Future ambitions for hospice care: our mission and our opportunity

The final report of the Commission into the Future of Hospice Care

October 2013
“As the environment of care again threatens to fail too many and too often, hospices will need to unite in their thinking and develop a strong voice individually and collectively.”

Dame Clare Tickell, Chair of the Commission
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How we care for the most vulnerable at the most vulnerable of times is a measure of our compassion as a society and securing this compassion for the future is a vital concern of the Commission. I hope our work will remind all hospice leaders of this mission, persuade them to re-state their ambition and encourage them to grasp opportunities amidst the challenges that lie ahead.

The concern to test hospice care against the challenges, not of this generation of users, but the next, shows foresight. In establishing the Commission, Help the Hospices has demonstrated courage. Its willingness to invite the independent thinking of the Commission deserves recognition. Its ambition to support hospice care for all in a world of increased demand, complexity and financial constraint merits applause.

Two years ago Help the Hospices recognised the need to help hospices understand the way significant shifts in demography and disease are likely to challenge the scale, scope and ethos of palliative and end of life care. Since then a combination of austerity in public finances, the constant reform of health and social care and the development of an emerging market in end of life care, particularly in England, have added to the relevance of the Commission.

The urgency for this work, which was anticipated then, is here now. The development of competition in provision has become clear to see. The pressure on limited public finances dominates current and future thinking. The inability of health and social care institutions and systems to provide consistent, effective and compassionate care, particularly to the elderly, is reprehensible. In short, the timing for the Commission is good and the need to consider the future and the place for hospice care in that future has become unavoidable.

Hospices have a history of innovating and developing new approaches to care in response to an external environment that had failed to understand or respond adequately to people’s needs. As the environment of care again threatens to fail too many and too often, hospices need to unite in their thinking and develop a strong voice individually and collectively. Hospices will need to keep an unrelenting focus on the needs of all those who live with life-shortening illness, their families and their carers and be brave in their response to these needs.

They are well placed to do so. They are intimately connected to people with palliative and end of life care needs and their communities who can offer support. They are advocates for those who may be less visible in society. These characteristics are the foundations for effective influence and practical compassion which have given rise to a most valued brand of care. This must be protected and expanded.

During the two years of the Commission’s work I have met many hospice staff and hospice organisations as well as countless people with a passion for good palliative and end of life care. I want to thank them not only for their honesty, openness, and generosity of opinion but also for the inspiration of their commitment. I hope the rigour and clarity of our call for action can channel their extraordinary energy into shaping a future that protects, sustains and extends the best of care to all who need and deserve it.

In chairing this Commission I am much indebted to Barbara Monroe and my fellow Commissioners for their invaluable help and expertise. I have also been magnificently supported by the Commission Support Team, Heather Richardson, Steve Dewar and Laura Hamblin. Their calm professionalism, hard work and ability to take ideas, passion and debate and distil them into the tangible have been exemplary.

Dame Clare Tickell
Chair, Commission into the Future of Hospice Care
Modern hospice care was developed in the sixties as a response to appalling deficits in the care of those coming to the end of their lives and the neglect of those close to them. Nearly fifty years later the challenges persist and grow. In recent years government inquiries and media documentaries have reported systemic and shameful lapses in care. Hospices have a unique opportunity as well as a responsibility to step up once again and play their part in achieving a new transformation. In its first flourishing hospice care brought creativity, confidence and compassion to new services that transformed the lives and the deaths of many. Hospices should again work to put right an absence of care and an ignorance of need.

Our commitment to the idea that everyone gets the care they deserve when illness can no longer be cured, has a significant implication. Each hospice that welcomes this aspiration must also accept the consequent obligation to consider how best to use their resources as part of the system of care that will need to be deployed. To obtain change on the scale required means working in partnerships with each other and with local providers of health and social care.

Hospices are uniquely placed to lead this new revolution. They are rooted in their local communities connecting to all those that use or have used the service, their families and carers, their volunteers and their supporters. Hospices can and should use these vital connections to ensure a renewed and unrelenting focus on the challenge, working with local people to help reach and be ready for the growing numbers of people who will need care and support to live with life-shortening illness.

Hospices have many attributes that make them fit for the task ahead. They are well positioned to be creative in expanding the contribution of the volunteers who will be essential to ensuring that care is expertly delivered with only a discriminating use of what will be scarce clinical resources. The best hospices have a short ‘idea to action’ time that releases innovation quickly. Hospices have unique resources for effective training, drawing on the expertise of those who practice with confidence the skills that they seek to disseminate. Hospices have well trained multi-professional teams, accustomed to working together, who can support people with complex needs and fashion the most bespoke care for the most vulnerable.

However, to partner, educate, influence and disseminate good care will mean challenging some of our comfortable and sometimes complacent orthodoxies. We must collect and understand data to build evidence about outcomes; developing better research partnerships so that we can articulate to others what support is most effective, for whom, at what cost. We should examine our practice and our workforce to ensure that expensive expertise is used to greatest effect and where it is most needed. We must recognise that this will need greater flexibility and a willingness to embrace new technologies.

We will also need to think about how we work with others. It is through our place in this wider system of care that we will find ways to deliver services to populations rather than reaching only those individuals who find their way to us. We must develop new ways of doing things that are less demanding of resources and do so with a realistic eye on the need to expand our delivery of care so that it can work at scale and be replicable by others. We need to be fierce with ourselves and others about ensuring access, reaching out to people who need us and responding robustly to inequalities. We have to be the champions of those in need and hold fast to the disadvantaged, rather than defending our history and finding ourselves ossified and irrelevant.
Meeting the challenges of an ageing population with an increased incidence of frailty and dementia, as well as the needs of a younger population in transition from children to adult services, will demand new ways of working with those who use our services and their carers. It will also mean working harder to understand the preoccupations and problems of the NHS, care homes and local authorities: it may mean criticising less and learning more.

As well as our mantras we must remember what matters. A home death is not a guarantee of a good death. As we support the drive to achieve effective care in the community, we must not neglect the support of care in beds elsewhere—in hospitals, care homes and supported housing. Our endless deliberations about whether we are specialist or generalist are getting in the way of purposeful collaborations. The reality is that most organisations do a bit of both; and what matters is working together to achieve an effective response to need. So when some hospices deliver personal social care services and care coordination centres, what matters is the achieving of improvement both in the experience and the quality of care.

Hospices need to work harder at finding common cause and the common platform on which to use their influence. There is power here that we can use to benefit patients and families. We know effective training can change care for the better as well as extend our reach and influence. We know that education is a central part of many hospice strategies. To take advantage of new possibilities in the market for education we should be working together to develop common products and establish consortia large enough to compete and to win the resources that we need. Hospice fundraising would similarly benefit from a reduction in our competitive instincts and the development of coherent and shared messages alongside common and co-ordinated efforts.

When it comes to preparing for the future, each hospice will need to make individual decisions based on their environment, their experience and their capacity to change themselves as well as lead the change they need to see in others. However, in all that we do, we must be ready to take creative and calculated risks, particularly in developing services and in forging vital partnerships with the people we care for and their families and carers, as well as the organisations and professionals who provide the care with which our own services must connect and dovetail.

If we wait for a fair and level playing field the critical moment for change will pass us by. We can’t wait for commissioners to issue invitations or potential partners to knock on our door. We have to be prepared to go more than half way to engage others in our cause. We must not hesitate waiting for the respect we think we deserve; we must act with urgency, responsibility, generosity and optimism—attributes that are already in our DNA. The prize is worth it and the yardstick is clear: what would we want for ourselves and our families and friends when facing life-shortening illness and how do we extend that to all?

Professor Dame Barbara Monroe, Vice chair, Commission into the Future of Hospice Care
Executive summary

The aim of the Commission into the Future of Hospice Care is to help hospices look ahead so they can anticipate and meet the changing and growing needs of the communities they serve.

Set up by Help the Hospices in November 2011, the Commission has spent two years bringing together people, organisations and research evidence to provide this help. Along the way the Commission has also published many working papers so that others can follow the discussion. These publications describe the future for hospice care and identify the challenges and the opportunities for hospices to shape a system of palliative and end of life care that might match future need.

The Commission is ambitious for the future of hospice care. It imagines a future where hospices work in partnership so that high quality palliative and end of life care might be provided to all, across the many different settings where it is needed. It is committed to a future where hospice care is dynamic, innovative and responsive, and hospices are constantly adapting to meet the needs of people with life-shortening illness and their relatives and family carers. It wants a future where hospice care helps people cope with the reality of dying, death and bereavement, and always does so with confident expertise.

This future builds upon the history and mission of the hospice movement, making the most of hospices’ innovative, influential and pioneering nature. It is a future where hospice care can be shaped by systematic knowledge of future need and supported by robust evidence of effectiveness. It is a future in which hospice care dovetails with the NHS, local authorities, and care homes; as well as being shaped by the communities that each hospice seeks to serve.

The Commission believes that there is a compelling case for hospices to adapt and re-invent their contribution to care in a way that recognises the challenges ahead but never shirks from the ambition to find ways of extending care, using influence and identifying new opportunities to respond to need. The report illustrates the way in which the demand for palliative and end of life care will rise. It also highlights the growing vulnerability of those who will need care, as well as the increasing complexity of their needs.

As hospices strive to do their best, the Commission acknowledges a background of increasing public expectations for hospice care. The report identifies and illustrates a range of perceptions of hospice care, some of which may need to be changed if hospices are to flourish, as they should. The Commission also understands the difficulties hospices face with constrained and uncertain income, as well as the need for English hospices in particular to operate in a new and more competitive commissioning environment.

However, despite these difficulties the Commission is optimistic that with adaptation can come opportunity and success. The Commission has identified key principles that hospices might use to guide and drive this process of adaptation. These include a responsibility to assess future needs for palliative and end of life care on a population basis, and to be active and outward-looking in developing the new partnerships and understandings that might enable these needs to be met. Hospices should seek to reach more people both through their care and their influence on other local health and social care services. Working as good partners, campaigners and educators across local health and care systems can enable hospices to make a difference on a larger scale.
Most importantly, hospices should commit to innovate and evaluate those new approaches that have the potential to extend the practice and ethos of their care. Hospices should make their care more accessible, around the clock and throughout the week, as well as doing more to reach out to those who have not traditionally used their services. The Commission suggests hospices consider the development of their workforce so that it can deliver the different portfolio of services that the future will demand. In addition, hospices should invest in new ways to raise money and achieve greater efficiency. Lastly, the Commission suggests strong engagement on the part of hospices with the national organisations that exist to support their work.

The Commission recognises that hospices will want to adapt these principles locally. It proposes a checklist of questions designed to ensure that the needs of local communities are put at the heart of hospice decisions over the shape and organisation of future services.

Finally, the Commission has identified five key steps that hospices might take to ensure they are fit for the future, able to achieve maximum impact and well placed to deliver the best outcomes for those with palliative and end of life care needs – now and in the future. These steps are:

1. Prepare for significant change in the context of palliative and end of life care.
2. Strengthen understanding of the contribution of hospice care.
3. Establish hospice care as a solution to future challenges in palliative and end of life care.
4. Strengthen the connection between hospices and their local health and social care systems and their local communities.
5. Strengthen the leadership of hospice care.

Taking these steps will require action by hospice boards, staff and volunteers as well as organisations supporting hospice care, commissioners, the NHS, national and local government, and academic centres. All play a part in creating the environment in which hospice care can flourish; the report contains recommendations for all of them. By taking action the Commission believes hospices, their national organisations and others can make a significant contribution to meeting the future palliative and end of life care needs of people living across the United Kingdom.
Help the Hospices established the Commission into the Future of Hospice Care in November 2011 to help hospices meet the changing and growing needs of the communities they serve.

The Commission was established in response to the publication of the 2010 Demos report Dying for Change. This report proposed radical changes to improve care for anyone facing the end of life, their relatives and family carers.

The Commission has made a response that is equally as radical and which positions hospices and the care that they provide as a vital part of the solution to the challenges so well described by the Demos report. It has been independent in its thinking and has involved a diverse group of members. Its efforts have been focused on enabling hospices and others to make plans for the future of hospice care that will ensure a positive experience for people who face life-limiting and life-threatening conditions (hereafter referred to as life-shortening conditions), their relatives and family carers.

