



## Perspective

### Summary of roundtable discussion in December 2014: Transforming care at the end-of-life

#### Dying well matters

The Deloitte Centre for Health Solutions roundtable discussion brought together key stakeholders from across the health and social care spectrum, including public and private health and social care providers, the voluntary sector, policy makers, commissioners and academics. The aim was to explore more widely the key challenges and solutions highlighted in our report “Transforming care at the end-of-life”.

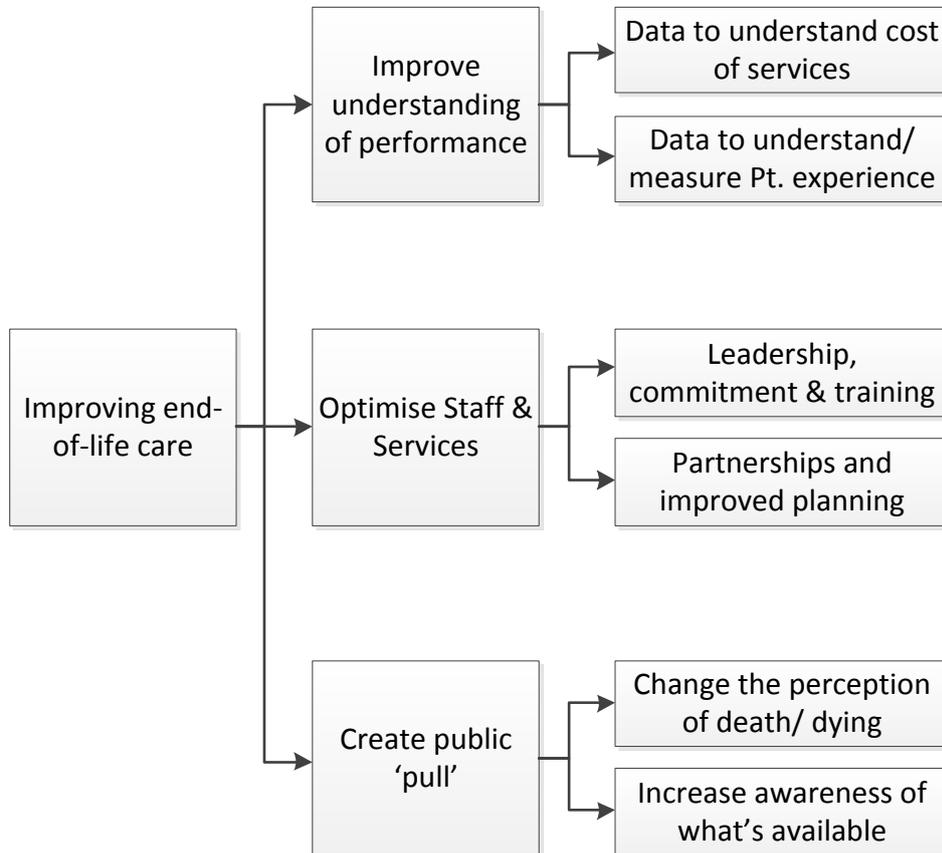
The roundtable event, in December 2014, was chaired by Karen Taylor, Director of the Centre for Health Solutions. It explored:

- the need to improve information on and understanding of the extent and cost of end of life care
- how co-production and partnerships could help optimise delivery of care

- the need to change individual and public perceptions of death and dying.

Following a brief overview of the key findings in the Centre’s report<sup>1</sup> the participants highlighted the specific challenges they faced in their day to day involvement with end of life care and, at the end of the discussion, everyone was given the opportunity to identify a solution(s) that they thought could help transform care. Figure 1 and the rest of this write up summarises the key points from discussion.

**Figure 1. Improving end-of-life care: Driver tree of key themes of the discussion**



## Improve understanding of performance

Good quality palliative care does not have to cost a lot, indeed in resource terms it can be extremely cheap, however it’s difficult to get people in the healthcare system to understand this. There is a lack of robust data/ evidence to measure cost and quality of end-of-life-care services. We know that currently majority of resources are spent on hospital care and care in crisis rather than in preventative and planned care. The Palliative Care Funding pilots have begun to provide the basis of an understanding of costs but understanding costs and quality will be essential to move to an outcomes based, integrated commissioning model. Participants agreed that there three steps would help the NHS and social care move to a new commissioning model:

1. develop a clear understanding of the local services that people who are identified as being in the last months of life are experiencing now (including where they are cared for and where they want to be cared for)

<sup>1</sup> Transforming care at the end-of-life. Dying well matters. Deloitte Centre for Health Solutions. October 2014. See also: <http://www2.deloitte.com/uk/en/pages/life-sciences-and-healthcare/articles/transforming-care-at-the-end-of-life.html>

2. develop a register of who is providing the services, at what costs ( both funded and unfunded care) and calculate national norms
3. model different scenarios to establish impact of changing demand and delivery models and the associated cost implications.

