North West Children's Cancer
Operational Delivery Network

Working Together for Children with Cancer

A Strategy for the North West 2023-2028

V1.0

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Operational Delivery Network

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Contents

Foreword from our Clinical Leads

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 has 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 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.

Professor Bernadette Brennan

Consultant Paediatric Oncologist,
Royal Manchester Childrens Hospital

Dr Lisa Howell

Consultant Paediatric Oncologist,
Alder Hey Children's NHS FT

1.0 Introduction/Background

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, funded and governed 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. ODNs ensure outcomes and quality standards are improved and evidence based, networked patient pathways are agreed. They focus on an operational role, supporting the activity of Provider Trusts in service delivery, improvement and delivery of a commissioned pathway, with a key focus on the quality and equity of access to service provision The success of an ODN is measured by: Improved patient outcomes, Cost-efficiency, Reduced unwarranted variation.

Formally established in October 2022, the NWCCODN aims to bring together clinicians, nurses, allied health professionals, managers, commissioners and patients to deliver high quality, patient-centred and outcome-focused cancer services across our region. The network 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 patients and their families. The network has already started to build key relationships and has worked hard to ensure the involvement of professionals working across the region with children with cancer and their families in the development of this strategy document. We have held engagement events both face to face and virtually for professionals to ensure that the vision, mission and strategic aims were co-produced and based upon current good practice across the region (see Appendix 1 for a summary pictorial of the outputs from these events). This has enabled us to highlight the good practice which is already in existence and assess where things are working well whilst also indicating where there are gaps. The network has also held 2 patient engagement events at the Principal Treatment Centres which has helped with understanding what children and their families want and what really matters to them (see Appendix 1 for a pictorial of the outputs from these events). This is in addition to analysing the national CPES survey results for our region (see Appendix 2). The network has undertaken a self-assessment review against the national service specification for all the POSCU's and PTCs in the region which has provided insight into the current baseline in service provision (see Appendix 3 for the key messages from this project).

The North West are leaders in the provision of world-class, high-quality care for children with cancer and provide cutting edge treatments such as Proton Beam Therapy via the Christie (the only centre outside London) and have access to many new clinical trials through the Principal Treatment Centres for children's cancer, RMCH & AHFT. Our aim is collaboration and bringing together clinicians, providers, commissioners, and patients to provide safe high-quality service across the Network region and to improve outcomes for children cared for within it.

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"

2.0 Vision, Mission, Aims & Objectives

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.

Our strategic aims:

Access
Ensure equitable access to care for children with cancer across the NW

Quality
Ensure quality of care to children with cancer across the NW

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

Our Objectives:

- Ensure, equitable, high quality care
- Improve interoperability and data quality
- Build and support a sustainable, competent and confident workforce
- Maintain excellent access to clinical trials and high quality research activity
- Enable patient and family engagement and voice

2.1 Network Values

The ODN values have been developed based on the collective regional workshops and through listening to the experiences of children with cancer and their families and include:

Patient focused care

Honesty & integrity

Evidence based transformation

Collaborative working

Compassion & Empathy

What is it we value in Children's Cancer Services? What is important to you?

The word cloud below was developed from the regional workshops that were held in Spring 2023. When professionals were asked what is important regarding CYP cancer. As can be seen the focus was on communication, education, collaboration, patient voice and provision of safe, quality care.

2.2 Network 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 via the Programme of care (POC) group. 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.