Led by Dame Clare Tickell as chair, and Dame Barbara Monroe as its vice-chair, the Commission has drawn together a wide range of perspectives on hospice, palliative and end of life care. Details of the members of the Commission are given in Appendix 2. Its focus has been the opportunities and challenges facing hospice care in 10–15 years time and the actions needed in the next two to three years by hospices and others, in order that they can prepare for the future with confidence.

It has, right from the start, tried to engage with anyone with a view about the future of hospice care. To that end it has hosted many different events, spoken to many individuals and organisations and encouraged feedback and reflection on its work. An overview of the Commission’s outputs is provided overleaf.

The Commission has captured, published and shared the learning that underpins this report during the lifetime of its work. The overview, overleaf, provides details of these reports and where they can be found. However, the conclusions and the recommendations of this report are those of the Commissioners alone.

(*) The term ‘life-shortening’ encompasses conditions that are both life-limiting as experienced by many children who require palliative care and life-threatening as experienced by many adults who need palliative care.
The Commission undertook a wide range of work. During the two years of the inquiry into the future of hospice care the Commission sought to publish and disseminate all reports and working papers through its website. All of this material can be viewed and downloaded from www.helpthehospices.org.uk/commission.

Understanding the unique contribution of hospice care

The Commission sought views from users of hospice care regarding their experience of hospice care. Over 700 users responded. Their views are described in a publication called Learning more. These views were discussed at an event that brought together users of hospice care and members of the public with an interest in its future. Participants worked together to develop recommendations for the Commission to consider. These are described in a publication: What would it take to ensure the best care for everyone at the end of life?

Identifying future needs and preferences for hospice care

The Cicely Saunders Institute was asked by the Commission to consider the nature and scale of future needs for hospice care. This work has been published in a Commission report: Current and future needs for hospice care: an evidence-based report.

Identifying operating principles that will guide the development of hospice care in the future

Members of the Commission and critical thinkers from health, social and end of life care came together to consider operating principles that should guide the future development of hospice services. These are described in a publication: Preparing for the future: key operating principles.

Identifying new models and approaches to hospice care

Following the publication describing current and future needs for hospice care, a workshop with hospices was hosted by the Commission to consider its implications and identify future priorities and opportunities for hospices. This work was published as a working paper entitled: Future needs and preferences for hospice care: challenges and opportunities for hospices.

The work led to a call for further thought pieces and reports – Supporting family carers, The role of hospices in supporting people with a diagnosis of dementia in the future and The role of hospices in supporting young people from children’s to adult service.

Establishing the workforce required to deliver hospice care in the future

The Commission hosted a national conference to consider the future role of volunteers in enabling hospices to meet the challenges of the future. This work was the first working paper of the Commission: Volunteers: vital to the future of hospice care.

Working with Skills for Health a subsequent event engaged a wide range of hospice staff to help consider the skills and roles required in the workforce delivering hospice care in the future. This event has also been published as a working paper of the Commission: Working towards a hospice workforce that is fit for the future.
In response to repeated enquiries, two opinion pieces were also commissioned: *Maximising the contribution of the palliative medicine consultant to meet the future opportunities for hospice care* (12) and *The future of clinical nurse specialists delivering end of life care in the community.* (13)

**Exploring new funding and income generating opportunities for hospices**

The Commission sought the help of nfpSynergy, a research consultancy working in the not for profit sector to consider ways in which hospices could generate income in the future. Their recommendations are the result of a survey, interviews and an event which engaged hospices in thinking about future opportunities and challenges. This work is described in a report entitled: *Strength in numbers: how independent hospices can raise more income from voluntary and donated sources to support their work.* (14)

**Supporting the development of new partnerships and collaborations**

The Commission, through a consultancy called Saffron Steer, has developed a practical toolkit to assist hospices to identify promising partnerships that may enable hospices to extend and develop hospice care. *The Collaboration Toolkit* (15) was introduced and developed in partnership with over 20 hospices at an event to pilot implementation. The toolkit is available on the Commission website.

**Exploring the future of education and training provided by hospices**

In partnership with the National Association of Palliative Care Educators, the Commission sought the help of educators and other providers of end of life education and training to identify future opportunities and challenges for hospice delivered education and training. Their learning and reflections on the day with some recommendations for the future are captured in a report: *The future of hospice education and training.* (16)

**Considering the role of hospices in future research to inform the development of end of life care**

The Commission sought the expertise of the team based in the End of Life Observatory at the University of Lancaster to consider what role hospices might play in future research. Their recommendations are described in the report: *Research in palliative care: can hospices afford not to be involved?* (17)

The Commission has also invited and captured personal and expert views from a wide range of individuals and institutions about the future of hospice care. Much of this evidence is also available on the Commission website.

In addition the Commission sought opportunities to engage with a wide variety of organisations and groups with a stake in hospice care, including: the All Ireland Institute of Hospice and Palliative Care, The Scottish Hospice Forum, Together for Short Lives, The Association of Day Care Leaders, the Association of Palliative Medicine, the Executive Clinical Leads in Hospice and Palliative Care, the Association of Volunteer Services Managers, the National End of Life Care Programme Facilitators, Hospices Cymru, Marie Cure Cancer Care, Sue Ryder and many independent and some NHS hospices.
2. Introduction to the report

Why now?

The Commission’s report is timely, as hospices become increasing aware of current and future challenges. These include rapid demographic change and changes in the patterns of life-shortening illness. Increasing financial constraints and uncertainty about future funding also increase the vulnerability of hospices and the services that they provide.

During the lifetime of the Commission these challenges have already become clearer and more acute. Commission members have seen English Clinical Commissioning Groups put elements of end of life care out to tender. They have also witnessed the private sector and alternative NHS providers compete and win tenders against hospices.

In addition they have seen government departments and health policymakers wake up to the stark implications of our ageing population. They are aware that some hospices are already being asked to make efficiency savings or accept reduced levels of statutory income. These are examples of pressures that are only likely to increase in the future.

The Commission is clear that hospices need to begin to adapt now to respond to these challenges. Unless hospices change they will see their contribution diminish and their relevance reduce. This would be a tragedy.

Furthermore, there are significant opportunities to be grasped. The National End of Life Care Strategy for England will shortly be undergoing a refresh, following its first five years. There are multiple other national reports identifying the need for improvement in the care for people at the end of life and increasing calls for integrated health and social care.

The next decade could be the age of hospice care if leaders in the sector recognise and take hold of the opportunities the future presents.

This report is designed to help hospices and all those with an interest in hospice care to secure the future of hospice care and most importantly ensure that all those facing the end of life, including relatives and family carers, receive the care that they need.

The Commission hopes that the report will help hospices make positive, informed decisions about how they operate in the future. It hopes that the report will enable hospices to take control of their destiny and find new ways of ensuring that hospice care can match future needs for palliative and end of life care. The Commission is keen that other players in palliative and end of life care recognise the value of hospice care in supporting people who face the end of life and help to maximise their contribution. New partnerships between hospices, and a whole host of organisations, will be vital to getting palliative and end of life care right in the future and all are urged to consider new and improved ways of working together.
This report describes the learning of the Commission over the last two years.

The report begins with a description of hospice care (Section 4). It has chosen to describe hospice care in an aspirational way, drawing on the historic strengths that have secured its success.

The report then makes a case for change (Section 5) identifying the challenges and opportunities facing hospices in the future. This section presents important perceptions of hospice care that hospices may need to consider in their plans for the future.

If hospices are to make the most of new opportunities and are to thrive in a challenging future, the Commission believes that they will have to adapt. To guide this process, the Commission suggests some key principles that it hopes hospices will adopt (Section 6).

While it is confident that these are relevant for all hospices to consider, the Commission recognises that plans for adaptation will need to reflect local capacity, appetite and opportunity. For this reason the Commission asks questions that hospices may want to consider as they reflect on their local context. A checklist to help hospices examine their local situation is offered in Appendix 1.

Finally, the Commission has identified five steps that are required to ensure hospices are fit for the future and can achieve maximum impact and outcomes for their users (section 7). These steps are:

1. Prepare for significant change in the context of palliative and end of life care.
2. Strengthen understanding of the contribution of hospice care.
3. Establish hospice care as a solution to future challenges in palliative and end of life care.
4. Strengthen the connection between hospices and their local health and social care systems and their local communities.
5. Strengthen the leadership of hospice care.

There are recommendations in relation to each step. Many of them are directed towards hospices. The Commission would advise boards of trustees (or alternative governing bodies) to review the strategy of their hospice in the light of these recommendations. Similarly, senior management teams of hospices will want to consider them in their future business plans.

Recommendations are also offered to other stakeholders including national organisations supporting hospice care, commissioners, health and wellbeing boards, the NHS, and national organisations overseeing health related education and training. The Commission asks these bodies to consider these recommendations.

The Commission has sought to be inclusive in its approach, identifying the opportunities and challenges facing adult and children’s hospices, those that are independent and those based in the NHS. While there may be differences in how the recommendations of the report are implemented, the Commission urges all players within the hospice sector to respond to those parts with which they find resonance.
Hospice care is palliative and end of life care provided by hospices for people of all ages with life-shortening illnesses, their relatives and family carers. It is delivered in partnership with others including local communities, so as to reach out to more of those who could benefit from it, and into the many different settings where care is needed. It is a dynamic and innovative response by hospices, which are constantly adapting to meet the palliative and end of life care needs of the communities they serve.

Hospice care is about dying, death and bereavement and about living with these realities

Hospice care helps and supports people who are living with life-shortening conditions or who face the processes of dying, death and bereavement. The care provided by hospices encompasses a wide range of help and support and may extend to people who live with life-shortening conditions for many years. It is focused on helping individuals, families and communities through these most difficult challenges. Maintaining this focus is a significant strength of hospice care.

Hospice care takes many forms, adapting to the trajectories and consequences of different life-shortening conditions, the circumstances and age of those affected and how near they are to death. Hospice care exists to ensure the best possible experience for individuals with a life-shortening condition, their families and family carers.

Feedback received by the Commission from users of hospice care indicates that there are unique characteristics of hospice care, which contribute to a positive experience. They include the highly individualised and compassionate nature of care; its focus on the multifaceted needs of families, friends and family carers alongside those of the person who is unwell; and its accessibility and sustained presence throughout the experience of illness.

At a time when we felt completely alone and scared, the hospice helped us through our darkest times; providing support, comfort and reassurance. It also set up our support network in the community – invaluable.

Hospice care embraces family carers and recognises their vital and indispensable role in caring for someone affected by a life-shortening conditions. It seeks to support them and works in partnership with them, recognising their important and often expert contribution.

Hospice care is innovative

Hospices were a response to the gaps in the provision of care for people at the end of their lives. They were led by individuals and community groups who were pioneering and visionary in nature and driven to ensure that the experience of individuals who were dying or bereaved was as positive as possible. Hospices are part of a movement that has produced radical innovations in institutions, services and beliefs. The Commission accepts the argument that such innovation is only possible because modern hospices developed outside the NHS and were therefore free to develop their own approach to care. This helps explain the importance that many hospices place on their independent status.

Hospice care is integrated

The Commission believes that hospices must continue to use their independence of spirit and creativity to challenge and campaign for high-quality care in response to the unmet needs in people who are living with life-shortening conditions.
conditions, or who are bereaved. This independence is a vital strength that hospices can use to design new ways of caring and to advocate on behalf of those whose needs may not be met. The independence of many hospices gives them the chance to fulfil these roles in a way that can be difficult for many other organisations.

However, alongside this independence of spirit and approach, hospices must also be highly integrated in their delivery of care. Being integrated means combining efforts with the NHS, local authorities, care homes and other providers in order to work together to improve care for all who have life-shortening conditions wherever they are. While independence provides the freedom to act or advocate for improvement, a strong working connection with local services creates important practical opportunities to influence plans and decisions, to shape the care of others and to be an authoritative voice on palliative and end of life care. It also provides an opportunity for hospices to listen and learn from others.

**Hospice care is led by people’s needs**

Hospices are recognised by their mission to improve people’s experiences of dying, death, and bereavement. To do so they must constantly consider the changing needs of the communities they serve, put these needs at the heart of new approaches to care and adapt accordingly. Over the last four decades hospice care has constantly evolved to embrace new groups and their various needs. It has extended from a largely building based service to one delivered in a variety of settings including home, care homes, prisons, sheltered housing and hospitals. The profile of its workforce has changed too, embracing new professionals and new roles for its staff and volunteers. The care of the individuals receiving hospice care is led by their needs. To that end it is highly personalised and reviewed on a regular basis to ensure an approach that acknowledges changing needs. This attribute of ongoing adaptability is characteristic of hospice care and it is one of its strengths.

