



Yorkshire and Humber
Children's Palliative
Care Network

Network Update

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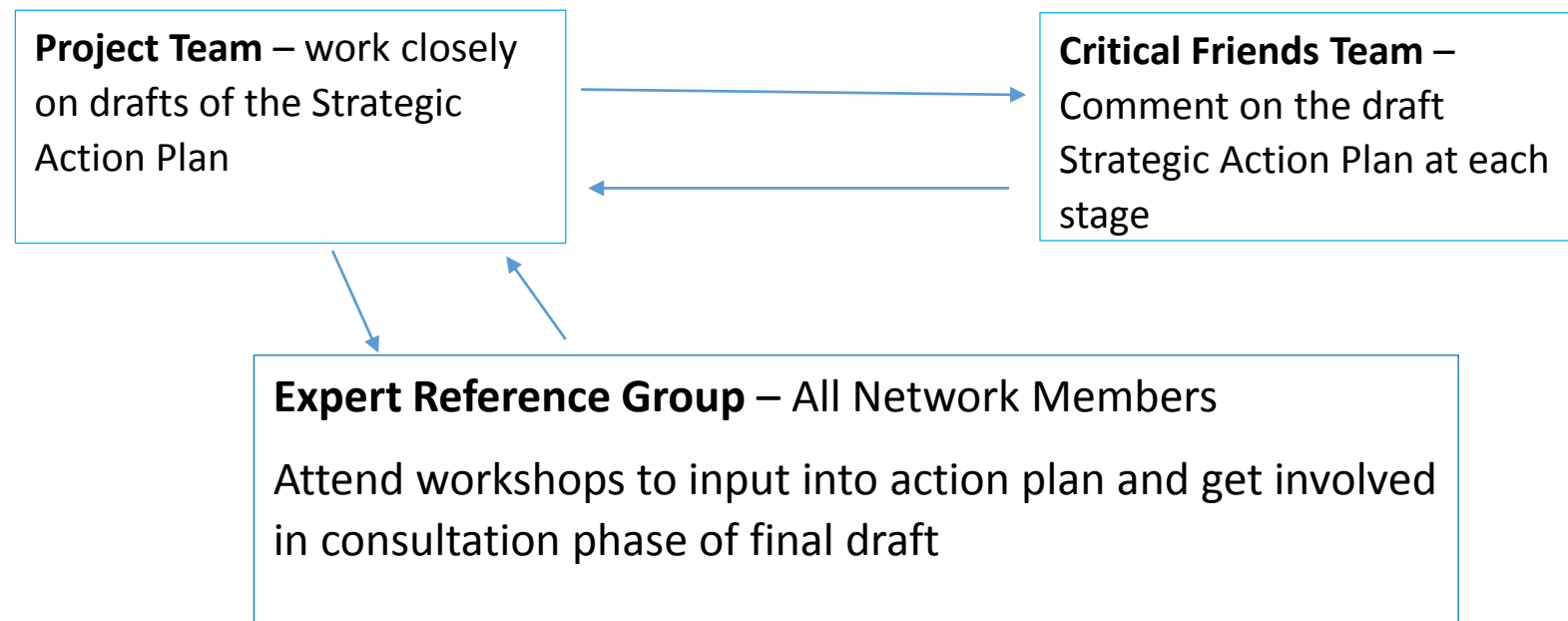
Progress to date

- Strategy development events - June 2017 and Jan 2018
- Revisit mapping 2015 -All responses returned (delay), analysis, links other organisations (CCG, STP, Social Care, education, CDOP, ODN's)
- CDOP Regional Audit
- Website development
- MCN development
- CYPACP and ReSPECT
- Links with STP's (Sustainability and Transformation Partnerships)



Strategy Development

- Strategy and work plan out for consultation – March 2018





Strategy Development Day – June 2017

- A Network Development day June 2017.
- 51 professionals working in palliative care from across the Region attended.
- Looked at what is working well, what could be improved and what should a future model of delivery look like across the Region.
- Presentations and workshops held.
- Feedback used to inform the strategy development.



Strategy Development Day – Jan 2018

- Project Team met
- Strategy Document Developed with recommendations
- 5 Year Work Plan for the Network Developed
- Vision and Measurable Objectives
- Will be circulated for comment/ consultation prior to final version



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Strategy

Closing the Gap in Children's Palliative and End of Life Care: A Strategy for Yorkshire and Humber 2018-2023.





Strategy

- Vision

Yorkshire and Humber Children's Palliative Care Network (YHCPCN)

To close the gap and ensure that every child with a life limiting condition has access to high quality 24/7 paediatric palliative care wherever, however and whenever it is needed.

- Mission Statement

The aim of the Yorkshire and Humber Children's Palliative Care Network is to develop an appropriate and adaptable model of care for all children and young people with life limiting and life threatening conditions across the Yorkshire and Humber region, according to need. The focus is to provide choice to families and reduce variation in palliative and end of life care by working together to raise standards for all.



