

NORTHWEST CHILDREN'S PALLIATIVE CARE NETWORK

Registration of Local Area commitment to Expert Patient Parent and Carer Reference Groups



The Northwest Children's Palliative Care Network brings together representatives of babies, children and young people with palliative care needs and their families, commissioners and providers of 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.

As strategic leaders within our Local Area we the undersigned recognize that

- Services provided for children, with serious and potentially life-threatening conditions, their families including parents and carers and siblings must be appropriate and meet the needs of service users.
- This can only be achieved by actively involving service users in the design, feedback and evaluation of the services they require.
- Indicate our commitment to working collaboratively with the Northwest Children's Palliative Care Network Expert Parent and Carer Reference Group, *Parent Voices Count*, and with the Northwest Children's Palliative Care Network Expert Patient Reference group when this is established.

And through inclusion of our signatures below hereby commit to

- **Co-operate** with the Northwest children's palliative care network in ensuring the sustainability of Expert Patient Parent and Carer Reference Groups comprising children and young people, with serious and potentially life-threatening conditions, their parents and carers and siblings from across the Northwest.
- **Empower** the Expert Patient Parent and Carer Reference Groups to participate individually or as a group in service design, feedback and evaluation through a variety of mechanisms according to their individual preference and capacity.
- **Actively listen**, at senior executive level, and on a regular basis, to the views of children and young people, with serious and potentially life-threatening conditions, their parents and carers and siblings regarding their experience of the care they receive
- Work collaboratively and constructively with children and young people, the Northwest Children's Palliative Care network and other key stakeholders to **identify the outcomes that matter most to children and young people** with serious and potentially life-threatening conditions, their parents and carers and siblings.
- Work collaboratively and constructively with children and young people with serious and potentially life-threatening conditions, their parents and carers and siblings, the Northwest Children's Palliative Care network and other key stakeholders to **develop, resource and implement appropriate action plans** to meet identified shortfalls in care, as identified through the work of the Expert Patient Parent and Carer Reference Groups.
- **Provide accurate and timely progress reports** to the Expert Patient Parent and Carer Reference Groups and the Northwest Children's Palliative Care network regarding local progress on these action plans.

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Expert Patient Parent and Carer Reference Groups



Local area covered by this Registration of commitment to Expert Patient Parent and Carer Reference Groups

Signed by:

Name:

Title:

Contact email:

Specific responsibilities:

Signature:

Date:

Name:

Title:

Contact email:

Specific responsibilities:

Signature:

Date:

I hereby acknowledge the registered Local Area commitment to Northwest Children's Palliative Care Network Expert Patient Parent and Carer Reference Groups indicated by the signatories above and in my capacity as Chair of the Northwest Children's Palliative Care Network pledge to support the Local Area

Signature:

Date:

Chair Northwest Children and Young People's Palliative Care Network
Lynda.Brook@alderhey.nhs.uk



Appendix:

Core Standards for Expert Patient Parent and Carer Reference Groups

- Each member of the expert reference group will be supported and empowered to participate and contribute in the way that they feel is most appropriate for them. It is recognised that how people feel able to contribute will change over time as they proceed through their illness journey
- The group will be led by its members and affiliated to, but not accountable to, the Northwest Children's Palliative Care Network
- When participating as a group, and wherever possible, the balance will be with more expert group members than professionals
- Recruitment to the group will continue on a rolling basis both by group members and also professionals offering information on the group through professional contact and other related areas e.g. PALs, Hospice user groups etc
- Group members will be under no obligation and will be able to decline in participation or step down from the group at any time depending on their individual needs across their illness journey.
- Every effort will be made to ensure that the emotional health and wellbeing of the expert reference group must not be compromised by participation in the group. This will be facilitated through ensuring an appropriate induction for new members of the group together with availability of peer support, counselling and psychological support to debrief if required.
- Confidentiality will be respected at all times
- The NW Children's Palliative Care Network will work closely with partner organisations such as hospices and acute trusts to ensure that group members are not overburdened with multiple similar requests for participation in short succession
- Members may include those bereaved
- Members may include siblings