Minutes

Clinical Advisory Committee ECHO 1

Prepare for significant change in context of Palliative and End of Life Care: National Regional and Local Context

Date: 20 June 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)

Dr Teresa Tate, Consultant in Palliative Care

Linda McEnhill, CEO, Ardgowan Hospice, Greenock

Jonathan Ellis, Director of Advocacy and Change, Hospice UK

Carole Walford, Chief Clinical Officer, Hospice UK

Hazel Webb, Clinical Team Coordinator (Minutes)

Apologies:

Dr Mike Bennett, St Gemma’s Professor of Palliative Medicine, Leeds Institute of Health Sciences

Prof Julia Downing, Professor in Palliative Care, Chief Executive of ICPCN and trustee of Hospice in the Weald

Dr Amy Proffitt, Consultant In Palliative Medicine, Barts Health NHS Trust

Judith Park, Deputy Chief Executive, St Luke’s Hospice, Sheffield

Tracey Bleakley, CEO, Hospice UK

Rowena Lovell, Director of Strategy and Governance
1. Didactic Presentation: ‘Preparing for significant change’ – Jonathan Ellis, Director of Advocacy and Change

1.1 Jonathan Ellis gave an overview of the following areas to the CAC during his presentation, ‘Preparing for significant change’ in response to the first recommendation for change by The Commission in 2013:

- What was the context for the change that the Commission recommended?
- What policy change did we predict?
- What policy change occurred?
- How does it play out across the UK?
- What are the common themes?
  - National, Regional, Local

1.2 What was the context for the change that the Commission recommended?

1.2.1 JE stated that the reasons given by the Commission of why change was needed are the same today as they were in 2013.

1.2.2 JE reflected on the contextual changes which have occurred throughout the last 5 years.

1.2.2.1 JE summarised that there has been enormous structural change since 2013 within each nation. Palliative and End of Life Care was still seen as something separate in 2013, however now it is recognised as mainstream within the Health and Social Care system. One of the consequences of this structural change is that there is now a requirement for a completely different approach to supporting improvements in Palliative and End of Life Care.

1.2.3 JE informed that there have been significant changes in funding and resourcing, namely the NHS resources and old order of funding is under increasing pressure across the UK. There has been a shift from service planning as the infrastructure and approach to commissioning has become more widespread across the nations.

1.3 What policy change did we predict?

1.4 JE discussed that the sector identified the challenge which the sector faced of more competition in terms of fundraising and charitable resources which did change the sector over the last 5 years.

1.5 In terms of regulation within the English context, 2013 marked the early stages of new CQC regime and the new approach that came with that. 2013 also introduced new management and regulation of competitive market in healthcare, which identified the demand for evidence of quality, outcome and impact.

1.6 What policy change occurred?

1.6.1 JE summarised the key policies which have been established throughout the last 5 years, and identified that the context and agenda is different across the nations however there are some common themes and the focus should now be placed on how we deliver those ambitions.

1.7 What are the common themes?

1.7.1 JE discussed how integration is the centre of all the policy frameworks across the UK; we have seen strategic integration of Health & Social Care as well as practical and operational integration, for example work around shared care records and IT solutions to bring services together to share intelligence and patient information.
1.7.2 Other common themes JE highlighted are Individualised/tailored care, improving access, tackling inequalities, more care in the community, improving patient and family experience and outcomes and doing more for less, or more with the same.

1.8 National, Regional, Local
1.8.1 JE suggested that these are becoming increasingly difficult concepts as there is increasing divergence of how Health & Social Care is being guided across nations and even within nations, there is significant devolution. Due to this, regionalisation is emerging in each of the nations for example; Health & Social Care partnerships in Scotland are taking on much more of the responsibilities which would have previously sat with more local organisations.

1.8.2 JE posed the question; What do we actual mean by local, and by who’s perspective? From a system perspective it means the most local structures in system e.g. CCGs or Health Boards. From the public and service user’s perspective, it’s about neighbourhoods and communities.

1.8.3 JE summarised that if we are aiming to provide a more individualised, personalised and responsive service then our definition of local needs to change, meaning we need to focus on community resilience, community empowerment and the Public Health approach to Palliative and End of Life Care.

1.2 JE introduced three discussion points for the committee to consider throughout the ECHO Session:
- What are the practical steps hospice and palliative care services now need to be taking?
- What does the integration agenda mean for hospice and palliative care?
- To what extent should there be a consistent national offering? Or is the future local and bespoke?

2. What practical steps hospice and palliative care services now need to be taking?

2.1 CW reflected that over the last five years some aspects have dramatically changed and some have not; what has changed are the people we are caring for are greater in number with greater need, however the palliative and end of life care services have the same or less resource.

2.2 CW invited LM to discuss the challenges Scotland are facing and how we can face them to which LM emphasised that funding is the main issues at the moment, in particular the CEL12 issue. LM explained how there is a significant positive difference in the way CEOs have approached this issue, rather than ask for funding to health and social care partnerships, CEOs are talking about being co-commissioners. As were hospices not to be appropriately funded and therefore have to close this would remove a huge amount of finance and unpaid(volunteer) labour which would completely destabilise palliative care in Scotland.