Surveys of patient and family that capture end-of-life-care experience could help understand and reduce the huge inequality that exists in access to, and spending on, palliative care services across the UK (especially between cancer and non-cancer end-of-life-care). Indeed, there was strong support for the idea that policy makers should develop a national policy that describes a 'normal'/'acceptable' end-of-life-care standard and prescribes a standard end-of-life-care dataset, which would be collected and collated so as to provide commissioners and providers with real time feedback on use and costs.

As always there are examples of high performance when it comes to collecting outcomes data. For example the Midhurst Macmillan Service – a community-based, consultant-led, specialist palliative care service in a rural community in the south of England.<sup>2</sup> But participants also acknowledged that this approach was still quite rare and there are significant barriers to accepting and adopting good practice in other parts of the NHS. The main challenge being the fact that the NHS remains a collection of independent entities

While a better understanding of performance was expected to facilitate service improvement, there was also a recognition of the need to invest in new and more effective treatments/ approaches to care. Currently there is little money (or return on investment) to be made for the life science industries in end-of-life-care drugs or medical technology, as a result it appears difficult to justify or making the business case for new investment.

In the same way that technology enhanced care is starting to help transform other aspect of health and social care, there was agreement that technology could have an important role to play in providing information on end-of-life care. However, adoption of technology is generally slow with cultural resistance to using IT to, for example, help coordinate end-of-life-care. The Deloitte report highlights examples of how electronic palliative care co-ordination systems are improving the recording and sharing of people's care preferences and other important details of their wishes at end-of-life, and also how health Apps, tablets and smart phones can be used to reduce crises, and improve the confidence of patients and carers. Likewise Telehealth service can link care homes to hospitals and other palliative care providers and help care home staff manage end-of- life care more effectively (this is especially important for the many people for whom the care home is their home and where they would prefer to die).

## Optimise staff and services

### Challenges

Care homes have largely evolved into a crises driven service – indeed for many people a place in a care home has become a distress purchase – as a result there is no time to plan and organise appropriately which makes it very difficult to get the right things in place at the right time. Care homes therefore often receive complex individuals (very elderly with multiple morbidities and frailty) who are already in their last twelve months of life (therefore entirety of stay could be classed as end-of-life-care)

There was a general consensus that if end-of-life-care is to improve it will require investment. Money will need to be re-directed from secondary care services and while this is generally

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<sup>2</sup> <http://www.kingsfund.org.uk/publications/midhurst-macmillan-community-specialist-palliative-care-service>

difficult to achieve, the overall savings to the health economy should be evident quite quickly. This is a classic example of a service that cuts across the silos of primary community and secondary care and health and social care and even housing – getting the right services in place at the right time in the right place for end of life care could also help the wider integration agenda.

Concerns were expressed about the lack of clarity in how to bridge the gap between good national or regional policies and guidance and how this is translated into action at the coal face. While there has been a lot of talking about improving end-of-life-care there was a general recognition that now the time is right to move on from talking and writing about what good looks like to focussing on doing something /anything to make the situation better for people who need end-of-life care. The big challenge here is prioritisation specifically the need to identify people at the right time to allow for end-of-life-care planning – which is recognised as being more difficult for non-cancer conditions as the prognosis is harder to predict but which is nevertheless equally important

There's also a lot of confusion as to when end-of-life-care conversations/ planning should be initiated and by whom. Part of the challenge is Doctors not wishing to admit to themselves that the patient is dying and there's little they can do to treat/cure the patient also doctors lacking the communication skills to tell the patient and their families. Doctors nevertheless need to be more transparent about this to enable end-of-life-care planning to start earlier. Similarly many healthcare professionals (HCPs) generally find it difficult to deal with uncertainty and as a result patients may only be classified as being at end-of-life when they are literally days from death. There is no consensus regarding who should be having conversations about end-of-life-care - Hospital doctors think it's up to GPs to have the discussion as they have the on-going relationship but GPs think it would be better to have the conversation at the time of crisis.

## Identified Solutions

Good end-of-life-care should be about compassionate care, continuity, and being surrounded by familiar people. There was a clear consensus about the need to design a system that has less of a disease specific and more of a personalised approach to end-of-life-care so that privacy, dignity and control is achieved at end-of-life. There is the potential to use the PEACE document (Proactive Elderly Advance Care Planning), given at discharge to a care/ nursing home, to indicate that a patient is dying. If used in this way, it will be the responsibility of the hospital team to 'start the process'; to say the patient is going home to die which will then enable the care/ nursing home team to talk to the patient and plan end-of-life-care.

