



**NW Children's
Cancer ODN**
Annual Report 2022/23



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1.0 Introduction/Foreword

The North West Children's Cancer Operational Delivery Network (NWCCODN) is a regional Network for Children's Cancer Services. Children's Cancer ODN's are mandated through NHSE following recommendations set out in the NHS Long term Plan and are designed to deliver a collaborative model of care to improve the experiences and outcomes for children with cancer and their families based on regional and local need. ODN's have 3 main functions: Increasing operational effectiveness and consistency, Improving Care and Managing Patient Flows.

Formally established this year in October 2022, the NWCCODN aims to bring together clinicians, managers, commissioners and patients to deliver high quality, patient-centred and outcome-focused cancer services across our region. We will work hard to

interconnect our region around a shared goal, and strive to build a culture of collaboration, trust and respect between NHS organisations and our patients and their families. We have started to build key relationships and have worked hard to get the Network up and running as quickly and efficiently as possible. We have started to draft some strategic aims based on the views gathered within our initial scoping and strategy co development events, however the aims and proposed workplan are subject to change following the patient and public consultation and engagement events which are planned for May/ June 2023. We really want to ensure that our strategy and workplans are based on regional need and we really value the views of all of our colleagues and ultimately the patients and families who use the services.

Our strategic aims*:

Access

Improve equity of access to care for children with cancer across the NW

Quality

Improve quality of care to children with cancer across the NW

Experience

Improve the experience of care for children with cancer across the NW

(please note the wording of these are subject to change based on the co-development and co design of our Network strategy and 3-5 year work plans which will be going out for formal consultation early next year 2023/24)*

The NWCCODN is made up of professionals from 3 different NW England regions (Cheshire and Merseyside, Greater Manchester and Lancashire and South Cumbria) and 2 non English regions (North Wales and Isle of Man). Collaboration and joint working exists to offer optimum cancer care to children and young people affected by cancer. The NWCCODN consists of 2 large Principal Treatment Centres and 7 paediatric oncology shared care units or POSCU's including across the North West and the Isle of Man plus 3 *supra* Network POSCU's (North Wales). There is also patient flow from Stoke due to shared borders, however, Stoke is a member of the Midlands ODN. The NWCCODN exists alongside and works in collaboration with the North West Teenage and Young Adult Cancer ODN.

Around 250 children up to the age 16 are diagnosed in the area the NWCCODN covers each year. Whilst many aspects of care are delivered as close to home as possible, many families have frequent long journeys to access care. Some aspects of care such as radiotherapy and allogeneic transplant are only delivered in 1 centre. Close working practise is vital to offer the best management and experience for our young patients and their families. We aim to put the patients at the centre of our mission and include their voice in service improvement and development.

The NWCCODN is jointly chaired by clinicians, Dr Lisa Howell and Professor Bernadette Brennan and has a manager, Ms Davina Hartley, Quality Improvement lead Ms Charlotte Lloyd and Project Support Officer, Ms Abi Abimbola. During the first few months of establishing the NWCCODN, the Network worked hard to engage with wider professional groups in the region's hospitals and other involved organisations to publicise the aims and opportunities of the development of the NWCCODN. This culminated in a successful launch event run as a hybrid event on 20th January 2023.

We have subsequently developed a strategy to move our work forward including developing the joint aims and priorities of different stakeholders and patients and families. We aim to balance the need for effective and safe treatments with the experience of our patients. In the coming months we aim to collaboratively approach the needs of children affected by cancer in our region. This includes focus on the stated aims of the NHS cancer programme of care service specification for children and young people with cancer

We are positive about the future and determined to make the most of the opportunities the NWCCODN presents for the benefit of children's cancer care services across the region and beyond.



