Our nurse led model for children's palliative care within a managed clinical network

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Introduction

- Why and how
- Definitions
- Development of MCN
- Current practice and resources
- Evaluation of specialist element
- Governance issues
- Funding
- Costs
- Critical success factors
- Current drivers NICE guidelines and quality standards

Context of Care: The EoE Network

- Population 550,000 children
- Area of 5000 square miles
- Predominantly rural with pockets of urban areas
- Tertiary hospital x1
- PICU x1
- Level 3 NICU x2
- General hospitals with paediatric wards x10
- Children's community nursing teams x7

Which children may benefit from palliative care?

- Any children with a life-threatening or life-limiting condition may benefit from palliative care input, which is tailored to their needs.
  - http://www.togetherforshortlives.org.uk/assets/0000/7089/Directory_of_LLC_v1.3.pdf
- Age range (0-19 years)
- Children with the following conditions:
  - Life threatening conditions
  - Life-limiting conditions where premature death is inevitable, but where there may be long periods of intensive treatment aimed at prolonging life and facilitating participation in normal activities.
  - Life-limiting conditions which are progressive and without curative treatment options, treatment is exclusively palliative and may extend over many years
  - Life-limiting conditions which are irreversible but non-progressive associated with severe disability leading to susceptibility to health complications and the possibility of premature death.
  - Children who have not responded to maximal intensive therapy (PICU or NICU) for a variety of conditions may be referred for palliative care support for withdrawal of intensive treatment

The Network Model – Why & How

Address identified gaps back in 2009 through review commissioned by EACH:

- Access to specialist level medical PPC expertise
- 24/7 face to face symptom management and hands on nursing support

By:

- EACH used its position as a children's palliative care provider to broker the arrangements and bring people together
- Building on existing partnerships and services
- DH £30m funding
- Current levers: NICE guidance and quality standards

The Network Model – Definitions

- A linked groups of healthcare professionals and organisations from primary, secondary and tertiary care, working in a coordinated manner, unconstrained by existing professional and organisational boundaries, to ensure equitable provision of high quality, clinically effective services; SE (2002)

- The mechanism to bring the commissioners, planners and providers of care together with services users to work collaboratively, to improve the quality and effectiveness of the service; Henderson, L. & McKillop, S. (2008)

- SE (2002) Promoting the development of managed clinical networks in NHS Scotland, NHS Circular: HDL(2002)69, http://www.sehd.scot.nhs.uk/mels/hdl2002_69.pdf

- Henderson, L. & McKillop, S. (2008) Using Practice Development Approaches in the Development of a Managed Clinical Network. In *International Practice Development in Nursing and Healthcare* (Ed Manley, K., McCormack, B & Wilson, V.). pp 319-348. Blackwell Publishing, Oxford.

The Network Model – Principles

- Children's palliative care is everyone's business
- Every child who may need palliative care has access to universal and targeted support and lead Consultant Paediatrician(s)
- Not every child needs level 4 Consultant in Palliative Medicine input
- There are low numbers of children with high level of need
- Provision across wider area is more efficient, cost effective and sustainable
- Person centred symptom management and advance care plans are made and delivered which reflect local ways of working and resources
- The Specialist Palliative Care team always works in partnership with core services and with local paediatricians

