North West Children's Cancer
Operational Delivery Network

NW Children's Cancer ODN

Annual Report 2024/25

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North West Children's Cancer
Operational Delivery Network

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 8

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 15

6.0 Care Closer to Home Regional Project 18

7.0 Achievements 2023/24 19

8.0 Key Priorities 2024/25 20

9.0 NHSE Safe and Sustainable Programme (TP) 21

Appendix 1: Progress against workplan 2023/24 22

Appendix 2: Workplan 2024/25 23

Appendix 3: Genomics Abstract 2025 27

Appendix 4 : PTC Specific Data 2024/25 28

Appendix 5: CTYA Cancer Conference Evaluation 31

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 2024/25. The NWCCODN is a maturing network and has developed rapidly over the 2.5 years since its inception in October 2022. This report covers the period 1st April 2024 to the 31st March 2025. The network has grown as a team and the relationships with partner organisations across the region.

We have a clear strategy document which sets a vision and mission for the network going forward. This was co developed and had input from professionals working in the region and families. We have developed an easy read version of the strategy to ensure accessibility, this is available on the NWCCODN website.

We now have 4 established working groups to continue to progress our aims and objectives and to deliver our annual workplan (which you can find in the appendices). The working groups include Workforce and Education, Data and Digital, Parent and Family Experience and most recently Equitable High Quality Care. We have had a fantastic response to these and have had really great engagement from across the region. We are pleased to report that this year we accessed funding from the three regional cancer alliances (C&M, GM and L&SC) to deliver a proof of concept project to bring care closer to home for children and young people across the region. The delivery of this will be a priority focus for the network in the coming year.

We held our second regional Children and Teenage Young Adult Cancer Conference in March 2025 which was sponsored by the Cheshire and Mersey Cancer Alliance. This is a partnership approach between the NWCCODN, The TYA Cancer ODN and the 3 Cancer Alliances. We had excellent attendance to the conference with 139 delegates, speakers, lived experience representatives and exhibitors. We were able to develop and increase capacity for 2025 due to increased interest. The NWCCODN were invited to open the national CCLG conference this year (2025) with a plenary session on delivering Care Closer to Home delivered to circa 750 delegates. We also presented the work we have been doing on Whole Genome Sequencing (see abstract in appendix 3). This details an increase in numbers of children having access to WGS and a reduction in the turnaround time for testing which were highlighted as issues by the ODN last year following their audit.

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 currently exist). We are continuing to work with the NHSE Business Intelligence team to develop the first regional children's cancer data dashboard in England. We have developed the dashboard and are currently validating the data it contains. We will be focussing on developing the health inequalities section of the dashboard and a coding strategy. .

The data contained within this report is from national datasets including QSIS, the National Cancer registry and regional HES data in addition to the dashboard.

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

North West Children's Cancer
Operational Delivery Network

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

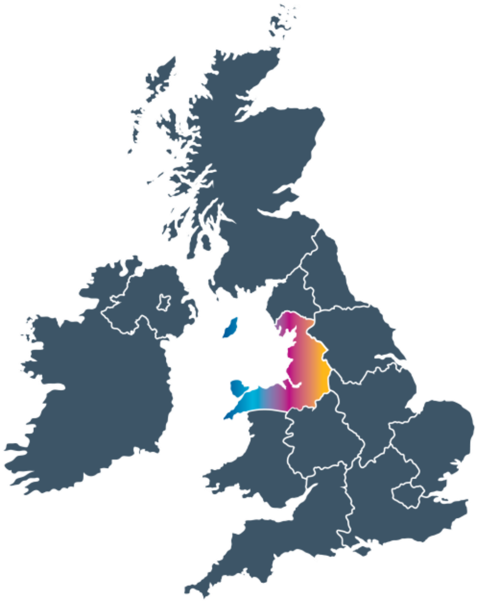
Andrea Doherty
Commissioner & Co Chair

Laurie Niland
PMO Project Officer

Jane Elsey
Lead Nurse PTC

Caroline Bains
Lead Nurse PTC

2.2 The Network



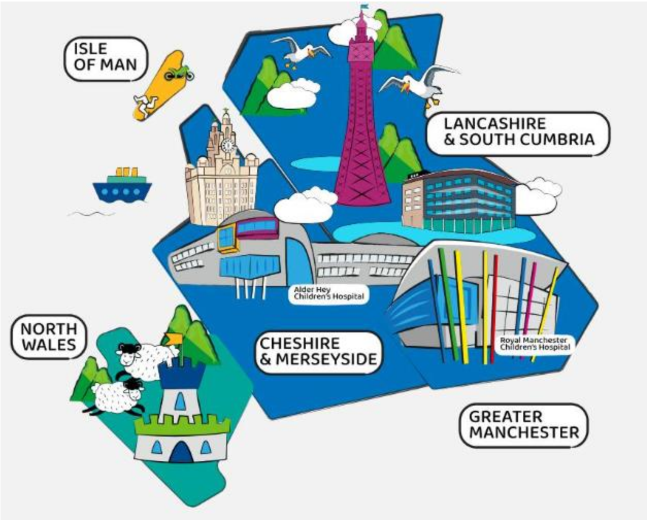


Diagram 1: Map of NW Region

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. A recent report by Young Lives Vs Cancer (Running on Empty) suggested that children in our region are travelling on average a 4 hour round trip to access treatment.

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 especially in light of the current financial and political climate.

Patient voice is important within our network and continues to drive the work that we do through the patient and family experience group and the U16 CPES survey analysis.

2.3 Provider Organisations

Provider	Trust	Integrated care board (ICB)	Status
Alder Hey Children Hospital	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 supra network POSCU*
Ysbyty Gwynedd	North West Wales NHS Trust	North Wales Health Board	Standard supra network POSCU*
Ysbyty Glan Clwyd	North West Wales NHS Trust	North Wales Health Board	Standard Supra Network POSCU*
Royal Manchester Childrens Hospital	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 Infirmary	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 therefore come directly to RMCH for all of their treatment. Currently all of the POSCU’s within the region are standard level. POSCU level designation within the region is being considered as part of the NHSE Safe and Sustainable Programme (previously transformation programme).

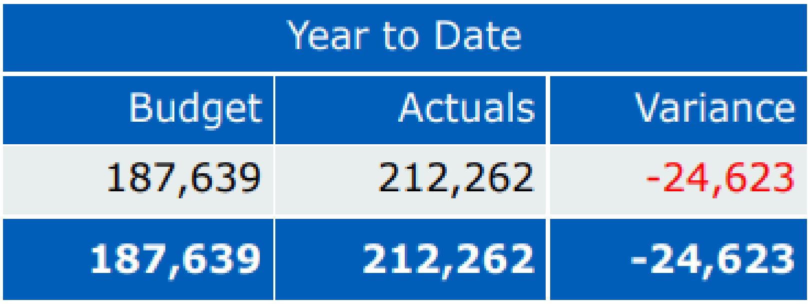
3.0 Governance

3.1 Budget – Spend against income

The NWCCODN is funded by regional NHS England and had income of £187,639 for the year 1st April 2024 to the 31st March 2025.

We had £50,000 slippage from the previous year (2023/24 due to internal spending delays. The NWCCODN is overspent by £24,623 this year to mitigate against some of this.

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.



Year to Date		
Budget	Actuals	Variance
187,639	212,262	-24,623
187,639	**212,262**	**-24,623**

3.2 Risks

Top 3 risks for the network currently

ODN finance	Risk	Current political and financial situation with NHSE potential to affect the ODN finance	15
ODN finance	Issue	Not all our finance requisitions were signed off and processed in time for year end which means there is a possibility we will be overspent this year as items come out of this years budget that were identified for last financial year	15
Safe and Sustainable Programme (TP)	Risk	Uncoupling the 4 workstreams and only progressing neonates via the formal gateway NHSE Service Transformation Process. Risks to CYP Cancer re: finance, access to NHSE support, Delayed business case development, lack public consultation - risk of legal challenge to any service development.	12

3.3 Governance Structure

The NWCCODN is governed by the Network Oversight Group (NOG) and NHSE Specialised commissioning. All North West provider Trusts of children's cancer services form the working groups (sub groups) of the NWCCODN. Each working group 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 we are in discussion with the regional ICB's following delegation as to how we directly report.

