

The
BOW
GROUP

Target Paper



Hospice Care – A Framework for the Future

by

**Dr. Daniel Poulter MP, Stuart Carroll,
Gary Jones & Ross Carroll**

with a foreword by Rt. Hon Lord Michael Howard CH QC

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Dr. Daniel Poulter MP

Dr Dan Poulter was elected MP for Central Suffolk and North Ipswich in May 2010, having previously worked as an NHS hospital doctor specialising primarily in obstetrics, gynaecology and women's health. Dr Poulter continues to practice medicine as an NHS hospital doctor on an occasional basis in order to keep in touch with the problems and concerns of the people of Suffolk. He also has a Law Degree from Bristol University and is a member of the Health Select Committee.

Mr. Stuart Carroll

Stuart Carroll is a Senior Health Economist and Policy Analyst, and the Chairman of the Bow Group Health & Education Policy Committee. Stuart specialises in pharmaceuticals and health policy, and has authorship credits in a number of policy papers on topics including military healthcare, the National Institute for Health and Clinical Excellence (NICE), the Quality and Outcomes Framework (QOF), health education, value-based pricing (VBP), and the role of pharmacy. Stuart is an outgoing member of the Bow Group Council having previously served as Treasurer in 2010 and recently as Editorial Adviser for the Bow Group's political magazine, Crossbow.

Mr. Gary Jones

Gary Jones is a Public Affairs Consultant who specialises in health and education policy. Previously, Gary worked in the office of the then Conservative Shadow Minister for Business and Enterprise, Mark Prisk MP. Gary is an outgoing member of the Bow Group Council, where he has served as the Editor of Crossbow, and the Health & Education Policy Committee.

Mr. Ross Carroll

Ross Carroll is a Public Policy and Government Affairs Manager. Ross is a qualified pharmacist, NHS Foundation Trust Governor and a member of the Bow Group Health & Education Policy Committee through which he has published policy papers on topics such as military healthcare. Ross has also published work on the development of the Northern Irish economy.



The Bow Group (BG) was founded in February 1951 as an association of Conservative graduates, set up by a number of students who wanted to carry on discussing policy and ideas after they had left university. They were also concerned by the monopoly which socialist ideas had in intellectual university circles. It originally met at Bow, East London, from which it takes its name.

Geoffrey Howe, William Rees-Mogg and Norman St John Stevas were among those attending the first meeting. From the start, the Group attracted top-flight graduates and quickly drew the attention of a number of government ministers, notably Harold Macmillan. In the intervening time, Michael Howard, Norman Lamont and Peter Lilley have all held the BG chairmanship. Christopher Bland, the current Chairman of BT, was BG chairman in 1969. In the recent General Election five recent members of the BG Council were elected to the Commons.

Since its foundation the BG has been a great source of policy ideas, and many of its papers have had a direct influence on government policy and the life of the nation. Although it has no corporate view, it has at times been associated with views both of left and right - always within the broad beliefs of the Conservative Party. The BG has four clear objectives:

- To contribute to the formation of Conservative Party policy
- To publish members' work and policy committee research
- To arrange meetings, debates and conferences
- To stimulate and promote fresh thinking in the Conservative Party

Recent publications include (all available at www.bowgroup.org):

'Putting the Health Back in Education'

Tracey Bleakley, Stuart Carroll & Ross Carroll with a foreword from Charlotte Leslie MP (BG Health & Education Committee) **February 2011**

'Delivering Enhanced Pharmacy Services in a Modern NHS: Improving Outcomes in Public Health'

Ross Carroll, Mike Hewitson & Stuart Carroll with a foreword from Baroness Cumberlege (BG Health & Education Committee) **September 2010**

'Equity and Excellence: Liberating the NHS' – Opportunities and Challenges

Stuart Carroll & Gary Jones (BG Health & Education Committee) **August 2010**

The Enterprise Nation? Developing Northern Ireland into an Enterprise Zone

Ross Carroll with a foreword by Lord Trimble (BG Economics Committee) **April 2010**

The Quality and Outcomes Framework – What Type of Quality and Which Outcomes?

Gary Jones, Stuart Carroll & Jennifer White (BG Health & Education Committee) **February 2010**

The Right Track – Delivering the Conservatives' Vision for High Speed Rail

Tony Lodge with a foreword by Lord Heseltine (BG Transport & Energy Committee) **January 2010**

"People Power: Reforming QUANGOs" – Is this Applicable to Health Agencies?

Stuart Carroll & Nick Hoile (BG Health & Education Committee) including contributions from Sir Andrew Dillon, Dr. Richard Barker and Dr. Bill Moyes **November 2009**

More for Less: Cutting Public Spending, Protecting Public Services

The Rt. Hon John Redwood MP & Carl Thomson (BG Economics Committee) **November 2009**

Doing Veterans Justice: Conversations with the Forgotten Fighters

Ross Carroll, Stuart Carroll and Julien Rey (BG Health & Education Committee) including contributions from Simon Weston OBE and Captain Surgeon Morgan O'Connell **June 2009**

FOREWORD



Rt. Hon Lord Howard of Lympne CH QC

Michael Howard served as a cabinet minister for 12 years and a Member of Parliament for 27 years. He has been Leader of the Conservative Party and Her Majesty's Opposition, and led the Party at the 2005 General Election. He has held the cabinet posts of Home Secretary, Secretary of State for the Environment, and Secretary of State for Employment. In addition to his work in the Upper House, Lord Howard recently became Chairman of Help the Hospices where he continues to campaign passionately on the issues of hospice and end of life care.

The Importance of the Hospice Movement

It is just under a year since I became Chairman of Help the Hospices. It has been a year of immense privilege for me. The work done by the hospice movement is one of the unsung successes of our system of care. Up and down the country countless volunteers care for those near the end of their life with amazing dedication. Not for nothing did the Economist in 2010 find that Britain topped its overall "Quality of Death Index" which compared the quality of provision of end of life care services across 40 countries.

And this enormous achievement is largely accomplished on the basis of charitable and voluntary support. On average, adult hospices in England received only 34% of their running costs from Government funds in 2009. Little wonder, then, that the hospice movement has been acclaimed by the Prime Minister as an outstanding example of the Big Society, or that I feel so privileged to be associated with it.

But of course the hospice movement faces considerable challenges. Our ageing population means that the demands placed on the movement are bound to increase. The changes to the funding of the NHS have very significant implications, and perhaps opportunities, for the future funding of hospice care. And advances in medical science themselves pose questions for the future role of hospices.

So I am delighted that the Bow Group has decided to address some of these questions in this very stimulating pamphlet. Traditionally, hospice care has been far from the forefront of political debate. For the reasons I have given, the authors recognise that this may be about to change. So they have entered what promises to be an invigorating debate with their own well-researched contribution.

This pamphlet is not the end of that debate, but its conclusions merit serious consideration. It is well worth a read.

Rt. Hon Lord Howard of Lympne CH QC

25th October 2011



**A Report by Dr. Daniel Poulter MP and the Health & Education Policy
Committee of the Bow Group**

(October 26th 2011)

Dr. Daniel Poulter MP, Stuart Carroll, Gary Jones & Ross Carroll

Bow Group Health & Education Policy Committee

The Health & Education Policy Committee is committed to researching and analysing the issues and challenges facing the NHS, wider healthcare sector, and education system as a result of Government policies. The Committee regularly meets to discuss new research projects and how it can support viable, sustainable and effective policies to improve the provision and delivery of healthcare and education services.

Technical Acronyms and Abbreviations

AUD	Australian Dollar
CCG	Clinical Commissioning Group
CQC	Care Quality Commission
CSCI	Commission for Social Care Inspection
CSR	Corporate responsibility strategies
DH	UK Department of Health
DWP	UK Department of Work and Pensions
GP	General Practitioner
HSCB	Health and Social Care Bill
HSC	Health Select Committee
HWB	Health and Wellbeing Board
MP	Member of Parliament
NCPC	National Council of Palliative Care
NICE	National Institute for Health and Clinical Excellence
NHS	National Health Service
HTH	Help the Hospices
ONS	Office of National Statistics
PCT	Primary Care Trust
QIPP	Quality, Innovation, Productivity and Prevention
SHA	Strategic Health Authority
SPA	State Pension Age
US	United States
UK	United Kingdom

Executive Summary

The Issue

- A significant number of hospice services are managed and funded by the voluntary sector, operated either as independent hospices or by national specialist charities. The funding voluntary sector organisations receive from the state is generally insufficient to cover full running costs.
- There is currently no clear or definitive statement outlining what the Government will provide in terms of palliative and hospice care services in order to meet people's palliative and end of life care needs. In the absence of an explicit and codified "end of life care covenant", it is difficult to ascertain the overall percentage of hospice services provided by the voluntary sector which should be provided by the state.
- Government funding for children's hospices is typically much lower than for adult hospices, and on average constitutes only around 15% of overall running costs.
- It has been widely recognised that, although the previous Labour Government used warm rhetoric, it failed to tackle the key issue concerning the funding of social care. Whilst the NHS has seen increased funding to help cope with increased demand, social care funding has not kept pace. Since 2004, spending on the NHS has risen by £25 *billion* compared to spending on social care which rose by just £43 *million*.
- There are wide geographical variations in funding – in part because spending on social care is handled by local councils, whose circumstances vary. Local social care services are funded in an entirely different and in a much more localised way than the NHS.

Key Recommendations

- Britain should be well-placed to meet the end of life care challenge given its long-established hospice care network, which in some quarters is recognised as a benchmark on the international stage. However, there are still areas where Britain's system of end of life care could be improved with examples of best practice provided internationally.
- Faced with the unprecedented task of properly looking after a growing elderly population, hospices in Britain will need to become more closely integrated with NHS healthcare and wider service providers, whilst being firmly rooted within, and responsive to, their local communities if they are to meet this demographic challenge.
- An ongoing challenge for the delivery of healthcare services is a lack of integrated care and patient choice. It is therefore vital that there is a pooling of the health and social care budgets to ensure integrated patient treatment pathways and to overcome existing deficiencies in commissioning. This would also offer potential funding synergies and help alleviate the funding shortage for social care and hospices.