The Network Model Development

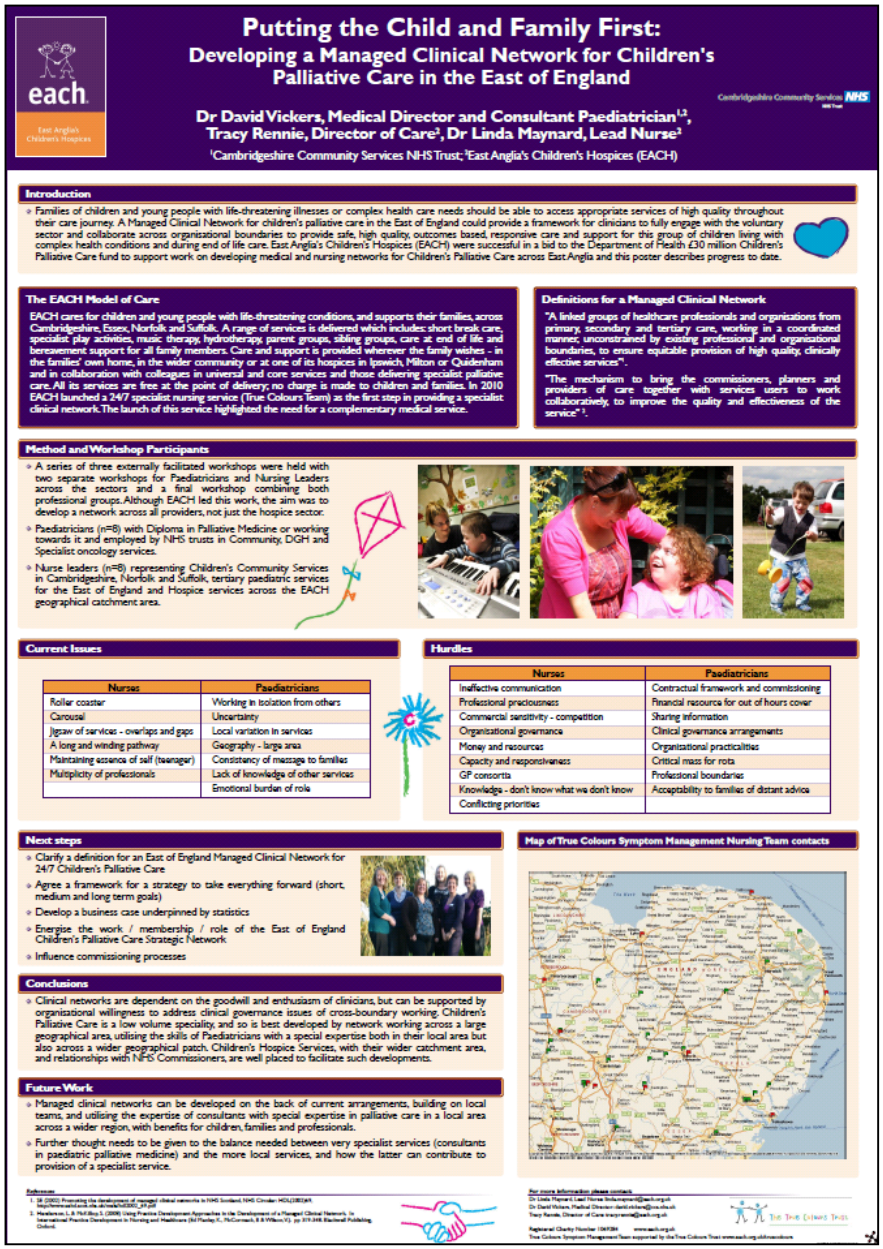
DH £30m funding

- 3 facilitated workshops (Paediatricians (n=8), Nursing Leaders (n=8), joint)

Issues and Hurdles

Next steps

- Clarify definition for an EoE Managed Clinical Network for Children's Palliative Care
- Agree strategy framework with short, medium and long term goals
- Develop business case (with stats)
- Energise work / membership / role of the EoE Children's Palliative Care Strategic Network
- Influence commissioning processes



Putting the Child and Family First:
Developing a Managed Clinical Network for Children's Palliative Care in the East of England

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Introduction

Families of children and young people with life-threatening illnesses or complex health care needs should be able to access appropriate services of high quality throughout their care journey. A Managed Clinical Network for children's palliative care in the East of England could provide a framework for clinicians to fully engage with the voluntary sector and collaborate across organisational boundaries to provide safe, high quality, outcomes based, responsive care and support for this group of children living with complex health conditions and during end of life care. East Anglia's Children's Hospices (EACH) were successful in a bid to the Department of Health £30 million Children's Palliative Care fund to support work on developing medical and nursing networks for Children's Palliative Care across East Anglia and this poster describes progress to date.

The EACH Model of Care

EACH cares for children and young people with life-threatening conditions, and supports their families, across Cambridgeshire, Essex, Norfolk and Suffolk. A range of services is delivered which includes short break care, specialist play activities, music therapy, hydrotherapy, parent groups, sibling groups, care at end of life and bereavement support for all family members. Care and support is provided wherever the family wishes - in the families' own home, in the wider community or at one of its hospices in Ipswich, Milton or Quidenham and in collaboration with colleagues in universal and core services and those delivering specialist palliative care. All its services are free at the point of delivery; no charge is made to children and families. In 2010 EACH launched a 24/7 specialist nursing service (True Colours Team) as the first step in providing a specialist clinical network. The launch of this service highlighted the need for a complementary medical service.

Definitions for a Managed Clinical Network

"A linked groups of healthcare professionals and organisations from primary, secondary and tertiary care, working in a coordinated manner, unconstrained by existing professional and organisational boundaries, to ensure equitable provision of high quality, clinically effective services"[1].

"The mechanism to bring the commissioners, planners and providers of care together with services users to work collaboratively, to improve the quality and effectiveness of the service"[1].