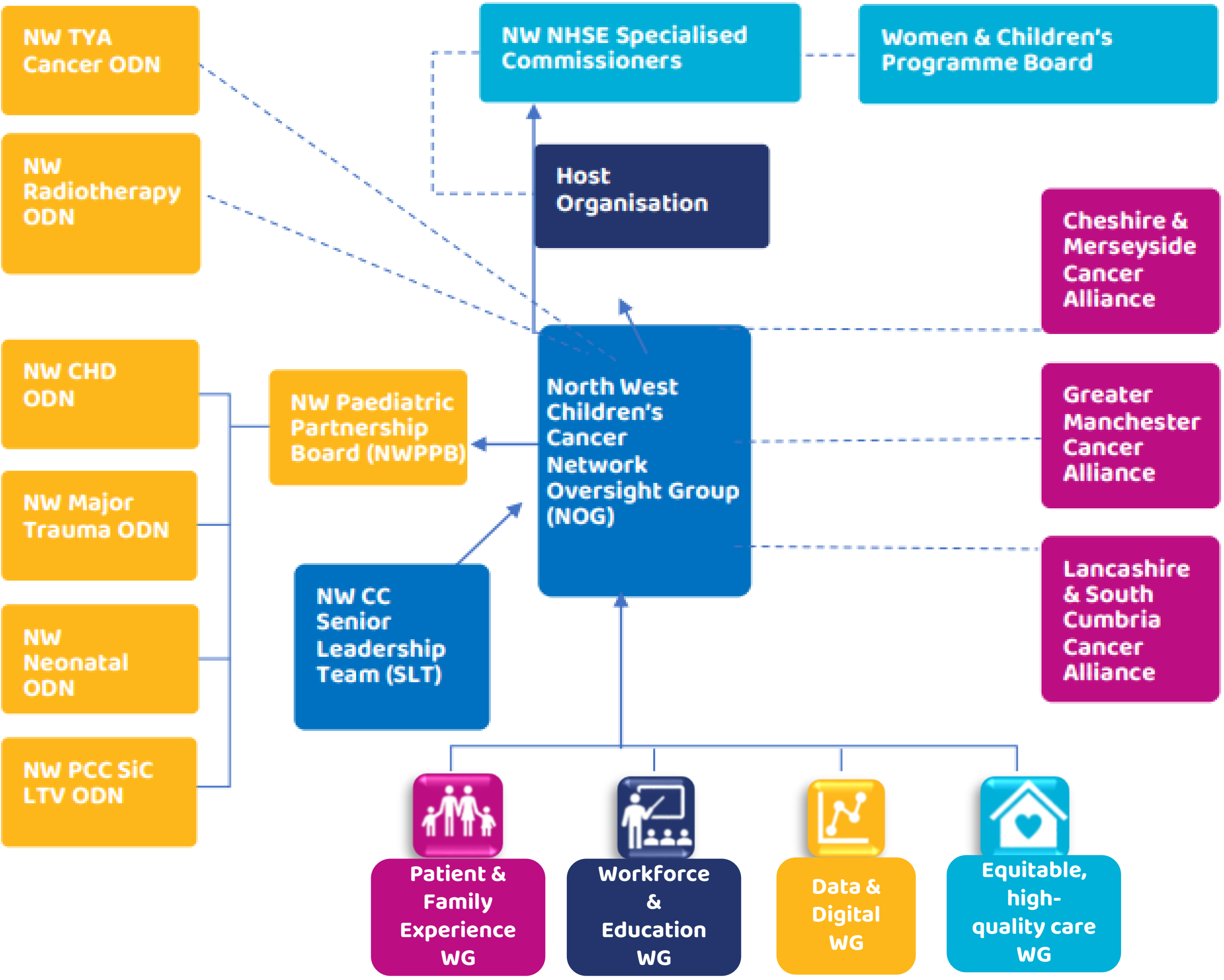


Diagram 2: Overarching governance structure

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 rising 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.

*data from national Census 2021, WHO, NECS, & CCLG -Source Realworld Regional Baseline Report 2023

4.2 Regional Data

There are several data sets required from cancer services within our region 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. Providers 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. The NWCCODN continue to work with the NHSE BI team to update and develop the bespoke data dashboard to support services in activity mapping and for use in the current NHSE CYP Transformation project.

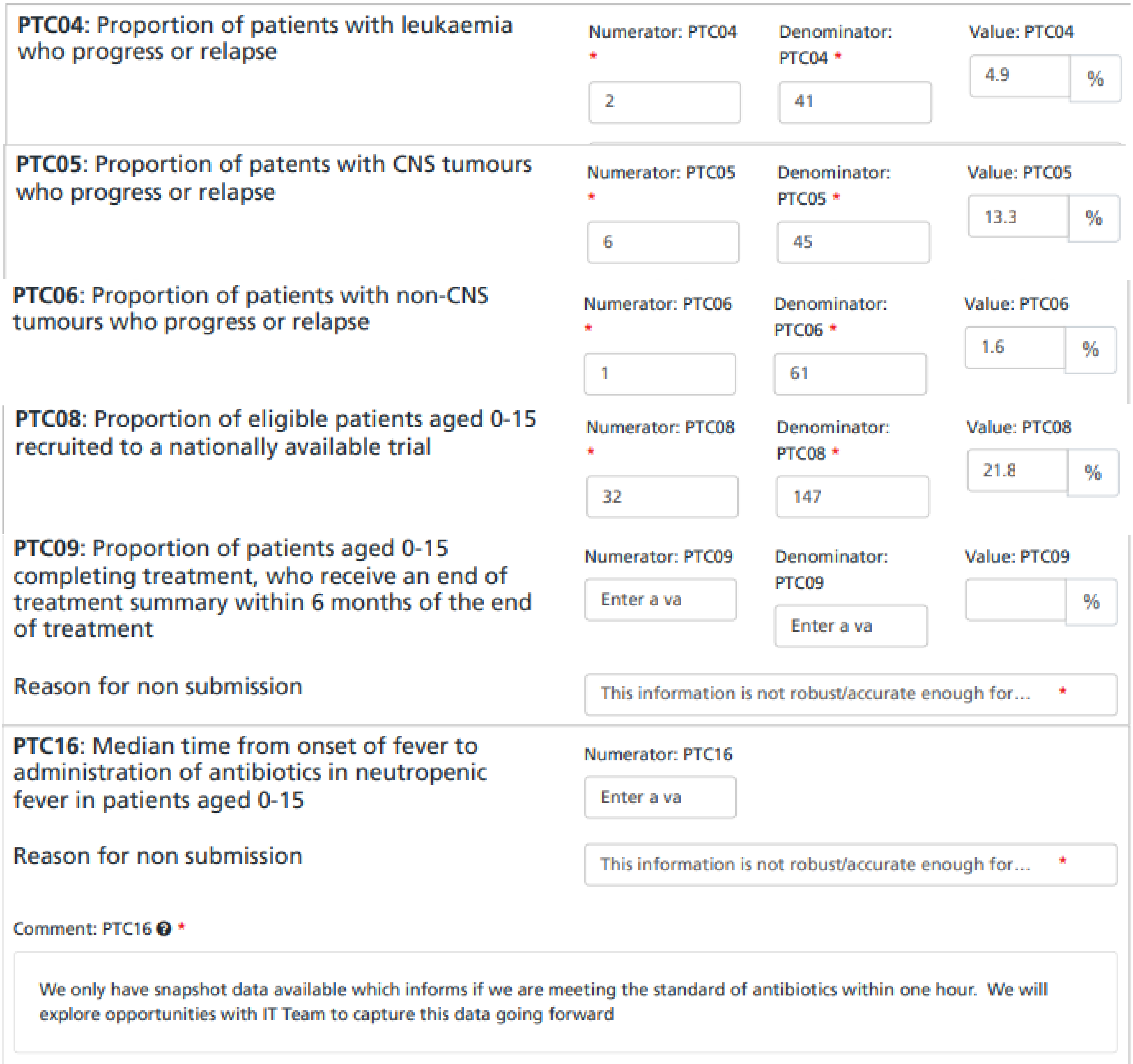
Within the region there is a higher proportion of Leukaemia prevalence in Greater Manchester area than seen nationally across all genders. Within Lancashire & South Cumbria malignant cancers excluding non-melanoma skin cancers has a higher prevalence than nationally, this is also seen within <16 year 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 requirement. See results on the next page for the year 24/25:

*data from national Census 2021, WHO, NECS, & CCLG -Source Realworld Regional Baseline Report 2023

4.3 PTC 1 SSQD Submission for 2024 (covering April 2023 – March 2024)



PTC04: Proportion of patients with leukaemia who progress or relapse

Numerator: PTC04 * 2
Denominator: PTC04 * 41
Value: PTC04 4.9 %

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

Numerator: PTC05 * 6
Denominator: PTC05 * 45
Value: PTC05 13.3 %

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

Numerator: PTC06 * 1
Denominator: PTC06 * 61
Value: PTC06 1.6 %

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

Numerator: PTC08 * 32
Denominator: PTC08 * 147
Value: PTC08 21.8 %

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 Enter a va
Denominator: PTC09 Enter a va
Value: PTC09 %

Reason for non submission: This information is not robust/accurate enough for... *