2.3 TT introduced discussion around tension between concept of individualised care, of reducing inequality and of allowing regional divergence summarising that the concept of the public’s belief of localisation will drive us as we begin to focus on individualised
care, which TT believes is not economically achievable. This introduces a challenge for us to ensure as we move on with policy, we move on with public education and information at the same time to make sure we are realistic.

2.4 Discussion followed around the need for workforce planning and compassionate neighbours to building the resilience of communities and to give provision of support as well as education. The Compassionate Employers programme was also highlighted as a priority to make better use, and empower volunteers by training them up for example.

2.5 AS followed with discussion around the integration agenda in which she commented in next year hospices within Essex will need to merge into one STP Hospice (due to a larger population size); this prompts HUK to think about asking local hospices whether they could merge some services, but keep beds local to allow viability. LM added that the shortage of palliative care consultants will be the driver for service mergers or shared services. This poses the fundraising problem of how we deal in with a community wanting to support their own local hospice when it is a merged service and the meaning of ‘local’ is becoming smaller.

2.6 Solutions followed; challenges encourage us to review how we deliver to people, whether this be through mobile workforce integration or using technology to reach a greater number of people i.e. professionals using the technology while volunteers are the ones present at the service.

3. What does the integration agenda mean for hospice and palliative care?

3.1 Discussion began around the multiple definitions of ‘integration’ and how the language gets in the way of the ‘why?’, which is to find better ways of meeting the needs that exist in our communities. How we meet those needs are by identifying better ways in which to deliver services and by designing better services to meet the changing need.

4. To what extent should there be a consistent national offering? Or is the future local and bespoke?

4.1 CW introduced the question; if the future is local and bespoke, how to ensure the barriers involved with being a specialised service don’t reappear after our efforts to tackle them over the last 5 years.

4.2 AS followed with the emphasis that the future of hospice care is ‘local’ and we should be moving towards ‘hospice without walls’ approach, in that hospices should aim to be accessible but not involved with every patient. LM agreed by adding that the boundary between what is hospice and what is end of life care more generally is disappearing with hospices beginning to provide more of the services that previously would have been provided by generalist social or healthcare.

4.1 Discussion followed into how compassionate communities are involved with this social movement with the help of the NODA ‘no one dies alone’ initiative (part of the Ardgowan based/funded Compassionate Inverclyde Programme). These non medical interventions have huge impact on savings, ensuring sustainability.

4.2 TT introduced challenges with the CAC supporting a national offering such as; How do we effectively evaluate the effectiveness of these services; to what extent do we need to prove they are clinically or economically effective before we recommend them to
other areas; the mechanism by which learning happens across all systems seems to be less effective than when there was a hierarchy in place so how do we get around this?

4.3 CW introduced ‘Conversations with’, a space at the national conference where delegates can talk about ideas and have an information exchange with the People in Partnership group and Alison burns etc. without presentations. CW’s discussion followed around the national offering; how it plays out in each demographic area will be different, how can it do this without it becoming competitive, but more about sharing learning.

4.4 JE summarised that there is a fundamental question which national services can’t answer and that individual services will need to answer themselves – who do services see themselves there for: the need in community or for people who walk through the door?

4.5 TT added that services will develop in different ways with inequalities built in therefore we need to ask the question of how do we counter that with regulation when this concept goes against framework.

4.6 CW suggested introducing Dr Sarah Russell into the discussion as she works on looking at whether hospices are research ready, and identifying clinicians with doctorates to engage in clinical research.

4.7 LM followed by asking whether there needs to be a better emphasis on impact and helping hospices to understand and demonstrate impact. Following a session she attended at HUK conference, LM then reflected there was a call for HUK to find a way to resource Hospice staff’s learning on how to cost new models of care that save money. LM commented that we will need to demonstrate how we saved resource across whole system by doing things differently and then be commissioned to do those things.

4.8 JE followed by commenting on the way public policy moves very slowly due to incremental processes suggesting we need to be bolder at offering up challenges or solutions.

5. Closing remarks

5.1 AS commented that we need to move swiftly to avoid hospices being left behind,

5.2 LM praised the Scottish Heath & Social care partnerships for the positive changes they are making.

5.3 JE commented the big opportunity for us is the system waking up to the need to be more focused on ‘need’.

5.4 TT commented that we need to stop focusing on needs assessments and getting bogged down with not getting any funding as TT believes there is still something there for the future. TT suggested we should be more honest with public about where our funding comes from and treat/talk to them as grown ups.

6 Date of next meetings

ECHO 2: Strengthen understanding of the contribution of hospice care
National Regional and Local Context
18 July 2018, 10:30-12:00
Facilitator: Carole Walford and Tracey Bleakley / SMT from HUK
Hospice UK or join on zoom: 165 413 726

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