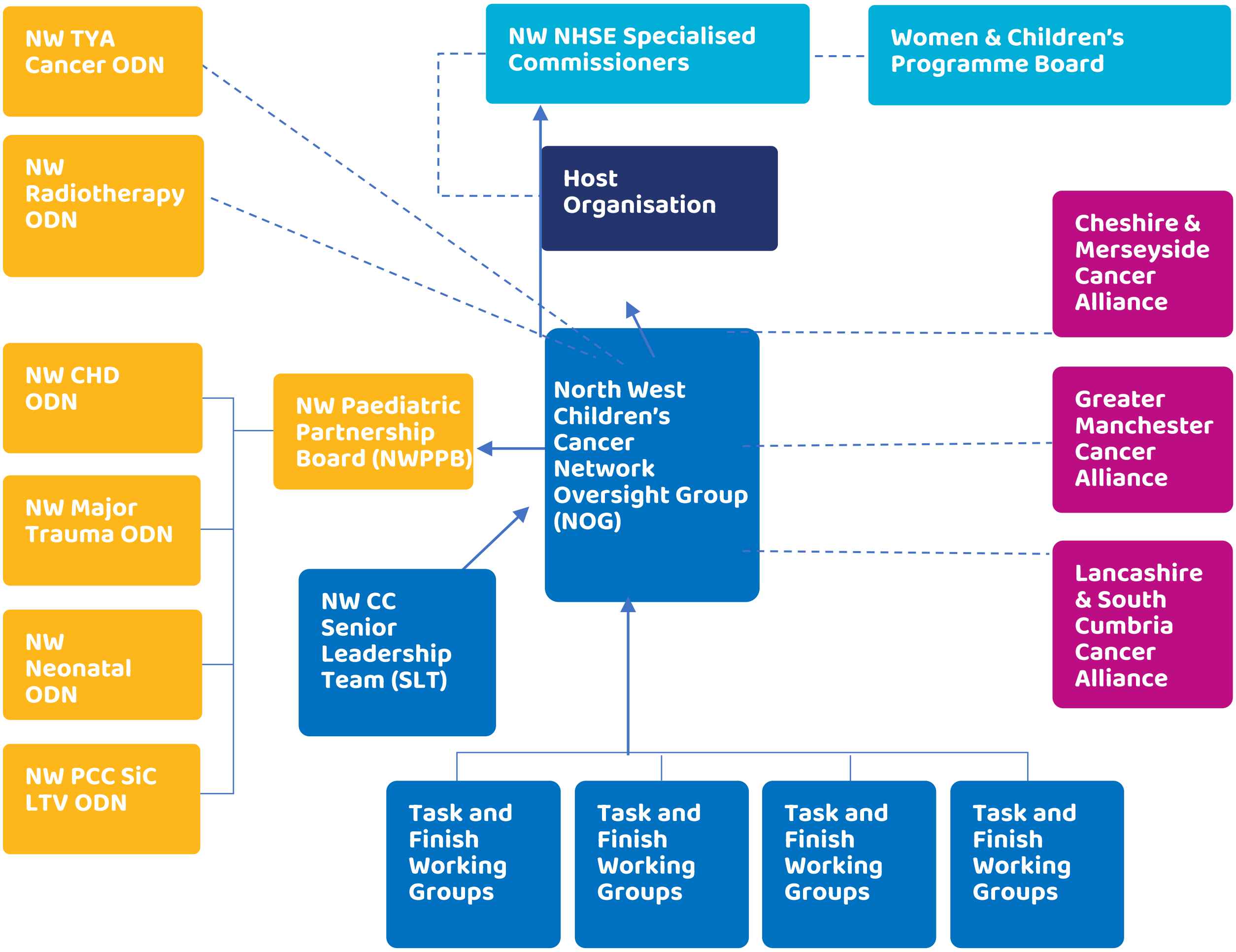


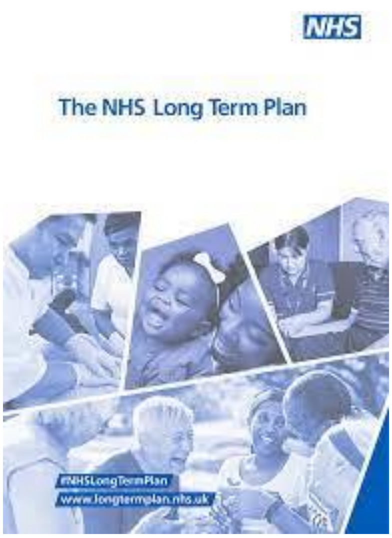
Diagram 2: Overarching governance structure

