



1 VISION STATEMENT

“All children¹ with life threatening and life limiting conditions, and their families will have access to the highest quality of supportive and palliative care throughout their journey from diagnosis or recognition to bereavement or transition to adult services. This will be provided in the most appropriate place according to needs and wishes of the child and family, regardless of geographical location, cultural social or ethnic factors. There will be full integration of services with seamless transition of care between primary, secondary and tertiary healthcare settings and close partnership between healthcare, education and social services care.”

2 THE NORTH WEST REGIONAL CHILDREN'S PALLIATIVE CARE NETWORK

- 2.1 The North West Children's Palliative Care Network brings together representatives of babies, children, young people with palliative care needs and their families, commissioners and providers of perinatal and children's palliative care from NHS, Voluntary sectors, Social Services and Education, across primary, secondary and tertiary care with the aim of improving co-ordination availability and delivery of palliative care.
- 2.2 The North West Regional Children's Palliative Care Network (the Network) includes representatives for the North West together with representatives from the Children's Palliative Care Zonal Networks for Greater Manchester, Lancashire & South Cumbria and Merseyside & Cheshire, with the aim of avoiding duplication and facilitating a consistent, coherent and coordinated approach.
- 2.3 Significant modifications to these terms of reference must be ratified by the North West Regional Children's Palliative Care Network and the three Zonal Networks to ensure that the overarching aims and objectives remain compatible and that the three Zonal Networks of the North West Regional Children's Palliative Care Network can work in partnership where a broader geographical footprint is more appropriate.

3 SCOPE

- 3.1 The scope of the North West Children's Palliative Care Network includes both oncology and non oncology diagnoses
- 3.2 The main focus of the work of the Network is children from 0 to 19 years. However the scope of the work of the Network also includes antenatal diagnosis and young people aged 19 and over in transition to adult services.
- 3.3 The geographical area covered by the Network includes the entirety of the North West Region of England. The three constituent Zonal Networks (Lancashire & South Cumbria, Greater Manchester and Merseyside & Cheshire are co-terminus with other similar Networks).

4 REMIT AND FUNCTIONS

- 4.1 To raise the profile of palliative care for children in the North West
 - Ensuring that palliative care provision is included in the wider North West agenda for perinatal, children's and young people's services
- 4.2 To inform strategic development palliative care children in the North West through:

¹Throughout this document the term child or children should be read as referring to babies, children and young people unless otherwise stated

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- Development of a children's palliative care strategy (to be renewed every 3 – 5 years as appropriate) for the North West Region, through effective partnership between service commissioners and providers
 - Review of appropriate local and national guidance
 - Active participation and partnership working with parents and carers through the affiliated parents group "Parent Voices Count"
 - Ensuring relevant links and consistency with other national and regional strategies
- 4.3 To develop and implement procedures for feedback and performance monitoring in order to oversee the delivery of the strategy for children's palliative care across the North West
- Development of a performance monitoring framework for the delivery of specific objectives for children's palliative care
 - Feedback, using performance monitoring, progress against specific objectives with identification of areas where additional resources are required
 - Monitoring inter-organizational incidents and near misses relevant to children's palliative care across the Northwest in order to improve patient safety and identify ways of preventing problems happen in future
- 4.4 To implement relevant (operational) aspects of the North West children's palliative care strategy
- Through individual work-plans via each of the three Zonal Networks
- 4.5 To act as an expert resource to appropriate statutory bodies on issues relating to palliative care for children in the North West
- Providing expert advice and responses to regional and national consultations
 - Identifying areas of best practice and ensuring that these are shared with other partner organizations across the network
 - Avoiding unnecessary duplication of work through effective networking sharing policies and practice
- 4.6 To ensure co-ordination and consistency of care facilitating partnership working across the Network
- Supporting the three Zonal Networks to ensure continuity and sustainability
 - Developing, where appropriate, network-wide policies, clinical guidelines and service directories and coordinating their implementation
- 4.7 To ensure appropriate education and training for professionals working in palliative care for children across the Network
- Identifying Network-wide education and training needs
 - Coordinating, in consultation with appropriate agencies, the development of training programmes to meet identified educational needs