**Hospice care is expert in nature**

All those who work in hospices have expert skills and knowledge. Their expertise comes from working together as a team constantly assessing and responding to the needs of people who require palliative and end of life care, their relatives and their family carers. As part of their role in the team each person also plays a part in teaching others, using, reflecting upon and sharing their extensive experience in delivering palliative and end of life care day in and day out. This approach enables all to constantly refresh their knowledge and hone their skills.

The expertise of hospices allows them to address the most complex of needs in their patients or their families. Importantly, this complexity extends beyond clinical symptoms to encompass much else that is vital to living well including social, emotional, spiritual, and financial needs. The very best of hospice care considers these aspects of wellbeing and tailors the care that it provides to match the individual.

**Hospice care is influential in the quality of care provided by others**

Hospices have a long history of influencing care beyond that which they provide themselves. Indeed the vision of Cicely Saunders when she founded St Christopher’s Hospice was to create a place in which the multiple activities of compassionate care, good symptom management, teaching and research would thrive.

Hospices that are fit for the future will have an ambition to develop and support professionals and other carers involved in palliative and end of life care, so that they are competent and feel confident to deliver high-quality care wherever they practise. They will draw on their expert skills to deliver education and training and will be research active in order to contribute to, and build upon a strong evidence base for hospice care.
Hospices influence in other ways too. They have an important role in campaigning for improved care and support for people with life-shortening conditions, their families and carers. They also get involved in guiding local policy development and plans for service improvement drawing on their expertise, experience and connections with local communities and individuals.

**Hospice care engages with the community**

Help the Hospices has described hospice care as ‘community engaged palliative and end of life care in all settings for patients, families and carers.’

The Commission endorses this definition, recognising the distinctive nature of the connection that hospices have with their local communities to shape, fund and deliver its care.

Hospice care, provided in partnership with communities, is based on a shared vision of what hospice care can offer local people. Hospices and the communities that they serve often work together, through the involvement of local people on hospice boards and through joint efforts to design services that meet local needs or respond to local problems and local circumstances. Hospices benefit hugely from their relationship with local volunteers, who often provide practical help, care and assistance with fundraising. These relationships are reciprocal, and by being engaged with the hospice, communities become increasingly informed, capable and confident in helping those who are living with serious life-shortening conditions.

**Hospice care is pioneering**

It is appropriate that a movement established to redress the poor experience of end of life care through innovation still emphasises the aspiration to deliver care in all settings and to reach all those who need it by a continued investment in brave and creative activities. These are striking ambitions, particularly given the current and future challenges facing hospices. However, innovation and tenacity remain at the heart of hospice care and are the vital characteristics of an approach that is capable of thriving and continuing to adapt to the needs of a changing world.

**Hospice care is provided in partnership with others**

Hospices are not the only providers of palliative and end of life care. Indeed, in many areas of the country, they currently only deliver direct care to a minority of people living with life-shortening illnesses.

If, despite the realities of constrained resources, hospices are going to improve the experience for anyone coping with life-shortening illness, they will have to build partnerships. Through these partnerships hospices can enable, inform, encourage and ensure the delivery of high-quality palliative and end of life care by others as well as by themselves.

In working with others, including the NHS and providers of social care, hospices can find new ways to innovate, influence, speak up and share their expertise. They can help to collaboratively create local solutions and help empower others to provide the quality of palliative and end of life care that they would want available to all those living in their locality. It is a responsibility of hospices to engage with others and use their expertise to influence the care that others can give.

By working in partnership, hospices augment their own skills and services to meet the needs of those in their care. They can learn much from colleagues in other specialities and can provide more holistic and seamless care when they work closely together to support individuals with multiple needs.
The Commission is keen to emphasise the important role of others delivering palliative and end of life care. Indeed its concern is to encourage hospices to work with others including the NHS, local authorities and care homes, who also bring expertise to end of life care. It does not wish its interest in hospices and in hospice care to diminish, in any way, the contribution of other providers.
5. Why hospices will need to change

Making the case
The Commission believes that there is a compelling case for change on the part of hospices, if they are to live up to the Commission’s ambitious vision for future hospice care.

This case describes the challenging context in which hospices will be required to operate in the future. It considers the care that will be required, the resources available to respond, and the increasingly competitive and uncertain environment. The case for change is also informed by feedback from a variety of stakeholders regarding their views and experiences of the work of hospices. These perceptions are important to consider, either as a foundation upon which to build, or as areas for redress.

The challenges and opportunities in the future are explored separately in more detail below. However, when considered together, they leave the Commission convinced that without change, hospices risk future irrelevance.

Rising levels of need for palliative care
The Commission heard many hospices describe increasing levels of unmet need for palliative and end of life care often as a result of growing financial constraints in the health and social care system.

However, this is likely to be just the start of a dramatic increase in the need for care. Research by the Cicely Saunders Institute on behalf of the Commission makes clear that the number of people dying each year is set to rise from 2016 and that this rise will be steep. In England alone, the number will increase by over 4,000 a year between 2020 and 2025 and by over 8000 a year between 2030 and 2035. (4)

Our society is ageing and the consequences are significant. In 2010, 1.4 million people were aged 85 or older and deaths in this group represented 36% of all deaths. By 2035, this figure will be 3.5 million and deaths in the over 85s will represent half of all deaths in the UK. Meeting the needs in this older group of people will be challenging, many will be living with different health problems and suffering from chronic illnesses and increasing frailty. This situation may be compounded by socio-economic inequalities and significant levels of poverty in older age; indeed we recognise that deprivation is in itself a key risk factor for ill health. (21,22,23)

In addition, as older people experience the loss of their partner and as fewer family carers and relatives are able to remain at home in caring roles many will find themselves living alone, with reduced access to care.

At the other end of the spectrum there is evidence that the number of young adults living with life-limiting conditions is also on the increase. The Commission noted evidence of growing numbers of young people with highly complex needs moving from children’s services into adult care. (9) A review of an English Hospital Episode Statistics dataset (2000/2001–2009/2010) indicates that the prevalence of life-limiting conditions in children in 2010 was double the previously reported estimates. The largest increase in numbers was for 16–19 year olds and this was directly related to the increasing survival of people in this age group living with life-limiting conditions. (23) These young people need care from both children’s and adult hospices in order to help them to make a good transition into adulthood and to enjoy a good quality of life despite their challenging conditions.

Without doubt, there will be a greater need for more care at the end of life in the future. The Commission recognises that good palliative symptom management will be a common requirement for many adults with life-shortening conditions, regardless of the condition from which they suffer. Evidence provided to the Commission also indicates that a significant proportion of adults with life-shortening conditions would want to die in hospices, particularly as they get older, but on the basis of current provision, few of them are likely to
do so, particularly if they are very old or dying from a condition other than cancer.\textsuperscript{[4]} The work of the Cicely Saunders Institute tells us that ‘access to hospice care is still neither sufficient nor equal for people with different illnesses, ages or ethnicity’ and with the Black, Asian and minority ethnic population of the UK at 15% there is a clear need for hospices to lead the way in reaching out to all these communities.\textsuperscript{[4]}

Feedback to the Commission by members of the general public describes a mixed experience regarding access to services. It heard stories of people who had wanted hospice care for a member of their family, but who were unable to access this care. They described opaque and inconsistent referral criteria and hesitation or refusal by hospices on the grounds of a non-cancer diagnosis as reasons for this failure.\textsuperscript{[3]}

If you don’t have cancer, you’re almost treated as a second class citizen.\textsuperscript{[3]}

The test for hospices will be whether they can develop the greater reach, accessibility and complexity of service required to meet the anticipated needs of many different groups of people who would benefit from hospice care in the future.

**Increasing vulnerability and complexity**

Adult hospices have historically advocated and provided care for those they perceive to be most vulnerable or to be living with complex or multiple symptoms at the end of their lives. Such vulnerability and complexity is set to rise.

In terms of vulnerability, family structures are predicted to become less cohesive and families will have less time or resources to enable them to take on a share of the caring burden for those living with the end stages of life-shortening illness. In 1961 only 12% of English households were single person households but by 2033, 11.3 million people are predicted to be living on their own – a rise to 40% of all households. And this trend will apply across age groups with the number of people over 85 living on their own set to grow in England from the current level of half a million to 1.4 million by 2032.\textsuperscript{[24]}

The complexity of care facing hospices in the future is a consequence of the chronic nature of conditions from which people will be dying and the fact that many individuals will be living with multiple illnesses. Older age is closely linked with the development of cancer, dementia and cognitive impairment and for this reason the number of people with such conditions is on the increase. In 10 years’ time the number of deaths caused by cancer, (an increasingly chronic condition) is expected to increase by 30% for men and 12% for women.

The increase in the number of people with dementia is also dramatic. There are currently 800,000 people with dementia in the UK. It is projected that there will be 1,000,000 people with dementia in 2021, rising to 1,700,000 people with dementia in 2051.\textsuperscript{[25]} The Commission heard a passionate and convincing call for the engagement of hospices in end of life care for people with this condition given its high symptom and disability burdens and the challenges faced by carers of people with dementia.\textsuperscript{[8]} Given that the majority of people with dementia who require comprehensive health and social care live in care homes, there is a requirement that hospices work in this setting alongside care home staff.\textsuperscript{[8]}

Delivering care in response to the complex and multiple needs of people facing the end of life in the future will be challenging for all involved, including hospices. At its best, care will need to be highly integrated across health and social care systems, and be proactive and preventative as well as responsive in nature. The Commission noted the value of such an approach for frail older people in particular.\textsuperscript{[6]}
The Commission is particularly concerned to see work to support family carers improved in the future. Staff working in hospices have confirmed that this is an area of work in which they lack confidence. Research evidence presented to the Commission confirms that family carers, who remain vital in the care of people who are living with, or dying from a life-shortening condition, face many challenges of their own. The same report indicates that hospices are well placed to help them manage better through compassionate, flexible and respectful care which recognises that family carers are experts as well as in need of care themselves. It urges hospices to provide a variety of services to enable family carers to be sustained in their role, including those provided by volunteers and calls for more research in this under-developed aspect of hospice care.

New models of care are needed to respond to increasing and changing demands for palliative and end of life care. Innovation is vital to establish new ways of delivering care to more people, in different settings and across services. Where possible such innovation must be evidence-based. Where there is no evidence base, then rigorous evaluation of these innovations is essential to know about their effectiveness and cost-effectiveness. Without such innovation and related evaluation there is a risk of increasingly fragmented care and under-resourced approaches to end of life care in the future. There is much here that will require hospices to use their ability to campaign as well as provide. Hospices will need to play a significant role in ensuring system wide awareness of the inevitably increasing complexity of conditions suffered by the dying, many of whom will be living with chronic illness and with multiple co-morbidities including dementia.

Considering and organising a response to the challenges of meeting changing and increasingly complex needs can be uncomfortable for hospices, triggering concerns about how to make limited resources stretch further or how to re-focus resources on new and significant needs.

Increasing and unmet public expectations

The Commission believes that users of health and social care in the future are likely to have greater expectations of these services. Hospices describe increasingly demanding users in their services already, a trend that is likely to continue particularly as more members of the 1960’s baby boom generation need care towards the end of their lives.

One expectation is around choice. Early work by the Commission confirmed the importance of ensuring choice for people with life-shortening conditions with due attention to those dying of conditions other than cancer and those who are older. Research reveals that most people would like to die at home and a substantial group of people would like to die in an inpatient hospice, particularly as they get older. This is in part because they see hospice care as the gold standard. Mortality data suggests that the majority of people don’t die in their preferred place of choice; a challenge which hospices may wish to address in a variety of ways, including support for advance care plans, better coordinated care, improved communication between providers and new and flexible approaches to care, including a new look at ways to use hospice beds. They may also wish to address this by influencing the quality of palliative and end of life care that people receive in other care settings through partnership working.

The issue of choice extends beyond place of care and death. The Commission heard frustration on the part of some users of hospice care who wanted increased access to this care, in this case day hospice, but felt restricted by the service in the number of days they could attend a week. In response to an explanation of limited resources they confirmed an interest to enter into a different kind of contract with the hospice, within which they would offer some payment towards the cost of the service to enable them to attend more often. The Commission suggests that further conversations are had with members of the general public on this important issue.
The Commission received requests from members of the general public seeking increased access to hospice care. They asked for more services for older people, and for those with conditions other than cancer.