Recommendations

- To establish a managed clinical network for children's palliative care services in Yorkshire and the Humber and to develop a strategy for delivering the 24/7 service.
- To have a lead clinician and lead nurse for the region.
- To develop a hub and spoke model of delivering children's palliative care.
- To work towards having a clinical lead for all services providing children's palliative care in the Region (14 NHS Trusts and 2 tertiary children's hospitals in Yorkshire and the Humber).
- To work towards having a lead nurse in children's palliative care in all services which are covered by the 14 NHS trusts and 2 tertiary children's hospitals in Yorkshire and the Humber.
- To develop a regional Children's Palliative Care Register.



What families Want

Lot of research identifies what families want and often provides the same themes throughout:

- 1 point access / care coordinator
- Respite care
- High quality 24/7 nursing care when and where needed
- Support before a crisis occurs and crisis management
- Time out for 'normal family life'
- Transition services



What Children and Young People Want

- Chance to meet up with/ talk to those with a similar diagnosis
- 24/7 medical advice
- Life plans not illness or EOL plans – coordination all people have same plan
- Consistent care
- Psychologist advice
- Home care where possible
- “Living as normal life as is possible with support to enable this”.



Mapping - Background

- Mapping of clinical and nursing cover across the region 2015
- Revisited to see if any changes
- Contacted all NHS Trusts (14), Tertiary centres (2) and Hospices (4) across region
- Completed a pro forma detailing services provided, follow up telephone calls



Mapping Results - OOH

- **Weekend cover:** 10 CCN teams (62.5%) offer routine weekend cover with one of these offering on call. The hours of this cover vary. 2 of these services are for oncology patients only.
- **Routine on call provision:** 8 services out of 20 (CCN teams (16) plus Hospices (4)) routinely provide on call services (calderdale (rota basis), Rotherham CCN teams, Leeds POON team (Oncology only), Sheffield POON team (oncology only), Sheffield Helena Team and 3 of the hospices (24/7 telephone advice). This compares to 6 services (out of 24) in 2015. Although this is an increase this still only equates to (40%) and 2 of these services are for oncology diagnoses only. There are still large geographical gaps in on call service.
- **End of Life On call Provision:** 17 services out of 20 (85%) stated that they can provide EOL on call provision including 3 of the 4 hospices across the region. Of these 17 services, 7 (41%) were ad hoc (not funded services) and rely on the good will of staff. 2 were oncology teams (POON) for oncology diagnoses only.



Mapping – Results Hospices

- There are 34 Hospice beds available across the Region
- There is good geographical cover across the Region
- There is some overlap in terms of the geography/ areas covered by hospices (2 hospices covering same areas in some places)
- Around 1273 families are reached annually (some overlap possible)
- Clinical cover varies
- 3 hospices provide OOH cover
- 2 hospices have access to 24/7 pharmacy services
- All hospices report offering 24/7 advice to families



Conclusions

- The regional clinical and nursing cover is still very disparate and variable.
- Weekend and out of hours funded care is still inequitable.
- Bereavement support is variable across the region. There is a better coverage of bereavement midwives (9) than there are bereavement nurses (3).
- There is a good number (11) of EOL groups/ meetings across the region.