Brennan

Professor Bernadette Brennan
Consultant Paediatric Oncologist,
Royal Manchester Childrens Hospital



Howell

Dr Lisa Howell
Consultant Paediatric Oncologist,
Alder Hey Children's NHS FT

2.0 About Us



The NWCCODN covers all children requiring cancer treatment from 0-15 years (inclusive) old in North West region. Within the North West there are 2 Principal Treatment Centre's (PTC), Alder Hey Children's NHS Foundation Trust (Alder Hey) and Royal Manchester Children's Hospital (RMCH). In addition to the PTC's, there are 7 other provider trusts delivering Children's Cancer services as Paediatric Oncology Shared Care Units (POSCU's) across the North West and Isle of Man. There are also an additional 3 POSCU's outside of our region across North Wales that work as shared care units with Alder Hey in addition to patient flow from Stoke.

Due to the proximity of hospitals within the region to North Wales at least one of the district general hospitals may choose to be part of any North Wales ODN instead of the NWCCODN while remaining as a POSCU within the NW region for patients to access services at the PTC (Supra Network).

The NWCCODN delivers a whole system work programme for children's cancer services across the North West area within NHSE in collaboration with the Cancer Alliance's for the North West; (Cheshire & Merseyside, Greater Manchester and Lancashire & South Cumbria).