Method and Workshop Participants

A series of three externally facilitated workshops were held with two separate workshops for Paediatricians and Nursing Leaders across the sectors and a final workshop combining both professional groups. Although EACH led this work, the aim was to develop a network across all providers, not just the hospice sector.

Paediatricians (n=8) with Diploma in Palliative Medicine or working towards it and employed by NHS trusts in Community, DGH and Specialist oncology services.

Nurse leaders (n=8) representing Children's Community Services in Cambridgeshire, Norfolk and Suffolk, tertiary paediatric services for the East of England and Hospice services across the EACH geographical catchment area.

Current Issues

Nurses	Paediatricians
Roller coaster	Working in isolation from others
Carousel	Uncertainty
Jigsaw of services - overlaps and gaps	Local variation in services
A long and winding pathway	Geography - large area
Maintaining essence of self (teenager)	Consistency of messags to families
Multiplicity of professionals	Lack of knowledge of other services
	Emotional burden of role

Hurdles

Nurses	Paediatricians
Ineffective communication	Contractual framework and commissioning
Professional preciousness	Financial resource for out of hours cover
Commercial sensitivity - competition	Sharing information
Organisational governance	Clinical governance arrangements
Money and resources	Organisational practicalities
Capacity and responsiveness	Critical mass for rota
GP consortia	Professional boundaries
Knowledge - don't know what we don't know	Acceptability to families of distant advice
Conflicting priorities	

Next steps

Clarify a definition for an East of England Managed Clinical Network for 24/7 Children's Palliative Care

Agree a framework for a strategy to take everything forward (short, medium and long term goals)

Develop a business case underpinned by statistics

Energise the work / membership / role of the East of England Children's Palliative Care Strategic Network

Influence commissioning processes

Map of True Colours Symptom Management Nursing Team contacts

Conclusions

Clinical networks are dependent on the goodwill and enthusiasm of clinicians, but can be supported by organisational willingness to address clinical governance issues of cross-boundary working. Children's Palliative Care is a low volume speciality, and so is best developed by network working across a large geographical area, utilising the skills of Paediatricians with a special expertise both in their local area but also across a wider geographical patch. Children's Hospice Services, with their wider catchment area, and relationships with NHS Commissioners, are well placed to facilitate such developments.

Future Work

Managed clinical networks can be developed on the back of current arrangements, building on local teams, and utilising the expertise of consultants with special expertise in palliative care in a local area across a wider region, with benefits for children, families and professionals.

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

Workshops: Issues and Hurdles 2009

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Incremental development – specialist nursing

- 2 year external funding (True Colours Trust) secured by EACH
- Administrator to support recruitment and office development
- Specialist nursing service (True Colours Team) (Oct 2010) - first step in providing a specialist managed clinical network hosted by EACH
- Recruitment and induction of clinical nurse specialists (CNSs) to EACH and the local teams in Cambridgeshire, Norfolk, Suffolk and North Essex.
- Pay structure for being on call and for additional hours worked
- Identified early on a need for complementary medical OOH service
- SLA with a call handling service established to manage out of hours and weekend calls.

Incremental development – medical specialists

- Out of hours specialist advice is provided by four consultant paediatricians with DipPallMed qualification, and the EACH Nurse Consultant
- Telephone advice is available to the SMNS team of Clinical Nurse Specialists between the hours of 1800 – 0800, Monday to Friday and over the full 24hr period at weekends and bank holidays
- Specialist advice rota is maintained by the MCN Coordinator
- Calls documented independently by the Consultant Specialists and the Clinical Nurse Specialists using a feedback pro-forma.
- Low volume, always appropriate calls

Model of Care

- Pre-emptive planning
  - Symptom management plan
  - Just in case medication
- Direct family access to CNS team 24 hour on call
- CNS telephone access to specialist out of hours
  - Specialist on call 1 in 4/5
  - Category 'B': telephone only
  - 1% salary supplement funded by CCG
  - NHS indemnity
- Medical review: liaison with local hospital on call team

Current specialist resources

- CNS team (band 7 equivalent) 7.0 WTE (8 nurses)
- Matron (band 8 equivalent) 3.0 WTE (3 nurses)

- Specialist team
  - Level 4 Consultant 0.5 WTE
  - Nurse Consultant 1.0 WTE
  - General Paediatric Consultants level 3 0-3 sessions in job plans

Current core resources

- Hospice services (EACH, Keech)
- Health services, acute, primary - CCNT
- Varying resources in terms of competence and confidence

How to refer?

