excluding North Wales) showed a 72% compliance in meeting the service specification standards. There is a 27% margin of improvement with amber and 1% with red ratings.

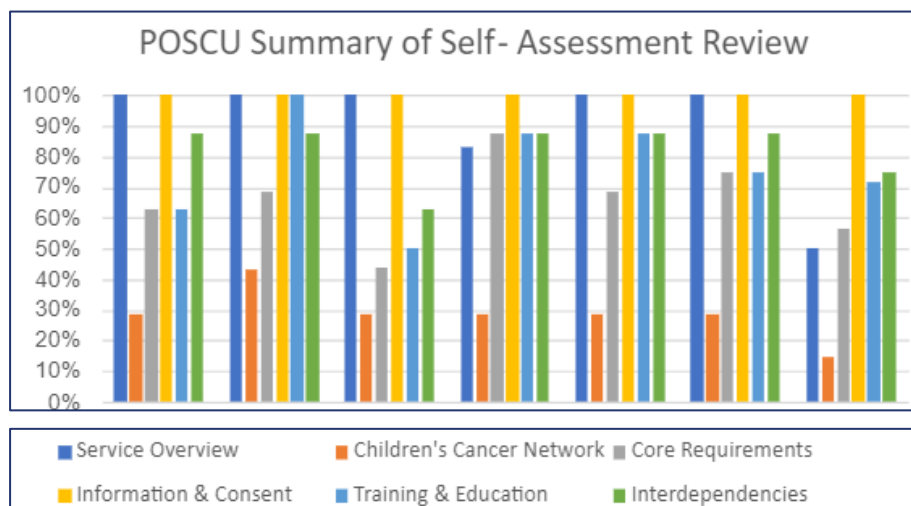


Shared learning and transparency is **recommended** across the POSCUs. There are secure platforms in place for these discussions to be had across teams and across organisations, particularly via the Network Oversight Group meeting and Children's Cancer Quality Groups which are both planned on a quarterly basis.

The bar chart below shows the results of 7 POSCUs, each colour represents a specific standard. For the purpose of this regional report, identification has been removed.

Common areas of focus with POSCUs:

- Children's Cancer Network
- Core requirements
- Training and Education
- Interdependencies



6.0 Achievements 2023/24

1st Children's Cancer regional conference March 2024 – 90 delegates, sponsored by GM Cancer Alliance



Patient and family Experience working Group set up and co-developed – U16 survey evaluation completed



Data and Digital Working group set up including task and finish groups. Use case for interoperability developed



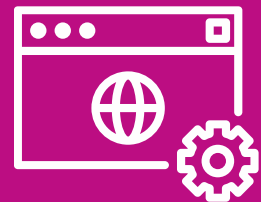
Data dashboard for NWCCODN developed & real world data report produced for region to understand current regional picture



Poster presentations accepted for CCLG conference focus on genomics and patient engagement



Website developed and launched, comms strategy developed, and regular newsletters distributed



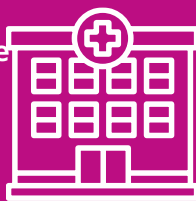
Network Strategy co developed and ratified Formal consultation undertaken



Band 7 Innovation Officer in post



Supported NHSE Transformation Programme – Cancer workshops, workforce survey drafted, patient engagement & service mapping



Support all POSCU and PTC to develop and implement QI plans based on SA against service spec



7.0 Key Priorities 24/25

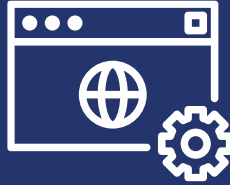
Support Long and shortlisting process for Transformation Programme



Develop easy read version of network strategy



Agree Performance Indicators/ Metrics for Network



Plan and hold annual conference March 2025- sponsored by C&M Cancer Alliance



Explore digital solutions and finance options re patient data sharing and pilot shared care record



Increase engagement and hear voice of underserved populations re CYP Cancer



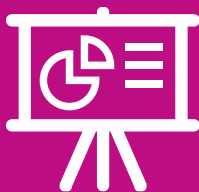
Map service pressures including genomics and day case capacity at PTC's



Scope mobile treatment options and support delivery of ambulatory care pilots



Complete workforce gap analysis and Training Needs Analysis for network



Support and monitor implementation of POSCU and PTC plans based on Self Assessment



8.0 Transformation Programme

The North West Children's Cancer Network continue to work very closely with, and input into, the North West NHSE Children's Transformation Programme. This programme aims to deliver real change for four workstreams within the North West via specialised commissioning. These workstreams are CYP Cancer, Paediatric Intensive Care, Surgery in children and Neonates. A case for change has been agreed nationally and has progressed through gateway 1 and the stages of



Appendix 1: Progress against 2023/24 work plan NWCCODN

Priority Area	Activities Planned	Progress	Improvement Outcomes	RAG Status
Access: Ensure equitable access to care for children with cancer across the North West	Conduct Whole System Review (POSCU and PTC baseline review against SS, site visits, inform NHSE Case for Change NW, baseline data and gap analysis) to inform improvement planning and needs analysis.	POSCU and PTC baseline review against service specification phase 1 and 2 completed, site visits undertaken. Baseline data collected analysed and regional report completed and signed off. Phase 3 site visits to commenced March 23 and completed.	Care is delivered closer to home which will improve the experience of care for children with cancer in the NW.	
	WGS, FP & Clinical Trial pathway review and gap analyses, to inform regional pathway development via working group.	3 of the 4 planned working groups have been set up to date. Equitable High Quality Care is the final WG and will be developed in 24/25	More children with cancer can access WGS, FP and access to clinical trials which will improve patient outcomes	
	Data sharing – make links via shared care record/develop options appraisal and date sharing agreement for regional data sharing	Links made with C&M and GM ICB re their shared care records. Test use case developed with NHSE national interoperability team. Ongoing exploration of options	Effective data sharing will improve cross-provider communication.	
	Develop clinical sub group to scope ambulatory and home care & joint MDTs & identify potential funding streams..	Task and finish group for ambulatory care set up and has started to work on Ambulatory care pilots in PTC's. This will form part of the new Equitable High Quality Care WG.	Pilots to deliver care closer to home will support effective delivery of care for families and will make a difference in terms of reducing travel. These will inform the TP and ODN going forward.	