3.0 National Picture

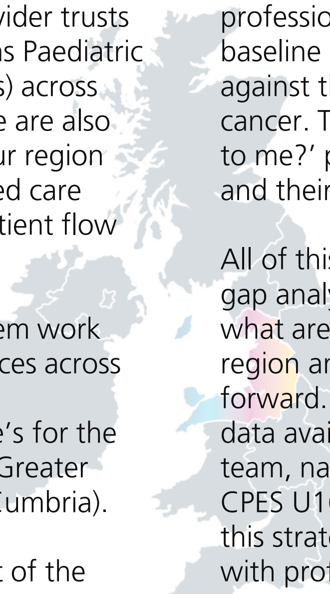
The current policy context regarding children with cancer in England includes a number of key documents, policies and service specifications setting out the required expected standards for care. These include:

- **NHSE Service Specifications for Children's Cancer (PTC and POSCU):** https://www.england.nhs.uk/commissioning/spec-services/npc-crg/group-b/b05/
- **Improving Outcomes; a Strategy for Cancer – Department of Health (2011) with updates in 2014:** https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/388160/fourth_annual_report.pdf
- **Five Year Forward View – NHS England (2014):** https://www.england.nhs.uk/cancer/strategy/cancer-fyfv/
- **Report of the Independent Cancer Taskforce - 'Achieving World-Class Cancer Outcomes: A Strategy for the NHS 2015-2020:** https://www.england.nhs.uk/cancer/strategy/cancer-one-year-on-2/
- **Long Term Plan (2019):** https://www.longtermplan.nhs.uk/
- **NICE Quality Standard for Cancer Services in children and young people (QS55):** https://www.nice.org.uk/guidance/qs55/chapter/about-this-quality-standard
- **NICE Quality Standard 'Fertility Problems' (QS73):** https://www.nice.org.uk/guidance/qs73
- **NHSE Service Specifications for TYA Cancer (PTC, DH & Network):** NHS commissioning » Children and young people's cancer service portfolio (england.nhs.uk)
- **National Cancer Patient Experience Survey (CPES) U16:** https://www.under16cancerexperiencesurvey.co.uk/
- **NHS Long Term Workforce Plan (2023):** NHS England » NHS Long Term Workforce Plan

U16 cancer patient experience survey



4.0 Regional Picture



The network covers all children requiring cancer treatment from 0-15 years (inclusive) old in North West region. The region is fortunate to have access to world leading cancer services. 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 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 to and from Stoke.

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).

The strategic design and development of the network has been co-produced across the region with the input of professionals working closely with families experiencing cancer and the patients themselves. This is an ongoing process and will continue to develop.

How Have We Consulted?

The NWCCODN held an interactive launch event, face to face professional workshops and virtual strategic development workshops for professionals across the region and completed a baseline Self-Assessment of services in the region against the service specifications for children's cancer. This is in addition to the 'What matters to me?' project to gather the views of children and their families via questionnaires.

All of this information has fed into a regional gap analysis to highlight what is working well, what are the gaps in service provision for the region and what are the priorities on moving forward. From this intelligence and using the data available to us through the regional NHSE team, national data and the feedback via the CPES U16 survey for our region we developed this strategy document. This has been shared with professionals working across the region for consultation and with parents and carers for feedback on the key aims and outcomes.

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*

4.1 Data Trends

National statistics:

Children's cancer statistics

Cases	Deaths	Survival
1,838	253	84%
New cases of children's cancer each year, 2016-2018 average, UK	Deaths from cancer in children, 2017-2019, UK	Survive children's cancer for 5 or more years 2012-2016, UK

Young people's cancer statistics

Cases	Deaths	Survival
2,374	248	87%
New cases of children's cancer each year, 2016-2018 average, UK	Deaths from cancer in children, 2017-2019, UK	Survive children's cancer for 5 or more years 2012-2016, UK

Regional Data:

The North West region has a population of circa 7.4 million, around 1.6 million of these are children under 16 years (this equates to19.1% of the overall population). The region has high levels of deprivation and has some of the most deprived localities in England with 4 local authorities being in the top ten most deprived local authorities in England (notably Blackpool, Manchester, Liverpool and Knowsley) according to the index for Income Deprivation Affecting Children Index (IDACI).

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.

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

Cancer incidence 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 the North of England Commissioning Service Unit (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. We have also worked with real world through the children's hospital collaborative to access a focussed data deep dive report for our region.