- To ensure proper financing, the introduction of a national tariff for hospice/palliative care based on need should be considered to help overcome problems of costing and to ensure better funding streams.
- To ensure better integration of care and policy planning there should be a representative from the hospice movement, or at least the palliative care movement, on clinical senates. This is important in the broader context of the Government's NHS reforms. Similarly, it is important local Health and Wellbeing Boards (HWBs) are effectively utilised to optimally coordinate, integrate and support local hospice services.
- The hospice movement resonates strongly with the principles underpinning the Big Society philosophy. In future, there is a vital role for the Big Society in ensuring hospice care is sustainable in the future, not least given 30% of hospices have reported having their statutory funding reduced as a consequence of Government deficit reduction measures.
- As the population ages and a greater burden is placed on hospices, the need for voluntary contributions and volunteer action will inevitably intensify. The Government must therefore recognise these increasing pressures and ensure that tax and regulatory systems – especially those relating to health and safety – are structured to enable those willing to commit finance and personal time to hospices are able to do so, minimising associated hurdles and barriers.

1. Introduction

As the old aphorism goes, nothing is certain but death and taxes. The former remains not just an inevitability of life, but a key policy consideration for any society. Dignity in death and the provision of proper end of life care remain amongst some of the most emotive and important issues topping the priority list of many individuals and their families. It is also an important duty and responsibility of any government to do rights by its citizens. This is not least the case given the UK's ageing population and the concurrent increase in chronic long-term conditions.

It is from this critical perspective that the role of the hospice movement, and hospice care, can be considered a central policy issue. Just like the UK's pension "time bomb", there is significant scope for "healthcare time bomb" as more and more people require end of life care. Moreover, it is an economic imperative as governments of all colours and persuasions continue to grapple with the basic health economic problem; infinite healthcare demands but finite healthcare resources. Ensuring people spend less time in hospital and more time in home, social and/or hospice care does not simply constitute good health and social policy, but also sound health economics.

It is pleasing to see the Coalition Government placing additional emphasis on the importance of social care, as exemplified by the Health and Social Care Bill (HSCB), but there is a need to further examine and explore the arrangements currently in place for the provision and delivery of hospice care. This has amplified importance in the light of the NHS Future Forum report, which emphasised the absolute need for more and better integrated healthcare and, in particular, an improved strategy for delivering end of life care in conjunction with other social services. As Professor Steve Field, Chairman of the NHS Future Forum, recently said: "Not only does integrated care give our patients the healthcare they need but it will prove to be the most effective way of treating a growing number of people living longer with long-term conditions".¹

So the challenge for Government is how it can best achieve integrated care, and it is the objective of this piece of research to answer five key policy questions:

- 1) How is hospice care provided and delivered in the UK and how has this evolved over time?
- 2) How does this compare with other countries?
- 3) What are the implications of the HSCB and Dilnot Review for the provision and delivery of hospice care in the UK?
- 4) How can the hospice care movement be best utilised as an example of the Big Society and how can the Government support hospices in this endeavour?
- 5) How should hospice care be provided, delivered and financed in the future?

For the purposes of this research paper, we focus on hospice care as a specific issue, but with appreciation for its need to be integrated and synergised with other parts of the NHS and social care framework. To this extent, we review arrangements pertaining to palliative and end of life care, and examine the role of hospice care and how this can be better integrated and improved. The purpose of our research paper is to provide a clear overview of current landscape and to provide recommendations on how policy can best be shaped moving forward. This paper is designed to feed directly into the Government's pledged White Paper on social and end of life care.

The Social Care White Paper was initially scheduled to be published by the end of the year but, the Department of Health (DH) has recently confirmed that it has been delayed until April next year, alongside a progress report on funding reform.

In addition to quantitative and qualitative analysis of current policies and the existing hospice care framework, our research methods included personal communications and interviews with hospice care and end of life care experts, and a structured literature review of published papers and viewpoints expressed by leading writers on this wider subject area.

2. The Hospice Movement

Whilst established hospices today continue to play a crucial role in caring for individuals with terminal illnesses, it is important to be clear on what is meant by hospice care; the types of services that hospices provide and deliver; and how and why the hospice movement has evolved.

2.1. What is hospice care?

In its earliest days, the concept of a hospice was rooted in the centuries-old idea of offering a place of shelter and rest, or “hospitality” to weary and sick travellers on a long journey. In 1967, Dame Cicely Saunders at St. Christopher’s Hospice in London first used the term “hospice” to describe specialised care for dying patients. This meaning is now associated with the modern day definition of hospice care where people receive humane and compassionate care in the latter phases of incurable disease.

Hospices can provide services at home, in day care or in designated hospices. The range of services provided by hospices typically includes pain control, symptom relief, nursing care, counselling, complementary therapies, spiritual care, social activities, physiotherapy, reminiscence, beauty treatment, and bereavement support.

2.2. Who is entitled to hospice care?

Hospice care is open to all helping people with cancer and other life-limiting illnesses such as neurological conditions (e.g. Motor Neurone Disease), HIV, and heart and lung conditions. Hospices also provide care and support for children and young people who have life limiting or life threatening conditions.

2.3. Background to the hospice movement

The hospice movement has grown dramatically in the UK since Dame Cicely Saunders opened St. Christopher’s. According to Help the Hospices, in 2009 UK hospice services consisted of 220 inpatient units for adults with 3,203 beds, 39 inpatient units for children with 298 beds, 314 home care services, 106 hospice at home services, 280 day care services, and 346 hospital support services.² These services together helped over 250,000 patients in 2003 and 2004. Funding varies from 100% funding by the NHS to almost 100% funding by charities, but the service is always free at point of need.

As of 2006, about 4% of all deaths in England and Wales occurred in a hospice setting (about 20,000 patients); a further number of patients spent time in a hospice, or were helped by hospice-based support services, but died elsewhere.³

2.4. The current funding model for hospices

In England, a significant number of hospice services are managed and funded by the voluntary sector, operated either as independent hospices or by national specialist charities. The funding voluntary sector organisations receive from the state is generally insufficient to cover full running costs. On average, adult hospices in England received 34% of their running costs from government funds in 2009.⁴ The actual percentage of state funding for local charitable hospices around the country varies considerably – from 0% to 62% of overall costs.⁵ Hospices are often run by small charities, but there are also

national charities such as Marie Curie Cancer Care and Sue Ryder who are able to generate the majority of their funding through active fundraising.

There is currently no clear or definitive statement outlining what the British Government will provide to meet people's palliative and end of life care needs. In the absence of an explicit and codified "end of life care covenant", it is difficult to ascertain the overall percentage of services provided by the voluntary sector which should be provided by the state. However, a National Audit Office survey suggested that 97% of independent hospices felt that the funding they received from Primary Care Trusts (PCTs) did not fully cover the costs of the NHS services they provided.⁶

Answering a written parliamentary question in September 2011 on the funding arrangements for hospices, Paul Burstow MP, the Minister of State for Care Services, said the previous Labour Government's 2008 "End of Life Care Strategy" is currently the reference point for determining NHS responsibilities and support for hospices (see **Appendix 1** for transcript of answers). Mr. Burstow confirmed that the DH has made an additional £286 million available to help implement the 2008 strategy for 2009 – 2011, and a further £40 million capital budget for hospices in 2010-11. Although the Government is currently considering the recommendations of the Palliative Care Funding Review, an evaluation of specialist palliative care spend by PCTs will continue for 2010-11 and be published as an updated benchmark. The Minister confirmed that the Government has not had any direct discussions or consultations with PCTs about their hospice care spend.

In addition to the voluntary sector hospices, there are around 40 NHS run hospices in England that provide care for adults. Although these hospices receive the majority of their funding directly from the state (generally through block grant arrangements), most supplement this income with voluntary fundraising activities from their local communities. The Palliative Care Review Team suggested that some NHS hospices are raising as much as 50% of their funding from voluntary sources⁷.

In helping to drive forward Government policy, it is significant that there is currently no national tariff for hospice care. Some work has been undertaken in various areas to develop local hospice tariffs, but so far these have not been properly developed or implemented despite the findings of the Palliative Care Funding Review.

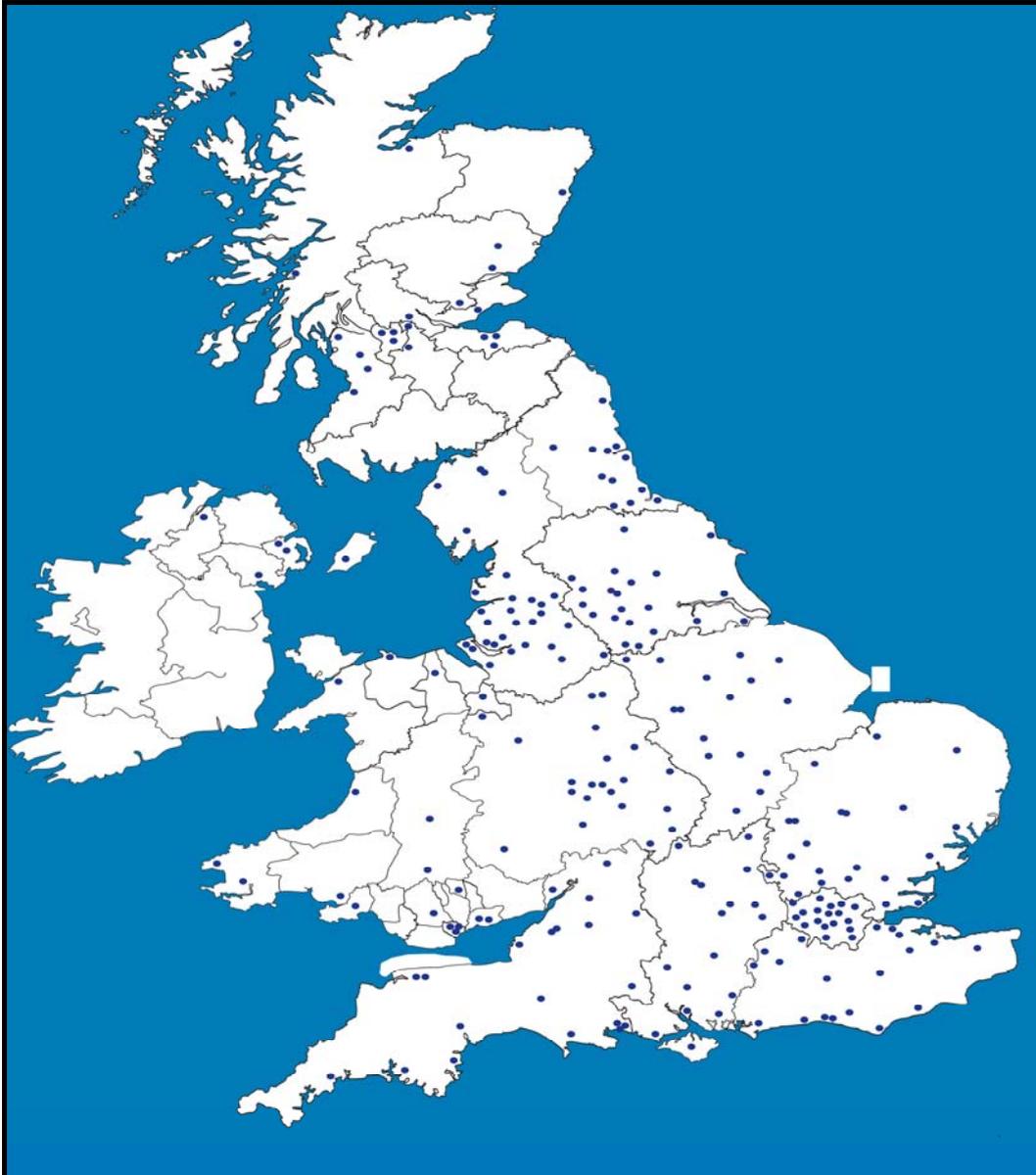
In response to a further written parliamentary question on what recent assessment the Government has made of the quality of hospice and palliative care provision in England, Paul Burstow MP answered by saying:

