Networks Summit Meeting

17 May 2018

Present: Amanda Whateley, Amy Volans, Beth Ward, Charlotte Mellor, David Vickers, Davina Hartley, Lynda Brook, Mark Hunter, Marian Williams, Tracey Rennie, Sue Picton

Present from Together for Short Lives: Hilary Cass, Katrina McNamara, Lizzie Chambers,

Apologies: Wendy Lewis-Cordwell.

1.	**<u>Welcome</u>** All were welcomed to the meeting.
2.	**<u>National Overview – Dr Hilary Cass</u>** Hilary gave an overview of the two key issues that she feels are impacting on the children's palliative care sector. 1) <u>Impact of growing number of CYP on Long Term Ventilation</u> Dealing with excessive waits for follow up appointments caused by the growing number of CYP with medical complexity who are going on to LTV. This number has doubled over the past year. We need to develop a consistent approach to LTV to ensure that it is about good quality of life and not poor death. There's an issue about the capacity of CCNs and children's hospices to deal with this complex step-down care in the community and the availability of suitable equipment/ housing etc. There's no formal assessment process and children will die on the waiting list who could have seen real benefit from LTV. 2) <u>Issues with the core community children's palliative care provision.</u> Paediatricians on wards are dealing with the stress of caring for children with medical complexity and with high levels of stress and anger from families. The hospital system is not set up to deal with this. There needs to be better coordination between hospital and community paediatricians. There's a huge impact on doctors and nurses and both disciplines need a safe space to think about this and the corrosive impact of high profile media cases. We all need to think about how we engage with social media and support families who are getting trolled in the press. Hilary has been working with Sarah Barclay a lawyer and journalist who set up the Medical Mediation Foundation. They've run training with 5 centres to develop a tool that helps recognise conflict earlier. We need to think how we can engage sensitive journalists to put the other side of the story across, even through NHS Trusts will not want to be in the press at all. It was suggested it might be helpful to engage with the Charlie Gard Foundation which is being launched and which is seeking to put forward a Private Members Bill about legal aid for parents. 3 key questions for the sector: • Should we develop a national decision-making tool for LTV? • Do we need to train professionals differently in communication skills?

- How can we tackle the postcode lottery of care for children on LTV?

One of the key issues is that children's hospices are not commissioned to support children on LTV and they can't take this on because it's just too expensive.

There's a need for the British Association of Community Child Health (BACCH) to think about the roles of Community Paediatrics. Their focus has become safeguarding and children with autism rather than dealing with complex children in the community. This has been recognised and a short life working party has been set up to think about this. It might be a good idea to establish a partnership of organisations to lobby for this 'complex-ologist' model. Alder Hey have been doing some work on this which Lynda can share.

It might also be a good idea to carry out a point prevalence exercise in DGH & acute hospitals about the numbers of children with complex needs that they see in one day. This was done in Manchester by Lisa Kaufmann. In Leeds and East Anglia data shows that the number of CYP on LTV has quadrupled. This is further complicated by the availability of competent staff who are able to carry out the complex care needed. For eg, there are only 2 acute hospitals East Anglia who can provide safe care. The only other option is for parents to be present 24/7.

There does need to be a better framework for decision-making about LTV. Often the conversations happen with hospital intensivists and families don't know what this really means for their child. Palliative care consultants need to be involved to discuss longer term impact of LTV.

The growing number of children on LTV means that the social needs of families are also growing and there's not enough resource to meet this need.

3. **Networks in Action: East of England (Dr David Vickers)**

David Vickers gave a presentation (attached) about how East of England established a Managed Clinical Network for children's palliative care. A key challenge is about how to bridge the gap at the core level of the pyramid, such as at DGHs where doctors at need support to enable end of life care and have an understanding on the basic use of drugs. A key issue is how to provide medical expertise safely across a region when the consultants don't know the family. The EACH model uses clinical nurse specialists who know the child and can manage the links with the medics. At the moment the MCN just works for children on the EACH caseload. The service is covered by EACH insurance.

4. **Networks in Action: Yorkshire & Humberside (Davina Hartley)**

Davina has a role as full-time network coordinator, funded by the four children's hospices in the region and the CCG. It's funded until next March and she's 1-year in. She has developed a 5-year network strategy (2018-23) called 'Closing the Gap', which is now being finalised. They have 300 child deaths per year and have approximately 4,000 CYP living with a life-limiting condition, so as a region are about the same size as Scotland. They've also developed a website for the network which will go live next month.