Data is important in helping the network set a baseline to understand the current regional service delivery against the national standards and to help monitor progress. It will also help inform the transformation programme and any changes which may be required to the way services are delivered going forward. We plan to identify and set ODN KPI's in addition to the national data requirements set in the service specification.

*data from national Census 2021, WHO, NECS, & CCLG

4.2 North West NHSE Transformation Programme

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. This is now being developed into an ambitious transformation programme across the region.

Specifically, regarding Children and Young People (CYP) Cancer the Case for Change highlighted the need for review of compliance against the new service specifications, gap identification and action plans regarding the two NW Principal Treatment Centres (PTC) and the seven NW POSCUs. There was also discussion that other models of care need to be explored to look at how cancer care across the region can be provided closer to home.

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 in Summer 2024.

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 forward. If anyone wishes any further information regarding the NW W & C Transformation Programme, then please contact:
england.wcyptransformation@nhs.net

One of the issues that the North West Transformation Programme is considering is the impact of travel for children with cancer. 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 (both financial and time). Many children with cancer have numerous episodes of care provided so this compounds the burden of travel.

The distances children and families travel to access their care is a challenge for some and the financial burden is compounded for those families living in the areas of lower deciles on the social deprivation scale. We will be planning to work with NHSE and the Children Transformation Board regionally, to understand how we might be able to support poverty proofing of services and the impacts of those with additional needs. We will consider an equity impact assessment as part of the work through the transformation programme to fully understand any impacts of additional needs and demographic factors for children with cancer in the region.

4.3 Regional Service Offer

The North West region has access to some of the most innovative and world leading cancer services and treatment centres which includes:

Alder Hey Children Hospital (AHCH) – Principal Treatment Centre:
Alder Hey Children's Hospital (AHCH) has a strong commitment to research in children's cancer and is a ground-breaking children's hospital providing care for over 333,000 children a year. It is one of the top ranked paediatric hospitals being in the top 15 best specialised paediatric hospitals in the world.

Royal Manchester Children Hospital (RMCH) – Principal Treatment Centre
Royal Manchester Childrens Hospital is one of 5 designated phase 1 trial centres for children's cancer in the UK and 1 of the 5 UK innovative therapies for childhood cancer (TCC). RMCH is a lead research centre offering early phase clinical trials and holds a large research portfolio covering the full range of childhood cancers.

The Christie:
The Christie is the largest single site cancer centre in Europe delivering world class cancer research and care. There are often more than 400 clinical research trials running at any given time and they are internationally renowned for their expertise in cancer research. In December 2018, the Christie became home to one of only two high energy NHS Proton Beam Centres in the UK (the other being based at UCLH).

North West Genomic Laboratory Hub:
The NWGLH is a world class genomic testing resource that underpins the NHS Genomic Medicine Service led by Manchester University NHS Foundation Trust with regional delivery partners including Liverpool clinical laboratories, The Christie, Lancashire Foundation Trust. They provide the regional genetic testing and Whole Genome Sequencing (WGS), an innovative technique using DNA to help personalise treatments and help peoples own immune systems fight cancer.

National Institute Health Research (NIHR): Greater Manchester and Lancashire and South Cumbria BRC
Manchester biomedical research centre (BRC) is transforming scientific breakthrough into diagnostic tests and lifesaving treatments for patients. They were recently awarded £60m (2022- 2027) and bring together world leading researchers from across 6 NHS trusts and the university of Manchester with a vision to drive health improvement and lasting change for all through creative, inclusive proactive research. They are pioneering research in cancer.

Liverpool BRC
Liverpool Biomedical Research Centre provides state of the art purpose-built facilities, embedded within the Royal Liverpool Hospital and offers a safe and regulated environment to perform clinical research trials to the highest possible standards.

Children's Hospices and Cancer Charities
There are a number of cancer charities and children's hospices within the North West that offer services and support to children with cancer and their families. A child with cancer has a life-threatening condition and as such can access the facilities and support of their local hospice. Hospices in the North West include Derian House, Jacks House, Claire House, Brian House, Hope House, Francis House, Ty Gobaith (in North Wales), Eden House and Rebecca House (in the Isle of Man).