2.1 Location and Boundaries of ODN

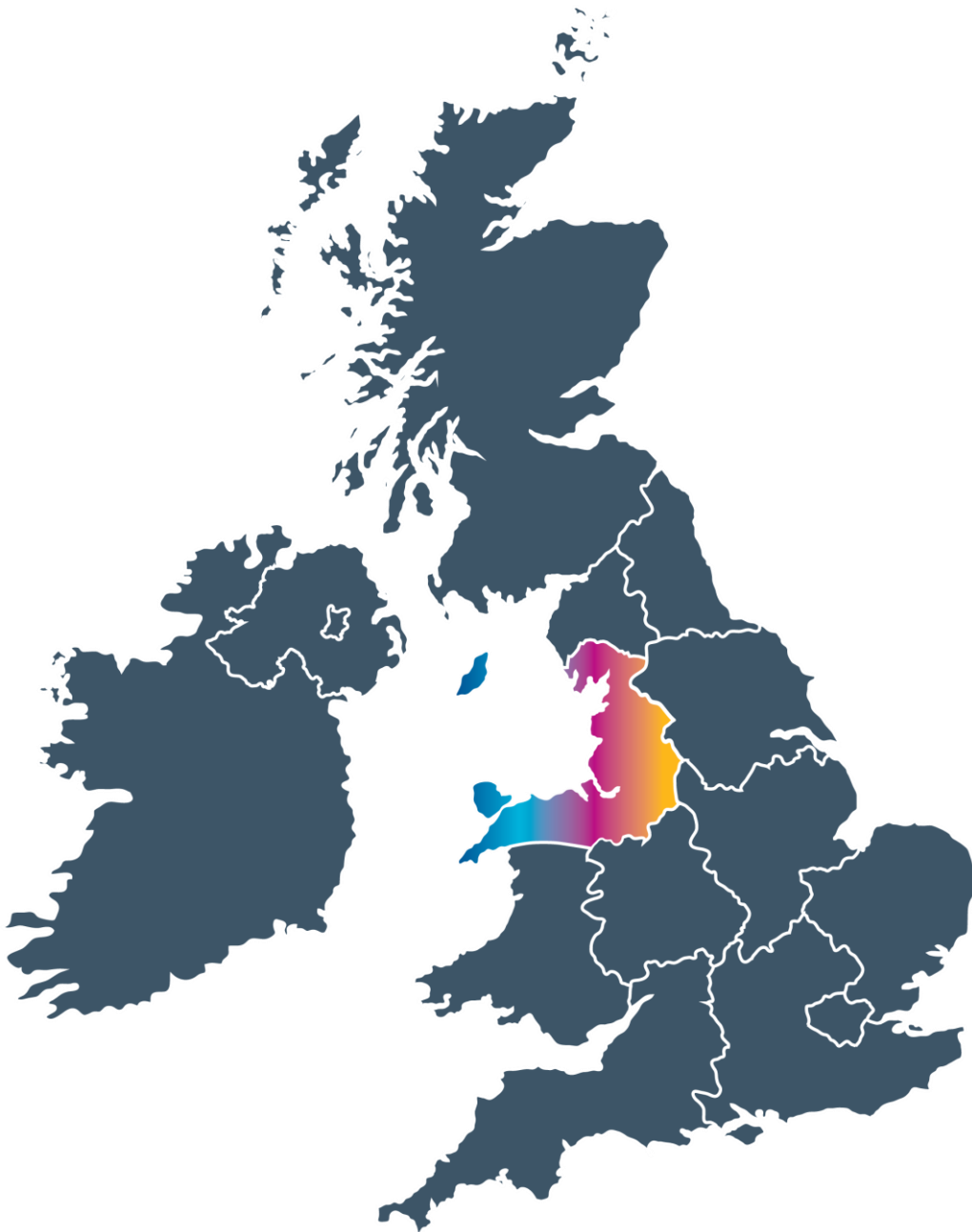


Diagram 1: Map of NW Region

2.2 Provider Organisations

Provider	Trust	Status
Alder Hey	Alder Hey Children's NHS FT	PTC
Royal Manchester Children's	Manchester Foundation Trust	PTC
Royal Blackburn	East Lancashire Teaching Hospital Trust	POSCU
Victoria	Blackpool and East Lancashire Trust	POSCU
Leighton	Mid Cheshire Hospital Foundation Trust	POSCU
Countess of Chester	Countess of Chester NHS Foundation Trust	POSCU
Royal Preston	Lancashire Teaching Hospital	POSCU
Royal Lancaster	University Hospitals of Morecambe Bay	POSCU
Nobles Isle of Man	Manx Care, Isle of Man Government	POSCU
Gwynedd North Wales	North West Wales NHS Trust	POSCU*
Maelor North Wales	North West Wales NHS Trust	POSCU*
Glan Clwyd North Wales	North West Wales NHS Trust	POSCU*

2.3 Meet the team



Davina Hartley
ODN Manager



Charlotte Lloyd
QI Lead



Abi Abimbola
Project Support Officer



Prof Bernadette Brennan
Clinical Lead & Deputy Chair



Dr Lisa Howell
Clinical Lead & Co Chair



Andrea Doherty
Commissioner & Co Chair

3.0 Governance Structure

The NWCCODN is governed by the Network Oversight Group (NOG). All North West provider Trusts of children's cancer services will form the working groups (sub groups) of the NWCCODN. Each working group will have representation from across the region relevant to its individual purpose. The working groups will be accountable to the NWCCODN. The membership of the NWCCODN is represented in table 2, below.

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 will be co-chaired by NHSE and one of the Network clinical leads. The NWCCODN host Trust will be represented on the NOG by the Trust Medical Director.