"The Mandate and National Health Service Outcomes Framework will drive quality improvement throughout the NHS. The end of life care Quality Standard being developed by the National Institute for Health and Clinical Excellence will set out the evidence-based characteristics of a high quality service for end of life care, which will help commissioners and providers to improve the quality of services. We are commissioning a national survey to ask bereaved relatives about the deceased's experience of care, as well as asking them about their own experience. The survey, which should be complete by March 2012, will inform a new indicator on end of life care within the patient experience domain of the NHS Outcomes Framework, as well as informing local service improvement activity. We have made no recent assessment of the quality of hospice and palliative care provision." (See **Appendix 1** for full transcript).

2.5. Access to hospice care

A keystone of the NHS is equal access to care free at the point of need. It is therefore important to consider access to hospice care across the UK.

Figure 1: A map of adult hospices and children hospices across the UK.



Source: Provided by Help the Hospices, September 2011. Blue dots = hospices.

Figure 1 is a map of all adult hospices and children hospices across the UK. Each ‘hospice’ is represented by one blue dot. Adults and children’s hospices are both included, and it is important to note that on the map hospices which have multiple sites are only represented by one single dot. Similarly, the map only depicts the distribution of hospices – there are other providers (such as community or hospital palliative care teams) which are not hospices and so **not** included in this illustration.

Although as the map shows hospices are fairly well scattered across the UK, with reasonable coverage and reach for most geographical areas, it is striking that Northern Ireland only has four hospices and there are rural parts of the UK where access appears rather limited. In the case of Northern Ireland, which has an estimated population of **1,799,392**, this translates to one hospice per **449,848** people.⁸ This is in comparison to the

entire UK, which based on the population data from the World Bank has one hospice per 281,000 people.⁹

Importantly, this does not account for other palliative and end of life care services in The Province, but does highlight the potential supply versus demand for palliative care services confronting hospices in particular areas. It is also accentuates the importance of having hospices, palliative care and end of life care services well integrated to ensure there is local coordination and synergistic service provision. Without such integration, the optimal delivery of services will likely be undermined and blunted. From the perspective of the Government's NHS reforms, there is clearly an important role for HWBs and clinical senates in this regard.

2.6. Children's hospices

Government funding for children's hospices is typically much lower than for adult hospices, and is on average constitutes only around 15% of overall running costs.¹⁰ Children's hospices receive a large proportion of their state financing through a programme of emergency funding by the DH, which is distributed as an ongoing annual £10 million grant to children's hospices under Section 64 of the Health Services and Public Health Act 1968.¹¹

Children's hospices also receive a proportion their funding to deliver short breaks. Short breaks funding comes through Local Authorities and the NHS. Department for Education ministers announced £800 million for short breaks in December 2010, with plans to provide an additional £40 million of capital investment in 2011-12.

3. The Challenge and the Problem

The ageing population is almost certainly the greatest challenge facing contemporary society, not least because of its multifaceted social, economic and political implications. This is demonstrated by basic descriptive statistics alone and highlights the critical need for better integrated care, which in turn means better end of life and hospice care. In future, more people will be living and dying with complex health and social care needs, increasing the demand for hospice care.

3.1. The Age of Gerontocracy

There are currently around 10.1 million people aged 65 and over in the UK, which equates to an 80% increase over the last six decades. Over the last 60 years, there has also been a substantial change in the age composition of older people. In 1951, those aged 65-74 represented 67% compared to those aged 85 plus that comprised just 4% of the 65 plus population. Today, the two age groups represent 52% and 14%, respectively.

Estimates from the Office of National Statistics (ONS) project that the UK population will increase from 61.4 million in 2008 to 65 million in 2017, passing 70 million in 2028, and reaching 71 million by 2031¹². This represents an increase of 10.2 million over the period 2006 to 2031, equivalent to an average annual growth rate of 0.62%, or 16.6% over the 25 years. In the longer-term, the projections suggest that the population will continue rising beyond 2031 albeit at a much lower rate of growth. The population is projected to continue rising until 2058; the end of the projection period.

Furthermore, the age structure of the UK population will gradually confer increasing gerontocracy. The number of children aged under 16 is projected to increase by 6.2 %

from 11.6 million in 2008 to 12.2 million by 2018, and then to increase further to 12.8 million by 2033. The number of people of working age is projected to rise by 5% from 38 million in 2008 to 39.9 million in 2013. Even when taking into account the change in women's state pension age between 2010 and 2020, the working age population will increase further to 40.8 million in 2018.

3.2. Elderly Dependents

Population ageing means there will be greater numbers of elderly dependents in the future. There were 3.23 persons of working age for every person of state pensionable age in 2008. By 2018, allowing for existing (Pensions Act 2007) changes to women's state pension ages this demographic support ratio is expected to decline to 3.18. Allowing for further changes in State Pension Age, the support ratio is expected to decline to around 2.8:1 in the 2040s, before stabilising.

The population will gradually become older with the average (mean) age expected to rise from 39.6 years in 2008 to 42.6 years in 2033. In the longer term, the projections suggest that the average age will continue to rise beyond 2033, reaching 43.8 years by 2051. In terms of the forecasting assumptions, life expectancy at birth in the UK is projected to rise from 77.6 years in 2008 to 83.2 years in 2033 for men; and from 81.7 years in 2008 to 86.9 years in 2033 for women.

The fastest population increase has been in the number of those aged 85 and over. Since 1985 this sub-population has doubled reaching 1.4 million in 2010. By 2035, the number is projected to be 2.5 times higher, reaching 3.6 million and accounting for 5% of the total population.¹³

These population increases mean the median age of the UK population has risen from 35 years in 1985 to 40 years in 2010. It is projected to continue to increase over the next 25 years rising to 42 by 2035.

3.3. Impact of Ageing Society

The state pension system is currently funded on a "pay as you go" basis, i.e. through the contributions of the current workforce rather than through any accumulated reserve of previous contributions. A fall in the ratio of workers to pensioners means that the funding of the state pension has become a predominant and financially crippling issue.

Initial rises in the State Pension Age (SPA), and the equalisation of the SPA between men and women, were a part of the Pensions Act 2007. This was based upon the second report of the Pensions Commission entitled A New Pension Settlement for the Twenty-first Century, which was in turn based around the 2004 based ONS population projections. The revised 2008 based population projections suggested that the population was aging more rapidly, and this is the basis for the 2011 Pensions Bill, currently going through Parliament.

However, there is more to population ageing than just pensions. There has been a growing debate about how far changes in the demographic profile of society will constitute a burden on the NHS and social care. It is generally accepted that the increase in the elderly population, and in particular the number of people aged 85 and over, will put greater pressure on the NHS and care home capacity. Understanding the demographic trends will help precipitate debate and fundamental changes in the way health and social care are managed and funded. The degree to which the health and social care needs of the elderly are provided for by the state, or on a private basis, will depend largely on future political decisions about the NHS and the appropriate role of the state.

Today, family members provide the majority of informal care to the elderly. While ageing demographics are largely a result of a sustained low birth rate, in the short term these trends have not implied an increase in the proportion of old people who lack close family. On the contrary, those now attaining older ages include larger proportions who have had children, larger proportions not yet widowed, and smaller proportions who have never married. As yet the proportion of elderly people who are divorced is small, but this proportion is rapidly increasing. Cohorts born since the mid-1950s have shown different patterns of family formation and dissolution, and the longer term prospects for the family support of old people are therefore likely to be less favourable.

3.4. Analysis

The UK's ageing population has considerable consequences for public services. Much of the Government's public spending, particularly for healthcare and social benefits, is focussed on elderly people. It has been estimated that around 65% of Department for Work and Pensions (DWP) benefit expenditure goes to those over working age; equivalent to £100 billion in 2010/11 or one-seventh of public expenditure. This has led to projections that show by continuing to provide state benefits and pensions at today's average would result in additional spending of £10 billion a year for every additional one million people over working age.

Population ageing also has important implications for economic growth and productivity, which are acutely important in the current economic climate. Not only will the size of the working age population decrease, but increases in old age dependency may drain resources that may otherwise be used to support economic growth.

It should, of course, be remembered that these challenges and problems are not UK-specific, with population ageing representing an international phenomenon. In 1950, just 8% of the world population was aged 60 years or over. By 2005, that proportion had risen to 10% and it is expected to be more than double over the next 40 years, reaching 22% in 2050. Globally, the number of people aged 60 and over will nearly triple in size, increasing from 671 million in 2005 to almost 2 billion in 2050. It is therefore salutary to explore how other countries are addressing this end of life and hospice care challenge, and the potential insight that can be gleaned.

4. International Comparisons and Best Practice

In some ways, Britain should be well-placed to meet the end of life care challenge given its long-established hospice care network, which in some quarters is perceived as a benchmark on the international stage. Since the founding of St Christopher's Hospice, Britain has arguably led the world in terms of its quality of hospice, and end of life, care. An Economist report compiled in 2010 found that Britain topped its overall 'Quality of Death Index', which compared the quality of provision of end of life care services across 40 countries.¹⁴ Nevertheless, there are still areas where Britain's system of end of life care could be improved with examples of best practice provided internationally.