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

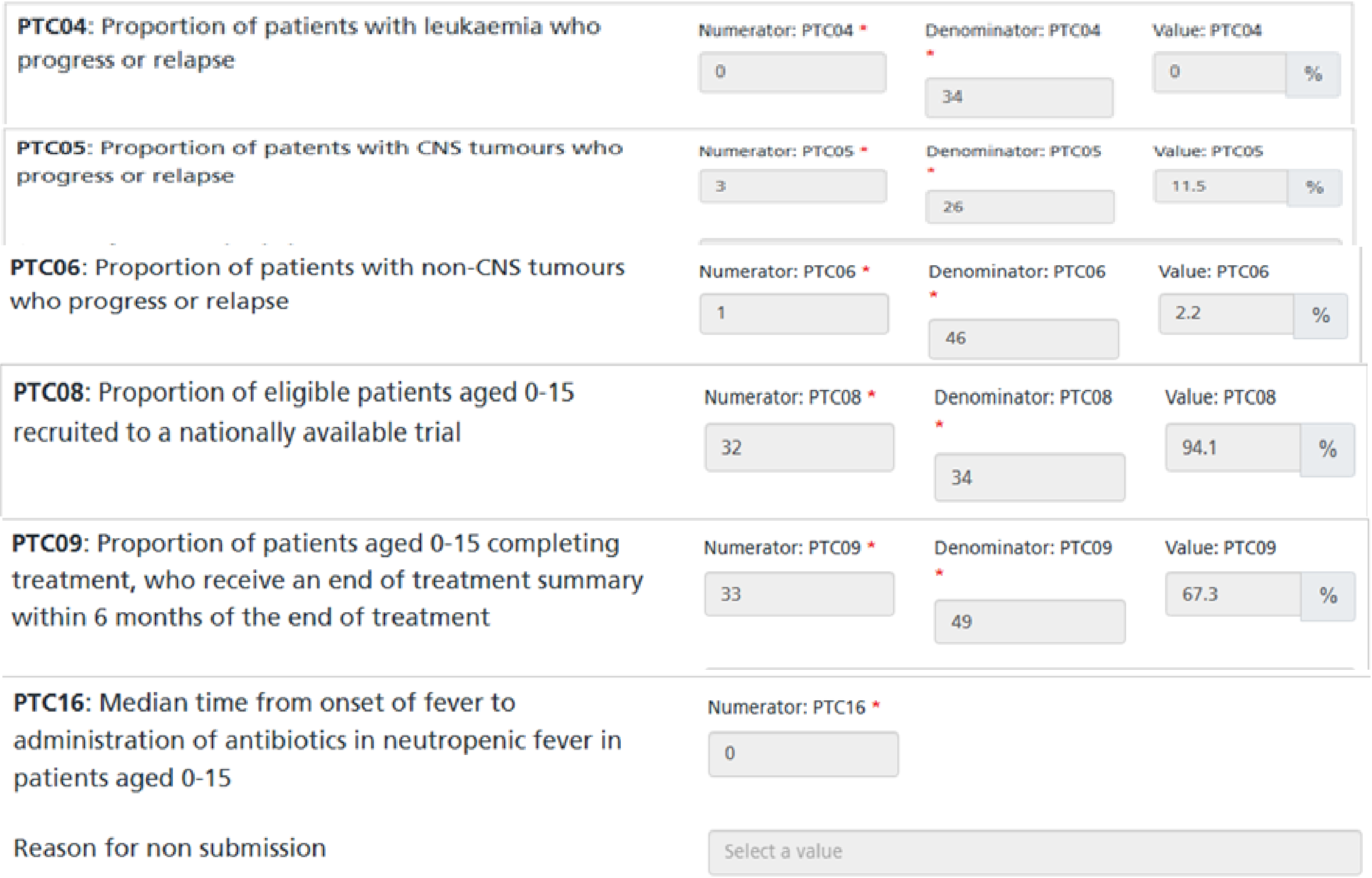
Numerator: PTC16 Enter a va

Reason for non submission: This information is not robust/accurate enough for... *

Comment: PTC16 ? *

We only have snapshot data available which informs if we are meeting the standard of antibiotics within one hour. We will explore opportunities with IT Team to capture this data going forward

4.4 PTC 2 SSQD Submission *(this is the submission from June 2024 Covering April 2023- March 2024)*



PTC04: Proportion of patients with leukaemia who progress or relapse

Numerator: PTC04 * 0

Denominator: PTC04 * 34

Value: PTC04 0 %

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

Numerator: PTC05 * 3

Denominator: PTC05 * 26

Value: PTC05 11.5 %

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

Numerator: PTC06 * 1

Denominator: PTC06 * 46

Value: PTC06 2.2 %

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

Numerator: PTC08 * 32

Denominator: PTC08 * 34

Value: PTC08 94.1 %

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 * 33

Denominator: PTC09 * 49

Value: PTC09 67.3 %

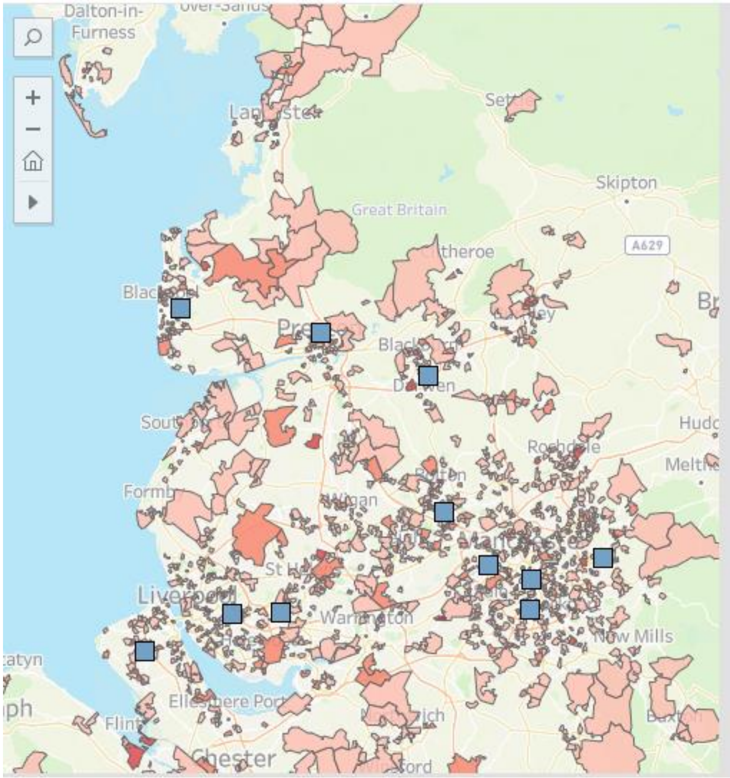
PTC16: Median time from onset of fever to administration of antibiotics in neutropenic fever in patients aged 0-15

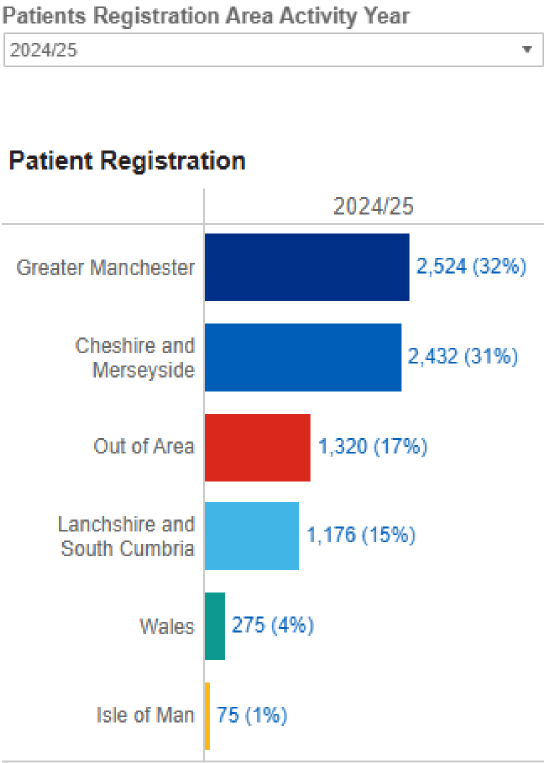
Numerator: PTC16 * 0

Reason for non submission

4.5 NWCCODN Regional Data Dashboard

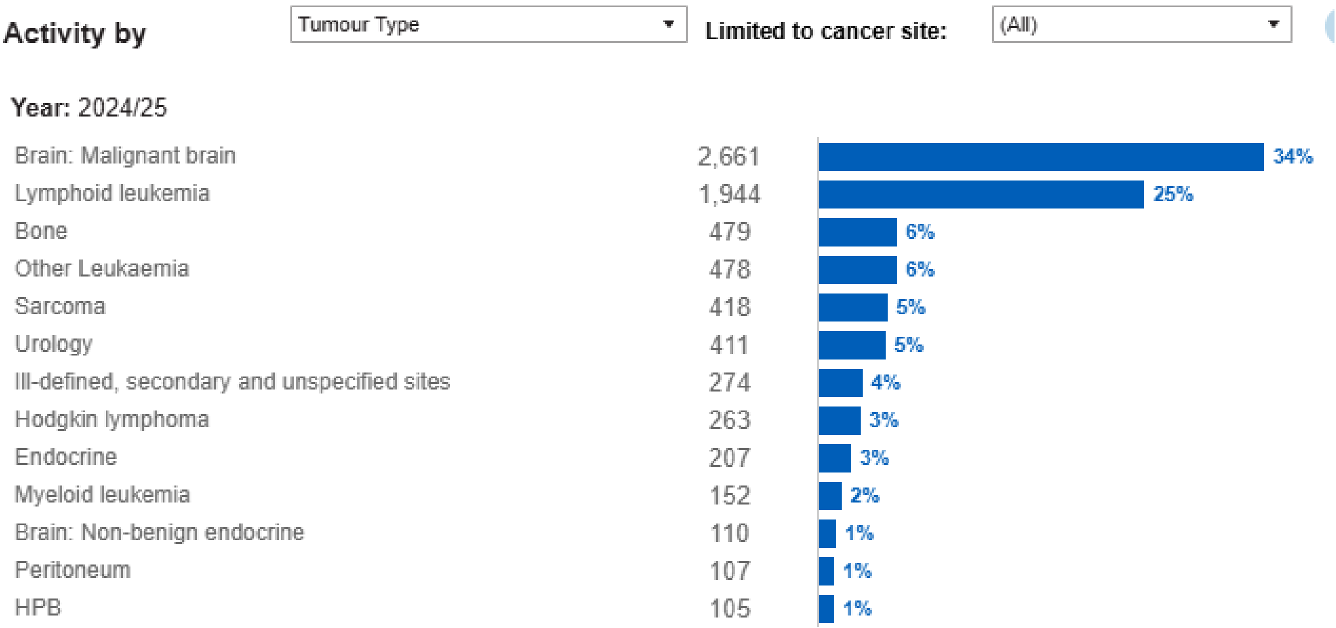
The NWCCODN (BI NHSE) Dashboard utilises SUS data from all providers in our region. For the year 2024/25 there were 605 Unique Patients aged 0-15 treated for cancer in the two PTC's.
For the age range 16-19 there were 78 unique patients treated in the region. (please note there is a time lag on the data so this is not a full year (relates to Apr – Feb only).