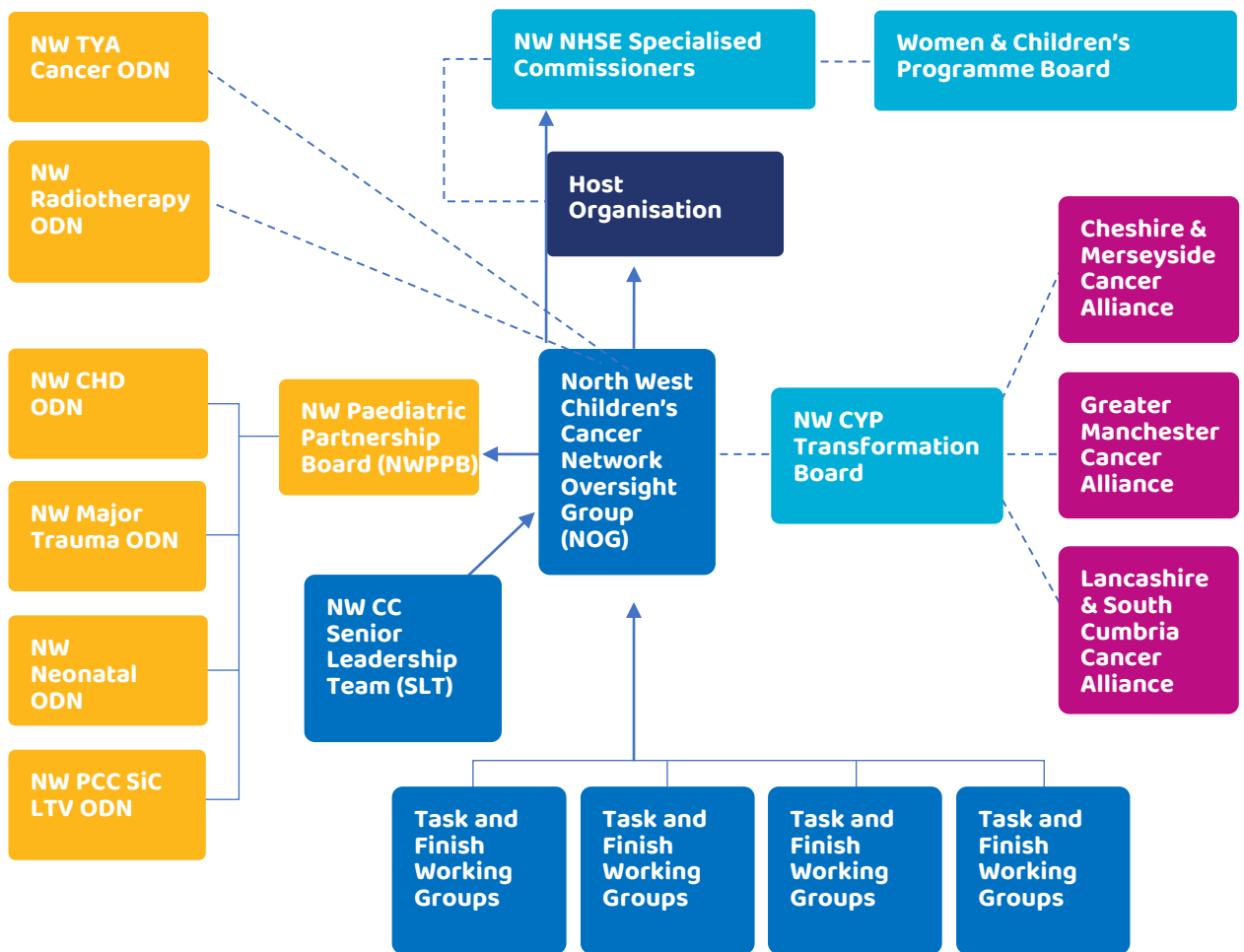
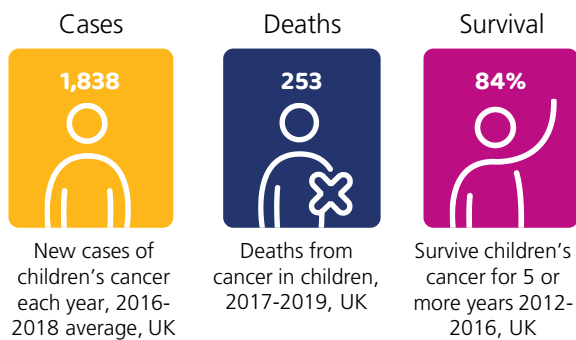