I do not want to hear he was lucky “he had cancer so he got hospice care” any more.

We need hospices for the elderly not necessarily diagnosed as terminal, who need good, safe, kind, appropriate end of life care because they are very old, or have degenerating conditions like dementia.

They asked for greater clarity and uniformity between organisations about how hospice care could be accessed and by whom.

End of life care would be improved with a national definition and brand for hospice care, which confirms clearly what it offers, who can get it and how they get access to it.

The Commission heard requests from carers and relatives to be supported better by hospices so that they could continue to provide care for someone close to them, approaching death.

The care that I would want…as a carer would be support from the hospice at home team explaining how things go.

People also wanted better access to information and more help to enable them to use this information to inform their decisions about care at the end of life. They felt this would help them take greater control of their situation and they believed that hospices could do more to help with this. Although importantly, their request for more information was not limited to choices about care, but also extending to wanting to know more about giving to the hospice and volunteering to help with its work.

The Commission also heard from young people living with life-limiting illness who were moving from children to adult services. They described this move as traumatic, not least because they were unconvinced that adult hospices would meet their needs adequately or appropriately. Parents of young adults also told the Commission of the discomfort that they felt about their son or daughter receiving care in a setting that they associated with much older people. Many young people told us of a wish to live life to the full, despite their diagnosis, and of a willingness to take risks to that end. They wanted hospice services to support them and were uncertain that adult hospices would enable them to fulfil this ambition.

Hospices should change practices to enable young people to ‘reach for the stars’ not just sit and wait for the inevitable to happen whilst looking at a nice view…it’s not what we want…we want to go shopping or go to the cinema even if it is at the absolute last point of our lives and even if it involves risk.

Carers attending a Commission event described what they felt were unrealised possibilities in relation to their continued involvement in hospice care. Many described themselves as “experts through experience” in end of life care. They wanted to find ways to continue to use their expertise and were keen to work with hospices to achieve this. One attendee described new-found confidence and competence arising from the care she coordinated and provided for her mother who had died at home with dementia some seven months earlier. Since her mother’s death she had found no way to maintain these skills or to use them to benefit others.
Carers such as myself could be used to design and roll out training by speaking from experience.\(^{(3)}\)

Similarly, many users asked hospices to listen more carefully to their experience and to engage them in co-designing future services as well considering the role that they may play in the delivery of care.

Hospices could do things more radically. They need users and members of the public to be critical and help them with this.\(^{(3)}\)

Hospices need to involve patients, families and carers constantly. In developing and improving their services. Not as a one-off exercise but in genuine partnership. Harness their insights, experiences and use these to improve care services.\(^{(3)}\)

A workforce unready for the future

The future will make significant demands on the hospice workforce. These demands must be seen in the wider context of workforce challenges for the whole system of health and social care. These systems face the challenge of changing working patterns, greater flexibility of roles, new educational arrangements and a shortage of skilled workers.

The Commission is aware that in 10 years the workforce is unlikely to exist in the same form in which it exists today. A significant proportion of the hospice workforce is due to retire in the next 10-15 years and hospices are already struggling to replace those that leave. However, our ageing society not only means a significant rise in need but it also means a proportionally smaller pool of health professionals who will be increasingly in demand across the health and social care system. As the competition for registered professionals increases, questions arise about how hospices continue to recruit and retain high quality staff. Opportunities undoubtedly exist for hospices to implement different employment practices to retain good staff; providing flexible working to enable people to work longer, seeking out opportunities to use retirees. However these require imaginative approaches to human resource management and leadership in this area of hospice organisation.

Future workforce scenario planning shared with the Commission highlighted the radical shifts that are anticipated in the future of health care and related workforce requirements.\(^{(11)}\) These scenarios reflect a changing business context, new priorities and ‘non-traditional’ settings for, and ways of delivering healthcare including increased use of technology. Hospices will need to be fleet of foot to respond. Significantly, there is a shift from a top down model of health care driven by medicine to a bottom up, co-created model in which individuals and networks of users are at the forefront of caring, supported by information. In this new model, professionals move into a position of facilitation and partnership.

The skills of professionals and others working in hospices will need to be different. The skills required will be wide-ranging and will include business and marketing, education for the patient and their carer, and an understanding of how to receive and use data to support self monitoring on the part of patients. Skills for Health recommend the development of a number of new roles on the part of those providing hospice care including associate health practitioners, IT technicians and care navigators in order that hospices take the opportunities opened by the future to continue to provide high quality care but in new ways.\(^{(11)}\)
New ways of working on the part of other systems will require new skills and ways of working on the part of hospice staff and volunteers. If, for example, hospitals establish new approaches to care for people with life-shortening conditions, then hospices may also want to work differently to ensure that their contribution continues to support such new initiatives. They may wish to introduce new roles or offer training. Recent guidance produced by the Royal College of Physicians about the future care of critically ill medical patients in hospital provides such an opportunity. Hospice care needs to adapt and contribute positively to such new ways of working.

The Commission heard of specific skills that must be developed in the hospice sector to respond to the needs of new groups of people seeking hospice care. Professionals working in adult hospices must gain new expertise related to the needs of people with conditions other than cancer, including young people who live with complex life-limiting conditions. For too long, a lack of competency or confidence in such skills has limited people’s access to hospice care. Clinicians working in hospice care will also need additional skills to respond to individuals with multiple co-morbidities in older life.

Early work on the part of the Commission highlighted the importance of aligning the workforce to the evolving mission and purpose of hospices. The workforce needs to look beyond their organisation to influence plans and practices beyond their immediate team and engage in new partnerships with other providers of care. This approach will be important given the changing picture of ill health for people in the last years of life. Collaboration will be required between organisations, specialisms and teams working with people with life-shortening conditions. Specifically, hospices will need to work with mental health, care of older people, social care providers, hospitals and primary care and other specialisms supporting people with conditions such as heart failure and lung disease.

The Commission also heard of the importance of developing leadership for a new era in order that hospices can serve as major players and influencers within the larger health and social care system and in local communities. Such leaders must exist throughout the system, comprise volunteers as well as paid staff, and be characterised by political adeptness, a willingness to have a professional and public profile and the capacity to take an entrepreneurial approach to developing new partnerships and new services.

Finally, it heard a number of requests for clarity regarding the contribution of the most senior clinical staff in hospices. An area of concern highlighted by a number of leaders in hospice care related to role of the clinical nurse specialist, which has become increasingly unclear in recent years. A similar question was raised about how doctors practising palliative medicine are most effectively used to meet future needs and grasp opportunities. The Commission sought the advice of experts in these two areas. A summary of their thoughts as well as others who shared opinion and evidence with the Commission are provided in boxes 1 and 2.
Box 1: The role of the clinical nurse specialist in palliative care in the future:

- Creating mature partnerships with community nurses that support the inevitable blurring of roles and task allocation
- Delivering highly skilled palliative care for all who could benefit from it regardless of diagnosis
- Providing care such as venipuncture, in addition to advice and support
- Delivering advanced nursing skills such as prescribing and clinical assessment
- Developing new skills in patients, families and family carers including health literacy
- Developing more sophisticated partnerships with patients and families as a basis for sharing risks around treatments
- Providing expert care and advice around the clock and seven days a week
- Providing training for professionals within and beyond the hospice team
- Establishing close complementary working relationships with medical and nursing consultants within the hospice team
- Engaging in audit and research, particularly related to outcomes and effectiveness
- Engaging with local health and social care leaders to identify gaps in provision and solutions for their improvement

Box 2: The role of the doctor practicing palliative medicine in the future:

- Specialist assessment and treatment of symptoms and other problems arising as a result of advanced illness regardless of diagnosis. The doctor will draw on expert knowledge of palliative medicine, specifically pain and symptom management, applying advanced skills around diagnosis and treatment
- Actively engaging in integration, collaboration and partnership working – within and beyond the specialty of palliative medicine, ensuring extension of good practice beyond cancer. Doctors will also want to work more closely with geriatric and rehabilitation medicine, cardiology and respiratory medicine and with general practitioners in recognition of the changing profile of people seeking palliative care
- Modeling and supporting the provision of individualised and flexible care around the clock, and across all settings, recognising their vital contribution for people in the community as well as those in inpatient settings
- Helping people move between services where this is in the interest of the person who is unwell, or their family
- Educating and training junior medical staff and other doctors engaged in palliative and end of life care. Such training will seek to build the skills required to deliver palliative and end of life care to people in community settings including those required to care for people with multiple co-morbidities. This training should be extended to other professionals, encouraging them to join junior doctors in their learning
- Educating and training of other professionals within and beyond the specialty, particularly other senior members of the multi-disciplinary team. Clinical nurse specialists are a group that will benefit from support and training from senior doctors in the hospice team
- Commitment to the future development of hospice care, through leadership in strategic planning, attention to issues of clinical risk, engagement in care related innovation and contribution to the evidence base for hospice care via research and audit. Consideration is required about how these activities are achieved by a workforce that is largely part-time
- Providing strategic support for commissioning processes
- Engaging with the local community to further the understanding of hospice care
A more competitive environment in England

Feedback to the Commission highlights the way in which choices made by local commissioners are creating significant competition for hospices that operate in England.

Hospices will need to consider likely new entrants into their market. In particular community and acute providers may become new competitors for contracts that in some way subsume elements of hospice care. Private sector organisations that can invest significant resources upfront and include palliative care as part of a wider offer to the NHS, also present a threat. Historically, hospices have enjoyed a relatively protected place in the market but they cannot be complacent in thinking that this situation will continue. There are other providers who are willing and able to provide care that reflects the principles and practice of the hospice sector and indeed evidence exists that they have in some areas already gained afoothold in the market.

Key to the success of hospices in a more competitive future environment will be their ability to demonstrate that they represent better value; in terms of high-quality care and excellent outcomes. In business terms, hospices will need to be able to promote clearly their offerings, and will need sharp negotiation and contracting skills if they are to thrive. They may also wish to consider how potential competitors for care or education contracts may be brought into more constructive and potentially collaborative relationships to generate benefits for patients (and each other) through joint working.

Hospices will need to be fleet of foot given that competitive environments change swiftly.

We heard from hospices where changes in the local commissioning environment have already led to increased confusion on the part of professionals and users over how to access care, as well as duplication and fragmentation of services. The risk of such a consequence should compel hospices to become involved and to work to shape these services so they work together better, or campaign to ensure an effective tendering process that protects the interests of the most vulnerable.

Constrained and uncertain income

Views offered to the Commission suggest that there are likely to be significant constraints on the level of state resources available for health and social care in the future. A report on the future of fundraising for the Commission highlights the way a changing socio-economic environment will challenge future fundraising income. It anticipates changes in the availability of volunteers, which are so important in community fundraising; an increased demand from the public about how hospices spend their donations and a requirement for different ways of communicating key messages about hospice care to attract the interest of potential donors.

The same report anticipates changes in patterns of giving in the future. Some people are likely to have more money and time to spend in pursuit of their passions, both personal and charitable. Others will be using more of their own money to fund their care as they get older. Well researched future scenarios for health care suggest that health and social care will be supported by individual funds as well as state resources. For some people, such choices are unlikely to be available. There is evidence of disturbing numbers of older people currently living in poverty and social exclusion, who are left behind and on the margins of a relatively prosperous society.

While hospices currently do well in their efforts to raise funds from voluntary sources, evidence from the wider voluntary and charitable sector suggests a risk of a reduction in the available fundraising income for this expanding sector. In short, there will be a requirement for an increasingly entrepreneurial approaches to income generation and efficient delivery of services within a context of continued austerity. The Commission heard how hospices could do better in these respects.
The uncertainty around future funding is currently compounded both by the unresolved issue of a new funding mechanism for palliative care in England and the requirement to build relationships with new English commissioners. The constant change of funding structures has hindered meaningful engagement between many English hospices and their commissioners. Many hospices told us of the difficulties they face in not knowing who to engage with and how to establish the sustained relationships necessary to support the development of meaningful local strategies for palliative and end of life care.

**A context of increasing accountability**

There has been much evidence, particularly in the last year or so, of a system of care for people who are dying or facing bereavement that is far from adequate. The many reports that describe the failings in the system identify multi-faceted reasons for poor experience and outcomes on the part of those approaching the end of life, their families and carers. Perhaps most clear is the picture of a culture that fails to respond to the needs of people who have a terminal illness and those who are affected by it. In response, efforts have been made to ensure a health and care system that is tightly regulated and inspected.

