PUTTING THE CHILD AND FAMILY FIRST: DEVELOPING A CLINICAL NETWORK FOR CHILDREN'S PALLIATIVE CARE

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Abstract

National reviews have identified the need to provide 24/7 access to clinical expertise especially around the time of end-of-life. In the East of England locally commissioned reviews have recommended improvement in collaboration and joined-up clinical working between voluntary and statutory sectors.

This presentation describes a DH £30 million Children’s Palliative Care Fund project to develop a managed clinical network of services throughout the East of England and reports how challenges created by cross boundary working can be overcome.

A series of externally facilitated workshops, one for nursing leaders and one for medical leaders followed by a joint workshop aimed to develop solutions in an environment where there is little new funding, little recognition of the complexity of children's palliative care, and in a region where there is no specialist in paediatric palliative medicine.

Hurdles identified in the workshops were:

- Ineffective communication processes and information sharing
- Acceptability to families of distant advice
- Professional preciousness and boundaries
- Conflicting priorities
- Achieving critical mass of clinicians for a 24/7 rota
- Commercial sensitivity – competition among providers
- Organisational and clinical governance arrangements
- Contractual framework and financial commissioning.

Children’s Palliative Care is a low volume specialty, and so is best developed by network working across a larger geographical area, utilising the skills of Paediatricians with special expertise, Children’s Community Nursing Teams and Children’s Hospice Nurses both in their respective local areas but also across a wider geographical patch. Hospice Services, with their cross boundary catchment area, and relationships with NHS Commissioners, are well placed to facilitate such developments.

Further thought needs to be given to the balance needed between specialist services (nurse consultants and medical consultants in paediatric palliative medicine) and the more local services, and how the latter can contribute to provision of a specialist service.