There are also support services available from cancer charities such as The Joshua Tree, The Rainbow Trust, CHIC's, Children's Cancer North, Teenage Cancer Trust, Young Lives Versus Cancer among others.

4.4 What's Working Well?

These are some quotes from professionals working across the region via the network launch event & professional workshops regarding what is currently working well for children's cancer care across the region.

"Introduced medicine labelling in other languages for those that don't read English"

"Focused case studies via the Self Assessment = sharing good practice"

"Support for service development & support from NHSE (regional team) – Cancer in children is seen as a priority"

"Dedicated staff (working across the region) … wanting to improve outcomes for patients and families"

"MDT's, shared care and collaboration"

"Palliative Care and EOL service offer in some parts of the region"

"Commitment to patients and working together"

"Research trials. With most eligible children in PTC's being offered a trial"

"Excellent team working between centres"

"Hospice provision and charities across the region offering support to families"

4.5 Challenges

These are some quotes from professionals working across the region via the network launch event & professional workshops regarding gaps and challenges for children's cancer care across the region.

"Formal transition arrangements to TYA services are a challenge in some service areas (i.e. Late effects)

"Resource is needed to offer more care/ support at home"

"There is a gap in the infrastructure needed to keep up with treatments"

"Palliative care and EOL offer is not equitable across the region"

"One of the challenges is the geographical area as it means a lot of patient travel for some families with long distances"

"Offer for some TYA trials is a challenge for some"

" Patient engagement needs proper resource"

"Retention of skilled workforce"

"Formal communication is a challenge i.e. discharge letters, MDT outcomes etc this results in personal endeavour being required to compensate for system constraints "

"Co production has always been a challenge as families want to move on after the child's cancer experience"

5.0: High Level Work Plan NWCCODN

This is a high level 5-year plan setting out the aims and objectives for the workstreams that have been developed from the priority setting work conducted in the workshops (Professional and Families) & the national objectives set via the NHSE Service Specification. These will be developed into working groups over coming next year (2023/24 – 2024/25 with highlight reporting for each workstream feeding into the NOG on a quarterly basis. The work plan is aligned to the 5 CQC standards: Safe, Effective, Caring, Responsive & Well Led services.