Diagram 2: Overarching governance structure

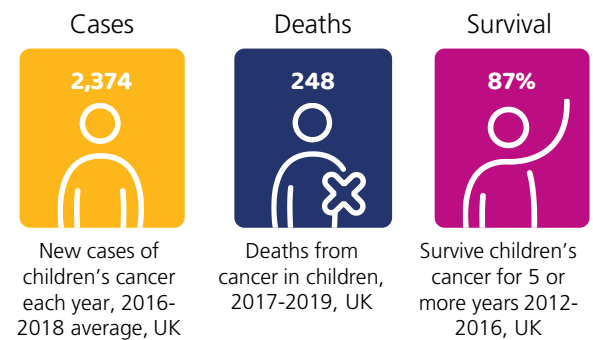
4.0 Data Trends

National statistics

Children's cancer statistics



Young people's cancer statistics



Regional Data:

The North West region has a population of circa 7.4 million, around 1.6 million of these are children. The region has high levels of deprivation and has some of the most deprived localities in England with 4 of the 5 most deprived local authorities being in the North West region (notably Blackpool, Manchester, Liverpool and Knowsley).

Cancer is now a leading cause of death for children and adolescents (WHO, 2021). This is despite numbers in real terms falling. This is, in the main, due to other causes of death falling.

Travel hugely impacts children with cancer in the region and causes an inequity in the delivery of, and access to, care provision. Some children in the region are having to travel in excess of a 4 hour round trip by car to access their cancer care putting a huge burden on families (financial and time). Many children with cancer have numerous episodes of care provided so this compounds the burden of travel.

On average around 450 CYP are treated with chemotherapy and radiotherapy in the region every year (2019/20 = 435).

Patient rates vary quite widely by locality and range from 5.9 per 100,000 to 41 per 100,000 with these increases corresponding to the increase in deprivation quintile.

The incidence rates of children's cancer are highest in the under 5's, with leukaemia being the most common cancer for children and young people.

We have been working closely this year with NECS and our NHS England regional team to develop a data dashboard to support the ODN in having access to regular data trends relating to children's cancer across the North West. Data from this will be monitored and shared at our regular Network Oversight Group meetings going forward.

5.0 Service Scoping and Self-Assessment Review

Clinical audit is a method used to ascertain if healthcare is being provided in line with current standards and enables care providers and patients to assess if their service is doing well and identify where changes might be made to improve outcomes for patients. This provides us with quality assurance. Audit forms an integral part of the NHS, clinical care and our Network.

NHS England have recently published the Children's Cancer Service specifications, which set out the requirements of Principal Treatment Centres (PTC's) and Paediatric Oncology Shared Care Units (POSCU's) in relation to the delivery of children's cancer care. The Network has the responsibility to audit and monitor the compliance of hospitals within the region against these national standards and during 2022-23, the Network has developed an audit tool (based on that used by other Children's Cancer ODN's) to assess how units are performing against these standards.

This has formed the basis of the Network's self-assessment baseline audit and service review which has been undertaken in a phased approach. We have completed Phase 1 (PTC's) and Phase 2 (POSCU's in Network scope) and are now moving into Phase 3 (Supra Network POSCU's) of the process. A full report will be completed Summer 2023, and the Network will support all units to develop their own bespoke quality improvement plan based on the findings of their self-assessment.

On the following pages are the high-level findings including the key successes, the challenges and the recommendations from the regional self-assessment (Phase 1 & 2):

Key Successes

Across the region, colleagues clearly demonstrated enthusiasm and commitment to developing the services for patients and families. It was inspiring to observe this and provides a solid base for embedding quality improvement and shared learning within the wider Network.

Monthly MDTs between 1 PTC and 4 POSCUs to ensure clear communication and update individuals on the treatment plan of the patient. This is an opportunity to highlight any changes in protocols, guidelines and discuss challenges such as complaints and incidents with the Oncology patients.

All Oncology patients have open access 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.

Effective referral process and transfer of patients with suspected oncological diagnosis to the PTC. Communication with on-call consultants is reported as clear and informative.

