Minutes
Clinical Advisory Committee ECHO 2 (CAC)
Strengthen understanding of the contribution of hospice care.

Date: 18 July 2018  
Time: 10.30 – 12.00

Venue: Via Zoom & Hospice House, 34-44 Britannia Street, London WC1X 9JG

Present:
- **Ann Smits**, Director of Clinical Strategy and Development, Farleigh Hospice, Trustee of Hospice UK and Chair of the Clinical Advisory Committee (CAC)
- **Tracey Bleakley**, CEO, Hospice UK
- **Dr Amy Proffitt**, Consultant in Palliative Medicine, Barts Health NHS Trust
- **Nigel Dodds**, Nurse Consultant at St Christopher’s Hospice
- **Prof Julia Downing**, Professor in Palliative Care, Chief Executive of ICPCN and trustee of Hospice in the Weald
- **Carole Walford**, Chief Clinical Officer, Hospice UK
- **Rowena Lovell**, Director of Strategy and Governance
- **Hazel Webb**, Clinical Team Coordinator (Minutes)

Apologies:
- **Dr Mike Bennett**, St Gemma’s Professor of Palliative Medicine, Leeds Institute of Health Sciences
- **Judith Park**, Deputy Chief Executive, St Luke’s Hospice, Sheffield
- **Linda McEnhill**, CEO, Ardgowan Hospice, Greenock
- **Dr Teresa Tate**, Consultant in Palliative Care
1. Tracey presented on the current understanding of hospice care and potential areas for improvement of that understanding in response to the second recommendation from The Commission in which she covered the following points:

1.1.1. ONS statistics cannot count everyone who is receiving care from a Hospice, only those who are dying in hospice and receiving inpatient care.

1.1.2. There is a lack of understanding from the public of the community service which a hospice provides; therefore, we need to build understanding around the different models of care for example, care received by patients at home and the work of community nursing teams.

1.1.3. We need to focus on how we connect with the public and have a conversation around where the gaps are in their understanding and how we fill them.

1.1.4. Bereavement services are the untold stories of hospices as Hospices provide bereavement support more than the top 3 bereavement charities. We need to link up with our partners to provide this support.

1.1.5. Hospice is a verb, not a noun. The perception that a Hospice is just a building still exists. We need to strengthen the understanding of what the ethos of a Hospice is.

1.1.6. The difference between Hospice and Palliative care is still confused. The WHO is changing the definition of palliative care so we need to be engaged in that process.

1.1.7. We need to communicate how our wider community isn’t just funders and commissions but carers as co-deliverers of Hospice care. In regards to carers, we are currently looking at our responsibility of who we class as a patient when there is a carer involved, the Carer’s Toolkit is an example of this.

1.1.8. This strand from The Commission informed every pillar of the Hospice UK strategy, it is implicit in all of them.

1.1.8.1. Without telling our story and explaining what we do and understanding how each partner can work together and the strengths everyone can bring, we can’t work in partnership.

1.1.8.2. Negative representation of dying in an NHS hospital in the news and the positive press has pulled the two sectors apart. We need to focus on showing that we are continuing to learn however we can still bring something to the partnership with the NHS and can find ways of implementing areas of our work in their setting to provide better care for everyone.

1.1.8.3. There is a significant gap between what hospices are currently able to deliver and the need for palliative care. Demonstrating shared understanding between faiths and how we embrace different values to our own without imposing our values is what we need to put forward.
1.1.9. Hospice UK are working with wider stakeholders to demonstrate the impact of hospice work and look for opportunities to extend.

1.1.10. All the Hospice UK programmes are focused on disseminating best practice. Tracey introduced a potential discussion point of when we are aware that so many hospices are fighting for sustainability – how do we target projects so they land well with hospices in a way that hospices can make the most of them.

1.1.11. Public perception not moved on however Tracey believes that this generation will embrace death and dying so we should open ourselves up so we can co-develop services.

1.1.12. Dying Matters was more successful than ever which shows an opportunity for development and opportunity to use it for research and evaluation.

1.1.13. We need to focus on getting more hospices and charities into media more as we currently have a struggle with spokes people. We need to be talking as if we are talking on behalf of general public.

2. Disparity between Hospice and Public understanding of the Hospice care offering

2.1. Carole asked the spokes their opinion on the disparity of what Hospices think they’re offering and the public’s understanding or expectation of what they’re offering.