Map showing patient (0-15 years) spread geographically for the years 2021- 2025

Graph of patient activity (0-15 years) for 2025 by locality



Activity by: Tumour Type
Limited to cancer site: (All)

Year: 2024/25

Brain: Malignant brain	2,661	34%
Lymphoid leukemia	1,944	25%
Bone	479	6%
Other Leukaemia	478	6%
Sarcoma	418	5%
Urology	411	5%
Ill-defined, secondary and unspecified sites	274	4%
Hodgkin lymphoma	263	3%
Endocrine	207	3%
Myeloid leukemia	152	2%
Brain: Non-benign endocrine	110	1%
Peritoneum	107	1%
HPB	105	1%

Graph of patient activity (0-15 years) for 2025 by tumour type for the region
Please see appendix 4 for detailed data by PTC for 2024/25.

5.0 Self-Assessment against Service Specification & Standards

All the regional POSCU and PTC’s continue to monitor their progress against the national service specification. The NWCCODN undertook a series of site visits throughout the year to update their work plans and demonstrate progress.

The programme of work is led by QI Lead Nurse, NWCCODN, and supported by the wider SLT. It is a 3-year cyclical process. The roadmap below highlights the current stage is Stage 7 which involves:

- Completion of Annual Site Visits
  - Year 1 = 2023
  - Year 2 = 2024
  - Year 3 = 2025 * *process re-sets every 3 years (2026)*

The site visits each year review the below:

- Discussion of successes and challenges
- Review of progress of Development Plan in line with Service Specifications (2021)
- Update RAG ratings & graphical visuals representing progress
- Complete yearly report updates into NOG

RoadMap

Initiation & Planning 2022
Y1 2023
Y2 2024
Y3 2025

1. Initiation & Planning 2022

2. Roll Out
- Communications
- Virtual Drop ins
- Dedicated Facilitator
- Phased approach
  - PTCs (P1) & POSCUs (P2)
  - N.Wales POSCUs (P3)

3. Data Collection
- Completion of Templates
- Gathering of information via virtual meetings, face to face meetings & drop in sessions
- Facilitation support

4. Analysis
- Analysis of information
- Recognition of themes
- Master Document incl. Graphical Data
- RAG Ratings
- Creation of provider specific development plans

5. Reporting
- Creation of Provider Specific Reports
  - 2 x PTCs; 7 x POSCUs; 1 Combined North Wales report (incl. reference to recent Peer Review)
- Providers to review reports and Feedback edits/comments
  - Finalise Provider Specific Reports
  - Finalise Provider Specific Development Plans

6. Regional Report
- Completion of Regional Report (2024) – network viewable (incl. CAs, ICBS & regional NHSE)
- Common themes
- Key Successes & Challenges
- Recommendations (influence ODNs work plan and working group actions)

7. Yearly R/V of Quality and Performance
- Completion of Annual Site Visits to providers
- Discussion of successes and challenges
- Review of progress of Development Plans in line with Service Specs.
- Update RAG ratings & graphical visuals showing progress
- Complete yearly report updates into NOG
- Programme of Work re-sets in 2026 (3yearly cycle)

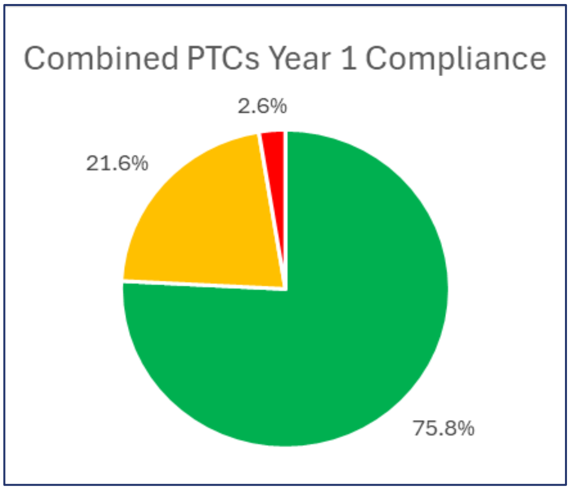
There are ratified documents for further information which should be read in conjunction to this annual report (NWCCODN Regional Service Scoping & Self-Assessment Report (CL, 2023)). All providers received a detailed Y1 Specific Service Scoping & Self-Assessment Report (CL, 2023) and progress reports each year (Y1, Y2 and Y3) following development plan reviews.

PTCs Performance

Year 1 (2023)

The pie chart (top right) demonstrates the combined PTCs results. From a regional perspective it demonstrates a compliance of 75.8% against the service specifications, fully delivered (green).

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.



🟩 Being fully delivered / no issue

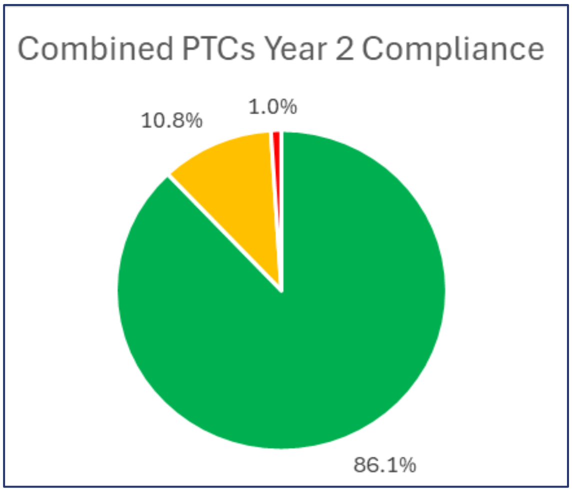
🟨 Partially delivered / plans in place to deliver

🟥 Not being delivered / no plans in place to deliver

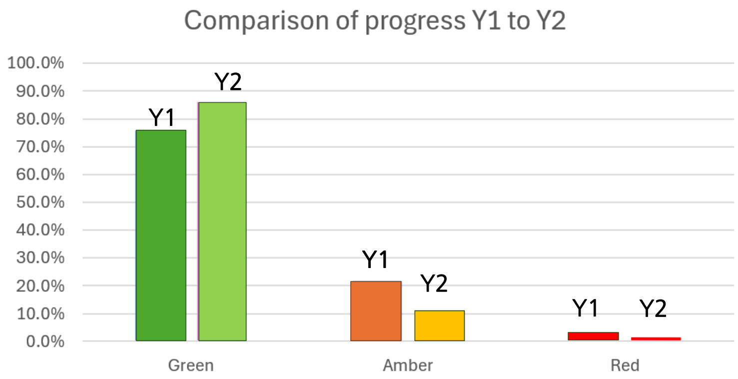
Year 2 (2024)

The pie chart (middle right) demonstrates the combined PTCs results for the Y2 review. There is a compliance of 86.1% against the service specifications, fully delivered. An overall improvement of standards being fully delivered by 10.3%.

Further analysis of the findings highlights a 12% margin for improvement when focusing on the amber and red ratings; partially delivering and not delivering RAG ratings.



An alternative view is shown in the bar chart below, showing an increase in Y1 and Y2 for green by 10.3%, a reduction in both amber and red ratings by 12.4%.



	Green	Amber	Red
Y1	75.8%	21.6%	2.6%
Y2	86.1%	10.8%	1.0%
	⬆	⬇	⬇

POSCUs Performance

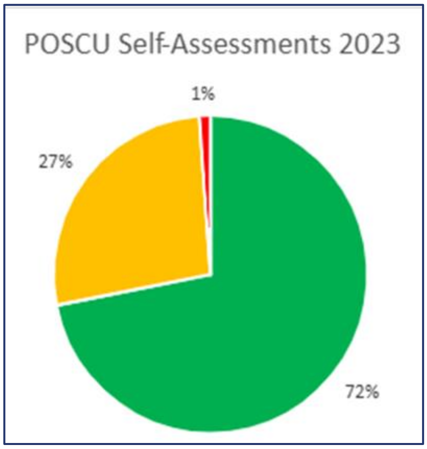
Year 1 (2023)

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.