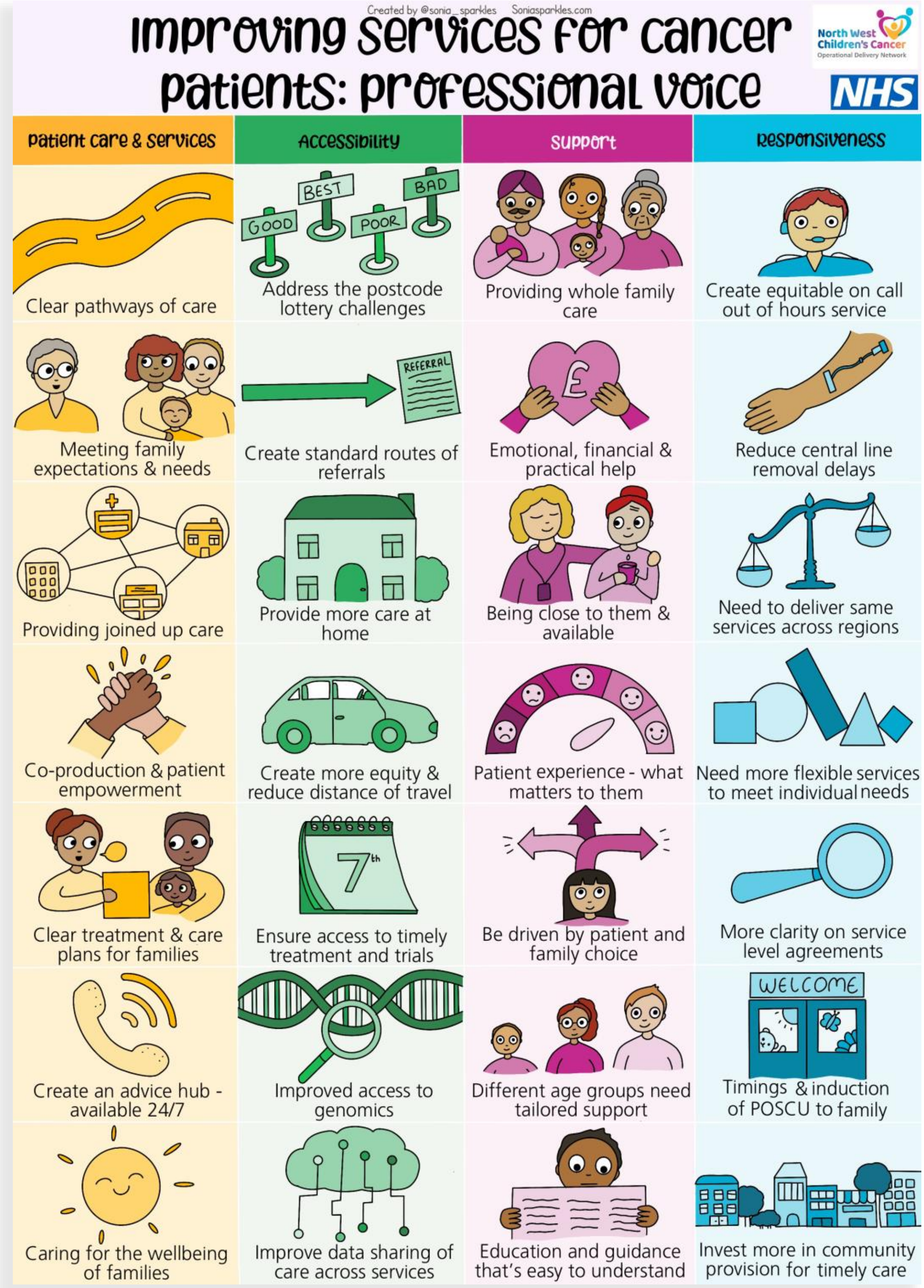
Work Stream	Aim/ Objective	Short, Medium or Long term	Improvement Outcomes
Workforce & Education	Training Needs Analysis	Short term	
	Regional policies and protocols central repository on website	Short term	
	NW Joint CTYA Annual Conference	Short term	
	Develop a workforce gap analysis underpinned by the NHS Workforce Plan (2023)	Short term	
	Deep dive into retention issues and develop associated action plan to improve these based on ACCEND	Medium to Long Term	
	Develop programme of training via a NW Childrens Cancer Academy	Medium to long term	
	Lessons learned - safe facilitated sessions	Long term	
Data & Digital	Develop ODN website	Short term	
	Pilot use of shared care record in C&M using 'share to care' for children's cancer care	Short term	
	Access funding and support for regional shared care record & Improve data coding	Medium term	
	Scope digital solutions to support care delivery closer to home (e.g. VR for staying connected to school, home handheld kits for recording patient data and upload)	Medium term	
	Develop children's cancer data dashboard and KPI's	Medium term	
	Develop shared care record across region	Long term	
	Fully functional interoperability across the region	Long term	

Short Term = **1-2 years** Medium Term = **3 years** Long term = **4 -5 Years**

Safe, Equitable, High Quality Care	Ambulatory care pilots	Short term	
	Access funding to extend ambulatory care project and provide evaluation of project	Short to medium term	
	Work with NHSE to develop the 'long list' of options for the issues raised in the case for change relating to children's cancer care	Short term	
	Scope genomics, & fertility preservation	Medium term	
	Support the development of action plans for each unit	Medium term	
	Complete Self Assessment review & Develop a joint approach to measure success against service specification	Medium term	
	Work with PEOLC network to support a model of 247 care for all children with cancer across region (PEOLC & On Call)	Long term	
	Work with the PEOLC strategic network to ensure equity of access to EOL care	Medium to long term	
	Scope holistic support on offer across the region and make recommendations based on findings	Medium term	
Patient Voice	Patient experience survey analysis & sharing	Short term	
	Support family & patient engagement in the NHSE case for change	Short term	
	Set up governance & develop Patient Reps network	Medium term	
	Develop engagement (patient board) & peer support tools	Long term	
	Patient and professional awards (NW)	Long term	
	Based on the feedback received implement wider patient and family support e.g increased use of therapy animals , develop facilities,	Short term	