The Commission believes that this is a trend set to continue. In the future, hospices will need to be accountable and transparent in all that they do and develop systems for ensuring the systematic assurance of quality, competence and compassion. Alongside this, hospices will need to enhance user involvement in service evaluation and development, outcome measurement and the capturing of patient experience.

**Mixed perceptions of hospice care**

The Commission heard mixed perceptions of hospices, particularly in its discussion with individuals offering a personal or expert opinion about the future of hospice care.

Most importantly, the care provided by hospices is usually well evaluated by those using it, and acknowledged as an important contribution to end of life care in the UK by many others, including parliamentarians, commissioners and policymakers.

Hospices bring values, commitment, expertise and experience. Hospices have turned something to avoid into something to acknowledge and even embrace, so they are well placed as champions for change.

Dr Bee Wee, National Clinical Director for End of Life Care, NHS England

Those who use hospices describe care that is affirming and comforting, which positively changes their experience of the end of life and bereavement and which enables them to cope with the significant challenges that they face at a very difficult time. This feedback resonates with other sources of evidence such as the National Voices Survey and the Qualycare study undertaken by the Cicely Saunders Institute.

The Commission also heard repeated praise for the innovative nature of hospices. Over the last 50 or so years hospices have been recognised as being influential in developing new approaches to the care of people who are dying or bereaved in the UK. There were repeated calls for hospices to continue to offer innovative solutions to the many challenges of end of life care in the future.

The Commission heard much about the positive brand of hospices. For many the term hospice was associated with the delivery of high-quality care which could be trusted and had a role to play in supporting people approaching the end of their life. However many people demonstrated relatively little awareness of the detail of what hospices offer in terms of care, or who is eligible to use their services.
Hospices need to think on a broader scale about how to inform stakeholders, MPs and the general public, as they often don’t know or understand the breadth of hospice services.

Fabian Hamilton, MP

There was evidence that many people, even those in senior public service roles have little understanding of what hospices provide. The Commission heard stories of this lack of clarity among health professionals too, even those who could be important referrers to hospice care. Questions were raised regarding the transparency of hospices’ fundraising messages and their overriding preoccupation to raise funds without necessarily being clear about the exact nature and accessibility of their services.

In order to fundraise effectively, there is a need to explain properly what the money is for.

The Rt Hon Stephen Dorrell, MP

A similar view was highlighted by members of the general public in a public consultation exercise hosted by the Commission.

Hospices must look closely at their fundraising profile and how that compares with their service provision, client profile, just cancer? and geographical provision.

Concerns were expressed to the Commission about the degree to which hospices plan their services or review their impact from a population-wide perspective. They are often perceived to be unaware of the needs of the majority of people dying in their area, and fail to evaluate the contribution of their service from this wider point of view.

The question for hospices should be: what can we do for our community and what can our teams do to meet local palliative care needs?

Dr Bill Noble, Medical Director, Marie Curie Care/Former Macmillan Senior Lecturer in Palliative Medicine, Sheffield University

Many of those who gave evidence to the Commission asked questions about the principles underpinning the way hospices used their resources. Regardless of service pressures it was suggested by some that hospices were giving too much to too few and didn’t balance their use of their resources against the needs of their whole population. Their creativity and flexibility is seen as a strength, but many want this approach matched with a determination to identify the intervention that is ‘good enough’ to meet the needs of the individual, yet sustain and support as many people as possible. The significant resources that hospices have at their disposal are arguably often underused, a criticism levelled particularly at children’s hospices.

Some staff value the ability to provide an excellent high-quality Rolls Royce service to a few and may find it hard to adapt to the challenge of reaching out to those whose needs are not being met.

Imelda Redmond, Director of Policy and Parliamentary Affairs, Marie Curie Cancer Care

Hospices were felt by some outside the sector to be insufficiently self-critical, focusing primarily on the very positive feedback that they receive from those who are using their services, rather than seeking additional data that could help them improve their care. This situation is exacerbated by the fact that there is relatively little data collected or reviewed routinely by providers of hospice care to consider the relative effectiveness and cost-effectiveness of their care.
Hospices find measurement difficult – when people are grateful, they are very uncritical. But hospices should work harder to engage with families and relatives as proxies for our patients.

Paul Woodward, Chief Executive, Sue Ryder

A number of key stakeholders described a perception of hospices as relatively troublesome partners with limited interest in working collaboratively. They described hospices as on the margins, expectant of statutory funding with little intention to deliver the integrated services that are now being put at the heart of system-wide aspirations for better end of life care.

The hospice movement needs to consider how to play a role in an integrated model of health and social care. Hospices should be leading from the front. Hospices are not at the front of this process at the moment.

The Rt Hon Stephen Dorrell, MP

There were mixed views regarding the independent position adopted by many hospices. Some saw it as vital to a movement that could challenge the NHS and other providers to give the quality of care deserved by those approaching the end of life. Others saw it as an excuse on the part of hospices to sit outside the system of care; to disengage from the wider concerns of equity, accessibility, demand and ignore the challenges of joined-up care in the community.

Hospices may need to reduce their separation from the NHS and the larger modern healthcare system of which they are part. Hospices may be too insular in their thinking, not necessarily considering their part in the whole system of care. Hospices must not protect their independence at the expense of recognising that hospice is only one part of the patient’s journey.

Dr Jane Collins, Chief Executive, Marie Curie Cancer Care

The critique of this position is that independence is a convenience for the hospice community; individually and institutionally. ‘Sitting outside’ makes hospices less accountable to others; this position gives hospices protection against being blamed or made culpable for a failure in service and can allow them to abdicate system-wide responsibility.

Some of those who offered their views to the Commission also questioned the degree to which hospices worked well together. Many described the sector as fragmented, missing opportunities to influence change in a collective way, and to challenge the NHS and other providers to improve the care needed by those approaching the end of life.
The large number of small hospice organisations may limit the ability of hospices collectively to think radically. What might hospice care do if it were able to organise itself around one hospice ‘hub’ for a population of 1-1.5 million?

Tom Hughes-Hallett, Executive Chair of Imperial College London’s Institute of Global Health Innovation. Former Chief Executive, Marie Curie Cancer Care

In summary

The Commission would be surprised if most hospices did not face at least one or more of these challenges or need to address some of these potentially critical perceptions of their role.

It believes that hospices will need to adapt if they are to face these challenges in the future. The next section of the report aims to help hospices to think through how to adapt, survive and ultimately continue to thrive in their mission to provide high-quality care to their communities. It does so by identifying principles to guide hospices in their future plans.
6. How hospices can become fit for the future

As hospices respond to the case for change, the Commission offers key principles that it believes should drive their change and adaptation in the future.

The principles reflect many of the founding values of hospices and build upon them. It is important that during the process of adaptation hospices retain a sustained connection with their ideals; many of which underpin the approach to care that is most appreciated by users. The Commission places particular emphasis on individualised care by hospices that extend services to people’s family, carers and wider social networks. It also places high value on the ambition of hospices to talk to their local communities and to help people face their fears around dying and bereavement.

1. Hospices should understand the needs of their local population and work with others to meet these needs.

Hospices must remain responsive to their local communities’ needs for palliative and end of life care.

**Why action is imperative:** Local communities have been central to the conception, development, funding and on-going sustainability of the majority of hospices. Their support is offered on the understanding that hospices will meet their needs and those of their family, friends and neighbours when they or someone close to them is dying. This is at the heart of the relationships established between hospices and the local people who support their work in so many ways, including most crucially their contribution to fundraising, and volunteering.

**The principle in action:** The senior team at the Martlets Hospice found it challenging, like many hospices, to engage with new local commissioners. In an effort to ensure that a city-wide review of end of life care services would lead to an effective model of care, Martlets Hospice joined forces with the local Community Trust (Sussex Community Trust). The model of care that was developed by the partners has guided the hospice’s strategic direction, reflects expected local challenges and is geared towards commissioning priorities which include end of life care services for people with dementia. Working closely with the Commissioners, the resultant Palliative Care Partnership, is formed around a central coordinating hub and single telephone access point for all end of life care, city-wide. The hub has been operational since April 1st 2013 and is manned 24/7, incorporating a 7/7 visiting service by community nurse specialists and 24/7 service by Hospice at Home.
2. Hospices should be active and adaptive in their approach to the future

Hospice care will only flourish in an environment where hospices accept the need to adapt and are active in doing so.

Why action is imperative: The world is changing and hospices need to be ready to adapt to emerging needs, requirements and opportunities in order to continue to meet their obligations to their local communities and others who depend on their care. Their board and senior teams need to engage proactively in plans to respond to this rapidly changing environment. Without this work hospices may find themselves surprised by the enormity of what they face, and may discover that they have to react to changes around them rather than being able to influence these changes in order to establish the role in which they believe they could be most effective.

The principle in action: The trustees of East Cheshire Hospice and the senior team at St Helena Hospice have both held engagement events with new health and social care commissioners and end of life care partners including other hospices and new organisations, to develop a new and collaborative approach to future challenges.

The principle in action: Clinical and non-clinical staff and trustees came together from eight hospices working across Sussex to consider future challenges and opportunities for hospice care in June 2011. They heard presentations regarding innovation required in the future, then discussed what they would like their individual hospices to be doing in 10 years’ time and agreed some first steps. An artist captured the meeting in a series of cartoon illustrations, providing a vivid, visual display of the conference’s flow for future reference. Many of the hospices that established a plan at that event are now putting these plans into action.
3. Hospices should look outward and engage in new partnerships

Hospices should engage with a wide range of organisations whose actions, alongside the hospice’s own, will shape people’s experience of care at the end of life.

Why action is imperative: Partnership and collaboration will enable more people to access services, they can secure a more joined-up approach to the provision of care and can ensure a better experience of dying and loss on the part of users. Partnerships can support more cost-effective ways of providing care and can help hospices learn new skills and approaches. Partnership and collaboration will be essential for hospices that want to work with the communities they serve so that they can promote and develop the care that people want and need.

If hospice care is to be more accessible, hospices must work closely with, and be joined up to, other services that are also supporting people at the end of life, including emergency services. Hospice care must reach into many settings, including hospitals and care homes. Some hospices may be tempted to wait for turbulence in the wider NHS to settle and may be frustrated by previous attempts to engage, negotiate or deliver in effective partnership with NHS organisations. However, there is a danger that such a course risks hospices going unheard and their ambitions unfulfilled.

Hospices need to serve as good and active partners if they are to sustain their position, build on their reputation and effectively advocate for those with end of life care needs.

The Commission received suggestions from a number of people that hospices (working individually or in partnership) should serve larger populations, making them bigger players in the English commissioning process. Depending on the nature of their collaboration, such partnership might also enable them to become more efficient and allow them to share systems, services and staff.

The principle in action: The Rowan’s Hospice has engaged in a partnership with five providers of hospice and specialist palliative care from both the NHS and the independent sector, who collectively tendered to provide training in end of life skills for local authority domiciliary care workers across Hampshire, to increase the reach of hospice care. This includes collaborating with hospices that have successfully bid to provide education and training to local authority social workers and social care staff.

The principle in action: St Margaret of Scotland Hospice is currently working in partnership with five other NHS Greater Glasgow and Clyde hospices to provide educationalist support; clinical skill training; loss grief and bereavement training for wider NHS Greater Glasgow and Clyde staff; advanced communication skills training; loss grief and bereavement awareness training for hospice and acute services; primary care and care home staff, and clinical skill practice development.
**4: Hospices should work to influence local health and social care**

Hospices should seek to influence the totality of end of life care and to do so their own services must work closely with the NHS and local authorities.

**Why action is imperative:** Hospices are an important part of the local care economy and have much to offer in the development and delivery of palliative and end of life services. They must seek to influence local care for two reasons; first because they cannot meet all needs for palliative and end of life care, and secondly because of their responsibility to advocate for those who face the end of life. Hospices should seek to use that influence to improve the delivery of palliative and end of life care across their patch.

To do this well, the hospice must work closely with local services, particularly in planning and delivery, so that it can secure the credibility that comes with being a respected and reliable part of the local system of care.