4.1. The case for integrated end of life care

As the Coalition Government has explicitly recognised during the troublesome passage of its NHS reforms, Britain still lags behind other developed nations when it comes to the level of integration between health and social care providers. Promoting greater joined-up thinking between NHS health care providers and council-run Social Services must continue to be a key reform priority for the Government. Faced with the unprecedented task of properly looking after a growing elderly population, hospices in Britain will have

to become more closely integrated with NHS healthcare and wider service providers, whilst being firmly rooted within, and responsive to, their local communities if they are to meet this demographic challenge.

One country which has successfully integrated its end of life care with wider mainstream healthcare providers is Australia. According to Professor David Currow, Chief Executive of Cancer Australia, a statutory body established by the Cancer Australia Act 2006, the number of standalone, purpose-built hospices has diminished in recent years, with palliative care services integrated into various local hospitals.¹⁵

A comparative study conducted in 2002 found that where end of life care was more integrated between home care services and mainstream healthcare, such as in parts of South Australia, hospice care was more likely to be rated highly by patients and carers.¹⁶ In Europe, countries such as Poland have also developed highly integrated palliative care services, with an emphasis on synergising specialist education and training with the delivery of end of life care. As discussed above, the funding of hospice care in the UK is heavily skewed towards private and charitable donations despite the Government's commitment to provide an additional £40 million in capital spend in 2010-11. This makes the business of integration and prioritisation evermore important; something which other countries have sought to emphasise.

4.2. Prioritising palliative care

In taking a step back from the British model of hospice care, one of the most striking differences lies in the approach national governments have taken. Whilst hospices have a cherished institution status in the UK, they do not necessarily occupy a central role in dictating health policy. In contrast, the Swedish hospice model, which has proportionality higher rates of taxation, has been tailored to fully incorporate elderly and palliative care, as part of its national plan of action for geriatric policy (Government Bill 1997/98:113): "According to the ethical principles applying to Swedish health and medical care, palliative care should be one of the most highly prioritised areas within the health care sector".¹⁷

Although it might be expected that Sweden and the UK finish towards the top end of any hospice ranking table, it is surprising that Hungary, Poland and Romania have emerged very high up the end of life care indexes.¹⁸ A key reason for this success is that, as newer nation states with smaller populations, lobbyists and interest groups have seemingly been able to deliver and communicate the need for better hospice care to national governments in a way that is more difficult in countries like the UK. The experience of these Eastern Bloc countries has shown that putting in place a comprehensive hospice care policy can have immediate and beneficial impacts on quality of death.

However, the challenge is not only ensuring that palliative services are central to a government's health agenda; there must be other variable factors such as ageing population rates, availability of finance and attitude to death of a wider population integrated into a wider policy. In Japan, where there are a very high number of elderly people, the policy of hospice care remains a high priority, yet Japan has been unable to construct a research base and funding formula that delivers effective end of life care¹⁹. It is clear that if the UK is to improve its hospice care framework dealing with the demographic challenge head on is essential.

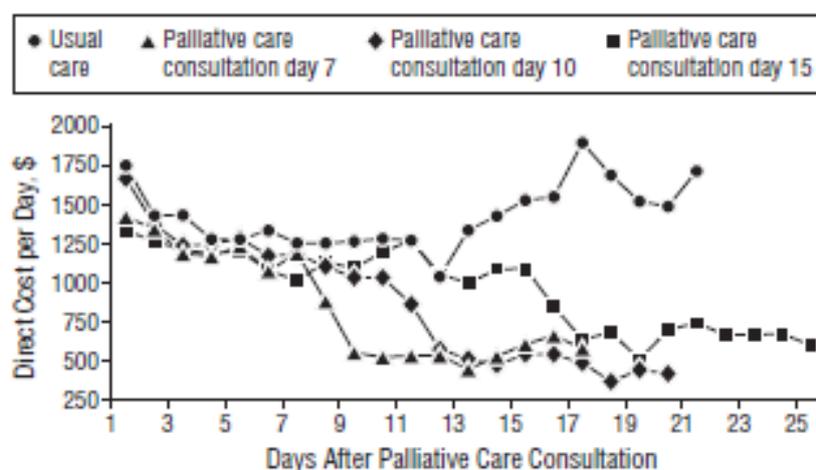
4.3. International funding hospice care

Similar to many European countries, the UK's hospice funding model is mainly reliant upon private funding and donations with a smaller (but significant) percentage from

central government. In recent years, Australia has based its funding model on a method that seeks to ensure that individuals are, where possible, looked after at home or in the community, and kept away from unnecessary hospital admissions. As part of this package, AUD \$14 million has been invested for palliative care in the community, for both patients and their families. This is a comparatively low level of investment to the UK's £286 million for 2009-11, yet Australia's high quality of death outcomes show that if finances are targeted appropriately in the community, money does not need to be spent on costly hospitalisations or hospice stays. This is not only an efficient funding model, but also creates a palliative care system that exerts the least possible stress and difficulty on patients and families.

Empirical evidence from the US has shown that where palliative care consultancy teams have intervened at an early stage of terminal illnesses, significantly reduced healthcare spending has followed. The reason behind this lies in a traditional hospital culture that follows a process of reactive and time-intensive treatment that often increases spending costs and exacerbates patient symptoms.²⁰ Although this hospital culture is not necessarily as prevalent in the UK, it does provide an empirical study of hospitals that made significant savings when palliative care teams intervened at an early stage. As Figure 1 makes clear, the impact is almost immediate.

Figure 1: A cross comparison in mean direct costs per day of patients who were visited by palliative care consultation teams in the US (Mean direct costs per day for patients who died and who received palliative care consultation on hospital days 7, 10, and 15 compared with mean direct costs for usual care patients matched by propensity score. Hospital day 1 is the first full day after the day of admission).²¹



Source: Taken from Morrison et al 2008.

It is clear that an early intervention in providing hospice care is central to establishing future funding formulas in the UK. Our research also shows that there is the issue of addressing *where* hospice funding should take place. In New Zealand, for example, additional focus has been placed on areas that do not have hospices at all. This is pertinent to the UK where many rural areas lack adequate hospice services. Ensuring such areas are not left behind must remain central to future hospice and palliative care provision.

5. The Health and Social Care Bill (HSCB)

The keystone of the Coalition Government's English health policy has been the NHS reforms as embodied in the Health and Social Care Bill (HSCB). Currently at the committee stage in the House of Lords, the HSCB's salient features include:

- establishing an independent NHS Board to allocate resources and provide commissioning guidance;
- increasing clinicians' powers to commission community based healthcare services on behalf of their patients;
- strengthening the role of the Care Quality Commission (CQC);
- developing Monitor, the body that currently regulates NHS foundation trusts, into an economic regulator to oversee aspects of access and competition in the NHS;
- setting up HWBs to better integrate health and social care at a local level; and,
- cutting the number of health bodies to help meet the Government's commitment to cut NHS administration costs by a third, including abolishing PCTs and SHAs.

Although the HSCB makes partial reference to "social care", it is arguable that the title and name of the Bill is something of a misnomer. It is mainly focused on the provision, delivering and commissioning of healthcare in the English NHS rather than social care as would typically be understood. It is therefore reassuring that the Government has committed to publish a White Paper specifically on the issue of social care and end of life care in April 2012. This is particularly important when considering the recent policy history in these critical areas.

Successive governments have failed to properly address the need to put sufficient NHS resources into supporting people through terminal and progressive illnesses, and the process of dying and death. This is made evermore acute and problematic in light of the UK's demography. As the population ages, and as medical interventions become more effective, more people are living longer. Yet more people are also living longer with chaotic terminal, and progressive illnesses. The demands placed on palliative medicine and hospices are significantly increasing; a general argument the Prime Minister and Health Secretary have made for the decision to ring-fence the English NHS budget by 0.4% in real terms over the life cycle of the current Parliament.

The current Government is looking closely at delivering more services in the community through local commissioning boards and improving integration between adult social services and the NHS, through HWBs. Undoubtedly, this will help to throw more attention on the need for more targeted resources being placed into community care for the elderly, and this will mean a greater role for hospices and palliative care. However, there remains the need for a national palliative care strategy and for the Government to take a stronger policy position in supporting NHS and other palliative care services, particularly the hospice movement.

5.1. End of Life Care Strategy

In July 2008, the previous Labour Government published the End of Life Care Strategy, which sought to promote high quality care for all adults at the end of life and was the first for the UK and covers adults in England. The main objective of the strategy was to provide people approaching the end of life with more choice about where they would like to live and die. It encompassed all adults with advanced and progressive illness, and care given in all settings (see **Appendix 2** for more details).

Specifically, the strategy presented new opportunities for how hospices would play a key role in delivering better end of life care stating: “Hospices will continue to have a pivotal role within the new vision for end of life care set out in this strategy. They will continue to be centres of excellence, providing a standard of care against which other services will be measured. They will also continue to be key providers of education and research.”

In particular, the strategy set out the following proposals for hospices:

- continue the work hospices are doing to expand the provision of care to people with illnesses other than cancer;
- expand hospice work in partnership with care homes.
- hospice staff to train care home staff in end of life care and work in the home caring for residents for several sessions a week;
- raise awareness of end of life care within their local communities;
- provide a central coordination function for end of life care within the local health economy;
- take on a wider role in education of non-specialists in palliative care;
- use volunteers in an innovative way in care support programmes; and,
- take on a wider role in the provision of carer support and bereavement care.

As outlined above, the Coalition Government has confirmed that the 2008 strategy remains the reference point for NHS responsibilities and support for hospice care in England. This has been followed up by the Palliative Care Funding Review.

5.2. Palliative Care Funding Review

In July 2010, Andrew Lansley commissioned an independent review of the funding of dedicated palliative care for adults and children in England.¹ The review was asked to develop, for the first time, a per-patient funding mechanism for palliative care. This was widely seen as an ambitious step especially because no country in the world has introduced such a system for both adults and children. The review had three key aims:

- to create a fair and transparent funding system;
- to deliver better outcomes for patients; and,
- to provide better value for the NHS.

The review team met with a wider range of stakeholders including hospices. Given the current paucity of data in this field, the review also commissioned detailed research to develop a classification system for palliative/end of life patients according to need and the cost of delivering services to meet patient needs.

The review published its findings on the 1st July 2011. The final report recommended the introduction of the first per-patient funding system for palliative care in the NHS. Proposals included the development of a palliative care tariff based on need, a funding system which incentivises good outcomes for patients, irrespective of time and setting, and providing incentives for commissioning integrated care packages which stimulate community service (see **Box 1** for details).