It's important to start small to help build trust between partners in the governance arrangements and then build momentum. It's also helpful to use the 'unstable, deteriorating, dying' descriptions to help build understanding.

In the East of England a £36k funds part-time coordination and events. This has been really fundamental. Commissioners' priorities are to keep children out of hospital. EACH had data on the numbers of children who died out of hospital which was useful to convince them. It's also important to think about quality outcomes such as achievement of the NICE Quality Standards.

Action:

It was suggested that TfSL could provide a platform to share useful documents, something like a Dropbox. We would need to secure external funding to do this. TfSL could also make some noise about the need for MCNs for children's palliative care nationally.

5. Show and Share

West Midlands:

They have a new Level 4 Consultant, Yifan Liang. They are revising the West Midlands Toolkit and will come back to TfSL about hosting the new version on the website. Another study day is planned. They have no coherent engagement with CCGs and STPs don't have children on their radar at all. Currently the network is co-chaired by Sarah Mitchell and Nicki Fitzmaurice, but they are actively seeking a new Chair.

Yorks & Humber:

Leeds hospital has no children's palliative care apart from in-reach from the hospice and the network is trying to persuade them to think about the NICE Guideline. Leeds hospital staff have received training from the Medical Mediation Foundation and found it very useful.

North West:

The network needs reinventing. Have decided to focus on the core group doing fewer things well, such as managing the website and holding a conference which will be used to reach a wider audience. The next meeting is in September.

South West:

There is a regional network which puts on 3 study days a year, led by a steering group.

East of England:

The MCN provides clinical leadership. There's also a Palliative Care Forum which brings together a range of providers, but the group needs re-invigorating. There have been discussions about doing a review of the specialist commissioning framework which may provide new impetus. They're also looking at developing new ACP tools. Last September they had a joint meeting of the MCN, Palliative Care Forum and the Regional Action Group for transition.

Northern Ireland:

Currently there is no network in NI, but there is a Special Interest Group. There is no CPC consultant at level 4. Max Watson at NI Hospice has been leading Project ECHO which provides monthly virtual learning on children's palliative care. It's open to all professionals. Project ECHO is led by Hospice UK. It was suggested that this might be good to link in to at network level, providing a hub & spoke model for training.

South East:

They are thinking about the boundaries of their network region. They're thinking about how to make CPC sustainable as much of the workforce is over 45.

East Midlands:

Dr Sat Jassal has developed the business case for a new CPC consultant and this is being tabled at next CCG meeting. The network is co-chaired by Dr Toni Wolff and they have a small steering group that takes work forward. They sent out a questionnaire to network members about what they want from the network. Davina from Yorks & Humber will be attending their next meeting in June to talk about established an MCN.

London:

There's been very poor attendance at recent Pan-London network meetings, despite agreement in January, that people want the network to continue. In NE London, the children's hospices are working with Barts Hospitals to look at their policies on palliative care. Kath Evans from NHSE is providing interim cover for the CYP Nursing Director and has pushed through the ACP documents in 4 weeks. The hope is that this will spread to the West of London.

Together for Short Lives:

The fourth edition of the former ACT Guide to the Development of Children's Palliative Care will be published in late summer. A project has been submitted for funding to develop an app, piloting this with providers in Bristol. This is something that other regions might want to adopt and populate with their own local service data. The RCN Competencies are now awaiting sign-off and publication. TfSL will be holding an ethics event in 2019.

Action:

It was suggested that TfSL develop a response for children's hospices to use if contacted by the media and maybe also provide some media training for staff.

6. **Networks in Action: Data Collection**

There was a discussion about what data is collected/analysed by networks and how they've used and shared it.