🟩 Being fully delivered / no issue

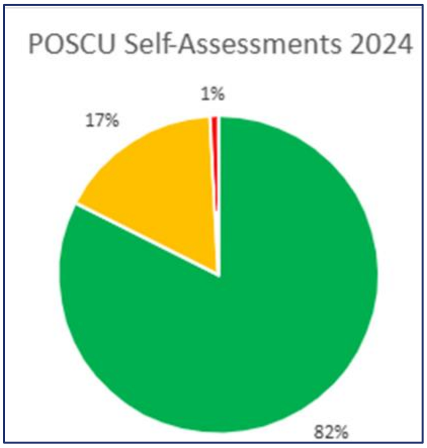
🟨 Partially delivered / plans in place to deliver

🟥 Not being delivered / no plans in place to deliver

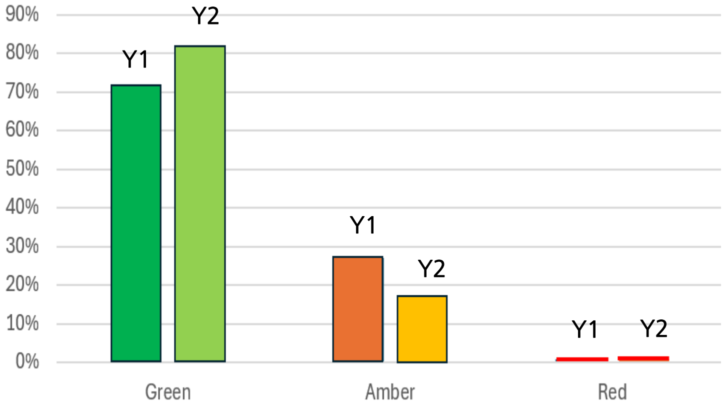


Year 2 (2024)

Following a review across the POSCUs, there is an overall improvement of 10% for standards being fully delivered. There is an improvement range of 18% which remains and has informed the development plans for Y2 to Y3.



An alternative view is shown in the bar chart below, showing an increase in Y1 and Y2 for green by 10%, a reduction in both amber and red ratings by 10%.



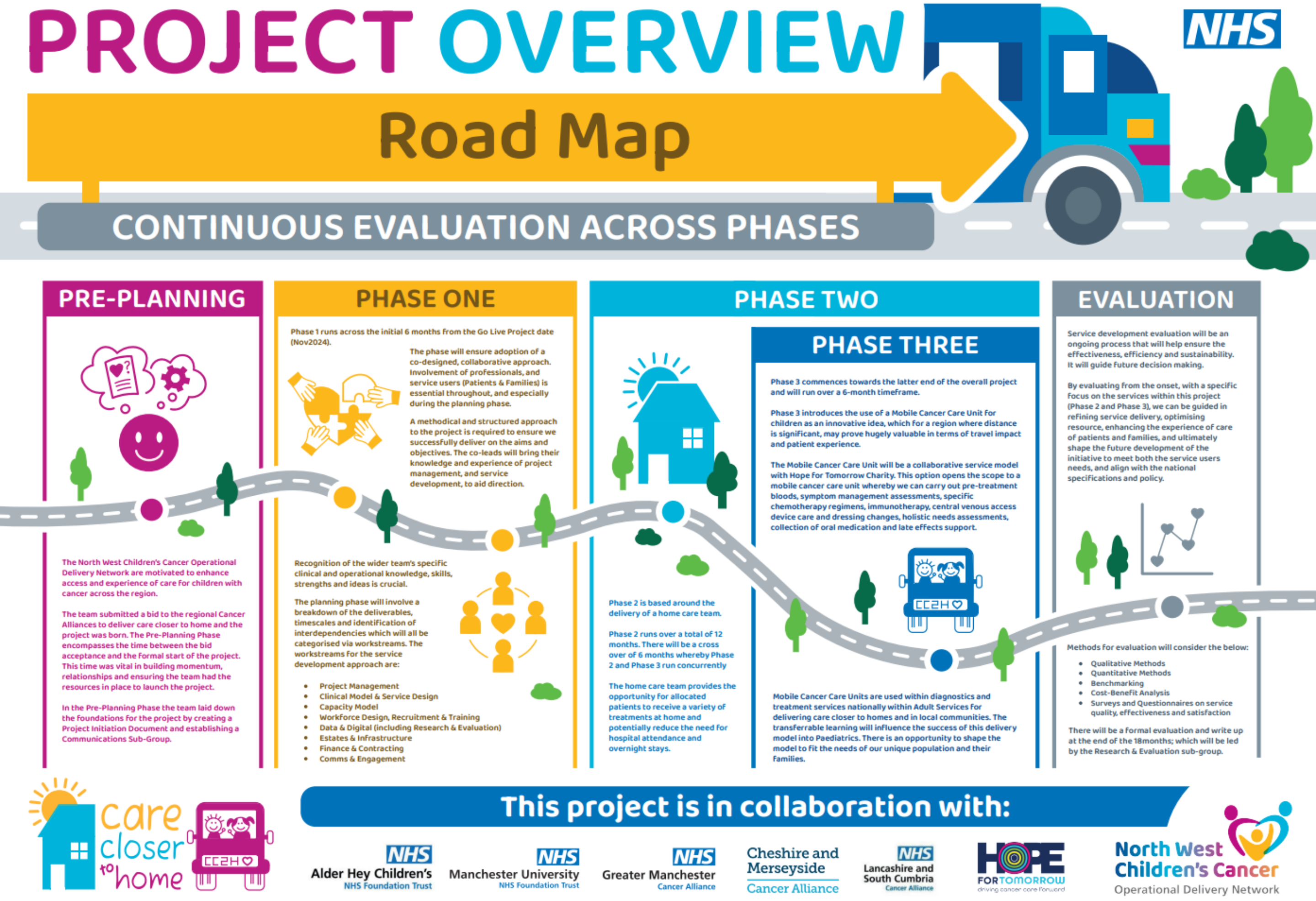
	Green	Amber	Red
Y1	72%	27%	1%
Y2	82%	17%	1%
	↑	↓	=

Summary

The assessment of providers against the service standards reveals areas of strength and development opportunities. Engagement across all providers has been crucial in undertaking a thorough assessment process. Thank you to all providers, and individuals, for their dedication and continued efforts to improve service delivery and maintain delivery of high quality, family-centered care. Year 3 site visits are currently being organised and we look forward to those in the near future.

6.0 Care Closer To Home

This Proof of Concept project aims to increase focus on the delivery of supportive care and chemotherapy closer to home, either in the home environment or via the Mobile Cancer care Unit at a location close to the patients home. This project has been jointly funded by the three Cancer Alliances in the region and is being delivered in collaboration with Alder Hey Children's Hospital and Royal Manchester Children's Hospital.



PROJECT OVERVIEW

Road Map

CONTINUOUS EVALUATION ACROSS PHASES

PRE-PLANNING

The North West Children's Cancer Operational Delivery Network are motivated to enhance access and experience of care for children with cancer across the region.

The team submitted a bid to the regional Cancer Alliances to deliver care closer to home and the project was born. The Pre-Planning Phase encompasses the time between the bid acceptance and the formal start of the project. This time was vital in building momentum, relationships and ensuring the team had the resources in place to launch the project.

In the Pre-Planning Phase the team laid down the foundations for the project by creating a Project Initiation Document and establishing a Communications Sub-Group.

PHASE ONE

Phase 1 runs across the initial 6 months from the Go Live Project date (Nov2024).

The phase will ensure adoption of a co-designed, collaborative approach. Involvement of professionals, and service users (Patients & Families) is essential throughout, and especially during the planning phase.

A methodical and structured approach to the project is required to ensure we successfully deliver on the aims and objectives. The co-leads will bring their knowledge and experience of project management, and service development, to aid direction.

Recognition of the wider team's specific clinical and operational knowledge, skills, strengths and ideas is crucial.

The planning phase will involve a breakdown of the deliverables, timescales and identification of interdependencies which will all be categorised via workstreams. The workstreams for the service development approach are:

- Project Management
- Clinical Model & Service Design
- Capacity Model
- Workforce Design, Recruitment & Training
- Data & Digital (including Research & Evaluation)
- Estates & Infrastructure
- Finance & Contracting
- Comms & Engagement

PHASE TWO

Phase 2 is based around the delivery of a home care team.

Phase 2 runs over a total of 12 months. There will be a cross over of 6 months whereby Phase 2 and Phase 3 run concurrently

The home care team provides the opportunity for allocated patients to receive a variety of treatments at home and potentially reduce the need for hospital attendance and overnight stays.

PHASE THREE

Phase 3 commences towards the latter end of the overall project and will run over a 6-month timeframe.

Phase 3 introduces the use of a Mobile Cancer Care Unit for children as an innovative idea, which for a region where distance is significant, may prove hugely valuable in terms of travel impact and patient experience.