CDOP Audit

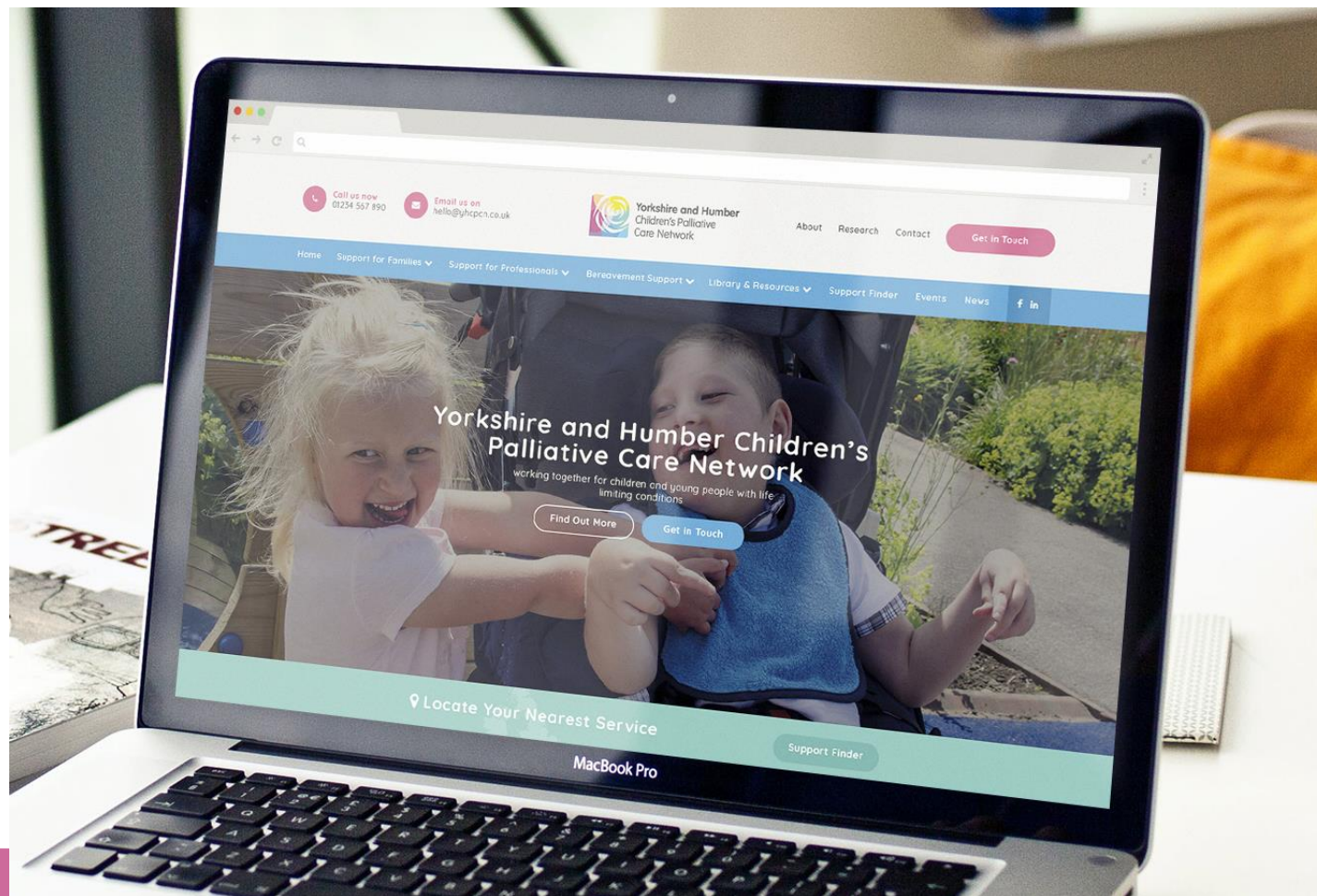
CDOP Audit – All CDOP's regionally responded to request for audit information

- 3 years worth of data (2013- 2016) – Working group to analyse and write up
- data on numbers of expected and unexpected deaths across region
- considers category of death, age, ethnicity and place of death
- Dr Kate Renton providing a detailed update

Website



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MCN Development

- The Network is to become a MCN- What is the difference between MCN and Palliative Care Network?
- Representative from *all* DGH, Tertiary centres, CCN teams
- Representative from pharmacy, allied health professions, social care and education
- Develop Terms of Reference and MoU between network and organisations
- Links with STP's and CCG's
- Write business case for MCN and development of regional 24/7 telephone advice service and lead palliative care consultant for the Region



CYPACP and ReSPECT

- Children and Young People Advanced Care Plan
 - Website www.cypacp.uk
- Resuscitation Summary Plan Emergency Care and Treatment
 - Website www.respectprocess.org.uk
 - Endorsed by YHCPCN
 - support for organisations across the region to sign up to use these
 - importance of having a regional acp format
 - ReSPECT vs LOTA



Links STP's / CCG's

- There are 3 Sustainable Transformation Partnership (STP) areas:
- West Yorkshire and Harrogate STP (covering 11 Clinical Commissioning Groups (CCG's): NHS Airedale, Wharfedale and Craven CCG, NHS Bradford City CCG, NHS Bradford Districts CCG, NHS Calderdale CCG, NHS Greater Huddersfield CCG, NHS Harrogate and Rural District CCG, NHS Leeds North CCG, NHS Leeds South and East CCG, NHS Leeds West CCG, NHS North Kirklees CCG, NHS Wakefield CCG)
- Humber Coast and Vale STP (Covering 7 CCG's: NHS East Riding of Yorkshire CCG, NHS Hull CCG, NHS North East Lincolnshire CCG, NHS North Lincolnshire CCG, NHS Scarborough and Ryedale CCG, NHS Vale of York CCG) and
- South Yorkshire STP (covering 7 CCG's: Doncaster CCG, Rotherham CCG, Barnsley CCG, Hardwick CCG, Sheffield CCG, Bassetlaw CCG and North Derbyshire CCG).



Next Steps

- Strategy and Work plan out for consultation
- Website to go live
- CDOP audit published
- Detailed breakdown of how Hub and Spoke model for Region will be achieved
- Detailed breakdown of how MCN will be achieved
- Business cases for work plan drafted
- Detailed work plan for education and workforce development
- Regular updates and Newsletters



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