There is an opportunity to build on the 'named GP' form that has recently been introduced and use it to ask questions about end-of-life-care. Potentially needs to be an online questionnaire and HCPs need to be trained to ask the questions. The third sector already has a big involvement in end-of-life-care, but there is enormous potential to partner or co-produce services with the third sector. The benefit of this (over and above funding) is the opportunity for innovation as the third sector are very good at innovating.

Leadership and commitment of staff is very important and can make a huge difference to care quality. HCPs need more training on how to communicate with families about end-of-life-care and also on how to reduce un-necessary hospital admissions. Acknowledging that someone is dying should not be seen as a failure – once this perception changes there can be earlier recognition that someone is dying earlier giving more chance to plan care, to avoid an unsettled last few weeks and instead make it a peaceful experience for all involved. There is a need for everyone to work together to make true partnership a reality – this means much closer

collaboration and sharing of information.

The role of hospices in many places is already less about being a place of care provision and more about being part of /belonging to a community of care – this needs to be more widely acknowledged and understood. For example:

- hospices should not be seen as a place to go to die, rather it should be seen as a place to obtain expert advice and support, specifically symptom control, and that can work with the family and others to enable people to die in their home – including the care home – hospice support of care homes is an important resource. However, the publicity around fund raising for hospices has created the perception that a hospice is a destination and for many the ideal place to go to die. This may well be true for some people but the potential to use the expertise within hospices to share with the wider community is enormous
- hospices are rightly considered the gold standard in end-of-life care but they should not, and cannot, be the solution for everyone (this would be far too costly). Instead Hospices should provide support to and influence other services for example, Care homes and patient's homes, to make them optimal for the majority of people's end-of-life-care needs.
- there are emerging partnerships between hospices and, hospitals and care homes which brings the strengths of all experts together to provide holistic high quality care. This is especially important when considering Dementia. Dementia requires a joined up approach to diagnose dementia early and start end-of-life-care planning while the patient has good mental capacity. The most complex patients coming into care-homes often have dementia plus other co-morbidities and usually live for only 12 months, requiring end of life care panning and provision from the outset.

Overall, there is a need to create more partnerships and a type of intermediate hospice – not all need to be so specialised and expensive. This would allow more people to access good quality end-of-life-care.

## Create public 'pull'

End-of-life remains very much a taboo subject – a perception that needs to change. The public need to be encouraged to discuss end-of-life-care as early and as naturally as possible. This will create demand for better services and an ability to plan for good quality care. For example:

- end-of-life-care discussions need to be changed from a negative to a positive conversation focussed on how people can make the most of their last weeks/ months of life and mend relationships, sort out legal and administrative issues and to celebrate the persons achievements
- it's also important to shift this conversation completely away from the clinical setting and bring it into 'normal life' – just like planning for retirement/ a pension
- crucially, whenever/ wherever a conversation happens, it needs to be officially documented and shared across all care settings/ care providers.

To change perceptions of end-of-life-care we need to mirror what happened with the breast screening campaign or the dementia friends campaign. A national, coordinated and structured campaign backed by the government. This includes:

- thinking about when is best to communicate/ educate the public – consider creating a service that targets people at retirement and educates them about social care and plants the seed about discussing end-of-life-care
- give the public multiple opportunities to engage on the end-of-life-care topic/ express

their preferences (the more the question is asked, the more likely people are to normalise it and engage)

- Care homes should be seen as a good place to die as well as a good place to live. The reality is that many people will die in care home and care homes have an opportunity to embrace the fact that people are going to die in a very positive way and work with everyone; staff, family and friends; to erase the fear of dying and ensure that everyone can live as well as possible in their last months and weeks of life.

The roundtable discussion concluded with an acknowledgement that there was no one size fits all approach but that the time has come to implement some of the more innovative solutions that are shown to be working in pockets of the NHS and social care. That end –of-life should cease to be seen as a medical condition to be treated no matter what. Importantly that the quality of life of people who are at the end of their lives should be the prime consideration of all health and social care providers and that living well until you die should be a human right.

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### **Further information**

Summaries of all our roundtable discussions are available on our website [www.deloitte.co.uk/centreforhealthsolutions](http://www.deloitte.co.uk/centreforhealthsolutions). If you would like to discuss the ideas and suggestions in this document or the Transforming care at the end-of-life please feel free to get in touch.

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