The Mobile Cancer Care Unit will be a collaborative service model with Hope for Tomorrow Charity. This option opens the scope to a mobile cancer care unit whereby we can carry out pre-treatment bloods, symptom management assessments, specific chemotherapy regimens, immunotherapy, central venous access device care and dressing changes, holistic needs assessments, collection of oral medication and late effects support.

Mobile Cancer Care Units are used within diagnostics and treatment services nationally within Adult Services for delivering care closer to homes and in local communities. The transferrable learning will influence the success of this delivery model into Paediatrics. There is an opportunity to shape the model to fit the needs of our unique population and their families.

EVALUATION

Service development evaluation will be an ongoing process that will help ensure the effectiveness, efficiency and sustainability. It will guide future decision making.

By evaluating from the onset, with a specific focus on the services within this project (Phase 2 and Phase 3), we can be guided in refining service delivery, optimising resource, enhancing the experience of care of patients and families, and ultimately shape the future development of the initiative to meet both the service users needs, and align with the national specifications and policy.

Methods for evaluation will consider the below:

- Qualitative Methods
- Quantitative Methods
- Benchmarking
- Cost-Benefit Analysis
- Surveys and Questionnaires on service quality, effectiveness and satisfaction

There will be a formal evaluation and write up at the end of the 18months; which will be led by the Research & Evaluation sub-group.

This project is in collaboration with:

Alder Hey Children's NHS Foundation Trust
Manchester University NHS Foundation Trust
Greater Manchester Cancer Alliance
Cheshire and Merseyside Cancer Alliance
Lancashire and South Cumbria Cancer Alliance
HOPE FOR TOMORROW driving cancer care forward
North West Children's Cancer Operational Delivery Network

The team are currently in Phase One (Planning Phase) having set up monthly Steering Group meetings, PTC Project Team meetings and other sub-groups feeding into an agreed governance structure via the NOG. The team have selected and started working through a service development structure to prepare for Phase 2 (Home Care) go live.

The team intend to nurture a co-development approach having facilitated professional workshops and engaged with patients and families via numerous onsite visits and virtual meetings. For more information visit the website or contact the team via the info.nwccodn@mft.nhs.uk

7.0 Achievements 2024/25

2nd Childrens Cancer regional conference March 2025 – 140 delegates, sponsored by C&M Cancer Alliance *(See appendix 5 for evaluation summary)*

Development of Henry's Wi-FI legacy digital story to try improve WiFI for CYP with Cancer in hospitals

Workforce audit for PTC's completed & Training Needs Analysis (TNA) completed for region.

Data dashboard for NWCCODN developed & data validation exercise completed with PTC and POSCU's. Demo of dashboard.

NWCCODN headlined CCLG conference with CC2H panel session and poster presentation demonstrating genomics audit (increased numbers of WGS in region)

ICB's have worked with us based on our use case to access funding to pilot a shared care record for CYP cancer.

Easy read version of Network Strategy developed and available on the website to enable accessibility

Successful funding bid for Care Closer to Home (CC2H) proof of concept. Project launched Nov 24.

Supported NHSE Transformation Programme – Long listing and modelling of options. Supported site visits with Estates team.

Support all POSCU and PTC to update and implement QI plans based on SA against service spec. Demonstrable improvements

8.0 Key Priorities 25/26

Support Long and shortlisting process for Safe and Sustainable Programme (TP) with modelling

Develop a bank of patient stories

Develop a data and coding strategy for CYP cancer and undertake deep dive on health inequalities

Plan and hold annual conference March 2026- sponsored by L&SC Cancer Alliance

Pilot Shared Care record for CYP cancer – led by ICB's

Develop a you said we listened approach to patient engagement

Support VR innovations for CYP cancer.

Deliver Care Closer to Home Pilot

Develop a North West Children's Education and Training Programme based on the TNA results.

Review Self Assessment against Service specification Process

9.0 NHSE Safe and Sustainable Programme (Previously The NHSE Regional 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, newly termed the Safe and Sustainable Programme. This programme aims to deliver real change for three uncoupled workstreams within the North West via specialised commissioning. These workstreams are CYP Cancer, Paediatric Intensive Care and Surgery in Children. Neonates will continue the formal transformation programme route. A case for change has been agreed nationally and the programme has progressed to gateway 1. To move to gateway 2 the programme has uncoupled and separated the workstreams to enable neonates to progress on the formal process and the other workstreams including CYP cancer to progress via the quality improvement route.

The implications of this for the CYP cancer element are that there will no longer be a requirement for us to meet key milestones such as formal gateway. NHSE will however continue to lead the development of a Quality Improvement programme regarding Children's Cancer in the region which will utilise the evidence available through the dashboard to enable modelling of delivery of care. This will include modelling options regarding the possible development of enhanced POSCU's, the development of additional standard POSCU's and the delivery of care closer to home using the evaluation of the proof-of-concept model that the NWCCODN are working on. This is to address the need for change identified in the original case for change based on the new service specification development. In our region we do not have any enhanced POSCU's offering enhanced shared care, there is an over capacity issue within the PTC's and children are having to travel significantly to access their care currently. All of these issues are to be considered within the modelling of options. An options appraisal will be developed based on data modelling of the options and a demand and capacity assessment of the PTC’s will also be undertaken to inform a short list and clear recommendations. These will be developed for the regions ICB's and specialised commissioning to consider.

North West Children's Cancer
Operational Delivery Network

Appendix 1: Progress against 2024/25 work plan NWCCODN

RAG KEY
🟩 Achieved/ on track
🟨 Paused
🟥 Slipppage
🟦 No change
▪ = deadline aim
Not started

Working Group	Activities Planned (deliverables)	Deadline Aim	Progress Report			
			Q1 (Apr-Jun)	Q2 (Jul-Sept	Q3 (Oct-Dec	Q4 (Jan-Mar
Data & Digital	Develop & Agree KPI's for ODN, identify activity data and develop data dashboard	Q1	🟨 ▪	🟨	🟩	🟩
	Interoperability – digital solutions to be explored, further development of the test use case for CYP cancer	Ongoing	🟨	🟨	🟩	🟩
	Scope finance options for interoperability	Q4			🟩	🟩 ▪
	Pilot shared care record	Q4				🟥 ▪
Workforce & Education	Conduct a regional workforce gap analysis (PTCs) underpinned by the NHS Workforce Plan for children's cancer services across the NW	Q1	🟥 ▪	🟨	🟨	🟩
	Conduct a regional workforce gap analysis (POSCUs / DGH) underpinned by the NHS Workforce Plan for children's cancer services across the NW (alongside NW PCC SiC LTV ODN)	Q1	🟥 ▪	🟥	🟨	🟩
	Conduct a regional Training needs analysis (TNA) for children's cancer services across the NW	Q2 & Q3	🟨	🟥	🟩 ▪	🟩
	Develop regional pathways and protocols repository on the NWCCODN website, develop region wide pathways for RT, CAR- T etc	Q2	🟨	🟥 ▪	🟨	🟨
	Scope holistic support needs re CYP cancer care across NW	Q2		▪	🟩	🟨
	Develop an educational programme across the NW for children's cancer services based on the results of the TNA	Q4			🟥	🟨 ▪
	Plan & hold regional annual conference (joint CYP & TYA) March 2025	Q4				🟩 ▪
Patient & Family Experience	CPES patient experience survey analysis and sharing	Ongoing	🟨	🟨	🟩	🟩
	Develop PPI Strategy	Q2	🟨	🟨 ▪	🟩	🟩
	Understand and promote equality, diversity and inclusion	Ongoing	🟨	🟨	🟥	🟥
	Support patient and family engagement in NHSE Transformation Programme	Q1	🟥 ▪	🟥	🟥	🟥
	Scope accommodation options for families in relation to RT and Ambulatory Care Offer	Q2	🟨	🟨 ▪	🟩	🟩
	Collect analysis of 'you said we listened' approach – to inform service development from service user feedback	Q1	🟩 ▪	🟩	🟩	🟩
Equitable high quality care	Set up working group	Q2		🟩 ▪	🟩	🟩
	Set up Ambulatory care pilots at PTC's & develop business to access funding for these	Q2	🟨	🟥 ▪	🟨	🟨
	Scope mobile treatment options	Q2	🟨	🟩 ▪	🟩	🟩
	Service pressure mapping projects including Genomics audit, mapping and access to AHPs / PEOLC	Q3			🟩 ▪	🟩
	Work with and support the providers to implement positive changes via their SA work plans	Ongoing	🟨	🟨	🟩	🟩
	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	🟨 ▪	🟨 ▪	🟥	🟥

Appendix 2: Proposed work plan 2025/26 NWCCODN (as per 4 working groups)

Data & Digital

Priority area	Activities Planned	Quarter
Access *(Ensure equitable access to care for children with cancer across the North West)*	Interoperability: Pilot a shared care record	Q1
Access	Agree regional activity data (KPI's)	Q1
Access	Develop Coding and Data Strategy	Q2
Access	Scope VR and innovations for cancer services	Q3
Access	Roll out shared care record	Q4
Access	Complete development and optimise use of Children's Cancer Activity Dashboard	ongoing

Proposed work plan 2025/26 NWCCODN continued...