¹ The Review was chaired by Thomas Hughes-Hallett, Chief Executive of Marie Curie Cancer Care. Professor Sir Alan Craft, Emeritus Professor of Child Health, Newcastle University co-authored the report.

Box 1: How the proposed model would work in practice

Patients – once they are assessed as needing palliative care, patients will know that there is a tariff available to cover their palliative care needs in all settings, including hospitals, care homes, hospices or the patient's own home.

Commissioners – will have a tariff by which to purchase palliative care services based on activity, using a system which is weighted based on complexity of patient need. They would be able to commission to quality and outcomes, and would be able to monitor activity closely and plan future services accordingly.

Providers – will be paid for the care they provide to patients on an activity basis. The level of payment will be dependent on the complexity and resource use of the patient cases, providing a fairer payment for the services provided.

The review recommended that the DH commits funds to support the transition and implementation of the new funding system. It was argued that the NHS should continue to fund drugs and pharmacy services in all settings and the NHS Commissioning Board should fund palliative care education and training for NHS professionals. The review also suggested that commissioners must continue to provide appropriate support for patients, families and carers, ensuring they commission services which support their needs. In particular, the importance of bereavement services, respite care, short breaks, carer support and spiritual care was highlighted.

The review concluded that the proposed funding system would be cost neutral, and if implemented effectively could deliver improved recognition of palliative care needs and an optimised provision of services outside of the hospital setting. Projections suggest that this could potentially reduce deaths in hospital by up to 60,000 a year by 2021. Using the QIPP estimate of £3,000 per hospital death, this would translate to a potential reduction in hospital costs of £180 million per year. Recommendations from the review have now been passed to the DH.

While the review recognised that the UK has some of the best hospice and palliative care services in the world, it found there were still significant challenges to address. It noted that palliative care in England is provided by a plurality of providers from both the NHS and the voluntary sector. It also criticised the lack of integration and coordination between services, and the provision of palliative care varies between geographical areas.

The review considered that because of the lack of a clearly defined funding model and any national tariff, block contracts with some spot purchasing are the most common funding mechanisms currently employed in palliative care services. This meant that payments do not follow patients, and providers are paid regardless of activity, impeding commissioners from performance-managing services. It, therefore, concluded that the current system does not ensure best possible value for money.

It was noted by the review team that a recent survey by the DH estimated that PCTs spent £460m on adult palliative and end of life care in 2010/11, with one PCT spending around £0.2m on specialist palliative care alone, and another around £21m. This variation means that one PCT spent approximately £186 per death on specialist palliative care, while another spent £6,213. A total of, 61% of all PCTs spend less than £1,000 per death in their PCT. This means there is significant scope of health inequalities across end of life care.

5.3. National Institute for Health and Clinical Excellence (NICE) Consultation

NICE is currently working to draw together some end of life care quality standards. A consultation on the end of life care quality standard took place from June to July 2011 and it is expected that the standards will be published in November 2011. NICE quality standards are developed in accordance with a scope that defines what the standard will, and will not, cover.

This quality standard covers all settings in which care is provided by health and social care staff to adults approaching the end of life and adults who die suddenly or after a very brief illness. It sets out markers of high quality care for adults aged 18 years and older with advanced, progressive, incurable conditions, adults who may die within 12 months, and those with life threatening acute conditions. It also covers support for the families and carers of people in these groups. Each quality statement is relevant to care in all settings unless otherwise stated. The quality standard does not cover condition-specific management and care, clinical management of specific physical symptoms and side effects, or emergency planning and mass casualty incidents.

5.4. Analysis

Work to bring together a set of quality standards for end of life care is to be welcomed and should be particularly helpful in forming the basis for commissioning guidance and for clinical auditing. However, in their current draft form the indicators are quite vague and more work is needed to ensure that consideration is given to separating out the specific and different needs of individual patients. It will also be crucial that this work is drawn together with the palliative care funding review and the outcomes framework to ensure incentives are in place to encourage best practice in end of life care.

6. The Social Care Challenge

The hospice movement is closely aligned with social care, which covers a vast array of services designed to help vulnerable people to maintain their independence. Social care and support may be required as a result of infirmity in old age, learning or physical disability, accident, long-term illness or mental illness. It is staffed by the biggest workforce in the country, with around 1.5 million people working for an estimated 39,000 different organisations. In addition, the system depends heavily on the unpaid work of around 6 million informal carers. It is designed to help people perform day-to-day activities like whilst living in their own homes or via funding for residential care.

A complex area, it is widely viewed that social care is not well understood by policymakers and has for many years been the poor relation to health care. Although NHS care is funded by the taxpayer and is free to all, much social care is only available on a means-tested basis. The result is that many people's needs do not fit closely defined health criteria, and those who have assets above a certain level then have to pay for their own care or may go without help.

6.1. Previous Government Policy

In late 2007, the Labour Government published the 'Putting People First' concordat which promised a bigger role for councils and the creation of a personalised service, allowing users more independence and greater choice and control over their care. One of the main mechanisms for delivery of this are personal budgets – an amount of funding allocated to a

user that allows them to control which services that funding is used to purchase; the Government pledged £520 million to ensure most users could personalise their care by 2011.

This was backed by a range of initiatives to improve the care of often neglected groups. Valuing People in 2001 promised a new deal for people with learning disabilities and set a 2025 deadline for achieving full equality. The first National Carers' Strategy was unveiled in 1998 and was revamped and expanded last year. A campaign was launched to promote dignity and respect in the care of elderly people. In 2009, the Labour Government launched its first National Dementia Strategy.

There are also moves to coordinate health and social care planning, aided by most PCTs and local authorities now covering the same geographical areas. The inspection regime has also been brought together with the merger of the Healthcare Commission, Commission for Social Care Inspection (CSCI) and the Mental Health Act Commission into the new CQC, which started work on 1st April 2009.

6.2. The Social Care Financial Time Bomb

It is widely recognised that although the previous Labour Government made the right noises, it failed to tackle the key issue concerning the funding of social care. Whilst the NHS has seen increased funding to help cope with increased demand, social care funding has not kept pace. Since 2004, spending on the NHS has risen by £25 **billion** compared to spending on social care which rose by just £43 **million** (0.1% per year in real terms)²². Chronic underfunding has contributed to significant unmet need and decreasing access to sub-optimal services. Official DH figures show that, over the last 4 years, demand has outstripped expenditure by around 9%.²³

In addition, there are wide geographical variations in funding – in part because spending on social care is handled by local councils, whose circumstances vary. Local social care services are funded in an entirely different and much more localised way than the NHS. This reflects the continuing legacy of the settlement after the 2nd World War in which the NHS was established as a centrally directed service, largely free at the point of use, while personal social services were the responsibility of local councils and subject to means-testing. Some of the resulting variations in local services have given rise to perennial concerns about a 'postcode lottery' in care.

A major review of social care for older people by Sir Derek Wanless for the King's Fund in 2006 suggested the system needed to be radically overhauled. One of the principal reasons was the huge predicted growth in the very elderly with increasing health and social care needs. He proposed a "partnership" funding model in which everyone would be guaranteed a basic level of care that they could then choose to top up. The overall extra cost would be around £1.7 billion a year. Those ideas fed into the previous Government's announcement in 2008 of a "once in a generation" review of how social care is organised and funded. A Green Paper on the future of social care was unveiled on 14 July 2009 and a White Paper followed on 30 March 2010 although future reform was interrupted by the 2010 General Election.

6.3. Developments since the 2010 General Election

Following the 2010 General Election, the Coalition Government promised a fresh approach to social care. They specifically promised to break down barriers between health and social care funding to incentivise preventative action and extend the greater roll-out of personal budgets to give people and their carers more control and purchasing power.

In response to growing concerns about funding, the Government identified additional resources in 2010 – including £1 billion from the NHS budget – for social care. They also set up the Commission on Funding of Care and Support as an independent body to make recommendations on how the UK can achieve an affordable and sustainable funding system for care and support, for all adults in England, both in the home and other settings. While the Commission was hosted by the DH, it was considered independent of both the Department and Government.

Launched on 20th July 2010, the Commission was chaired by Andrew Dilnot with Lord Warner and Dame Jo Williams as fellow Commissioners. The Commission aimed to build on the extensive body of work that has already been done in the social care area, and provide recommendations and advice on how to implement the best option to Government within a year.

In November 2010, the DH published a document entitled ‘Vision for Adult Social Care’, which sets out how the Government wishes to see services delivered for people; a new direction for adult social care, putting personalised services and outcomes centre stage. The document does not discuss how adult social care is to be paid for, leaving this for the Commission on Funding of Care and Support, but details a list of aspirations outlining what the future of social care will look like.

The vision sets out a new agenda for adult social care based on a power shift from the state to the citizen, by committing to:

- extend the rollout of personal budgets;
- increase preventative action in local communities;
- keeping people independent and helping to build the Big Society;
- break down barriers between health and social care funding; and,
- encouraging care and support to be delivered in a partnership between individuals, communities, the voluntary sector, the NHS and councils - including wider support services, such as housing.

Amongst other suggestions, the document advocates a wider uptake of personal care budgets, which are currently used by only 13% of the eligible recipients. The aim of personal budgets is to give people, and their carers, greater choice and control over the social care services they receive. The vision also continues the Coalition’s preference to see more care delivered in the community, with a focus on helping people stay in their homes longer.

The Commission presented its findings to the Government in its report Fairer Care Funding, published on 4th July 2011. The Commission declared the existing system “not fit for purpose”, describing it as “confusing, unfair and unsustainable”.

The Commission has recommended a partnership model between the state and the individual, where people are expected to make a contribution to the cost of their care. Key recommendations include:

- Individuals’ lifetime contributions towards their social care costs – which are currently potentially unlimited – should be capped. After the cap is reached, individuals would be eligible for full state support. This cap should be between £25,000 and £50,000. The commission considered that £35,000 is the most appropriate and fair figure.

- The means-tested threshold, above which people are liable for their full care costs, should be increased from £23,250 to £100,000.
- National eligibility criteria and portable assessments should be introduced to ensure greater consistency.
- All those who enter adulthood with a care and support need should be eligible for free state support immediately rather than being subjected to a means test.

The Commission estimates that its proposals – based on a cap of £35,000 – would cost the Government around £1.7 billion.

For those reaching the end of their life, the Commission called for there to be better integrated health and social care services, and that there is a strong case for these being free at the point of need. At this time, the last thing that individuals and families need is arguments over who funds care, and where care is provided. Dilnot also emphasised support for the direction of travel being taken by the independent Palliative Care Funding Review, which is looking into the funding of end of life care.

