

North West Children's Cancer Operational Delivery Network

Patient and Family Involvement Strategy

2024 – 2028

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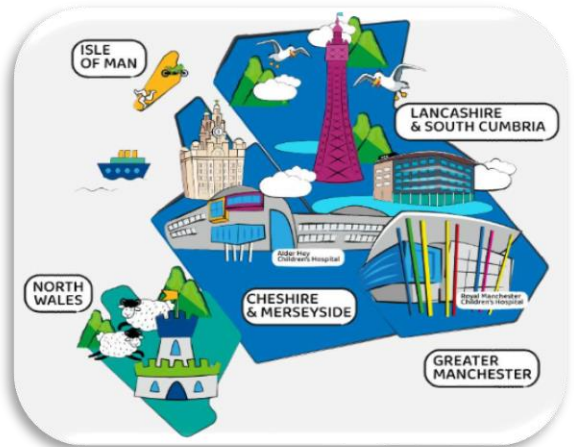
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1.0 Introduction

1.1 Overview

The North West Children's Cancer Operational Delivery Network (NWCCODN) aims to bring together professionals, providers, commissioners, patients and families to provide safe, high-quality cancer services across the region. Our region consists of the North West of England, Isle of Man and North Wales, as shown on the creative map. Regional collaboration is essential to ensure delivery of high quality, person-centred and outcome-focused cancer services across the region. We recognise our patients and family members are best placed to understand what they require as service users, what is working well and what can be improved.



The NWCCODN recognises the benefits and valuable impact that the involvement of patients and family members can have. An objective within our network is creating a safe space and respectful culture so they can contribute through providing perspective, expertise and sharing their own experience of care. By incorporating involvement of patients and family members they can provide expertise and guidance. Involvement of their voice will ultimately contribute to service development and improvement work. We encourage those involved to challenge our thinking, contribute to innovation and improvement ideas, voice their experience and ultimately ensure we are responsive to meeting the diverse needs of service users within our region.



To enable patient and family involvement within our network, we have produced this document to ensure supportive structures and guidance is in place. This document is relevant to any patient and family involvement work which the NWCCODN undertake and therefore all involvement needs to be in accordance with this document.

For further context, the document should be read in parallel to the NWCCODN Strategy (Appendix 1), NWCCODN Volunteer Handbook (Appendix 2) & NWCCODN Communication Strategy (Appendix 3).

1.2 Patient & Family Involvement

Patient and family involvement within the National Health Service (NHS) can be described as:

- The involvement of individual patients in their own care and promoting shared decision making.
- The involvement of users and parents/carers in service design, innovation, improvements and evaluation/feedback through lived experience of care.
- Engagement of communities and public in prioritisation and forward planning.

The network will be responsible for any of the above involvement pathways, and we recognise there are differing platforms of involvement from a one-off basis, ad hoc basis, frequent basis or as a volunteer representative sitting on a specific programme of work. We understand engagement will vary per individual and all patients (+/- parents/carers) are acknowledged equally for their contributions and input in positive change.

1.3 Aims & Objectives for patient & family involvement

AIM: To ensure the voice of children with cancer, and family members, is central to the work which the network undertakes.

To creatively capture voice through various methods of engagement; whilst recognising the benefit of already established platforms.

Promote a safe space and listening culture for patients and family members to share their experiences, journeys and suggestions of improvements. This should be an accessible platform for all.

Recognise and appreciate all contributions are important in adding value. Communication and feedback to patients and family members is essential; via written communication, website updates and a You Said, We Listened approach.

Ensure involvement across the network is available for patients and family members to get involvement and influence the work across all the Working Groups and service improvement projects.

The NWCCODN shall ensure that anyone within the North West region who has a lived experience of Children's Cancer Services (child, young person, parent(s) or carer) will be able to share their experiences and input into our work. We acknowledge the region have well-established forums and charitable services where patient engagement is embedded so we confirm utilisation of these existing platforms as well.

2.0 Involvement Approach

Different pieces of work require different levels of involvement as outlined in figure 1. All network projects will state which level of involvement is required via the document control page.

The network's SLT felt the PPI Strategy requires the highest level of involvement and has therefore been co-produced with the NWCCODN Patient & Family Experience Working Group.