- Yorkshire & Humber use the CDOP data and have looked at the correlation between 24/7 nursing provision and place of death. This will be presented to CCGs/STPs where there is currently no 24/7 provision. They used the network members to contact all CDOPs in the region.
- West Midlands also did this. The biggest gap was with links to NICUs.
  South East has looked at different ways of categorising expected / unexpected deaths. Have also done a mapping of services. They've looked at the national census, Fraser study and local population data for 2014. The national CDOP work is developing a national database called EMBRACE and they want to include children in this. They've also been involved with the Learning Disability Mortality Review Programme (LeDeR) and tried to get CYP with complex needs involved in this.
  https://www.england.nhs.uk/publication/learning-disabilities-mortality-review-leder-programme-briefing-information/
- East of England had a refresh of their data by Public Health England. Currently they have 2k children, but if this is overlaid with the new methodology this is predicted to be 6k children by 2025. They've also worked on place of death data, with 49% of teenagers dying in hospital, mostly with cancer. Need to look at why older teenagers with cancer don't use hospice. There's a similar issue with neonates as the vast majority of babies die in hospital and this can skew the findings. They've also used the HUK 'Equalities and Access' project, showing how demographic data can link with Community Services Dataset and other datasets. EACH is happy to pilot this for children's hospice services and be a critical friend.
- North West has done the 'spectrum' mapping, but need further resourcing to do more work. They're looking to embed CSDS dataset in their systems. It's difficult to define the data items. CQC used data as part of their recent inspection at Alder Hey. They focussed on EOL care, 24/7 consultant cover, Links to ICU, with a criticism that the cpc team is not reaching enough

CYP at end of life. It was less holistic than in previous years. CQC reported that the NICE Guideline is not being met, yet still commissioners don't provide funding – it should be a lever to get funding! There is also a mismatch in the reporting lines to commissioners, it looks at specialist commissioning but the reporting is at CCG level. No children's hospices have yet had the new style CQC inspection.

- Midlands have done service mapping which shows that provision is patchy. They've also mapped hospice users.
- South West have not done any network-level data collection.

It was suggested it might be helpful to collect CDOP data on an annual basis and track the trends in place of death. There are also cultural/ethical issues that impact on choices. The most helpful thing will be Lorna's new study.

Action:
It was suggested that TfSL keeps an eye on CQC inspections and shares learning from the report on Alder Hey's inspection.

7. **Networks in Action: Workforce**

There was discussion of how the network supports professional education:

- London doesn't hold educational events.
- East of England has £36k of funding and uses this to fund events.
- Yorks & Humber have held a conference attended by 100 people and charged for this. They also hold smaller workshops.
- West Midlands learning events are currently funded and well attended. Acorns also run training programmes for CCN's.
- North West used to provide free quarterly training sessions for doctors as they had funding, but have not run these for the last couple of years. They held a conference last year which they charged for. It was poorly attended. Nurses have no protected study leave and no budget. They year they are holding a free event in September.
- Northern Ireland hold 3 events per year.
- South West holds study days 3 times per year and charges £5 a head.
- East Midlands has hosted a trainee at Rainbows funded by RCPCH – part of CSAC. They're also involved in nurse prescriber training.

Action:
All are encouraged to send through any training opportunities to guy.privett@togetherforshortlives.org.uk

There was a discussion about wider workforce recruitment and retention issues and the following approaches had been tried.

- In the South West when one of the CNS posts became vacant this was advertised as a rotational secondment opportunity at the hospital, hospice and hospice @ home service, with a postgraduate module in cpc. Two nurses were recruited to this.
- At Rainbows they have had 3 nursing associate roles, recruiting nursing assistants who are doing their training. It provides training and gives them a sense of value.
- Demelza has had 6 Assistant Practitioner roles, with 3 still in post.
- In the East there's no problem recruiting CNS level posts, but the problem is with recruiting of core nursing posts. Need to think about what it is that only trained nurses can do – what's important to nurses so that they don't lose skills. There is also a need to think about

	succession planning for the Medial Director and Level 4 Consultant at EACH. The Palliative Care Forum plans to engage with local education people and develop a hub and spoke model. • In Yorks & Humber the education and workforce forum is a sub-group of the network. They are developing a training forum for nurses, linked to local university. • There has been a focus on education in London, but not linking with academics yet. • In the West Midlands Sue Nielsen at Birmingham University has developed courses, but they’re not well attended and get cancelled. Katrina is now the lead of the RCN Special Interest Group for children’s palliative care. Duncan Randall is the lead on education for this group. It’s also helpful to have Hilary as the Chair of Together for Short Lives because of our links with HEE. TfSL is looking at options for developing education such as a web crawler that provides a personalised search for appropriate training.
8.	**Round up** Katrina shared the policy update that had been prepared by James Cooper. **Action:** **TfSL will find out whether the NHSE children’s hospice grant will continue.** The date of the next Network Summit meeting is 18 October in Birmingham.