- To Core Palliative Care Services (EACH)
  - Any professional may refer a family to children's hospice and families may self-refer
  - All referrals will be considered at a weekly panel meeting or equivalent
  - A senior member of staff from the hospice team will make contact with family and arrange a meeting
  - Following initial assessment, a package of care will be tailored to meet the needs and preferences of the individual child and family.
- To Specialist Palliative Care Services (Symptom Management Nursing Service and MCN)
  - Any professionals e.g. Consultant Paediatricians and Clinical Nurse Specialists may refer children to the Symptom Management Nursing Service
  - Doctor to doctor referrals may be made to any of the consultant paediatricians in the MCN
- Urgent referrals are managed through the Symptom Management Nursing Service on the 24 hour number 08454 501053
  - Discharge guidance and checklist

How do we know this works, that we are meeting the needs of families and team members?

- Focus: providing 24 hour symptom management in preferred location of care
- Can we do this with limited resources?
- How can we do this with limited resources?

Needs of child and family

- Access to medication

- Access to expert symptom management advice 24 hour
  - Telephone support
  - Home, hospice, hospital visit & assessment

- Recognition & planning for end of life care

Needs of team members

- Safe service
  - Working within competency
  - Access to support from more senior team members

- Sustainable service
  - Avoiding onerous rotas
  - Recognising other commitments
  - Evaluation and feedback

Pilot study: 01.10.13-30.09.14

- Information collected after every call
  - Demographics & Diagnosis
  - Reason for call
  - CNS and consultant evaluation of call

- 6 month evaluation

- Staff questionnaire of their experience after 1 year

Demographics & Diagnoses 1

- 180 calls from families to CNS team
  - 54 children aged 22 weeks to 19 years (median 9 years)
  - 31 boys 23 girls
  - 1 to 16 calls per patient

- Diagnoses
  - Neurological 26
  - Malignancy 9
  - Other 8
  - Unknown 11

Demographics & Diagnoses II

- 24 calls from CNS team to on call Specialist
  - 11 children aged 7 days to 19 years (median 14 years)
  - 9 boys 2 girls
  - 1 to 6 calls per patient

- Diagnoses
  - Neurological 6
  - Malignancy 3
  - Other 2

Staff questionnaire: CNS

Top three reasons for contacting the on call specialist

- Symptom/dose not covered by Symptom Mx Plan
- Symptom management
  - Escalating symptoms
  - Unexpected symptoms
  - Poorly controlled
- Support for decision-making
  - Starting syringe driver
  - 'Phone a friend'
  - Support change in management

Staff questionnaire: Specialist

Most frequent reported reasons for being contacted

- Support for CNS decision making
- Advice about medication
- Advice about symptoms esp beyond SMP
- Support with End of Life diagnosis
- Support for CNS in dealing with acute services / other medical professionals
- 'Sounding board' – discuss options
- Support with family issues

Planned developments

- Currently only half the region (covers EACH catchment area)
- Written guidance: Specialist children's palliative care services available in the East of England, how to refer and general information about children's palliative care
- Commissioning risks
  - Boundaries between specialised and local commissioning systems
  - Role of voluntary sector providers and interface with statutory sector providers
- Workforce
  - Succession planning – growing expertise for the future

Governance

- NHS indemnity
- Communications
- MDT meeting is key
- Identification of lead consultant and nurse
- CYP / family engagement through seeking permission to share information across network of professionals (i.e. team around child principle)

Funding and commissioning

- No formalised arrangements
- Specialised NHS commissioning – NHSE specialist commissioning funding to CUHFT
- EACH contribution – specialist nursing and lead nurse contribution to specialist CPC specification
- Local funding through CCGs to EACH – variable across region – better with contracts now being signed
- Local funding through individual medical practitioner job plan negotiations

Critical success factors

- Recruitment of staff with advanced technical, problem solving, motivation and interpersonal skills
- Formalised and funded on call procedures
- Anticipatory care planning with Monday to Friday working
- Development and presence of Symptom Management Plans in lay language
- Boundary spanning and co-location
- High quality clinical supervision for Team


thank you
gracias
merci
danke
obrigado
謝謝
شكراً جزيلاً
ngiyabonga
teşekkür ederim
go raibh maith agat
mochchakkeram
dziękuję
bedankt
sukriya
kop khun krap
terima kasih
arigatô
dakujem
grazie
takk
tapadh leat
спасибо
Баярлалаа
рахмат
dank je
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mauruuru
sagolun
taiku
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감사합니다
ありがとう
мерси
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спасибі
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blagodaram
misaotra
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