End of life care coalition of charities written representation to: A country that lives within its means - Spending Review 2015

RECOMMENDATION:
Phased annual increases in funding to £400m (gross) over the spending review period to deliver implementation of a ‘national choice offer’ by April 2020, as outlined in the independent Review of Choice in End of Life Care.

Policy proposal for a ‘national choice offer’

While end of life care has made great strides forward in recent years, too many people still do not receive good quality care that meets their individual needs and wishes. This proposal seeks funding of £400m over three years to implement a ‘national choice offer’, as outlined in A review of choice in End of Life Care, hereafter referred to as the Choice Review.

The Choice Review was an independently-led review established in July 2014 as part of the Government’s commitment to enable greater choice and high quality care for people at the end of their lives. The review published its advice in February 2015. The advice identified the issues that people approaching the end of life face, and provided a framework for achieving greater choice of high quality care at the end of life. The framework outlined a range of tangible policy solutions, which would enable better commissioning and delivery of services. Delivery of a national choice offer would give people what they want – good quality end of life care. The Government are yet to provide a full response. As a coalition we fully support the recommendations within this review.

The Choice Review used a person-centred model of careii to assess the costs and benefits if the system was reformed to provide good personalised care that would deliver choices people want in their end of life care. Moving from the current state to increased service availability in order to to enable choice and improve care requires investment in the system. It was estimated that an extra £400m annually would need to be invested in NHS community services to achieve £370m savings in the acute sector (£30m net spend in the NHS); and a further £100m would need to be invested in local authority social care.

The realisation of the full ‘national choice offer’ requires incremental gross spending increases up to £400m per annum during the Spending Review period with the annual incremental spend reducing to £130m once offsetting savings (mostly due to reduction in hospital costs) are realised (by 2020–21). We believe it is critical to ensure the level of additional gross spending is reached in a phased manner as quickly as possible to deliver high quality, personalised end of life care for all and start realising expected savings.

The modelling in the Review included a wide range of services: NHS acute and community costs (such as community pharmacy services); specialist palliative care staffing; hospice inpatient costs; social care costs including care home fees; domiciliary home care; and equipment and adaptation costs. A number of costed scenarios were produced, showing that a realistic level of service improvement can be achieved through relatively modest investment annually while still making a significant difference to quality and experience of care. Our coalition is united in support for this model as the best available to deliver a step-change in care at the end of life. For further comments on our analysis of this modelling and support for its findings, refer to Annex 1.
This proposed investment will:

- deliver a significant increase in out of hospital care – including district nurses, allied health professionals, pharmacists, social care services, health care assistants and specialist palliative care teams – to ensure every dying person has access to round-the-clock care in the place of their choice, seven days a week;
- provide greater coordination and integration between services to improve the quality of end of life care and to support carers and families;
- empower patients and carers to be able to exercise greater choice in their place of death, through person-centred, coordinated care;
- deliver reduction in hospital admissions for people at the very end of their lives; and
- support for the use of the latest technologies to support end of life care.

Rationale

Implementation of the national choice offer is in line with the priorities set out in A country that lives within its means—Spending Review 2015 and will:

- promote innovation and greater collaboration in public services;
- support the delivery of high quality public services;
- promote choice; and
- drive efficiency and value for money across the public sector.

Improvement in end of life care is a cross-government priority: the 2015 Conservative manifesto recognised the need to ‘combine better health and social care services for the terminally ill so that more people are able to die in a place of their choice’.

The majority of people will need access to end of life services at some point, either when dying themselves or through supporting someone they know. End of life care is a near universal requirement, yet urgent improvements are needed to increase choice and quality of the care most people receive. Developing sustainable and adequately resourced end of life services that keep people out of costly acute care unless it is required is becoming more critical, particularly as the number of people dying each year is expected to grow by 15% by 2035.