Workforce & Education

Priority Area	Activities Planned	Quarter
Quality: Ensure quality of care to children with cancer across the North West	Conduct a regional workforce gap analysis underpinned by the NHSE Workforce Plan for Children's Cancer Services (**POSCU element**)	Q2
Quality	Develop a North West Education & Training programme / Strategy for Children's Cancer Services based on the results of the TNA	Q3
Quality	Deliver Annual Conference	Q4
Quality	Develop regional pathways and protocol repository on NWCCODN Website, develop regional pathways for RT, Car-T etc.	Ongoing

Proposed work plan 2025/26 NWCCODN continued…

Patient & Family Experience

Priority Area	Activities Planned	Quarter
Experience (Improve experience of care for children with cancer across the NW)	Understand and promote equality, diversity and inclusion (i.e. Makaton signs on website)	Q2
Experience	Develop a bank of patient and family experience stories	Q3
Experience	Support patient and family engagement in NHSE QI Safe and Sustainable Programme (TP) and CC2H	Q4
Experience	Collect analysis of you said we listened approach - to inform service development from service user feedback	Ongoing

Proposed work plan 2025/26 NWCCODN continued...

North West Children's Cancer
Operational Delivery Network

Equitable high quality care

Priority Area	Activities Planned	Quarter
Quality (*Ensure quality of care to children with cancer across the North West)*	Develop a network agreed research strategy and improve research links (Including focus on access to Clinical Trials & WGS)	Q3
Quality	Review Service Specification Self Assessment Process for 26/27	Q4
Quality	Implement QI initiatives based on gap analyses (PEOLC, Psychology, AHP's, Genomics and service pressure mapping)	Ongoing
Quality	Work with and support the providers to implement positive changes via their SA work plans	Ongoing
Access *(Ensure equitable access to care for children with cancer across the North West)*	Deliver Care Closer to Home Pilot	Ongoing
Access	Work with NHSE to develop a 'long list', short list and preferred option to inform the NHSE QI programme relating to Children's Cancer Services	Ongoing

Appendix 3: Genomics Abstract Presented at CCLG conference 2025

North West Children's Cancer
Operational Delivery Network

CYP ONCOLOGY WHOLE GENOME SEQUENCING (WGS) TESTING; FOLLOW UP AUDIT FOR THE NORTH WEST CHILDREN'S CANCER ODN

Samantha Aldridge, Jessica Goncalves, Davina Hartley, Katharine Field, Charlotte Lloyd, Bernadette Brennan, Helene Schlecht, Rachel Hart, Kat Cooper, Minou Oostveen and Lisa Howell

Introduction

vancements within genomics continue to have significant impact on the ability to diagnose and treat children and young people with cancer. st year, the North West Children's Cancer Operational Delivery Network (NWCCODN) presented a baseline audit of whole genome sequencing GS) for children with cancer across the region*. This highlighted the low numbers performed and some of the reasons behind this. bsequent changes to practise were implemented, including utilising research practitioners to facilitate discussion, receive consent, sample llection and tracking. We have now re-audited our current WGS practise within the region. We have identified data fields of interest and llated the data over the different time periods and the 2 PTCs. Our joint cohort now amounts to around 270 patients, demonstrating that our GS testing has increased significantly, enabling us to interrogate results in a more meaningful manner. Sufficient numbers now exist to further d to the national data regarding practise and impact for patients. Demonstrating and understanding the impact of WGS testing is vitally portant in providing optimal care for our patients and increasing knowledge. Challenges currently exist in the access to and sharing of this ta, which we believe is a necessary part of this nationally offered service. ODN initiated projects can provide valuable resource for service velopment and patient benefit and enable multi-professional collaboration.

Objectives

To demonstrate the impact of dedicated resource for WGS
To create and interrogate a meaningful repository of data relating to WGS.
To identify any improvement in turnaround times
To identify limitations in testing including factors related to failed tests

*Scan to see last year's poster

Method

house databases and tracking systems of WGS patients were created in the 2 PTCs. We submitted a data request to the GLH. The data ailable from the GLH was limited due to GDPR, resource and systems issues and required significant input and time from the Bio-Scientist. We viewed the numbers, trends, turn around times and reasons for none testing for the entire 4yr cohort (some data items were only available 1 PTC). We analysed cases by tumor type and explored results in terms of pathological variants in both somatic and germline samples, with rticular interest in cases where there was impact on diagnosis, treatment or screening

Results

270 children in the North West had WGS over a 4 year period.

gure 1: Percentage of AHCH patients with WGS

umour Group		No. of Diagnoses	% with WGS	Change in %
eukaemia	21-23	77	53.2%	↑44.1%
	24	37	97.3%	
olids	21-23	55	27.3%	↑36.7%
	24	50	64.0%	
NS	21-23	47	8.5%	↑32.0%
	24	37	40.5%	

Figure 2: No of WGS By Disease Group & PTC

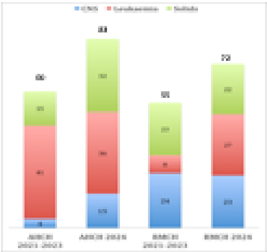
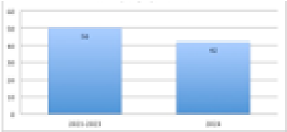


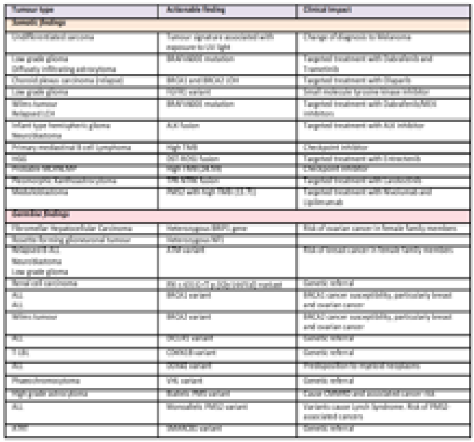
Figure 3: Mean Time from 2nd sample received into GLH to GTAB



Other Relevant Observations

- Tumour testing failed in only 11 patients
- Sample collection after the start of chemotherapy did not have an impact on failure rate (1 fail in a completely necrotic WT)
- Patients not having surgery at the PTC (AHCH); 6/16 Bone tumours and 6/6 Liver tumours had WGS – required team liaison
- 25 patients had WGS sent at the time of relapse
- Diagnostic M codes were used appropriately in the majority of cases
- 4/147 families at AHCH declined testing
- Very few cases had insufficient tissue after SOC

Figure 4: Pathogenic WGS findings and their clinical impact



Discussion & Conclusion

dicated staffing resource and pathways led to significantly increased numbers of patients offered WGS. This also led to the creation of in-house abases and tracking systems for audit purposes. Without this resource the numbers of patients offered WGS would fall significantly, as would data available. The proportion of CNS tumour and leukaemia patients differ significantly between the centres, suggesting a different team proach. WGS is obtained almost 100% of leukaemia patients in AHCH. We had concern regarding tumours managed at super-regional centres, small numbers indicate that rates of WGS may be more challenging to obtain for bone tumour patients. Turn around time within the GLH has uced by a mean of 8 days to 42 days. Our understanding is that this varies across the country and may be important for timely patient nagement. Challenges remain in accessing relevant data from the GLH. This limits the ability to judge impact and learning at a local and national el and is particularly relevant for the more rare tumour types. In house databases were required to assess the impact for each centre. In a mber of patients, WGS identified changes which led to an altered diagnosis and not previously known cancer predisposition syndromes. Both S and SOC testing picked up recognised alterations relevant for diagnosis and risk stratification. This rich data source provides the opportunity collaborate with colleagues elsewhere, to maximise learning from WGS results in CYP with cancer. Further steps include examining mographic data to expose any inequalities in accessing the WGS service as well as looking at the variants of uncertain significance identified.

NHS
North West
NHS Genomic Laboratory Hub

NHS
Manchester University
NHS Foundation Trust

NHS
Alder Hey Children's
NHS Foundation Trust

North West Children's Cancer
Operational Delivery Network

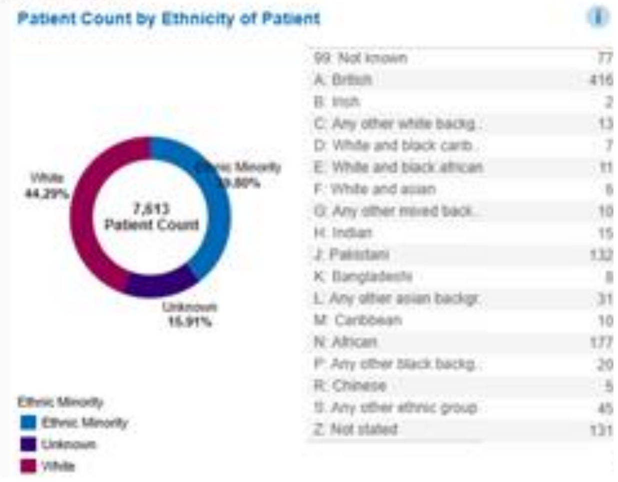
Appendix 4: PTC Data for 2024/25

PTC 1 Data from NHSE BI NWCCODN Dashboard HES data

Unique patients:362
Unique patients ages 16-19yrs: 38

Chemotherapy
Inpatient chemotherapy admissions 432 (30 out of area)
Daycase chemotherapy admissions 1648