5 OPERATING FRAMEWORK

- 5.1 The North West Children's Palliative Care Network will agree work streams and sub groups which will report to the Network and other relevant bodies as appropriate
- 5.2 The Network will have the power to co-opt other professional or lay representatives as appropriate

6 FREQUENCY

- 6.1 The North West Children's Palliative Care Network and Zonal Networks will meet at least quarterly

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- Regional Network Meetings will be open to non members from relevant professional groups via prior arrangement with the chair
- Zonal Network Meetings will be open to all
- Any task and finish groups will meet at a frequency determined by the groups to ensure their objectives are achieved

7 REPORTING PROCEDURE

- 7.1 The minutes of each meeting will be formally recorded and published in the Members-Only area of the Network Website following ratification and declarations of confidentiality
- 7.2 There will be a newsletter distributed to key stakeholders via the Zonal Networks at least twice a year
- 7.3 The Network will host a stakeholder event at least once every 3 years
- 7.4 The Network will be formally accountable, in line with other specialist children's Operational Delivery Networks in the North West, to the Paediatric Joint Operational Network Board
- 7.5 Feedback and recommendations will be made to relevant stakeholders as appropriate including:
 - Paediatric Operational Delivery Networks within the North West
 - NHS children's services providers in Acute and Community Trusts
 - North West voluntary sector services including children's hospices and bereavement services
 - NHS commissioners of children's services in Clinical Commissioning Groups, Health and Wellbeing Boards and Specialist Commissioning
 - Local Authority Directors of Children's Services

8 MEMBERSHIP

- 8.1 Core membership of the Regional Network will include representation from the following groups:
 - Expert parent and carer reference group, Parent Voices Count, facilitator
 - Paediatric palliative medicine
 - Specialist children's palliative care nursing
 - Community children's nursing including continuing care
 - Relevant national organizations including: Together for Short Lives, Child Bereavement UK
 - Children's Palliative Care Zonal Networks in the North West
 - Children's hospices and other voluntary organizations
 - Paediatric palliative care education and training
 - Paediatric tertiary care centres (Royal Manchester Childrens Hospital and Alder Hey Children's Hospital)

It is anticipated that members of the network may provide representation for more than one of these groups

- 8.2 Extended membership of the Regional Network will include
 - Specialist Commissioning (health)
 - Views of children and young people
 - Health Education North West
 - Workforce Development Lead

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- North Local Education Training Board (LET-B)
- Other relevant networks including the North West Neonatal Network

8.3 Core membership of the Zonal Networks will include representation from the following groups:

- Identified children's palliative care medical leads within each secondary care centre (DGH)
- Identified children's palliative care nursing leads within each secondary care centre (DGH)
- Expert parent and carer reference group, Parent Voices Count, facilitator
- Paediatric palliative medicine
- Specialist children's palliative care nursing
- Community children's nursing including continuing care
- Relevant national organizations including: Together for Short Lives, Child Bereavement UK
- Local children's hospices and other voluntary organizations
- Bereavement services

It is anticipated that members of the network may provide representation for more than one of these groups

8.4 Core members are expected to attend for at least 50% of meetings or ensure a deputy attends in their absence

8.5 Extended membership of the of the Zonal Networks will include

- Clinical Commissioning Groups
- Health and Wellbeing boards
- Views of children and young people
- Local Authority children's services

8.6 Meetings will be considered quorate when a minimum of the chair or vice chair and 4 other core Network members are present

8.7 The members of the Network, and Zonal Networks will elect officers from within the group: a Chair, and Vice Chair

- The officers will hold office for a tenure of 4 years with the option to stand for further terms with support from the Network members
- The role of the Vice Chair will be to deputize for the Chair both at North West meetings and if required nationally

8.8 The members will identify Regional Network Leads from within the group as follows. Network leads may also concurrently hold office within the group

- Lead Nurse
- Lead Doctor
- Lead for Education and Training

8.9 Other professionals or members may be invited to the group as appropriate