Numerous reports and inquiries have identified severe weaknesses in the care given to people at the end of their lives. Just 5% of people in the UK say they want to die in hospital, yet this is where around 50% of people die. According to the Health Select Committee in March 2015, ‘the experience that people approaching the end of life have varies and in too many cases is unacceptably poor.’ The Parliamentary and Health Service Ombudsman considered the subject in May 2015 and detailed the ‘unimaginable’ anguish felt by too many people approaching the end of their lives and their families at present, as the wishes of dying people are not met.

Delivery mechanisms

The Choice Review recommends a number of mechanisms to deliver a national choice offer, including:

- **Electronic Palliative Care Coordination System** (or equivalent) coverage increased to 100% of localities to enable the recording and sharing of people’s choices and preferences;
• every **local area** should establish **24/7 end of life care** for people being cared for outside of hospital by the end of 2019, with models of provision determined locally;

• each person in need of end of life care has a **named responsible senior clinician** (such as recent initiatives from the Government for people with the most complex health and care needs) who would have overall responsibility for their care and their preferences;

• each person in need of end of life care is offered a **care coordinator** who would be their first point of contact in relation to their care and their preferences;

• Health Education England, Local Education and Training Boards and Skills for Care ensure that staff responsible for the delivery of end of life care have **training focused on the key elements of their roles which enable choice** (such as early identification of needs, advance care planning, and working in partnership);

• local areas who already have the systems and services in place to offer and deliver choice do this at the earliest opportunity, sharing their expertise with others through a **central knowledge hub**; and

• the Five Year Forward View ‘**Models of Care Board’** explore the integration of health and social care at the end of life as one of the models of care that has the potential to be transformative in delivering care closer to home.

**Wider implications**

Mechanisms proposed in the Choice Review align closely with wider government priorities such as steps towards greater devolution and integration of health and social care services. Plans for devolution in Greater Manchester, the integration pilots and vanguard sites all have compatibility with delivery of a choice model locally.

Bottom-up planning is a critical element for delivering step-change in improved quality of care and we know there are local ambitions for this. The Choice Review references case study examples (e.g. Sue Ryder’s Partnership in Excellence for Palliative Support; STARS Liverpool Care service; Coordinate My Care; and Macmillan Specialist Care at Home). These all support the evidence for ensuring people are able to die in the manner and place of their choosing—through a focus on coordination, sharing records, and integration—many of which may also have opportunities and advantages for scaling up. Public health approaches to end of life care, such as the Dying Well Community Charter and the Compassionate Cities Approach should also be seen as beacons of good practice. We would be happy to provide further information if useful.

However, to support staff and organisations delivering care to build the services to ensure good quality care and enable choices by this date, the Government and other statutory organisations, including commissioners of health and social care services, need to create the right conditions.

**Financial impact and value for money**

Our coalition fully supports the person-centred model of care used in the Choice Review. It incorporates intelligence gathered to date in a comprehensive manner and is the best available starting point to fully understand the costs of delivering high quality end of life care.

We believe our call for a gross £400 million above the current levels of investment in health and social care is a cost-effective spending decision. Investment in social care and community end of life services has been proven to lead to considerable savings in the cost of acute care downstream. Once offsetting savings delivered by this investment are realised, the net cost to the Exchequer will reach a steady state of £130 million net costs per annum by 2020–21, comprising:
• £30 million of additional net spending on the NHS
• £100 million of additional net spending on social care

The model assumes that this additional expenditure will attract an additional £200 million of private contributions, comprising:

• £50 million from the voluntary sector
• £150 million of self-funded social care

Some of the costed benefits of a national choice offer include, but are not limited to:

• a decrease in hospital unit costs and a reduction in the number of admissions and A&E visits per person, as community services and more widespread provision of specialist care reduces the number of admissions and A&E visits per person; and
• an estimated 20% reduction in hospital deaths as people are able to exercise choice to die with appropriate care at home, in a hospice or in a care home.