Information and consent provided to the patients and families was consistent. Information was led through the PTC to ensure clear communication pathways. There is a vast range of booklets available.

All POSCUs have a shared care folder which is accessible to specific professionals to ensure patients care follows their individualised care plans.

1 PTC have assigned members of the Macmillan team to specify POSCUs; maintaining clear support and communication between the providers.

1 POSCU has introduced an End of Life care project SWAN MODEL (sign, words, action, needs). An initiative which could be measured and potentially rolled out across the NW region to other POSCUs.

1 POSCU developed a specific welcome to the unit booklet for the PTC to provide patients/families with that locality for shared care.

1 POSCU has set up a virtual blood clinic with clear communication pathways to patient/families and the PTC.

Challenges

Communication barriers between PCTs and POSCUs when patients are admitted/discharged from services.

Access to shared care patient records.

Delays in updating policies and guidelines.

Some colleagues reported communication between providers was challenging on a day-to-day basis.

Regional variation regarding CCNT/care closer to home.

End of Life care provision is locality and community dependent.

Access to psychology services is limited.

Access to wider holistic services – variation regionally and nationally regarding support available to patients and families.

Obtaining POSCU specific feedback to understand from patients and families their experiences.

Staffing pressures; junior workforce, upskilling colleagues, vacancies, high turnover of staff, staff burnout.

No protected time within POSCUs for staff to concentrate on POSCU specific work for link nurses.

Paediatric Pharmacy Provision – limited allocated time due to staff resources to focus on guidelines and training programmes.

Variation in medical training. Medical training is challenging due to rotation of colleagues every 6 months. Standard POSCU training package within their induction would be beneficial.

Recommendations

Monitoring service spec. compliance at provider level and across the Network.

Develop agreement with POSCUs regarding submission of annual reports to ODN.

Exploring options regarding models of care (potential development of enhanced POSCUs, Ambulatory Care, Home Chemo).

PTCs have a different approach to the delivery of Clinical Care Groups. Discuss equity across the region.

Develop standardised approach for information sharing between POSCUs and PTCs re. local admissions, discharges and patient care plans.

Awareness of CCLG membership for all clinical leads in line with Service Specification.

Workforce gap analysis of Community provision (skill mix, working hours, training, competencies, area covered).

Workforce gap analysis of PTCs (skill mix, working hours, training, competencies, effectiveness of acuity tool).

Access to specialist training and education for professionals without regular cancer exposure to maintain knowledge and confidence.

Development of workstreams – learning from experience staff/patient/family feedback, sharing clinical practice/advances in treatment, introducing new ways of working – sharing of learning and good practice.

Scoping of current education and training offered (nursing and medical opportunities). Linking in with cancer alliances.

Create a section within the ODN website (forum) for professionals to connect and share learning/resources/support each other.

Shared electronic system for sharing policies and guidelines

Document specific processes including quality and compliance procedures e.g. fertility preserving measures, clinical trials, genomic sequencing

Recommendations (continued)

Joint standardised reporting between PTC and POSCUs with agreed performance metrics – such as referral, interventions, response, complaints etc.

Demand and capacity review (inpatient and outpatient).

Facilities for parents/guardians varies – visit sites to view this.

Review referral pathways and access to psychology and holistic services for patients and families.

Development of Palliative Care and End of Life workstream.

Focus on patient and family experience. PPI involvement and including them in the development of future services.

Work with the NWCCODN in a 'You Said, We Did' project. A visual display and communication pathway to patients and families for improvements on the units. Links to Under 16 Cancer Patient Experience Survey.