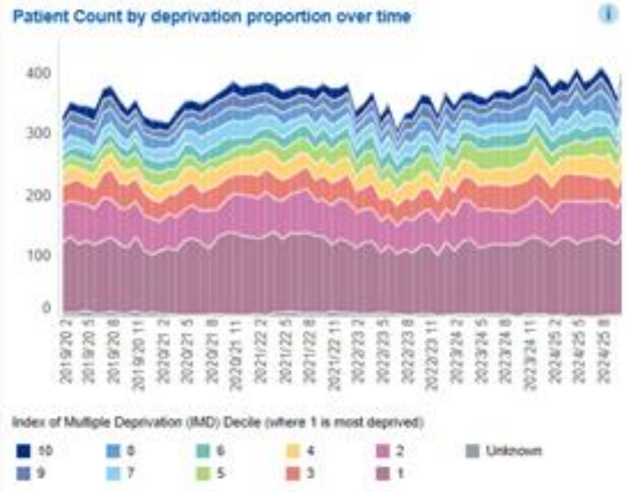
Ethnicity



Patient Count by Ethnicity of Patient

99: Not known	77
A: British	416
B: Irish	2
C: Any other white backg...	13
D: White and black carib...	7
E: White and black african	11
F: White and asian	6
G: Any other mixed back...	10
H: Indian	15
J: Pakistani	132
K: Bangladeshi	8
L: Any other asian backgr...	31
M: Caribbean	10
N: African	177
P: Any other black backg...	20
R: Chinese	5
S: Any other ethnic group	45
Z: Not stated	131

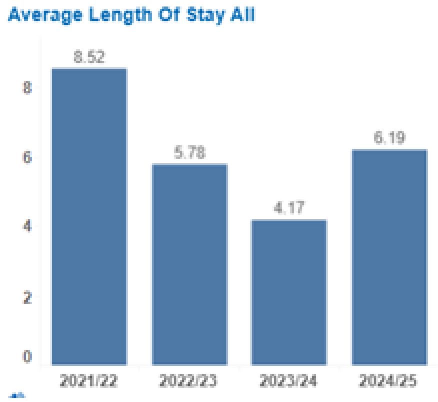
Deprivation



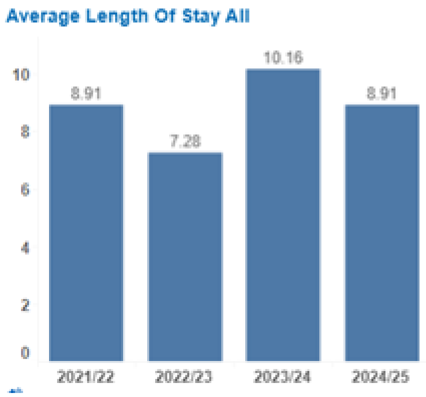
Patient Count by deprivation proportion over time

Length of Hospital Stay (nights)

Non elective (non emergency)



Elective Admissions



Radiotherapy Data (1-16yrs)
59 unique patients registered at The Christie
This includes 30 ‘local’ patients, 21 from GM and L&SC, 8 from C&M, Wales
29 additional ‘out of area patients’

Appendix 4: PTC Data for 2024/25

PTC 2

Data source * Inhouse cancer registry

** NHSE BI NWCCODN Dashboard HES data

Patient Numbers

Number of new patients; 133*

Number of unique patients managed; 213**

Number of unique pts aged 16-19; 26**

Number of relapsed/progressing patients 33*

Diagnostic Information*

CNS 42, Leuk 39, Solid 52

Ewing sarcoma	4
osteosarcoma	3
LCH	5
Hodgkin Lymphoma	10
NHL	2
AML	8 (2 secondary)
Lymphoblastic lymphoma	2
ALL	23
DIPG	2
DMG	2
NRSTS	2
Wilms Tumour	3
Neuroblastoma	1
ATRT	2
Ependymoma	4
medulloblastoma	5
Low grade glioma	10
Craniopharyngioma	3
Others	42

Patient Demographics

Number of new patients from Wales; 19*
Number of patients IOM; 3*
Number of new patients with a designated POSCU; 46*

Bangor	4
Wrexham	8
Glan Clywd	7
Chester	9
Leighton	10
Stoke	5
IOM, Nobles	3

SACT Information

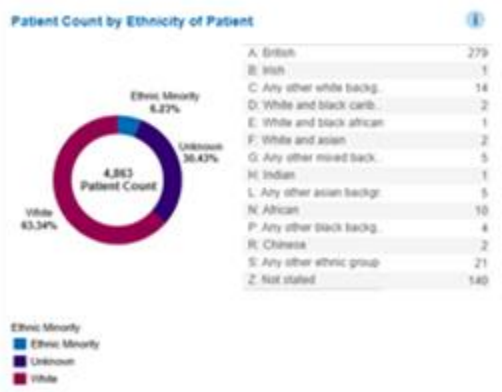
Number of new patients treated on SACT; 88*
In patient chemotherapy admissions; 350**
Daycase chemotherapy admissions; 1382**

Appendix 4: PTC Data for 2024/25

PTC 2

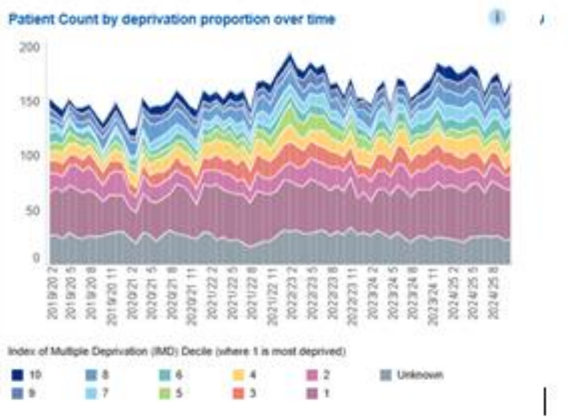
Data source * Inhouse cancer registry
**** NHSE BI NWCCODN Dashboard HES data**

Ethnicity**


Patient Count by Ethnicity of Patient

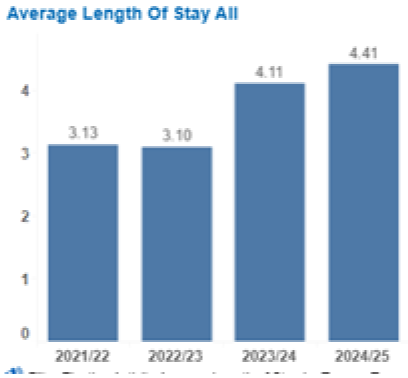
A: British	279
B: Irish	1
C: Any other white backg..	14
D: White and black carib..	2
E: White and black african	1
F: White and asian	2
G: Any other mixed back..	5
H: Indian	1
L: Any other asian backgr..	5
N: African	10
P: Any other black backg..	4
R: Chinese	2
S: Any other ethnic group	21
Z: Not stated	140

Deprivation**

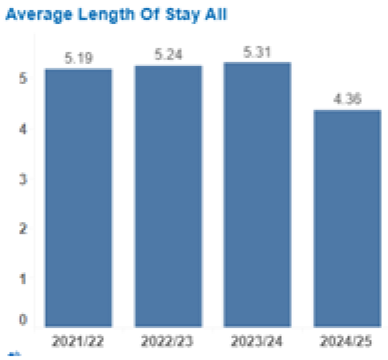

Patient Count by deprivation proportion over time

Length of Hospital Stay (nights)**

Non elective (+non emergency)


Average Length Of Stay All

Elective Admissions


Average Length Of Stay All

Appendix 5: NW CTYA Cancer Conference 2025 – evaluation summary

Overview

This conference was the second event to take place for the North West Children's Cancer Operational Delivery Network and the Teenage and Young Adult Cancer Network. The conference took place on the 7th March 2025 at the Spine, Liverpool, and was organised in collaboration with the Cheshire and Merseyside Cancer Alliance, this years hosts, Lancashire and South Cumbria Cancer Alliance and the Greater Manchester Cancer Alliance.

Aims & Objectives of the conference were to:

- Deliver a successful networking event which appeals and benefits to a wide range of professionals.
- Showcase exhibitor's and encourage networking across the region.
- Provide fresh perspectives and insights from our expert speakers.
- Showcase tools and strategies to implement into your everyday work.
- Create new partnerships and professional relationships to drive forward collaboration.

Attendees Breakdown

139

ATTENDEES

Total number registered on the day.

96

DELEGATES

Total number registered as delegates.

43

OTHER ATTENDEES

Total number registered as speakers, exhibitors and lived

51 of the 96 attendees completed the feedback form, giving a response rate of 53%

8.73

AVERAGE RATING

When asked how relevant the content of the agenda was to their role, with 1 being not relevant at all and 10 being very relevant/ transferable, the delegates average rating was 8.73.

98%

ANSWERED 'YES'

When asked, based on your experience, would you recommend future NWCTYA conferences to your colleagues, 98% answered yes, 2% answered maybe.

**Full report available via embedded document*

Microsoft Edge PDF Document

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