The Coalition Government has pledged to consider the recommendations of the Law Commission and the Dilnot Commission, alongside its previously published Vision for Adult Social Care. It intends to publish a White Paper on social care reform in April 2012 followed by legislation in the next parliamentary session.

Following a major review, the Law Commission has recommended radical reform of adult social care law, which dates back to 1948 and consists of a complex and confusing patchwork of legislation. This would be replaced by a single, clearer, modern statute and code of practice that would pave the way for a coherent social care system. Under the reforms proposed older people, disabled people, those with mental health problems and carers will, for the first time, be clear about their legal rights to care and support services. Local councils across England and Wales will have clear and concise rules to govern when they must provide services.

6.4. Analysis

In relation to end of life care, the Dilnot Commission stated:

“For those reaching the end of their life, we think that there should be better integrated health and social care services, and that there is a strong case for these being free at the point of need. At this time, the last thing that individuals and families need are arguments over who funds care, and where care is provided. Given this, the Commission is broadly supportive of the direction of travel being taken by the independent Palliative Care Funding Review, which is looking into the funding of end-of-life care”

The Commission’s proposal for a cap of £35,000 will make it easier in future for people to prepare for older age and has the potential to remove much of the uncertainty. It will be crucial that when responding to Dilnot the Government build up a national consensus around the funding of long-term social care so that the social care and end of life care agendas can be joined together to produce the best possible care. It will also be important that the patient experience is considered as well as the funding mechanism itself.

7. Expert Opinion and Case Studies

As part of our research, we elicited expert opinion to glean insight into some of the practical issues confronting hospices. Organisations contributing to our research included:

1. Children’s Hospices²⁴;

2. Help the Hospices²⁵; and,
3. National Council of Palliative Care (NCPC).²⁶

With each organisation, we posed six key questions:

1. Is the provision and quality of hospice care today sufficient, and what are the current issues around providing optimal hospice care?
2. What is the impact of the HSCB/NHS Future Forum report on hospice care in your view, if any?
3. What impact will the Dilnot Review have on hospice care in your view, if any?
4. What will optimal hospice care look like in the future, and will “redesign” of hospice care be required to meet any changing demands (rising birth rate for example)?
5. Who will/should provide hospice care in the future? (i.e. the state/private sector / voluntary sector or a mix)
6. Are there international examples of best practice the UK Government should consider and if so what does this entail?

We summarise the responses and expert insights below.

7.1. Is the provision and quality of hospice care today sufficient, and what are the current issues around providing optimal hospice care?

Acknowledging some of the strengths surrounding the provision and delivery of hospice care in the UK, **Help the Hospices** commented that there are some critical issues which need to be address to support and sustain the delivery of optimal hospice care. These mainly pertain to funding and commissioning.

“Independent charitable hospices provide the majority of hospice care throughout the UK. The hospice movement is one of the UK’s most successful models of community led care and has developed ground breaking services throughout its history. Hospices provide 26 million hours of care for a total of 360,000 people – 90% of which is provided through day care services and care in people’s homes . However, there remains variability in access to and quality of end of life care and there is still a major challenge ahead to ensure people receive the best possible end of life care, irrespective of where they choose to be cared for, where they live or the condition or conditions they have.

Adult hospices in England receive on average just 34% of their costs from the Government. Government funding as a percentage of total income for children’s hospices is much lower than for adult hospices – 17% on average, although funding levels are higher than they were three years ago. However, this masks significant variation across the country, with great divergence in the proportion of funding received by different hospices and many hospices receiving less than this average.

Hospices are unique among providers of healthcare because they contribute so significantly to the funding and provision of hospice and palliative car. Local communities and businesses are vital sources of support, with 64% of hospice income coming from donations, legacies and trading for adult hospices and 80% for children’s hospices. This represents more than £1.5 million raised each day. In 2010 hospices spent well over £500 million on caring for patients, their carers and families. In short, local charitable hospices deliver £3 worth of care for every £1 the state invests.

Help the Hospices has previously drawn attention to the challenges of the current commissioning system, which contributes to the uneven provision and funding arrangements across the country. The existing commissioning arrangements hamper the

*development of new services, reduce efficiency and act as a disincentive to service integration. Commissioning arrangements were recognised in the End of Life Care Strategy (2008) as a significant barrier to meeting increased demand”.*²⁷

It is from this perspective that there is an urgent need for change to the current arrangements informing the provision and delivery of hospice care across the UK. For the reasons outlined, this paper was told:

*“For this reason **Help the Hospices** have welcomed the Coalition Government’s commitment to reform commissioning in England, although we have some concerns about the mechanisms being established through the HSCB”.*

The National Council for Palliative Care (NCPC) pointed out that there are issues with training and extending access, but like **Help The Hospices** big challenges pertaining to the existing funding arrangements:

“Funding of hospices remains a concern. On average hospices receive a third of their funding from the NHS; the rest is usually collected through local fundraising. According to the Help the Hospices, £1.4 million is spent on hospice care every day in the UK, of this, only £447,000 comes from the government. In December 2010, a NCPC and Help the Hospices’ survey of specialist palliative care providers found: 1) a third were aware of care staff cuts in local palliative and end of life care services; 2) nearly 30% of hospices (voluntary sector and NHS) have already had their statutory funding cut in the current year; and 3) 30% of all respondents anticipate a decrease in their statutory funding in 2011/12”.

Children’s Hospices UK commented that there are some challenges surrounding the current provision of children’s hospices. Amongst others, these include:

- 1) A **general lack of awareness** of the services on offer to children, young people and families, with many parents surprised about the breadth of services statutory and voluntary that is available. The same also applies to many healthcare professionals, including GPs.
- 2) Parents find the **current assessment system** – which requires them to repeat the information about their child and family circumstances on multiple occasions – complex and difficult to navigate. This leads to frustration due a lack of integration across health, education and social care assessment for disabled children.
- 3) Although most parents speak very highly of the professionals involved in the care of their child or young person, many still felt **training was inadequate** for those generalist professionals who have only limited day-to-day contact with life-limited and life threatened children and young people. Better training for these professionals would help improve general awareness of the needs of life-limited children and young people, improve experiences at the point of initial diagnosis and ensure greater inclusion.
- 4) There is widespread concern in all areas about the potential impact of public sector cuts and the **general fragility of the economy** on both the charitable and statutory sectors.

7.1.1 Summary of key points

- Current funding and commissioning arrangements for hospices are insufficient.
- £1.4 million is spent on hospice care every day in the UK, of this, only £447,000 comes from the Government. Put differently, for every £1 the state invests in local charitable hospices, those hospices deliver £3 worth of care.

- There is a lack of awareness about children’s hospices and associated problems with assessment and training of staff.

7.2. What is the impact of the HSCB/NHS Future Forum report on hospice care in your view, if any?

Commenting on the HSCB, **Help the Hospices** told this paper:

“The current thrust of the Bill and the NHS Future Forums report focused on ensuring all types of care reflected what are in essence the principles of hospice care; care that is integrated and delivers the best outcomes for people by caring for a person as a whole. Despite amendments to the timetable for reform, Help the Hospices remains concerned about its scale, pace and cost and its effect on those receiving hospice and palliative care and, in particular, the continuity and quality of care. We have already highlighted the many changes and challenges that hospice and palliative providers face. We are concerned that as any transition to a new system is likely to be lengthy, the current provision of hospice and palliative care is at risk of being destabilised, which would have serious implications for people facing the end of life and their friends and family”.

NCPC told us that palliative and end of life care must be seen as a priority as part of the Government’s new public health arrangements, and must not be overlooked as part of the reform programme:

“It will be essential that hospice, palliative and end of life care is seen as an urgent priority by the new clinical commissioning groups and Health & Wellbeing Boards being set up as part of the health and social care reforms”.

Children’s Hospices UK commented:

“We welcome and support any plans to put patients at the heart health and social care services and have actively helped to influence the development and passage of the current Bill. We do have some concerns about its impact, particularly around how children’s palliative care will be commissioned in the new system.

The experience of children’s hospices in accessing funding from PCTs for the services they provide has been very mixed. According to our research, on average children’s hospices negotiate commissioning and funding arrangements with ten PCTs. Despite funding being included in PCT baseline allocations, this funding made up only 9% of children’s hospice income, with more than half of PCTs not commissioning any services from children’s hospices. The central funding under the NHS Section 64 arrangements between 2007-10 and the Coalition government’s commitment to continue with £10 million a year of funding while a new system is developed, have been crucial in addressing this funding shortfall in recent years.

These challenges are in part owing to the multiplicity of relationships with different commissioners, who have struggled to plan effectively for children with palliative care needs. We were therefore concerned when the White Paper was published, that should very local consortia emerge with responsibility for smaller populations, this challenge is likely to be exacerbated. Children’s hospice providers, already investing significant resources in managing relationships and accessing limited funding, will find it increasingly difficult to broker relationships with the greater number of commissioners”.

7.2.1 Summary of key points

- There are mixed views on how the HSCB will impact on hospices and whether the NHS reforms will be favourable.
- There are particular concerns around the pace of the reforms.
- Children's hospices have had very mixed experiences with PCTs especially around the issue of funding.

7.3. What impact will the Dilnot Review have on hospice care in your view, if any?

Commenting on the HSCB, **Help the Hospices** told this paper:

“An overhaul of the social care system is long overdue. The current system is characterised by unfairness and uncertainty, which is adding to the burden on people with life-limiting illnesses, their friends and family. Few hospices currently receive any funding from local councils to support the social care services which are so integral to the delivery of high quality palliative care. This is despite the ongoing rhetoric about the importance of partnership working between health and social care services, across both the voluntary and statutory sectors...Joined-up health and social care for palliative care services must become a reality and we would urge the government ensure the opportunity for the reform of social care isn't once again kicked into the long grass”.

NCPC told us that they are optimistic of positive reform following the Dilnot Review:

“We were pleased that Andrew Dilnot was broadly supportive of the Palliative Care Funding Review, which recommended that a person on an end of life care register should not be means-tested for social care. We await the Government's formal response to both the Commission on Funding of Care and Support and the Palliative Care Funding Review, but are optimistic that the proposals will have a positive impact on palliative, end of life and hospice care if carefully introduced”.

Children's Hospices UK commented:

“The Dilnot review (which is focussed on funding adult social care) provides an important opportunity to improve funding and services for young people making the transition from children's to adult services. This is a critical time for many young people and their family, many of whom find it very challenging to access appropriate adult services, which may not be designed to meet their needs.