**The principle in action:** A powerful example of a collaboration that seeks to influence wider strategy is the Children’s Hospices Across London (CHAL). CHAL brings together five of the children’s hospices that serve London, who have formed a company and a charity to act as a single body to reach out to more children, young people and their families and seeks to shape a London wide strategy for children’s palliative care, in partnership with others. In addition, this single platform is able to respond to the fast changing commissioning environment.

**The principle in action:** St Christopher’s Hospice has been delivering workforce development programmes on end of life care for generalist social care staff across several local councils since 2013. Their approach is a flexible one, developed in partnership with local councils, taking account of local priorities and responsive to the needs of the organisations as they become apparent. It is multi-pronged, aimed at staff groups at all levels, across disciplines and services and with crucial buy in at senior level. Its programmes aim to take local authorities beyond the delivery of isolated training days on end of life to the more holistic approach that is essential for the culture shift required to improve generalist social end of life care provision in the UK.

Programmes are commissioned by local authorities and delivered by hospice staff. Specialist palliative social workers are particularly well placed to deliver the programmes, with their understanding of the social care context and the ability to offer social care to colleagues. There is value for the hospice in this work too. Hospice staff benefit from newly established links with statutory services.
5. Hospices should seek to reach more people

Hospices must aim to meet the needs of more people. This may be through a variety of means – more direct care; more support and development of lay carers and volunteers; and more education and training for health and social care professionals.

Why action is imperative: Hospices are renowned for the high quality of care they provide to people with life-shortening conditions, their families and carers. It is clear that the need for such care will increase in the future and hospices are ideally placed to respond. They will need to give due consideration to how services can operate at scale, providing care for many more people, wherever they need it, including those that are marginalised or socially excluded. This requires hospices to extend their care into a variety of contexts, such as care homes and sheltered housing. Partnership working will be important in enabling such an extension of care and increasing the impact of the limited resources of hospices so that they are part of a mix of care, can influence the care provided by others and can learn new skills to help them to provide appropriate services.

Hospice-delivered education and training offers a particular opportunity to extend reach, building on the expertise of hospice professionals, many of whom want to be engaged in training and supporting others. The most successful offerings on the part of hospices will draw not only on their experience but also on well-evaluated interventions and elements of hospice practice. New approaches to education and training are needed; they need to be efficient, well evaluated and should use technology to enable a cost-effective and accessible programme of learning. New products are also required to enable hospices to respond to new opportunities such as vocational training for school leavers. Strong leadership and business skills are going to be needed if hospices are to make the most of education and training.\(^{(16)}\)

The principle in action: The Hospice of St Francis (Berkhamsted), Peace Hospice (Watford), Isabel Hospice (Welwyn Garden City), Keech Hospice (Luton), Arthur Rank Hospice (Cambridge), Sue Ryder Thorpe Hall (Peterborough), St Elizabeth’s Hospice (Ipswich), St Francis Hospice (Romford) worked in collaboration with other NHS providers in the design and delivery of the NHS Health Education East of England ABC End of Life Education programme for nursing/residential homes and domiciliary care providers as well as adapt the ELFH programme for hospital and community staff. Over 2 years, over 4000 staff have completed the blended learning programme with mentor support from care homes and domiciliary care agencies and 3392 staff from health and social care. Two independent studies from the University of Bedfordshire and Public Health Action Team have demonstrated the positive impact of the care home programme including a reduction in unscheduled hospital admissions and an increase in achievement of preferred place of death.
6. Hospices should ensure that their care and expertise is accessible to those who need it

Hospices should make certain that every effort is made to ensure equitable access to their care for those who need their expert services. To this end, clear criteria for care by hospices are required, of which all referrers and potential users are aware. In addition they must work creatively with other providers to promote their services, to create new opportunities to share their skills and to contribute to an increased availability of expert care around the clock and in a wide variety of settings.

Why action is imperative: Hospice care is highly valued by most users. Yet, many people who want such care fail to gain access to it. Some people are unaware of what it could offer even if they are eligible to receive it. Others live within communities or groups who are marginalised and fail to access many aspects of health or hospice care. Some people need care in places where hospice care is not ordinarily available, such as prisons.

To change this situation, hospices need to be explicit about what they do and the degree to which they achieve it. They also need to offer a clear description of how individuals can reach their care, taking into account the challenges that some people may have in understanding such as language difficulties, differences of culture or any particular vulnerability or disability that may mean hospices should make greater efforts in their communication.

Hospices need to reach out to local people and specifically those who do not currently use their services. Finding ways to encourage people to overcome their concerns about hospice care is crucial. The Commission heard that this is an important role for senior clinicians such as doctors working in partnership with managers (12).

Importantly, hospices must work with other providers of care, local communities and host of other groups and partners to extend their reach into new places within their community. Their services, provided alone or in partnership with others must acknowledge the round the clock needs of people with life-shortening conditions, their families and carers. Engagement with other services will be important if hospices are to widen access to previously underserved groups.

The principle in action: St Joseph’s Hospice (an adult hospice) and Richard House (a children’s hospice) are working jointly with the London Muslim Centre in East London to encourage broader involvement in hospices on the part of the Islamic communities. This partnership exists at many levels including those most senior in the organisations. By way of example, Richard House has the Chief Imam as a patron (who is also a member of the St Joseph’s Hospice ethics forum) and a member of the London Muslim Centre executive as a trustee. St Joseph’s has worked with local Muslim communities to promote access and engagement for a number of years.

The principle in action: Dorothy House has opened two outreach centres to bring services nearer to where people live as the hospice serves a large geographical area. In these centres they run a series of workshops, which are open to any patient with a life-threatening illness. Topics covered include fatigue and energy management (called ‘My get-up-and-go has got-up-and-gone’), breathlessness and anxiety management (called ‘How to pause and catch your breath’), sleep management (‘I can’t sleep’) and pain management.
7. Hospices must engage in innovation and its evaluation

Hospices should invest in innovation and evaluation and develop their services accordingly so that they can offer an effective response to emerging needs.

Hospice care needs to continue to adapt. Services have to continue to change and improve to meet the needs of people facing the challenges of life-shortening conditions, particularly chronic illness and dementia. New ways of providing care are going to be needed to meet the needs of new groups of users, for example young people with life-shortening illness who are becoming adults and leave the care of children’s services and the growing numbers of people with advanced dementia. Similarly, hospices will need to redress some of the gaps in current provision such as the need to offer better support for family carers.

To bring this principle of innovation to life, hospices will need to work differently. They will need to explore the use of technology in their provision of care, find new ways of sharing their expertise and promoting skills in others, and begin to provide information services for people interested in taking greater control of their illness.

Effective innovation means collecting, understanding, using and valuing data. Data are vital in demonstrating the impact of innovative services and then spreading the most effective new approaches. To do this, hospices will need to build partnerships with academic centres that are willing to engage in the difficult task of robust evaluation. Both organisations will need to commit to building an honest evidence base for improvement.

Why action is imperative: Innovation has been a characteristic of hospice services in the past and should be at the heart of the hospice. Leading the development of new and effective ways to organise and provide care must be central to meeting charitable aims. Hospices have to make full use of their expertise to develop new and effective ways of caring if they are to stand out in a more competitive environment.

The principle in action: Highland Hospice is using telemedicine to help it reach across a large rural area. It enables palliative care consultants to give advice from a distance without having to visit the patient. Dundee University is doing related research into this area and is considering how the working practices of the staff are affected by this development. Similarly Sue Ryder Manorlands Hospice started using telemedicine two years ago in partnership with the Telehealth Hub at Airedale Hospital. The hospice’s community team covers a large rural area, and the telemedicine service has proved to be an effective way of delivering support and advice to patients and health and social care professionals. Most recently the hospice has established a new plan to provide extra support to over 30 care homes across Airedale and Craven also using telemedicine.
8. Hospices should develop their workforce

Hospices need to rethink the deployment and the development of their paid and volunteer workforce in order to provide services that are fit for the future.

Why action is imperative: Providing more and different care will require a better use of all the people that work and volunteer for the hospice. Everyone will need to consider better ways of using their expertise across all the hospice’s services to ensure both ‘reach’ and ‘quality’. This action extends throughout the organisation and should include trustees as well as senior executives, managers, clinical and non-clinical staff and volunteers. Working with one another and their national organisations, hospices should review the way they use, train and support their volunteers. The Commission is convinced that volunteers are a vital component to the future provision of hospice care. Hospices need to recognise the potential that they bring, and be both ambitious and creative in how they are deployed. The Commission is keen that hospices consider using volunteers differently; extending their roles into the direct delivery of care and offering guidance to users about how to navigate their way through the intricacies of multiple providers of end of life care. To improve their impact volunteers need high-quality training, guidance about the boundaries of their work and on-going support.

Hospices should also give close attention to questions relating to the most efficient skill mix of paid staff for existing and new services. Hospices should ask if expert staff could do more to support, manage and ensure the effective delivery of services by others. In addition they must think carefully about the future role of the most specialist of the hospice workforce, including doctors practicing palliative medicine and clinical nurse specialists whose impact in terms of strategic planning, provision of education and training and partnership development is so important. In general, the hospice workforce needs to become increasingly flexible, working across many different settings and in response to the changing needs and preferences of users.

Hospices should identify and invest in the many new skills necessary to help professionals, patients, families and carers adapt to future ways of caring. Hospices may need to consider sharing specialist members of the workforce with other local hospices; particularly those whose expertise is scarce or expensive. Similarly, hospices will need to grasp opportunities for building a greater capacity to care in the local communities that they serve, effectively helping to create a new workforce amongst families, carers and the wider public.

To achieve the flexibility and responsiveness required in the hospice workforce in the future, hospices need to manage risk in a sophisticated way. Risk is often cited as a reason for the engagement of the most specialised in the delivery of care. However there may be different ways of managing risk in order to develop a workforce that is less reliant on expensive staff while still responding to individual needs and preferences in creative, flexible and valued ways. More sophisticated approaches to the management of risks should help with the increased and alternative use of volunteers.

The principle in action: St Nicholas Hospice Care identified the untapped potential of nursing assistants. As hospice care is interdisciplinary the hospice adopted a four-year plan to support some nursing assistants to become hospice care assistants with new skills to support physiotherapy, occupational therapy and nurse educators. The higher grade assistant posts undertake first assessments, lead on discharge planning and the coordination of clinical care volunteers, the benefit being that professionally qualified staff can focus on using their higher skills. The aim is to have four grades of care assistant thereby creating a career pathway and maximising a skills-mix approach to ever increasing local demand.
**The Principle in action:** A new volunteer pilot project is under way in partnership between St Luke’s Hospice Plymouth, Age UK Plymouth and Plymouth Hospitals NHS Trust. Funded by the Department of Health, Hospice Volunteering in Partnership (VIP) seeks to enhance the care that patients and service users already receive. Volunteers are required to “act as a caring relative or carer and do the things that can make a difference for elderly and vulnerable people”. In so doing, the project aims to complement the level of care received by patients across the three organisations. The training provided to the volunteers can work towards a qualification in association with City College Plymouth so the project can assist those involved with the VIP project to go on to further full-time employment or education. It is also intended that the use of VIP volunteers will help raise awareness of patients’ and service users’ end of life needs.

9: Hospices should find new ways to raise money

The need for hospice care will rise. If hospices are to provide more, be innovative in the development of new approaches to care and increase their impact they will also need to increase their income.

Hospices are good fundraisers, raising over £1.5 million a day. However, work undertaken on behalf of the Commission suggests they could do better. Recommendations include strengthening a culture of fundraising in local hospices, increasing the use of centralised approaches such as direct mailing, and strengthened communications and leadership at local and national levels.\(^{(14)}\)

Hospices must exploit new approaches to fundraising in order to remain competitive locally. However, the biggest potential lies in an additional and more coherent regional and national fundraising effort. This will require national hospice organisations to work closely with hospices to identify new ways of creating a national call for help.\(^{(14)}\)

Other options for generating more resources might include: increasing income from offering education and training at scale; attracting users who have personal budgets and may not have used the hospice previously; and sharing the costs and risks of funding innovation across hospices. Hospices may wish to find new ways of attracting investment from social impact bonds or from the private sector. Some hospices are also entering into full cost recovery contracts for specific parts of their service offering.

**Why action is imperative:** Hospices face increasing needs, increasing costs and potential loss of income from both statutory and voluntary sources. Hospices must adapt and innovate. However, this can only be achieved alongside a strategy for increasing resources.