Key:

Completed
 Ongoing
 Started but not complete
 Not started

Priority Area	Activities Planned	Progress	Improvement Outcomes	RAG Status
Quality: Ensure quality of care to children with cancer across the North West	Develop strategy and associated annual workplans for the NWCCODN including quarterly reporting into NWPPB & POC.	Reporting in to NWPPB & POC continues. Strategy developed and signed off. Easy read version planned. Annual workplans developed	Information gathering and gap analysis of current service delivery. Identification of improvement plans.	
	Develop research plan to identify blocks to opening trials and enable NW wide access to clinical trials.	Not yet started (focus for 2024/25).	Increased access to clinical trials research.	
	Undertake workforce mapping and training needs analysis for the region.	Started and drafted audits on hold awaiting DPIA via NHSE, will continue in 2024/25		
	Develop governance documents for NWCCODN.	All governance documents developed and signed off. To be signed via POSCU and PTC trusts		
	QI programme for POSCUs to develop improvement plans based on baseline data.	Conversations with POSCUs at site visits, Plans in place for all sites, completed.	PTC and POSCU improvement plans in place.	
	Develop NW CC Data Dashboard (metric reporting from PTCs and POSCUs). Travel data to be included.	Data Dashboard in development, continue to work on refining this in 2024/25. Travel data collated by NECS further analysis ongoing.	Development of Data Dashboard with NHSE/I NECs to collect and display data over a time.	

Priority Area	Activities Planned	Progress	Improvement Outcomes	RAG Status
Experience: Improve experience of care for children with cancer across the NW	Analysis of the U16 patient surveys at AH and RNCH. Produce improvement plan based on the findings.	Analysis of last two years of U16 survey completed. Improvement planning to be a focus for 2024/25 in addition of dissemination of findings.	Increased experience of care for children and families.	
	Scope PPI across the region and develop workshops for co-production.	Patient and Family engagement working group set up. Co developed with parent. Some scoping of Patient Public Involvement (PPI) groups undertaken, workshops planned to take place in March/April and What Matters To Me project.	Increased patient and family involvement.	
	Develop Network comms strategy plan.	Completed	Increased engagement professional and patient/family	
	Develop Network website and branding newsletters.	Website developed and live, Newsletters regularly distributed across network, social media channels set up and live.	Visible Network with website and branding	

Appendix 2: Proposed work plan 2024/25 NWCCODN

Working group	Priority area	Activities Planned	Quarter
Data & Digital	Access: Ensure equitable access to care for children with cancer across the North West	Develop & Agree KPI's for ODN, identify activity data and develop data dashboard	Q1 (June 2024)
	Access	Interoperability – digital solutions to be explored, further development of the test use case for CYP cancer	Ongoing
	Access	Scope finance options for interoperability	Q4 (Mar 2025)
	Access	Pilot shared care record	Q4 (March 2025)

Working Group	Priority Area	Activities Planned	Quarter
Equitable high-quality care	Quality: Ensure quality of care to children with cancer across the North West	Set up working group	Q2 (Sept 24)
	Quality	Service pressure mapping projects including Genomics audit and mapping	Q2 (sept 24)
	Quality	Work with and support the providers to implement positive changes via their SA work plans	Q2 (Sept 24)
	Access: Ensure equitable access to care for children with cancer across the North West	Scope mobile treatment options	Q3 (Dec 24)
	Access	Set up Ambulatory care pilots at PTC's & develop business to access funding for these	Q4 (March 25)
	Access	Work with NHSE to develop a 'long list', short list and preferred option to inform the transformation programme relating to Children's Cancer services	Q1 & Q2 (Sept 24)

Working Group	Priority Area	Activities Planned	Quarter
Workforce & Education	Quality: Ensure quality of care to children with cancer across the North West	Conduct a regional workforce gap analysis underpinned by the NHS Workforce Plan for children's cancer services across the NW	Q1 (June 24)
	Quality	Conduct a regional Training needs analysis (TNA) for children's cancer services across the NW	Q2 & Q3 (Dec 24)
	Quality	Develop regional pathways and protocols repository on the NWCCODN website, develop region wide pathways for RT, CAR- T etc	Q2 (Sept 24)
	Quality	CYP Accend Project	Q3 (Dec 24)
	Quality	Develop an educational programme across the NW for children's cancer services based on the results of the TNA	Q4 (Mar 25)
	Quality	Plan & hold regional annual conference (joint CYP & TYA) March 2025	Q4 (Mar 25)
	Access Ensure equitable access to care for children with cancer across the North West	Scope holistic support needs re CYP cancer care across NW	Q2 (Sept 24)

Working Group	Priority Area	Activities Planned	Quarter
Patient and Family Experience	Experience: Improve experience of care for children with cancer across the NW	CPES patient experience survey analysis and sharing	Ongoing
	Experience	Develop Patient and Family Engagement Strategy	Q2
	Experience	Understand and promote equality, diversity and inclusion	Ongoing
	Experience	Support patient and family engagement in NHSE Transformation Programme	Q1
	Experience	Scope accommodation options for families in relation to RT and Ambulatory Care Offer	Q2
	Experience	Collect analysis of 'you said we listened' approach – to inform service development from service user feedback	Q1