Short Term = **1-2 years** Medium Term = **3 years** Long term = **4 -5 Years**

Appendix 1: Summary Professionals Feedback



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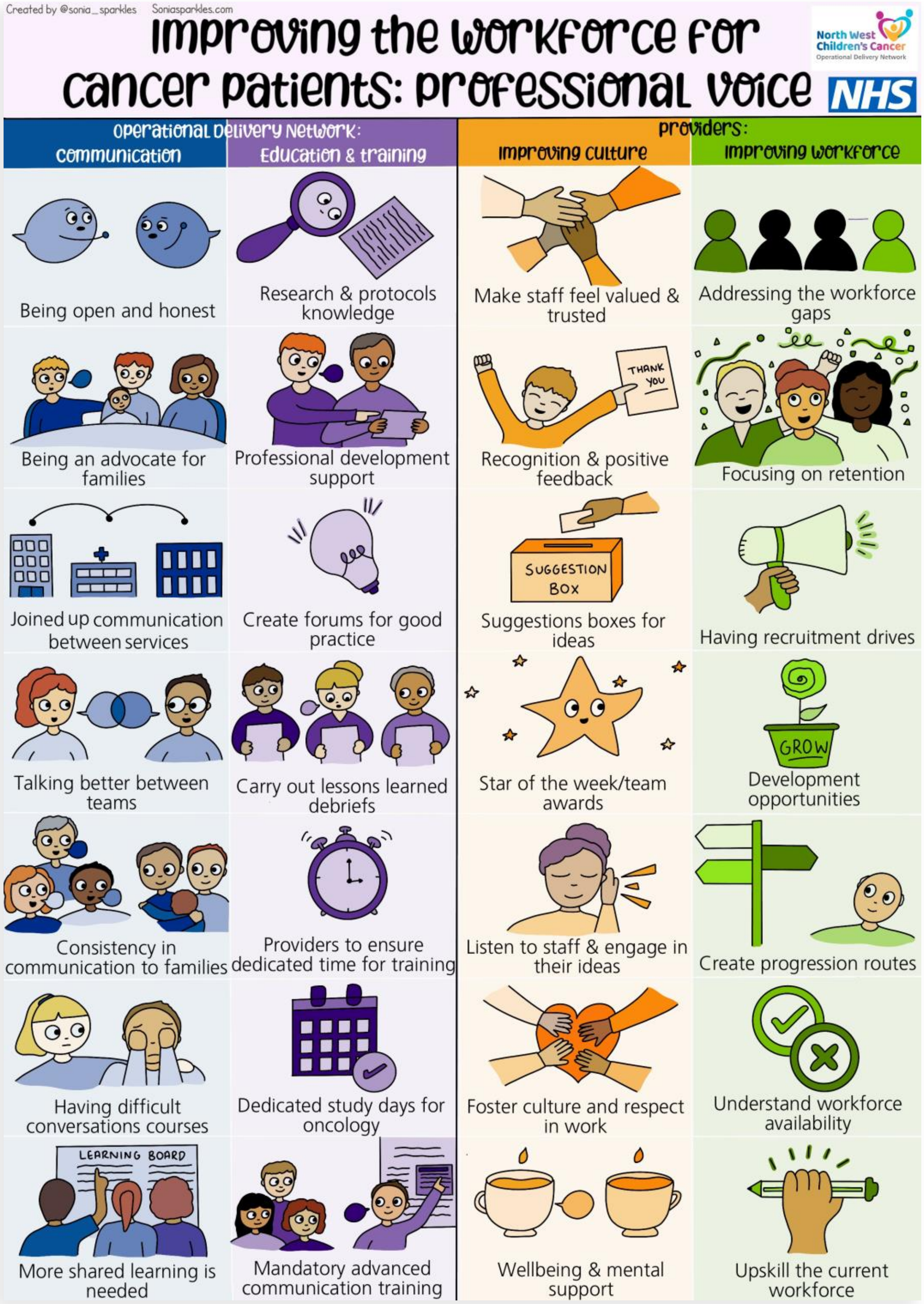
Improving services for cancer patients: professional voice