**The principle in action:** St Giles’ Care Agency began a contract in September 2013 with the local acute trust to enable rapid response home care for patients being discharged from hospital but for whom there is not yet a package of care in place. Not only is this an innovative model of care it also represents a new income stream for the hospice. This care is for general need, and not specifically end of life care.
10. Hospices should work to meet maximum efficiency

In the face of increasing demand, hospices need to be as efficient as possible. They will need to identify and take every opportunity to ensure they make the most of their assets.

**Why action is imperative:** To respond to increasing needs and the growing complexity of the care required, hospices will want to find ways to extend their care, investing in innovation, evaluation, and education.

To fund this investment they may find some income generation opportunities relating to new activity. However, they may also need to look for opportunities to be more efficient in how they use existing resources.

The Commission suggests that hospices consider developing services that take a discriminating approach to matching resources to needs. The Commission proposes that hospices break down what is often a standard package of high-quality care for everyone and develop more tailored responses that specifically reflect individual’s needs. It believes that such a shift may not require a hospice to sacrifice the quality of care they offer.

This approach is built on the notion of identifying personal interventions that are good enough to sustain and support the person, their family and carers, while allowing resources to be used in a targeted way. This may offer advantages both to the individual, as well as the hospice, when compared to a broader and more general menu of services offered as a matter of course. The Commission does not believe that this undermines a holistic approach to care, but it may limit the length and scope of involvement. The aim is to free up resources without a detrimental impact on quality, thereby allowing care for more people.

In addition, the Commission urges hospices to consider ways in which they might reduce overhead costs, particularly through new partnerships and collaborations with other hospices or other providers that could reduce fixed costs or generate new economies of scale.

It is important that the charitable contribution to costs does not hide inefficiencies by making relatively expensive services seem cost-efficient to commissioners without the rigour of scrutiny and review.

**The principle in action:** St Helena Hospice is working with a Draper and Dash a healthcare business informatics consultancy to develop the kind of informatics tools and approaches used in the acute sector in order that they can be applied to the hospice environment. The scope of the project includes clinical, financial, workforce and fundraising information requirements and KPI development. The hospice has secured support from BT Health and QlikTech for this work and is developing an approach that could evolve into a practical solution to support an information-sharing and benchmarking network across a number of hospices.
11. Hospices and the national organisations that represent them must support each other and work together

Hospices will have more influence, attract more resources and are more likely to be seen as credible and authoritative experts in end of life care if their actions and their words are echoed and amplified by their national organisations.

Why action is imperative: When it comes to the hospice sector, the whole can be greater than the sum of the parts. A clear articulation of the role of the future hospice nationally can help local hospices be understood. Effective influence at a national level enables local organisations to also be effective in the way that they seek to extend that influence in their locality. Enabling the development of new hospice services across the four nations benefits each and every local institution.

The Commission believes that there are substantial opportunities for national organisation to help hospices respond to our call for adaptation and development. National organisations can help with improving fundraising, creating more effective campaigning and influencing activities, and enabling collaboration and partnership. Ensuring a clear relationship between individual hospices (whether independent, NHS or part of a national organisation) and organisations such as Help the Hospices is a vital first step. The benefits that the Commission anticipates will be proportional to generating clear understandings between local hospices and national organisations. National organisations must constantly work to refresh their understanding of the realities on the ground and local hospices must constantly engage with national organisations to support, empower and direct their leadership.

The principle in action: Help the Hospices has been working with members to strengthen the voice of hospices, share best practice and lobby on issues of policy and legislation. Examples of joint achievements based on good local and national partnerships include the ‘Good Governance programme for hospices’. This initiative has engaged over 60 member hospices. Help the Hospices and a team of consultants, from CASS Business School (Centre for charity effectiveness) at City University, led a programme to collate and share good governance practice and to identify topics and themes where overall practice could be improved. The programme has offered direct benefits to participating hospices as well as to the hospice sector as a whole. As a result, Help the Hospices has published a report on learning from the Board Development Programme, commissioned a series of good practice guides, set up a online mechanism whereby member hospices can upload their own examples of good governance practice, and have developed an on-line Board Development Toolkit for hospice boards.

The principle in action: Children’s hospices across the UK worked with Together for Short Lives (TfSL), the UK umbrella organisation for children’s hospices and children’s palliative care, to deliver a programme of 50 local ‘Square Table’ moderated discussions, followed by four ‘Square Table’ discussions in each of the four nations. Around 2000 people concerned with children’s hospices and children’s palliative care, from parents and life-shortened young people to consultants, from commissioners to educators, from business people to local and national politicians, were able to take a seat at the table and make a direct contribution as a result. This collective, collaborative work has raised profile, informed strategies, given rise to action plans, helped identify priorities, exposed and marshalled evidence with which to press argument at national level, and above all given practical voice to children and families. The next outcome from the programme is a four nations gathering in Scotland in October 2013, this meeting will bring together senior government officials with leaders of the children’s hospice and children’s palliative care sector.
Making an appropriate and relevant local response

The Commission recognises that no one hospice is the same as another. Their origins and history are often a consequence of local vision and passion. Similarly the way they operate and the services they provide reflect local needs, resources and capabilities.

Hospices will have to make decisions about how they adopt these principles to fit their local context and the Commission offers some suggestions about the areas on which hospice boards and their senior management teams may wish to reflect.

As hospices consider these various questions, the Commission makes a strong recommendation that hospices adopt a needs-led approach to the decisions about what care they provide in the future, to whom and how. They must reflect what local people require and aim to complement and complete related care by other providers.

1. How will the underpinning values of the organisation shape its response to future opportunities and challenges?

2. What kinds of services will be required locally in the future?

3. How will new services and related innovation be funded?
   a. Should some services be withdrawn?
   b. Can the proportion of resources allocated to services be adjusted to reflect new priorities for care?
   c. Are local efficiencies possible?

4. Do opportunities exist to deliver care differently in order to free up limited resources?

5. How does the hospice workforce need to be developed to deliver new services in new ways?

6. What opportunities exist locally for new partnerships and collaborations to support plans for the hospice in the future?

These decisions will be determined, in part, by local opportunities and the strengths of each hospice’s own organisation. To help hospices undertake a review of them, the Commission offers a checklist to help bring together the right background information – this is in Appendix 1.
Introduction

The Commission has identified the following five steps as a means of getting care right for the future.

1. Prepare for significant change in the context of palliative and end of life care.
2. Strengthen understanding of the contribution of hospice care.
3. Establish hospice care as a solution to future challenges in palliative and end of life care.
4. Strengthen the connection between hospices and their local health and social care systems and their local communities.
5. Strengthen the leadership of hospice care.

It believes that action is required in relation to each by a broad range of organisations with an interest in hospice care to create an environment in which hospice care will flourish and thereby make a significant contribution to palliative and end of life care in the future.

The Commission offers recommendations for hospices to consider as they make their plans for the next two to three years. The Commission urges hospice boards and senior management teams to give them their close attention.

The Commission also makes recommendations for other organisations that have an interest in hospice care in the future. These include:

- National organisations supporting hospice care
- Local authorities
- Commissioners of local health services
- NHS England, and the relevant departments in the governments of Wales, Scotland and Northern Ireland
- Hospitals
- National leadership bodies for the education, training and development of the health workforce
- Other national charities, supporting a variety of related activities, including health, social and palliative care, fundraising and volunteering
- A wider range of community groups
- Care homes
- Patient groups

The recommendations and proposed actions draw on detailed work undertaken by the Commission over the last two years. The rationale for each can be found in the various reports to which they are referenced. Readers are urged to refer to these sources in order to put each recommendation in context.
Step One
Prepare for significant change in the context of palliative and end of life care

This is a call for hospices and others to actively consider the future opportunities and the challenges to palliative and end of life care.\textsuperscript{[4,6]}

The priorities for the future should be underpinned by working with others to understand the future needs of the local population. This intelligence will ensure future care is responsive to new needs, such as chronic life-shortening illness, dementia and young people with life-limiting conditions moving from children’s to adult services and those with needs inadequately addressed in the past, such as the needs of family carers.\textsuperscript{[4,6,7]}

The Commission would stress the urgency of considering the workforce that is likely to be required to deliver high-quality hospice care in the future and highlights three key areas for consideration.

1. Maximising the potential use of volunteers.\textsuperscript{[10]}

2. Creating a more flexible and efficient paid workforce, and preparing it to work differently in the future.\textsuperscript{[5]}

3. Building new skills in the workforce so that it is ready for the changing context of health and social care and can take full advantage of new opportunities provided by technology to support their learning, delivery of care and opportunities to work differently.\textsuperscript{[14,11]}

Given the likelihood of increasing challenges around recruitment and retention of a high-quality workforce, the Commission recommends that hospices consider flexible approaches to future employment that might enable people to continue to work despite competing calls on their time as family carers and a desire to share their time between work and other commitments.\textsuperscript{[14]}

The Commission would also highlight the importance for hospices of establishing strategies that ensure their future sustainability. It places particular importance on the opportunity for new partnerships and greater collaboration and for careful review of resource use and allocation with a view to freeing up resources to support innovation.

Recommendations for hospices

1.1. Adopt an active approach to identifying future opportunities and challenges.\textsuperscript{[5]}

- Undertake a local needs assessment in partnership with other organisations to establish current and future needs for palliative and end of life care. Examine the degree to which your care currently meets such needs and anticipate how to develop your services in response to the emerging future picture. Such developments are likely to require new partnerships, new skills and new plans of operation.\textsuperscript{[5]}

- Develop and share a range of scenario-based responses to possible changes in your local environment. Without this work hospices may find themselves surprised by the enormity of what they face and may be judged to have failed to prepare for challenges that could be anticipated.

1.2. Consider the hospice workforce required in the future (paid and volunteers) and establish a plan to achieve it.\textsuperscript{[11]}

- Prepare the workforce for a time of profound change, encouraging a highly flexible approach to how user needs are met in the future. Review the current workforce and its skill base. To what degree does it already incorporate the kind of skills that will be required in the future?
Invest in the development of the volunteer workforce, with attention to processes for recruitment, training, management and support. Think about the structures required to oversee a large volunteer workforce in the future, specifically one that delivers care.\(^{(10)}\)

1.3. Engage in strategies that ensure the future sustainability of the hospice.
- Consider new ways of working that allow provision in a more focused way.
- Consider opportunities for new strategic collaborations and partnerships using the toolkit developed by the Commission.
- Consider how the allocation of resources might be amended to allow investment in new services.

### Recommendations for other organisations

#### National organisations supporting hospice care

1.4. Establish a programme of support for hospices to help them establish local workforce plans and to share good practice concerning the development of new roles. Identify roles that would benefit from review and development such as the role of the clinical nurse specialist.

1.5. Support hospices in their work of anticipating the future through scenario planning and guidance about how they examine their population’s needs and the degree to which they meet them.

1.6. Find opportunities to develop strategic planning skills in the hospice workforce, including board members.

1.7. Work with hospices to explore opportunities for a national campaign to promote the value of hospice volunteering with a view to recruiting new and different volunteers.\(^{(10)}\)

1.8. Work with hospices to establish a national training programme for volunteers, drawing on existing good practice in hospices. Such work could extend to nationally generated guidance for volunteers to promote safe and effective involvement.\(^{(10)}\)

1.9. Establish a national programme to support innovation in volunteering, spanning new roles for volunteers and new ways of organising them, identifying good practice and encouraging its replication by others.\(^{(10)}\)

1.10. Promote research in hospice volunteering that will establish an evidence base regarding the effectiveness and cost-effectiveness of innovations and models of care engaging volunteers.\(^{(10)}\)

### Health and Wellbeing Boards in England and local councils in Scotland, Wales and Northern Ireland

1.11. Examine the implications of the growing demand for palliative and end of life care within their local communities, and the role that local hospices can play in responding to them.

#### Commissioners of hospice services

1.12. Engage with local hospices in the planning and design of services to meet palliative and end of life care needs and carefully consider the consequences of competition in health care commissioning on the stability of local hospices.

### Government departments charged with workforce development

1.13. Invest in the hospice and palliative care workforce so as to ameliorate the potentially negative effects of anticipated future shortages.\(^{(16)}\)
Step Two

Strengthen understanding of the contribution of hospice care

This is a call for hospices, their leadership organisations, and other players, including academic centres, to work together to establish a clear and evidence-based description of the role that hospice care plays in supporting people with life-shortening conditions, their families, carers, communities and broader society.\(^{(5)}\)

Achieving this step will require hospices to provide clear information for potential users that clarifies referral criteria and processes, confirms what care is available, and tells an evidence-based story in relation to anticipated outcomes and the degree to which they are achieved.