6.0 Achievements 2022/23

NWCCODN clinical leads and operational posts advertised & filled



Patient Public Involvement (PPI) – Questionnaires, art workshops with patients & U16 survey evaluation



NWCCODN Structure, Senior Leadership Team & oversight groups developed



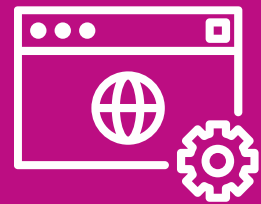
Development of data dashboard for NWCCODN



NWCCODN governance documents completed & ratified



Website in development & quarterly newsletter distributed



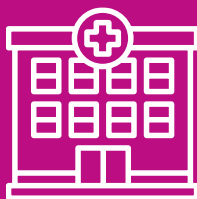
Launch event & strategic co development & design workshops held



Agreed funding for Band 7 Innovation role. JD & advert completed



Self Assessment service review and site visits held with all PTC & POSCU's



Funded projects across region to support cancer care



7.0 Finance – Spend against income

The NWCCODN is funded by NHS England and has an annual budget of £157, 400. This year (2022/23) due to mid-year start up and mid-year recruitment to posts there was significant slippage in the budget. Expenditure against the commissioned budget did not commence until October 2022.

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 2023 could be repurposed into the next financial year (2023/24) to enable the funding to be ring fenced for children’s cancer.

2022/23 Month 12 (Mar 23)	YTD Plan	YTD actual	YTD variance	FOT plan	FOT actual	FOT variance
Income	£157, 400	£157, 400	£0	£157, 400	£157, 400	£0
Costs – pay	-£141,228	-£60,116	£81,112	-£141,228	-£60,116	£81,112
Costs – non-pay	-£16,172	-£14, 548	£2, 204	-£16,752	-£14, 548	£2, 204
Costs sub-total	-£157, 400	-£74, 664	£82, 736	-£157, 400	-£74, 664	£82, 736
Total	-£157, 400	£82, 736	£82, 736	-£157,400	£82, 736	£82, 736

Underspend for this year has been deferred into the next financial year, 2023/24. It was agreed at the inaugural Network oversight group meeting in January 2023 that this would be used to finance a WTE band 7 innovation role for the Network. This has been agreed by NHSE commissioners.

8.0 Key Priorities 23/24

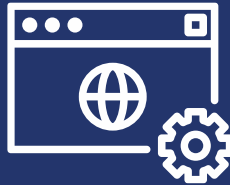
Complete self-assessment service review & complete report (Phases 1-3)



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



Comms: build website, set up twitter account and develop comms strategy



Undertake regional workforce and education mapping and gap analyses



Complete strategy workshops and develop draft strategy and workplans



Undertake formal consultation of network strategy and work plans



Complete WGS, Fertility Preservation & Clinical Trial pathway review and gap analyses



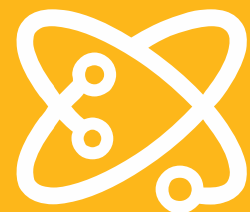
Scope care closer to home options and opportunities



Data sharing: make links via shared care record/ develop data sharing agreement for regional data sharing.



Develop network research plan to enable NW wide access to clinical trials



(please note these are subject to change based on the co-development and co design of our network strategy and 3-5 year work plans which will be going out for formal consultation early next year 2023/24)

9.0 Looking to the Future (Final word from our Commissioners)

The North West (NW) Specialised Commissioning Women and Children's Transformation programme was conceived in Summer 2021 and came into being Autumn 2021. This was as a result of a number of national standards and service specifications being developed related to:

- Children and Young People with Cancer
- Neonatal Critical Care
- Paediatric Critical Care
- Surgery in Children

Consequently a North West Case for Change has been developed and reviewed at NHSE Gateway Assurance on the 28th of April 2023. The formal report from this review is currently awaited.

Specifically, regarding Children and Young People (CYP) Cancer the Case for Change highlights the need for review of compliance, gap identification and action plans regarding the two NW Principal Treatment Centres (PTC) and the seven NW POSCUs. There is also discussion that other models of care need to be explored. However, these are not yet confirmed.