We have encouraged Ministers to ensure that the Dilnot recommendations are considered in conjunction with the recommendations from the Independent Review of Palliative Care Funding which reported to the Government around the same time this year, on 1 July”.

7.3.1 Summary of key points

- Radical reform of the social care system is much needed and is essential.
- The Dilnot Review proposes some important recommendations that should be fully considered for practical implementation.
- The Dilnot recommendations should be considered in conjunction with the Independent Review of Palliative Care.

7.4. What will optimal hospice care look like in the future, and will “redesign” of hospice care be required to meet any changing demands (rising birth rate for example)?

Help the Hospices commented:

“Help the Hospices will be supporting a Commission on the future of hospice care, whose overall purpose will be to: 1) to generate a menu of strategic options for hospices regarding their position and offerings in the future; 2) to make available to hospices intelligence around the need for hospice care, opportunities for its development and how these are best realised; and 3) to engage with hospices about the emerging themes of the future options for hospices regarding their position and offerings in the future, and their implications for hospices. The Commission is still being developed and so it is difficult to provide in-depth information, but we will keep you updated with its progress”.

Children’s Hospices UK commented that there are a number of important challenges for the children’s hospice sector. Amongst others, these include:

- 1) **More children are living to adulthood.** Advances in technology mean more and more life-limited young people are making the transition to adulthood. The level of services to support these young people after children’s palliative care is inconsistent.
- 2) **There are an increasing number of premature babies with complex health needs surviving.** This is due to advances in medicine and technology advancements.
- 3) **More and more families want choice of where they are supported.** Children’s hospices are about much more than buildings and more and more services are developing community and in-home based care and support to reflect the needs of families. This will only continue to develop in the future.
- 4) **Economic demands continue to put pressure on the sustainability of children’s hospices.** Funding is a key issue, which will affect service delivery in the future.
- 5) **The need for seamless care and support through partnerships.** Any optimal model of palliative care, be it in children’s or adult services, must be based on strong and effective partnerships. Effective partnerships between health, education and social care as well as the voluntary and statutory sector are at the cornerstone of ensuring the best possible care for life-limited children, young people and their families.

7.4.1 Summary of key points

- Work is ongoing to establish and identify the needs of hospices and how services will need to be designed for optimal delivery.
- Children’s hospices are confronting important challenges in the form of more children living to adulthood, increasing numbers of premature babies with complex health needs, and continuous economic demands.

7.5. Who will/should provide hospice care in the future? (i.e. the state/private sector/voluntary sector or a mix)

Help the Hospices commented:

“Hospices have always worked in partnership with the state, private sector and other members of the voluntary sector to ensure that patients have access to the best care. Help the Hospices supports a mixed economy in the healthcare market. Independent charitable hospices, as major providers of palliative care, are themselves outside of the immediate NHS family. However, we believe that further consideration needs to be given to the

potential destabilising effect of a rapid expansion of alternative providers on existing established services”.

Help the Hospices outlined its concerns that the content of the HSCB covering commissioning does not take into account the specific circumstances and contributions of independent charitable hospices to the health economy. Important questions remain around whether the HSCB will sufficiently support the development of a vibrant health provider market in which partnership working is encouraged. **Help the Hospices** also told this paper:

“...it is important to recognise that hospice care is not simply about providing a health care service. Hospices generate significant amounts of social capital, engaging communities in a number of different ways – be that through fundraising, volunteering or the wider sense of the hospice belonging to the community. Hospice care receives overwhelming public support in the UK, a recent survey showed more than 80% of people believe everyone with a terminal illness should have the right to receive hospice care”.

Children’s Hospices UK commented:

“Services are undoubtedly best delivered when children’s hospices work in partnership with NHS and social care professionals. In addition, they are best funded through a mix of voluntary and state funding. Where they provide core services which the state would otherwise need to provide and free up capacity in the NHS, they should receive statutory funding, in order to be sustainable in the long term. Voluntary sector funding allows children’s hospices to be flexible and innovative enough to meet the demands of care for children and families and to provide additional or enhanced services which the state is unable to provide, but upon which families rely.

Children’s hospices, like hospices for adults, also benefit from significant numbers of volunteers, undertaking important roles across the service, without whom the hospice could not function. This important social capital is a critical element of the continued success of the hospice movement, cited recently by the Prime Minister as an excellent example of a ‘Big Society’. Continuing to strengthen this volunteering is a crucial part of the development of hospices, and the communities they serve”.

7.5.1 Summary of key points

- A mix of service provision is highly desirable and partnerships with the NHS.
- The hospice movement is a “Big Society” already in action and thus strengthen opportunities for people to volunteer is essential.

7.6. Are there international examples of best practice the UK Government should consider and if so what does this entail?

On the issue of international examples of best practice, **Help the Hospices** commented:

“Hospice and palliative care has developed using different models around the world. It has grown responding to varying needs and contexts and is at very different stages of development around the world. There are lessons to be learnt from looking at examples of best practice abroad, particularly in provision in HIV/AIDS and TB.

The Palliative Care Funding Review used the Australian model of palliative care funding as a basis for some of its recommendations published earlier this summer. It remains to be seen if the Coalition Government will wholly adopt the recommendations but the commitment in the Programme for Government would lead to the first funding system of its type in the world”.

A recent study commissioned by Worldwide Palliative Care Alliance and undertaken by the International Observatory on End of Life Care highlights the different stages of development of hospice and palliative care worldwide. 136 of the world’s 234 countries (58%) now have one or more hospice-palliative care services established – an increase of 21 countries (+9%) from 2006. A regional analysis of palliative care development between 2006 and 2011 indicates that the most significant gains have been made in Africa. A significant number of countries continue to have no hospice-palliative care provision and global development may best be described as ‘patchy’”.

NCPC told this paper:

“The 2030 Vision we are developing is currently looking at examples of how innovative housing planning and design can better support older people and those approaching the end of life. Examples of good practice in this regard is found across the world, from rural Japanese retirement villages to America city tower blocks. We’re also interested in new ways of using volunteers to support dying people directly, looking at various models across the world. This forms a part of our thinking in relation to how the government’s idea of a ‘Big Society’ can be delivered in relation to supporting citizens through illness to the end of life”.

Children’s Hospices UK echoed the point about the need to look at examples of best practice to further improve hospice provision:

“Children’s Hospices UK is a founder member of the International Children’s Palliative Care Network (ICPCN) and invests significant time to ensuring the two-way sharing of best practice across the international children’s palliative care sector. Whilst the UK is considered to be at the forefront of children’s palliative care (Helen House in Oxford was the world’s first children’s hospice) we have much to learn from our international colleagues, particularly around the sustainability of services”.

7.6.1 Summary of key points

- The Australian model of funding for palliative care offers particular interest and has formed the basis of some of the recommendations from the Palliative Care Funding Review.
- Learning from international experience is critical to ensure the UK can glean from best practice and shape policy improvements.

7.7. Case Study

In **Box 2**, we provide a case study example of a local hospice.

Box 2: Case Study: St Elizabeth's Hospice, Ipswich

St Elizabeth's Hospice has provided a key service for local people in Suffolk since the late 1970s. It is somewhat unusual in that it facilitates patients and families from both urban and rural communities, serving Ipswich and East and Central Suffolk. Its care provision is split between inpatient services at the hospice, day care services and outreach work in the wider community.

Services

St Elizabeth's first aspect of care provision lies in its inpatient services:

1. 18 inpatient beds (not permanent).
2. For individuals who are in the last days of their life.
3. A way of providing carers with a means to help manage a heavy-workload.

The second lies in day care facilities.

1. Holistic therapy/Supporting patients with other aspects of their terminal illness, i.e. anxiety, stress and pain relief.
2. Occupational therapy, i.e. helping family members through the processes of caring and dying.

The third (and most common) is in outreach to the wider community.

1. Taking workers out to the community to have in house visits. This is especially frequent in rural areas, where patients are much less likely to be able to get to the Hospice. The success of St Elizabeth's has been to be more proactive and less reactive to patient needs, providing a better quality of care.
2. Uses a 24 Hour phone line: 'OneCall', which is the first in the region. This is a service used by patients, their families and clinicians, and has been very successful.

Funding issues

St. Elizabeth has around 1/4 of its money given by the NHS and local PCTs, with the other 3/4 dependent entirely upon private donations and charitable fundraising.

8. The Big Society in Action

The hospice movement resonates strongly with the principles underpinning the Big Society philosophy. Dame Cicely Saunders – often credited as a key leader in the birth of the hospice movement – was herself an individual that recognised the need for better care at an individual's end of life, and was motivated to do something positive in recognition of this consideration. Her initial efforts culminated in the opening of St. Christopher's Hospice in London in 1967. In addition to raising funds for St. Christopher's, she contributed finance of her own and the hospice model has subsequently been copied and mirrored across the world.²⁸

According to Help the Hospices £1.4 million is spent on hospice care every day, and yet only £447,000 of this comes from Government. The financial bottom line alone indicates that there is a vital role for the Big Society in ensuring hospice care is sustainable in the

future, not least given 30% of hospices have reported having their statutory funding reduced as a consequence of Government deficit reduction measures. In a recent speech in Parliament, Stuart Andrew MP recognised the importance of volunteers and the community ownership of hospice care:

*“The hospice movement is an exemplar of the Big Society, and it was my privilege to work in it for more than 12 years. Today, we see hospices throughout the country, and remarkably the vast majority are funded thanks to the generosity not of the Government but of the public. Most draw on the considerable help of thousands of volunteers to care for patients in both hospices and our communities. Such community ownership, and the community’s relationship with its hospices, mean that people are responsive to patients’ needs.”*²⁹

However, as the population ages and a greater burden is placed on hospices, the need for voluntary contributions and volunteer action will inevitably intensify. The Government must therefore recognise these increasing pressures and ensure that tax and regulatory systems – especially those relating to health and safety – are structured to enable those willing to commit finance and personal time to hospices are able to do so, minimising associated hurdles and barriers. Without an accommodating approach, particularly in terms of legislative and regulatory requirements, the hospice movement will struggle to prosper.

The amount of hospice care that occurs outside of direct Government provision is promising. Great examples of community action have been witnessed in some areas across the country, where individuals have come together to paint, clean and help with building projects at a number of hospices. Yet the Government must not be complacent. There is no certainty this will automatically sustain in a linear fashion over the next generation. The UK finances, both public and private, are under intense strain and people are facing increasing pressures on their time. This has potential implications for volunteering and thus the Government must make tax and regulatory systems as responsive as possible to facilitate voluntary action across the hospice movement.

