North West Children's Cancer Operational Delivery Network

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Patient & Family Experience Working Group Volunteer Handbook

2024

North West Children's Cancer
Operational Delivery Network

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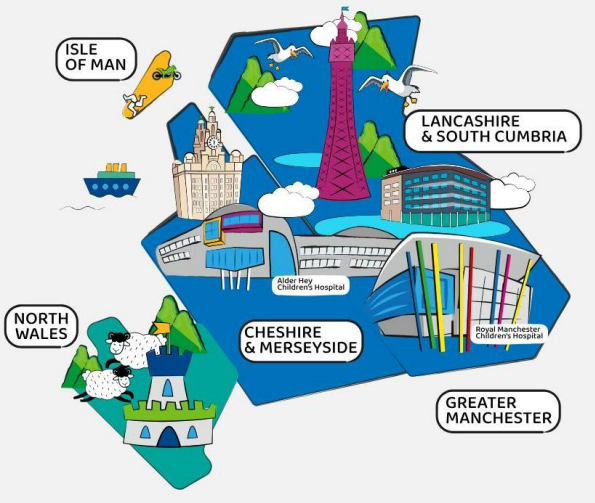


North West Children's Cancer Operational Delivery Network

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.

The NWCCODN works in partnership with 12 providers across the North West, set within the following localities; Cheshire & Merseyside, Greater Manchester, and Lancashire & South Cumbria. This consists of 2 Principal Treatment Centers (PTCs) and 10 Paediatrics Oncology Shared Care Units (POSCUs). The POSCUs are Standard Level POSCUs; 6 POSCUs in the North West of England, 1 POSCU in the Isle of Man (IOM) and 3 POSCUs in North Wales.

For more information on the Network visit our website:
https://www.nwchildrenscancerodn.nhs.uk/
Or follow us @NWCCODN on:

Instagram Twitter/X

Alternatively, you could speak to one of our team. Just email the NWCCODN at info.nwccodn@mft.nhs.uk to organise a call or video chat.

Getting Involved

The NWCCODN is committed to understanding and involving the lived experience of patients and their families in all the work we do across the North West England, Isle of Man and North Wales. It is vital that the NWCCODN hear the voice of families from across the region and that everyone feels welcome.

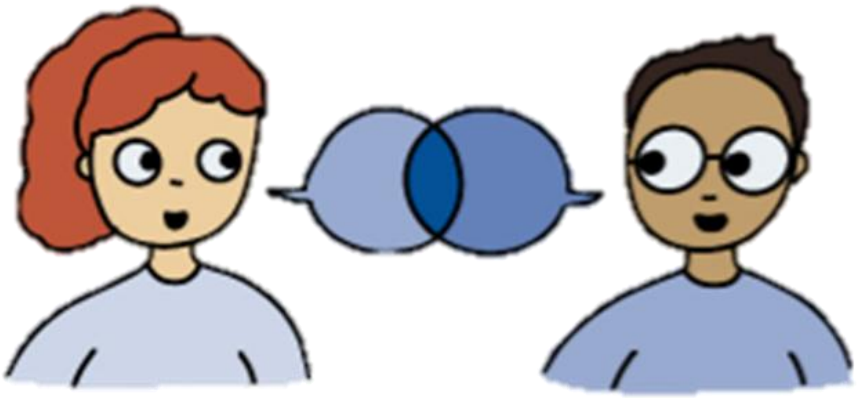
Our volunteers share their experience, insight and ideas to help make children's cancer care the best it can be.

The following pack sets out what volunteers can expect when working with the NWCCODN and what the Network expects from it's volunteers and colleagues.

There is no minimum or maximum amount of time a volunteer can work with the Network and volunteers can choose to step back from any involvement at any time by informing the Network team.

The Welcome Pack & Volunteer Agreement has been developed via the *Patient & Family Experience Working Group* of the NWCCODN. Hence, it has been co-developed with patient and family representatives and colleagues from across the region.

Please note that the Volunteer Agreement is subject to change and will be reviewed as and when is necessary. All changes will be communicated to all stakeholders involved.



Patient & Family Experience Working Group

The Network have developed a Strategy with feedback from colleagues and families from across the region. You can read the Strategy here: https://www.nwchildrenscancerodn.nhs.uk/professionals/documents/

The Strategy breakdowns the Network's priorities into four Working Groups. More information on the Network's Working Group can be found on the website: https://www.nwchildrenscancerodn.nhs.uk/professionals/workstreams/

One of these groups is the *Patient & Family Experience Working Group*.