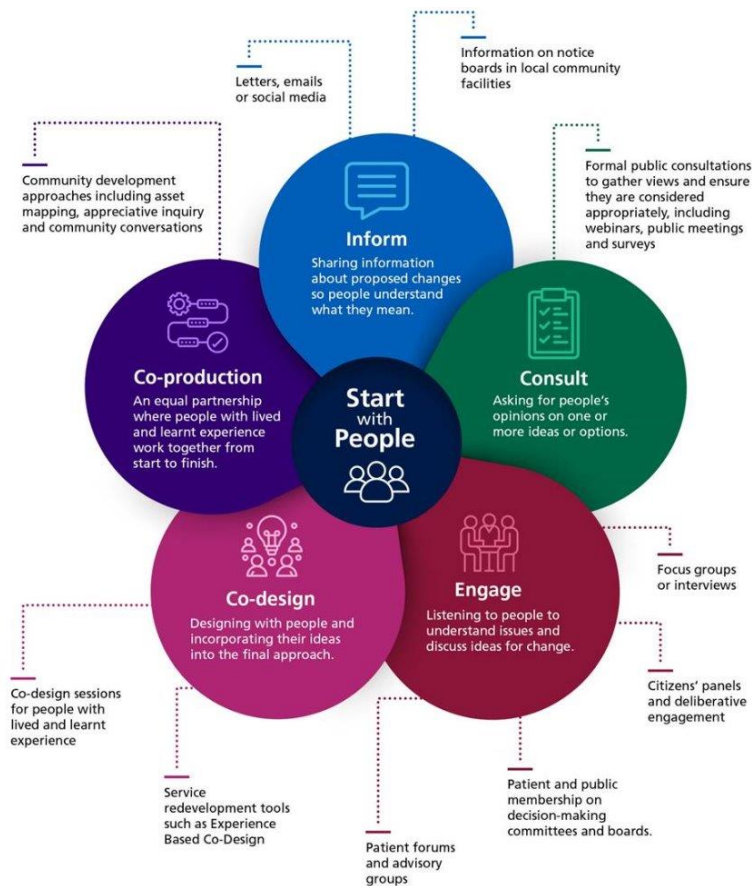


Figure 1: [NHS England » Working in partnership with people and communities: Statutory guidance](#)

2.1 NWCCODN Patient & Family Experience Working Group



This working group is being co-produced with patient and family representatives along with relevant professionals from across the healthcare system and charitable sector. The group is co-chaired by a parent and professional from the region. The group links patient and family voice into the network and is initially focused on mapping out and utilising the voice of patients and their families through existing support services, charities and services with the aim to mitigate any potential gaps. The working group reports into the Network Oversight Group and a representative sits on the network's Equitable, High Quality Care working group, therefore influencing network priorities and projects. Extensive research was undertaken when setting up the group and the group is expected to develop further as it matures. Further details of the working group can be found in the Terms of Reference (Appendix 4).

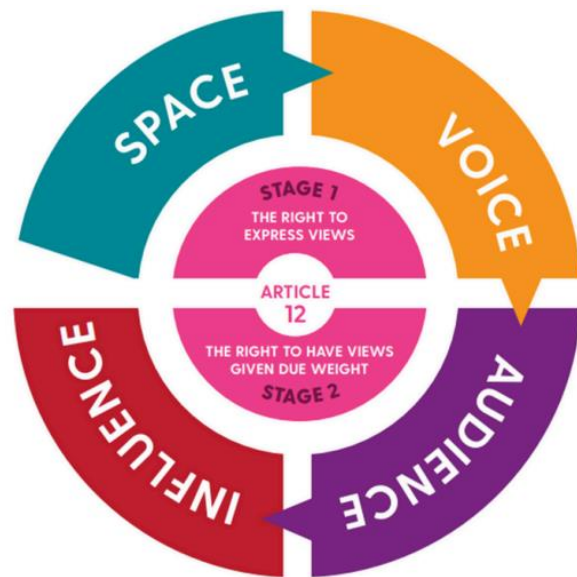
2.2 Inclusion

The NWCCODN are committed to ensuring representation of the region's diverse population and encourage the engagement of patients and families via numerous different routes to ensure accessibility. The network will be regularly reviewing patient demographics across the region and will ensure a focused effort on engaging with underrepresented groups.

Patient and family involvement in the network will be managed via the Patient & Family Experience Working Group and Volunteer Handbook (Appendix 2). Our CMCA patient/carer representatives are recruited by the CMCA Patient Engagement Team to ensure diverse patient voice is at the heart of cancer care improvement projects both within the Alliance and the wider system.

Further details of the network's stakeholders can be found in the Communications Strategy (Appendix 3).

2.3 The Lundy Model



The Network Manager, Quality Improvement Lead Nurse and Innovation Project Officer have been trained in applying The Lundy Model to patient engagement. The network will use this framework when planning engagement activities and will encourage partners to do the same. The model has been developed from the UN Convention on Rights of a Child and states 4 key elements to engaging with children and young people. These elements are outlined in figure x.