The Review recommended further work in relating to the costs to support the implementation of the choice offer. As a coalition we are doing our part to commit to the delivery of a choice offer by April 2020. We are continuing to work with the Department of Health to broaden the evidence base of the financial model and undertake further research on the level of needs of people at the end of their life.

Consultation undertaken

The Choice Review Board comprised 19 experts in end of life care from across the system including the voluntary sector; professional bodies; NHS England; the Department of Health; Public Health England; and people with experience of end of life care services. Extensive stakeholder engagement included: a detailed literature review; wide-ranging consultation with experts and stakeholder organisations; and a two-month public engagement exercise which included an online survey, engagement events and group discussions. Over 1,000 individuals contributed to the public consultation, including 943 respondents participating in the online survey and 111 joining the four workshops held across the country.

Legislative and operational requirements

The outlined proposal does not require new legislation and can be implemented through ‘business as usual’ mechanisms in both the NHS and social care sectors.

Contact details and further evidence

As a coalition of seven end of life care charities, we have access to numerous sector networks, local intelligence, and case studies of viable policy solutions. We would be happy to continue to support the Spending Review development process and provide any further evidence as required. For further details on our submission, please contact Danielle Brooker, Policy Analyst at Macmillan Cancer Support: dbrooker@macmillan.org.uk.
Modelling of costs in delivering choice at end of life

As a coalition we fully support the modelling of costs provided in the Choice Review (the Review). We believe the modelling provided provides a critical foundation for further work. The model is transparent and assumptions underlying it are easily identifiable – making it an effective tool for exploring costs of delivering good end of life care. This was an ambitious project, given there is limited data available in the area, which drew on available data sets and diverse evidence.

We believe the model is unique in that it provides a comprehensive picture of the evidence we currently have on costs. It incorporates a range of services: NHS acute and community costs; specialist palliative care staffing; hospice inpatient costs; community pharmacy; social care costs including care home fees; domiciliary home care; and equipment and adaptation costs. Other studies have been more sector specific or focused on specialist services, meaning the full range of services involved in providing high quality end of life care have not been captured. The Review’s model recognises the importance of basic care needs (in addition to specialist palliative care).

The modelling assumes hospital costs decrease to reflect improvement in community services and the more widespread provision of specialist care should reduce the number and of emergency and elective admissions per person. These savings were derived from the differences in the hospital patient records directly observed in 30,000 people receiving a Marie Curie Nursing service compared to a match control of 30,000 people.

Incremental cost to the state for NHS and social care services in the model takes into account the cost of enhancing community services, minus the savings in the acute sector from treating people in their own homes and care homes, such as reductions in hospital unplanned admissions. The highest savings are attributable to a decrease in emergency admissions, with further savings attributable to a decrease in non-emergency admissions, outpatient attendances and A&E services.

Scenario recommended in the Review offers a realistic level of improvement in end of life care which would still support a national choice offer. This features a relatively modest overall increase in spending from the NHS and a sliding scale of increasing spending on social care as more people are treating in community settings. There are additional costs on the voluntary sector, plus additional costs for people who fund their own social care.

We know that many of the savings derived from reductions in unplanned admissions and hospital stays, which have been identified at a national level in our model, can be achieved at a local level, such as the Midhurst Macmillan service where earlier referral avoided around 20% of total costs in the last year of life.

In addition there are numerous wider societal benefits of delivering improved quality of care for people at end of life (for example bereaved carers may return to work faster). Giving people the ability to have more control over their experience of end of life care directly impacts their quality of life, which is likely to have positive economic impacts outside of the health system.
This model was built with extensive input from members of the Programme Board to ensure as many services as possible were included, that a variety of providers and their respective contributions were incorporated and that service usage is realistic and representative. For more information, see Annex B of the Choice Review: https://www.gov.uk/CHOICE_REVIEW_ANNEX_B.

[Note: The original text contains images that are not visible in the provided content.]


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5 Office for National Statistics, National Survey of Bereaved People (VOICES), 2013