Speaking to this paper, NCPC recognise the need to not just value, but also innovate, where volunteers and society are concerned:

“We’re also interested in new ways of using volunteers to support dying people directly, looking at various models across the world. This forms a part of our thinking in relation to how the government’s idea of a ‘Big Society’ can be delivered in relation to supporting citizens through illness to the end of life.”

The Government and Local Authorities should also look to develop links with businesses, many of which have developed and sophisticated corporate responsibility strategies (CSR). Strengthening links with valued institutions such as local hospices is something that can benefit private sector organisations, whilst providing valuable funds and employee time for hospices.

9. Recommendations

Based on our research, we propose the following key policy recommendations. These are focused around three key areas: 1) the current funding model; 2) the current policy landscape; and 3) evidence and benchmarking.

1) Funding model

- As the NHS Future Forum report emphasised, an ongoing challenge for the delivery of healthcare services is a lack of integrated care and patient choice. This

has particular consequences for the **commissioning** of services and is relevant to hospices. It is therefore vital that there is a **pooling of the health and social care budgets** to ensure integrated patient treatment pathways and to overcome existing deficiencies in commissioning. This would also offer potential funding synergies and help alleviate the funding shortage for social care and hospices.

- Despite the UK's yawning budget deficit, it is important the Government seeks to **increase investment** in the social care area and specifically palliative and end of life care. The UK's **demographic projections** show that there is frankly no alternative given that the **demand pressures** on such services, including hospice care, will continue to significantly increase year on year. Thus, policymakers need to invert the key policy question of "can we afford it?" and ask "can we afford not to do it?".
- To ensure proper financing, we propose the introduction of a **national tariff** for hospice/palliative care based on need to overcome problems of costing and to ensure better funding streams.
- More generally, it is critical that a **new funding system** is introduced, which incentivises good outcomes for patients, irrespective of time and setting. This has important implications for hospices.

2) Policy landscape

- A **Hospice and Social Care Charter** codifying the Government's minimum responsibilities and to outline the DH's plans for hospice care in the future should be introduced. This would help overcome the ambiguity surrounding the Government's commitments and should help with funding and resource planning decisions.
- A review of the **role of the CQC** specifically in relation to hospices should be undertaken. In the light of recent exposes regarding social care, this is an important exercise to reassure the public and to ensure best practice.
- The hospice movement should be utilised as a flagship example of **David Cameron's Big Society**. It is an example of volunteering and is consistent with the Prime Minister's "mission in politics".
- As the population ages and a greater burden is placed on hospices, the need for **voluntary contributions** and **volunteer action** will inevitably intensify. The Government must therefore recognise these increasing pressures and ensure that tax and regulatory systems – especially those relating to **health and safety** – are structured to enable those willing to commit finance and personal time to hospices are able to do so, minimising associated hurdles and barriers.
- To ensure better integration of care and policy planning there should be a **representative** from the hospice movement, or at least the palliative care movement, on **clinical senates**. This is important in the broader context of the Government's NHS reforms. Similarly, it is important local Health and Wellbeing Boards (HWBs) are effectively utilised to optimally coordinate, integrate and support local hospice services as needed.

3) Evidence and benchmarking

- To ensure better monitoring of hospice care, implementation of a **yearly benchmark review** of individual PCT hospice care spending, and CCGs spending moving forward, is important. This would help improve policymaking in the future.
- We strongly recommend the introduction of an **integrated end of life care framework** that explicitly includes hospices.

- We believe that there should be a **NICE Quality Standard** focusing on reducing hospitalisations and promoting home care and community care for patients. There should be a strong emphasis on **local planning** for hospices to support this practical policy objective.
- The Government should commission an **evidence based review** to ascertain the actual **demand for hospice care** given the current lack of data on national and local resource needs.

10. Concluding Thoughts

It is incontrovertible that the UK is confronting a serious “healthcare time bomb” as more and more people require end of life care and people live longer. This is exemplified by the ONS projections, which forecast a significant increase in the UK population in the next 20 years. It is from this crucial perspective that dealing with this challenge is an economic imperative. The basic health economic problem is not going to disappear and will only get evermore acute and taxing. One of the key messages from our paper is the critical need to ensure people spend much less time in hospital and more time in their home, social and/or hospice care. This equals not only sound health policy, that is genuinely patient centric and designed to foster better patient health outcomes, but also sound economic policy. Financial austerity demands as much.

In this paper, we have identified three key areas where we challenge the Government to focus its policy thinking around hospice care. These pertain to 1) the funding model, 2) the broader policy landscape, and 3) evidence and benchmarking. It is axiomatic that there is a significant challenge around how to optimally and sustainably finance end of life care. Yet there are also key challenges around ensuring there is a truly integrated approach that fits with the Government’s NHS reform programme in England and the need to collect, collate and analyse the evidence base to better inform future policies.

More broadly, it is our belief that the hospice movement should be utilised as a flagship example of David Cameron’s Big Society. It is community volunteering at its best. As the population ages and a greater burden is placed on hospices, the need for voluntary contributions and volunteer action will inevitably intensify. The Government must therefore recognise these increasing pressures and ensure that tax and regulatory systems – especially those relating to health and safety – are structured to enable those willing to commit finance and personal time to hospices are able to do so, minimising associated hurdles and barriers.

In the end, we are all mortal and there is no escaping death. Dignity in death is a basic human right and a key policy imperative. Although an instinctively uncomfortable subject, it is important policymakers do not overlook the importance of end of life care of which the hospice movement plays a seminal and critical role. Perhaps politicians are just as afraid of discussing death, and dying, as everybody else. The policy focus has been very much to trust the healthcare professions, and in particular the medical profession to deliver effective end of life and palliative care. For example, the Liverpool care pathway, and an increasing trend in many areas for palliative care doctors to work more closely with local hospices, is a compelling evidence of the healthcare sector taking strong ownership of this issue.

However, the time has undoubtedly come for a more high level policy discussion and debate about the future of palliative care services and how best to support and maximise the role of hospices in this endeavour. It is our hope this paper will go some way to contributing to that discussion and debate, and the Government’s social care and end of life care paper in April 2012.

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10. Ms. Alice Thompson – Office of Dr. Daniel Poulter MP.

Further Information

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Appendix 1: Written Parliamentary Questions (Dr. Dan Poulter MP) and Answers (Paul Burstow MP) on Hospice Care Funding Arrangements and Provision

1. Questions on hospice funding arrangements

Dr Poulter: To ask the Secretary of State for Health (1) what recent discussions he has had with primary care trusts on funding for hospices; and if he will make a statement; [70628];

(2) what guidance he has provided to primary care trusts on funding for hospices; and if he will make a statement; [70629];

(3) what steps his Department is taking to ensure that hospices receive adequate funding; what plans he has for the future of hospice funding; and if he will make a statement; [70631]; and,

(4) what assessment his Department has made of the merits of introducing a national tariff for hospice care; and if he will make a statement. [70632].

Paul Burstow: The Department's "End of Life Care Strategy" (2008) makes clear the responsibilities of the national health service to ensure adequate support for hospices, including through stronger commissioning and adhering to the principles of the "Compact Code of Good Practice". The Department made £286 million additional funding available to help implement the strategy over 2009-10 and 2010-11. Hospices were in a good position to work with the NHS to secure some of this funding to deliver many of the initiatives recommended in the strategy. As part of this funding, the Department made available a £40 million capital budget for hospices in 2010-11 to support improvements to the care environment.

As part of the development of the strategy, a review was undertaken of specialist palliative care spend by primary care trusts (PCTs). This was published alongside the strategy, and provided useful data for PCTs to benchmark their levels of specialist palliative care provision. This exercise has been repeated for 2010-11, and will be published shortly. We have made a commitment to review payment systems to support end of life care, including exploring options for per-patient funding to meet the commitment in the coalition agreement. This work has been taken forward by the independent Palliative Care Funding Review, which reported on 1 July. The recommendations of the review will influence decisions on future funding policies for dedicated palliative care services, whoever provides them. We are currently considering these recommendations in detail and expect to engage with stakeholders on this later this year before running pilots. We have had no recent discussions with, nor provided any guidance to, PCTs specifically on funding for hospices.

2. Question on quality of hospice care provision

Dr Poulter: To ask the Secretary of State for Health what recent assessment he has made of the quality of hospice and palliative care provision in England. [70630]

Paul Burstow: We are committed to improving the quality of all services provided to patients, including those approaching the end of life. The Mandate and National Health

Service Outcomes Framework will drive quality improvement throughout the NHS. The end of life care Quality Standard being developed by the National Institute for Health and Clinical Excellence will set out the evidence-based characteristics of a high quality service for end of life care, which will help commissioners and providers to improve the quality of services. We are commissioning a national survey to ask bereaved relatives about the deceased's experience of care, as well as asking them about their own experience. The survey, which should be complete by March 2012, will inform a new indicator on end of life care within the patient experience domain of the NHS Outcomes Framework, as well as informing local service improvement activity. We have made no recent assessment of the quality of hospice and palliative care provision.

Appendix 2: End of Life Care Strategy

The End of Life Care Strategy was developed by an expert advisory board chaired by Professor Mike Richards, National Cancer Director, and included key stakeholders from statutory health, social care, and third sector organisations, professional and academic organisations.

The strategy comprised 10 objectives:

1. To increase public awareness and discussion of death and dying. This will make it easier for people to discuss their own preferences around end of life care;
2. To ensure that all people are treated with dignity and respect at the end of their lives;
3. To ensure that pain and suffering amongst people approaching the end of life are kept to an absolute minimum with access to skilful symptom management for optimum quality of life;
4. To ensure that all those approaching the end of life have access to physical, psychological, social and spiritual care;
5. To ensure that people's individual needs, priorities and preferences for end of life care are identified, documented, reviewed, respected and acted upon wherever possible;
6. To ensure that the many services people need are well coordinated, so that patients receive seamless care;
7. To ensure that high quality care is provided in the last days of life and after death in all care settings;
8. To ensure that carers are appropriately supported both during a patient's life and into bereavement;
9. To ensure that health and social care professionals at all levels are provided with the necessary education and training to enable them to provide high quality care; and,
10. To ensure that services provide good value for money for the taxpayer.

The strategy formed the backbone of the previous Labour Government's end of life care policy.

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