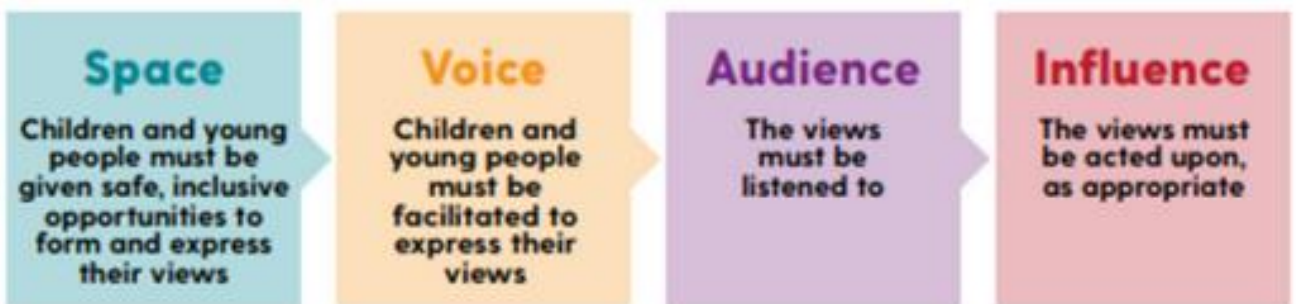


Figure 2: Lundy Model: National Framework for Children and Young People's Participation in Decision-making, Government of Ireland
<https://youthfocusnw.org.uk/>

3.0 Evaluating Success

Constant evaluation and reflection on progress is required to assess the benefit, monitor achievements and review the outcomes of our work. By evaluating our success, it helps us to determine whether goals and objectives have been achieved, and whether activities have had the desired impact.

We will evaluate our success in line with the below guidance:

Abbreviations;* **RAG (Red, Amber, Green traffic light system), **SLT** (Senior Leadership Team), **NOG** (Network Oversight Group), **QI** (Quality Improvement), **PTC** (Principal Treatment Centre – Alder Hey Children's Hospital and Royal Manchester Children's Hospital)

Category	Measurement	Frequency of Evaluating Success
Aims & Objectives of Patient & Family Involvement Strategy	<ul style="list-style-type: none"> On performance (with RAG system) Reflection of achievements 	Yearly (via team reflection day & April NOG)
Progress of Milestones and Activities completed on yearly workplans	<ul style="list-style-type: none"> On performance (with RAG system) 	Quarterly (via SLT and NOGs)
Aims & Objectives of the Working Group (+ any Task & Finish Groups associated with the Patient & Family Working Group)	<ul style="list-style-type: none"> On performance (with RAG system) 	Quarterly (via highlight reports for presenting at NOGs)
Monitoring engagement rates of professionals, charitable sector representatives and lived experience partners	<ul style="list-style-type: none"> % attendance rates Representation across region Volunteer Agreement records 	WG ODN Lead to monitor % attendance during stakeholder reviews
Impact of Patient & family Feedback on influencing service improvements	<ul style="list-style-type: none"> Ideas log – RAG rates QI Report for Service Improvement Projects You Said, We Listened approach Communication Loop 	Yearly (via team reflection day & April NOG)
U16 Cancer Patient Experience Survey (national) - monitor trends and response rates of survey	<ul style="list-style-type: none"> Comparison of PTCs performance against National % Improvement in feedback themes over time 	Yearly (via WG and NOG) Complete report summary for each PTC

4.0 Summary

This strategy has been co-produced with lived experience representatives and notes the commitment of the North West Children's Cancer ODN to listening and taking action on the voice of patients and their families. Outlining the networks patient and family involvement aims along with the chosen approach to involve and utilise the Lundy Model, this strategy serves as a guide for all NWCCODN work.

The NWCCODN is in a unique and privileged position to be able to engage with patients and their families as well as drive and influence service improvements and introduce innovations. This strategy outlines how the network will capture patient and family voice and use this as a force for positive change.

Appendices

Appendix 1: NWCCODN Strategy

<https://www.nwchildrenscancerodn.nhs.uk/wp-content/uploads/2024/02/NWCCODN-Strategy-Final-V1.0.pdf>

Appendix 2: NWCCODN Volunteer Handbook



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Appendix 3: NWCCODN Communication Strategy

<https://www.nwchildrenscancerodn.nhs.uk/wp-content/uploads/2024/03/NWCCODN-Communications-Strategy.pdf>

Appendix 4: Patient & Family Experience Working Group; Terms of Reference



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