The aim of the Patient & Family experience working group is to ensure that the voice of children with cancer is central to the work that the network undertakes across the region. The group will be responsible for ensuring that there is effective representation on all of our working groups and for the development of a patient and family experience group to support co development and design of the work programme for the network and also for regular collection and analysis of patient experiences across the region. The working group will feed into the Network Oversight Group, providing regular highlight reports and will work to an agreed workplan with clear aims and objectives in relation to patient experience.

Values & Behaviours

The Network's values have been developed based on the collective regional workshops and through listening to experiences of children with cancer and their families.

Value	Behaviours
Patient focused care	• Always considering the patient and their family when working to improve services • Be passionate about advocating for children with cancer and their families • Act in patient and their families best interest
Honesty & integrity	• Maintaining confidentiality. Being members of the WG may mean you are privy to information that the general public doesn't know • Respecting your personal boundaries and sharing what feels comfortable for you • Trust each other • Hold yourself and others to account • Act in an open and transparent way
Evidence based transformation	• Understanding the data available • Identifying gaps in the data • Considering underserved groups • Being objective • Thinking creatively to solve problems • Being action focused
Collaborative working	• Active listening to ensure all colleagues feel heard • Respecting other people's views and experiences • Ensuring that the right people are round the table • Support other group members • Be enthusiastic • Celebrate successes • Respect others by being punctual and sticking to agreed timeframes
Compassion & Empathy	• Avoiding judgement and bias • Act with kindness • Value diversity, everyone has something to offer

The NWCCODN value and want to empower its members to contribute to the best of their potential. This is only possible if a psychologically safe space is created and upheld therefore all volunteers will be expected to adhere to these values and behaviors.

Role Descriptions

Patient/Family Meeting Representative

Hours: 1 hour Working Group meeting every quarter (3 months) plus additional Task & Finish Groups. There is no expectation that volunteers attend every meeting. Meeting dates and times will be planned via a poll to agree the most popular date.

The role of the Patient/Family Meeting Representative is to advocate for children affected by cancer and their families and to guide the direction of the *Patient and Family Experience Working Group*. Reps will be supported to talk with professionals and share their views on the bigger picture of children's cancer care.

Key Responsibilities

- Ensure that patient/family voice is heard
- Represent different experiences of families that have been affected by childhood cancer
- Hold the Network to account, ensuring that patient and family experience is considered in all the work being undertaken
- Maintain confidentiality
- Work closely with other lived experience leads
- Be a good role model to others

Experience

- Lived experience of childhood cancer within the last 10 years

Other Roles

It is expected that as the network develops the need for other volunteer roles will arise. This handbook will be updated to include additional roles and will be re-reviewed by the Patient & Family Experience Working Group.

Support

The Network will ensure that volunteers feel welcomed and valued. The wellbeing and empowerment of volunteers is pivotal to the Network and therefore all volunteers will have an ODN buddy to support them and will receive an induction, tailored to their needs.

If volunteers find the role triggering, then the Network will support them to step down for a period of time or completely if required. The Network will support the volunteer to access any appropriate support services.

Policies & Procedures

NWCCODN Patient & Family Experience Strategy

The Network are co-producing a Patient & Family Involvement strategy which outlines how the Network engage with people with lived experience. This will but uploaded to the Network's website once complete.

DBS

Volunteers will not be required to complete a DBS check as they will not be left unsupervised with children as part of their role.

Safeguarding

If any safeguarding concerns are raised in the group, these must be passed onto the related provider's safeguarding team to investigate further by the person who raised the concern.

RMCH Safeguarding Team: 01612744981
Alder Hey Safeguarding Team: 01512284811

Risk Assessments

Risk assessments will be completed if needed and on a case-by-case basis.

Declaration

As a volunteer for the North West Children's Cancer ODN and a representative for children with cancer across the North West, North Wales and Isle of Man, I understand and agree to the values and behaviors listed in this agreement. I accept that my involvement with the Network will be reconsidered if I do not adhere to the expectations set out in this agreement.

I have been allocated an ODN buddy and I am aware I can access their support regularly.

Name:

Signature:

Date:

Contact details (e.g. email or phone number):

Thank you for volunteering with the North West Children's Cancer Operational Delivery Network and for advocating for children and their families across the region! We hope you find your experience enjoyable and rewarding.

Your buddy will be in contact soon to arrange a chat!

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