Patient care & services	Accessibility	Support	Responsiveness
Clear pathways of care	Address the postcode lottery challenges	Providing whole family care	Create equitable on call out of hours service
Meeting family expectations & needs	Create standard routes of referrals	Emotional, financial & practical help	Reduce central line removal delays
Providing joined up care	Provide more care at home	Being close to them & available	Need to deliver same services across regions
Co-production & patient empowerment	Create more equity & reduce distance of travel	Patient experience - what matters to them	Need more flexible services to meet individual needs
Clear treatment & care plans for families	Ensure access to timely treatment and trials	Be driven by patient and family choice	More clarity on service level agreements
Create an advice hub - available 24/7	Improved access to genomics	Different age groups need tailored support	Timings & induction of POSCU to family
Caring for the wellbeing of families	Improve data sharing of care across services	Education and guidance that's easy to understand	Invest more in community provision for timely care

Appendix 1: Summary Professionals Feedback



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Improving the workforce for cancer patients: professional voice

Operational Delivery Network:

Communication

- Being open and honest
- Being an advocate for families
- Joined up communication between services
- Talking better between teams
- Consistency in communication to families
- Having difficult conversations courses
- More shared learning is needed

Education & training

- Research & protocols knowledge
- Professional development support
- Create forums for good practice
- Carry out lessons learned debriefs
- Providers to ensure dedicated time for training
- Dedicated study days for oncology
- Mandatory advanced communication training

Providers:

Improving culture

- Make staff feel valued & trusted
- Recognition & positive feedback

- Suggestions boxes for ideas

- Star of the week/team awards
- Listen to staff & engage in their ideas
- Foster culture and respect in work
- Wellbeing & mental support

Improving workforce

- Addressing the workforce gaps
- Focusing on retention
- Having recruitment drives
- Development opportunities

- Create progression routes
- Understand workforce availability
- Upskill the current workforce

Appendix 1: Summary Patient Feedback

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CHILDREN'S CANCER OPERATIONAL DELIVERY NETWORK

"WHAT MATTERS TO ME?": PATIENT VOICE

North West Children's Cancer Operational Delivery Network

NHS

- Welcoming environment
- Celebrating progress

- Getting back home
- Can call staff anytime

- Scared of needles
- Lots of support

- Less travelling
- Less moving around

- Quick blood results
- Medication coming quicker

- Waiting less
- Told about delays

- Treatment at home
- Involved in decisions

- Better activities
- Open playrooms

- Bigger wheelchair spaces
- Hospital transport

- Having fun
- Music & art

- Going outside
- More family time

- Kitchen facilities
- Locker storage

- Washing machine
- Parent room

- TVs & good WIFI
- charging ports

- Therapy animals
- Colouring to relax

- Eat together
- Variety of food

- More time with staff
- Good communication

- Education
- The future

- Group activities
- Playing with others

- Watching movies
- Lots of hugs

Appendix 3: Self Assessment Summary

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 (in relation to fever and sepsis and timely antibiotic treatment) 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 shard 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 with some services holding a long wait list.
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 in some centres.
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 reported in some POSCU's.
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.
Issue with increased workload as patient care becomes more complex with additional lines of therapy,
Retention of suitably skilled nursing workforce.

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 – based on the SSQD.
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.
Shared review learning from significant incidents where appropriate.

Appendix 4: Detailed Annual Work Plan 2023/24 NWCCODN

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.	POSCU 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.	🟩
	Data sharing – make links via shared care record/develop options appraisal and date 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.	🟩
	Develop Safe Effective Care sub group to scope ambulatory and home care & identify any 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.		🟧

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.	🟩
	Undertake workforce mapping and training needs analysis for the region.	Not yet started (focus for 2023/24).		🟨
	Develop governance documents for NWCCODN.	All governance documents drafted (ToR, SOP & MoU), ratified at NOG 20 March 2023.		🟦
	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.	🟩
	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.	🟩

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.	🟩
	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.	🟩
	Develop Network comms strategy plan.	Not yet started (focus for 2023/24).	Increased engagement professional and patient/family	🟨
	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	🟦