Consequently, there are plans being developed to engage with NW Clinicians and other professional stakeholders, patient and public engagement and regional oversight and scrutiny leads as to what their thoughts are and possible solutions as to need. These will then be developed into a long list of options that will then be reviewed at NHSE Gateway 2, potentially Autumn 2023.

The NWCCODN is pivotal to the success of the NW Specialised Commissioning Transformation Programme. We have worked collaboratively together since the CYP Cancer ODN was formulated in Autumn 2022 and will continue to do so as we move forwards. If anyone wishes any further information regarding the NW W & C Transformation Programme, then please do not hesitate to contact us at:

england.wcyptransformation@nhs.net



Andrea Doherty

Head of North West Women and Children's Transformation (Specialised Commissioning NHSE)



Appendix 1: Proposed work plan 2023/24 NWCCODN

(please note these are subject to change based on the co-development and co design of our Network strategy and 3-5 year work plans which will be going out for formal consultation early next year 2023/24)*

Priority Area	Activities Planned	Progress	Improvement Outcomes	RAG Status
Access: Improve equity of access to care for children with cancer across the NW	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.	POCU and PTC baseline review against service specification phase 1 and 2 almost complete, site visits undertaken. Baseline data collected and being analysed. Phase 3 site visits to commence March 23. Report to be completed.	Care is delivered closer to home which will improve the experience of care for children with cancer in the NW.	Started but not complete
	WGS, FP & Clinical Trial pathway review and gap analyses, to inform regional pathway development via working group.	Working groups to be set up following inaugural NOG meeting on 20 January 2023.	More children with cancer can access WGS, FP and access to clinical trials which will improve patient outcomes	Not started
	Data sharing – make links via shared care record/develop options appraisal and data sharing agreement for regional data sharing	Links made with C&M share to care, planning development of a test use case, still need to make links with other areas and region wide LHCRE.	Effective data sharing will improve cross-provider communication.	Not started
	Develop clinical sub group to scope ambulatory and home care & joint MDTs & identify potential funding streams..	Clinical Working group and task and finish groups to be set up following inaugural meeting on 20 January 2023. Plans in place. Task and finish group for ambulatory care agreed.		Not started

Key: Completed Ongoing Started but not complete Not started

Priority Area	Activities Planned	Progress	Improvement Outcomes	RAG Status
Quality: Improve quality of care to children with cancer across the NW	Develop strategy and associated annual workplans for the NWCCODN including quarterly reporting into NWPPB & POC.	Reporting in to NWPPB & POC commenced. Strategy development plan drafted, workshops to enable co-production taken place March 23. What Matters To Me project agreed to support PPI.	Information gathering and gap analysis of current service delivery. Identification of improvement plans.	Yellow
	Develop research plan to identify blocks to opening trials and enable NW wide access to clinical trials.	Not yet started (focus for 2023/24).	Increased access to clinical trials research.	Red
	Undertake workforce mapping and training needs analysis for the region.	Not yet started (focus for 2023/24).		Red
	Develop governance documents for NWCCODN.	All governance documents drafted (ToR, SOP & MoU), ratified at NOG 20 March 2023.		Dark Blue
	QI programme for POSCUs to develop improvement plans based on baseline data.	Conversations with POSCUs at site visits, planning to take place 2023/24.	PTC and POSCU improvement plans in place.	Yellow
	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 2023/24. Travel data collated by NECS further analysis ongoing.	Development of Data Dashboard with NHSE/I NECs to collect and display data over a time.	Green

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 2023/24 in addition of dissemination of findings.	Increased experience of care for children and families.	Green
	Scope PPI across the region and develop workshops for co-production.	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.	Yellow
	Develop Network comms strategy plan.	Not yet started (focus for 2023/24).	Increased engagement professional and patient/family	Red
	Develop Network website and branding newsletters.	Network branding developed, website designer agreed and initial design meeting held. Newsletter sent out and template completed. Newsletter 2 drafted.	Visible Network with website and branding	Yellow