2.2. Discussion highlighted that the more professionalised and specialised Hospices become, the more they move away from being what the public want (i.e. access to a Hospice and a bed when they need it). suggesting Hospices have become very specialist centres who may exclude people without specialist needs.

2.3. Discussion followed regarding the challenge for hospices to provide care to a larger group of people due to offering all services to every patient rather than tailoring the care to suit individual need. This raised the question of whether hospices need to adapt to a more tailored or consultancy approach.

2.4. Tracey asked the CAC their opinion on whether frailty should be covered under Hospice care; the CAC agreed that frailty should be covered as it has the biggest implications on hospice care.

2.5. The CAC debated the idea that Hospices need to define who they are, and agree this with each other before they clarify the question of what they are there for. Following this they should offer a consistent approach, tying the supportive care, acute and voluntary sector together.

3. Hospice Funding

3.1. Nigel introduced the discussion asking why Hospices don’t demand more funding from the NHS as without the existing funding end of life
care would fall apart. It was suggested that Hospice UK should have the key role in lobbying for core commissioning and funding from the government to provide more robust training and to highlight that end of life care is a key area of healthcare.

3.2. Tracey updated the CAC on the upcoming board meeting in which she is asking permission to start a new project which will consult all hospices on a different funding mechanism. When it has been decided what the funding mechanism should be, Hospice UK we’ll go to government and campaign on it. This is to sustain good palliative care as it was agreed the current funding model is shrinking and no longer sustainable.

4. National, Regional, Local

4.1. Carole guided discussion back to looking at the issue in a national, regional and local context explaining the need for a national strategy but within that scope, the need for a regional flexibility reflecting the nature of the hospice demographic.

4.2. Amy expanded on the challenge of breaking down the barrier between the Acute and Hospice sectors; the Discovery Programme has linked the computer data between hospice and acute setting which has helped however without the financial input into end of life care it is difficult to fully join up the services.

4.3. Discussion followed around how end of life care services are less centred on the patient and patient’s family but on the professionals a due to a lack of communication with patients.

4.4. This discussion highlighted again that there is an urgent need for the Hospice sector to define it’s contribution and be more honest about what it provides and how it provides it.

4.5. This led Ann to give her opinion on how beds should be separated from the rest of hospice services as beds could be provided elsewhere enabling the Hospice to focus more on their specialist services. Amy highlighted the challenge with this is that commissioning is based on bed occupancy.

4.6. Discussion followed on commissioning, concluding that that the focus should be on changing the public perception of inpatients to seeing patients as a ‘revolving door’.

5. The Remit of Hospice Care

5.1. Carole suggested whether Hospices should be providing everything that they currently do or whether the offer needs to be honed down. The CAC suggested that Hospice’s key contributing factors are:

5.1.2. Working together with other providers to provide different and joined up care to avoid wasting resources for example, presenting patients with a choice of providers instead of thinking Hospices need to provide it all. Taking the beds out of Hospices will mean better understanding of the services provided as patients will be in the community: the natural place where care is provided.
5.1.3. Hospices being ‘knowledge brokers’; in the past the Hospice sector have been secretive about their knowledge however now it should be about sharing it.

5.1.4. The current funding model based on competition is not aiding the joint up approach to care; funding needs to become mainstream.

6. Closing remarks

6.1. Concluding the session, Carole summarised that Hospice UK will be focusing on the National work and the ongoing challenges of the regional work in regards to definitions of what services might look like with differing regional need. Continuing, Carole concluded that Hospices cannot meet every need anymore and in regards to the commissions work HUK are beginning to challenge the understanding of Hospice care however the understanding has not progressed very far since the commissions work. Due to funding it will take boldness to more real progress in regards to the understanding.

6.2. Tracey commented that the consensus of the committee throughout the discussions has given her confidence to have stronger discussions when talking about funding. Following this she concluded that there will be challenges with certain organisations who are inward-focussed and are, potentially in communities which fund them well however there is now mostly a consensus about covering frailty, separating beds, investing in the community and the nature of hospice care.

6 Date of next meetings

Clinical Advisory Committee Meeting
3 October 2018, 10:30-12:00
Chair: Ann Smits
Hospice UK or join on zoom:165 413 726

ECHO 3:
Establish Hospice Care as a solution to future challenges in palliative and End of Life Care
Guest Speaker: Jack Garber
7 November 2018, 10:30 – 12:00
Zoom meeting ID:165 413 726