To do this it is vital that the evidence base for hospice care is strengthened significantly. This will require investment and engagement in the activities of research and audit, with greater attention on outcomes of care. The evidence base cannot be established without significant improvement in the processes of data collection, reporting and interrogation about the services provided by hospices and their costs.\(^{(17)}\) It also requires close attention to the detail of data collected and how this is reported. For example, data is available to describe deaths in hospice but much less about ‘hospice-supported’ deaths at home, even though this constitutes the majority of care currently provided by most hospices.

The Commission believes that hospices need to share a clear narrative about what they do and what difference they make. Hospices must be clear about how hospice care is funded and how money from the NHS and from individual donation is used.\(^{(5)}\)

Although difficult to achieve, the Commission believes that all hospices and their national leadership bodies must share core elements of this story. In this way, key messages about hospice care that are used nationally will be consistent with local understandings and vice versa. Achieving this virtuous circle between local and national voices will help create a widespread understanding of the modern contribution of hospice care.\(^{(34,35,31,30)}\)

**Recommendations for hospices**

2.1. Establish a strong, transparent story about the work of the hospice, its activities and care, how it is funded, who can access it and how.\(^{(5,14)}\) Emphasise the expert nature of the care provided by the hospice, its high level of specialism and broad range of skills and its contribution to care in a wide variety of settings.

2.2. Engage with other hospices and national organisations supporting hospices to identify a shared story about hospice care that can be promoted locally, regionally and nationally.

- Identify areas of work where a collective message from the sector as a whole would help develop influence, support and understanding locally.

2.3. Strengthen the evidence base of the care you provide. Engage in processes of data collection, interrogation and reporting; invest in more audit, including that related to outcomes of care.\(^{(4)}\)

- Ask whether your current data collection and analysis helps you plan and improve your services, identify areas of risk or inefficiency or clarify how you perform in relation to other hospices.

- Consider opportunities to work in partnership with other local hospices to share resources and expertise and generate better data.\(^{(15)}\)
2.4. Establish or revisit your strategy for research and evaluation, identifying current activity and future aspirations and objectives as well as the necessary staff training and the resources that you are willing to invest. (17)

- Identify local, regional or national opportunities for partnerships that would help you achieve greater engagement in research and evaluation.
- Develop research champions within the organisation and identify those activities that will promote the culture of curiosity and inquiry within which research and evaluation can flourish. (17)

2.5. Invest in the development of systems and processes to support the collection, reporting and interrogation of data pertaining to care provided, what it achieves and what it costs. (6)

Recommendations for other organisations

National organisations supporting hospice care

2.6. Establish a story that is shared with local hospices and can be used by all players in hospice care. Consider leadership of campaigns that promote a strong evidence-based story about the role of hospice care and its impact.

2.7. Promote research on the part of hospices as a marker of high-quality services.

2.8. Invest in programmes that support research and audit in hospices. (17)

2.9. Work with other national organisation to strengthen and share data regarding the provision of palliative care.

2.10. Establish a new national initiative that encourages hospices to collect and share data regarding activity, costs and outcomes. Aggregate and report nationally.

2.11. Nurture regional and national networks and relationships that encourage research in hospices. (17)

2.12. Build a case for presentation to government and national research organisations for funding to support hospice-based research. (17)

2.13. Find a national solution to the burden of local indemnity on the part of hospices related to research. (17)

Academic centres

2.14. Engage with local hospices to establish long-term relationships that support shared costs, resources and aspirations. Create relevant new structures to support these relationships. (17)

NHS and other funders of research

2.15. Recognise the gap in evidence that exists regarding the effectiveness and cost-effectiveness of hospice care and establish new funding streams in response.
Step Three
Establish hospice care as a solution to future challenges in palliative and end of life care

Hospice care needs to be seen as having an important part to play in addressing future challenges; in particular those faced by government, local planners, commissioners and local people around future provision of palliative and end of life care.\(^{24}\) It is important that hospice care is seen as a significant part of the answer to many future challenges presented by the future.\(^{11}\)

To achieve this step, hospices need to acknowledge their important role in developing new and innovative models of care, providing education and training, and advocating for those living with or dying from life-shortening conditions. They will want to draw heavily on their relationships with their local communities and users to ensure a process of co-design and production of future services.\(^{6}\)

Hospices need to build those aspects of their work that are most pertinent to the future. For example, they will want to consider increasing their role in education and training and give further thought as to how programmes might be made available to a wide variety of professionals and carers as well as patients, their families and carers.\(^{12}\) They will also want to focus on particular areas of palliative and end of life care that are currently under-developed. Developing further work on how to support family carers in their vital role is one such area where a significant and positive impact could follow a modest investment.\(^{7}\)

Recommendations for hospices

3.1. Establish new ways of providing care to new groups of users. Invest in innovation and service development to help ensure that new needs for palliative and end of life care are addressed in an effective way. Identify sources of funding to support hospice-led innovations in response to new needs.

- Be active in finding and implementing ways to use technology to increase accessibility, timeliness and flexibility of palliative and end of life care for people at home or in similar settings.

3.2. Engage in new clinical and other partnerships that help the hospice to deliver seamless and appropriate care fit for the future.\(^{5}\)

3.3. Find opportunities to use in-house knowledge and skills to explore local challenges.

- Engage with local health and wellbeing boards, or other relevant decision makers, to inform their agendas and plans.
- Engage with local care commissioning groups, offering help to develop local plans for palliative and end of life care.

3.4. Develop and invest in hospice-delivered education and training. Find new ways to deliver it and new markets seeking training in end of life care.\(^{12}\)

- Identify new opportunities to deliver education and training to a range of professionals and other carers who will need end of life care skills in the future.\(^{12}\)
- Consider opportunities to educate the expert patient and their families and carers. Engage with them to understand what kind of skills they would like to develop and how they wish to access this learning.\(^{12}\)
Engage with other hospices to explore opportunities for sharing the development of new educational products.\(^{(12)}\)

3.5. Identify marketing opportunities that help confirm your contribution to the development of palliative and end of life care services locally and build on your profile as a key player in the future provision of care.

Seek out and use data to understand better how you are perceived locally and what contribution other local stakeholders believe you make to meeting local palliative and end of life care needs.

Strengthen your image as innovative, can-do, and a good partner. Ensure that you understand your current users and those who will use hospice services in the future, engaging all the local communities that you need to serve.

Collect and report on data regarding the reach and impact of your care in order that this can be regularly communicated to local commissioners and planners.

3.6. Engage proactively in improving care and support for family carers with due attention to their needs as experts.

3.7. Promote hospices as a vital part of society’s response to the need for compassionate care, particularly in hospitals.\(^{(24)}\) Identify opportunities to influence care through involvement in training of hospital-based staff.

3.8. Contribute to the establishment of a confident collective voice that can further the ambitions of hospices to influence local and national plans for end of life care.\(^{(5)}\)

3.9. Create national partnerships that will be essential in developing new approaches to care.

3.10. Find early adopters to take forward new initiatives, led nationally and delivered locally.

3.11. Engage in a programme of learning about the future role of technology in hospice care in order that hospices can lead on this particular area of innovation. Identify areas of good practice within and beyond the sector, support their evaluation and the replication of best practice by others.

3.12. Promote local developments to better support family carers, with due consideration to the need for an improved evidence base in this area of work.

Commissioners of hospice services

3.13. Invest in hospice-led innovations to establish palliative and end of life care that is fit for the future.


NHS England and government departments in Scotland, Wales and Northern Ireland

3.15. Support the development of the evidence base related to the provision of end of life care as a basis for future models of care.

Government departments charged with workforce development

3.16. Recognise and invest in the role that hospices play in workforce education and training.\(^{(12)}\)

Recommendations for other organisations

National organisations representing hospice care

3.7. Promote hospices as a vital part of society’s response to the need for compassionate care, particularly in hospitals.\(^{(24)}\) Identify opportunities to influence care through involvement in training of hospital-based staff.

3.8. Contribute to the establishment of a confident collective voice that can further the ambitions of hospices to influence local and national plans for end of life care.\(^{(5)}\)
If hospices are to meet the ambitions of improving end of life care for all who need it, hospices have to work in a joined up way with the services around them and use their voice and credibility to influence the pattern of services in the round, working to ensure that high-quality care is available in all settings and to all those in need. In short, this will require a greater degree of integration between the work of the hospice and the work of others particularly in local health and social systems. (38,39,30)

As part of this, hospices will need to consider partnerships. These will be essential if hospices are to respond to the needs of people living with life-shortening illness. They will be essential if hospices are to continue to meet rising demand with diminishing resources. These partnerships might be valuable not only when they can improve care or increase efficiency but also when they can help hospices operate at sufficient scale for commissioners to consider them as the providers of choice for end of life care. (15)

Hospices should continue to invest in their relationships with their local communities. This is one of their unique strengths and it enables them to sustain their role as advocates and campaigners, to make the most of the contribution of volunteers and create opportunities for community participation and the involvement of local people in designing approaches to care that will work in the future. We are keen that hospices recognise that community engagement is more than fundraising and the use of volunteers; it is also about asking people in the community to work with the hospice to influence future services. This work will be important if the hospice is to continue to deliver services that are responsive to the needs and aspirations of local people.

We urge hospices to engage in a conversation with the general public about what it wants and needs at the end of life, and what solutions it would generate in response to the challenges of the future concerning increased need, limited resources and changing public expectations. This will allow hospices to advocate powerfully for services that reflect the preferences of users, services that can improve their experience and services that can lessen the suffering associated with dying and bereavement.

**Recommendations for hospices**

1. Establish the hospice as a vital component of the local health and social care economy.
   - Work with members of your multi-disciplinary care team to identify health and social care professionals with whom you are likely to need to work in order to extend care to new groups of people. (5)
   - Use the toolkit developed by the Commission at Board and senior management levels to consider other partnerships that may be beneficial. (15)
   - Review the scope of current services – who uses them and whether they are used to full capacity. Similarly, consider your physical space and identify areas of the hospice that are underused and could be made available to other local services.
   - Find ways to encourage innovation and service development on the part of your clinicians – providing them with time and resource to do this important work.
   - Seek opportunities to engage in local discussions regarding future plans for palliative and end of life care.
4.2. Continue to engage with, and develop relationships with local communities.

- Identify opportunities for involving local people in designing services with the specific aim of matching future needs.
- Seek opportunities to hold conversations with local communities about their experiences and aspirations for end of life care.\(^{(3)}\)
- Nurture your relationships with local groups and their leaders. These will be important in supporting efforts to recruit new volunteers and other initiatives that call for community involvement.

**Commissioners of hospice services**

4.8. Work with hospices as local providers and funders of care to identify local priorities for action.

4.9. Ensure that hospices are included in information and data sharing arrangements.

4.10. Work with hospices to enable them to extend the reach of their services (e.g. improving referral pathways).

**NHS England**

4.11. Encourage commissioners to work together and collaborate in the commissioning of hospice care services (encouraging hospice collaboration and possible merger).

**Hospitals**

4.12. Explore partnership approaches with hospices to better meet people’s needs at the end of life that reflect relevant emerging guidance, for example that which relates to the interface between hospitals and community based services.\(^{(27)}\) Consider their role as providers of education and training, as experienced providers of coordinated care, and in the development of seamless provision.

**Other end of life care provider organisations (in the public or private sector)**

4.13. Explore opportunities for collaboration with hospices in the furtherance of common objectives to ensure that people get the best possible care at the end of life.

**Recommendations for other organisations**

**National organisations supporting hospice care**

4.3. Model an approach of integration and partnership working with others engaged in health and social care on issues relevant to hospice care at national level.

4.4. Provide national leadership regarding models of community engagement for hospices that are fit for the future, identifying good practice and supporting its replication.

4.5. Support the development of an evidence base for community engagement activities.

4.6. Seek the views of users and of the general public about hospice care, and ensure that they shape future development of hospice care.

**Local authorities**

4.7. Involve hospices in the development of joint strategic needs assessments to meet the growing demand for palliative and end of life care.
Step Five
Strengthen the leadership of hospice care

The Commission is clear that major investment is required at local and national levels to strengthen strategic leadership within the hospice sector. Hospices need to become bigger organisations with more influence in the wider health and social care system.\(^{(5)}\)

Achieving this objective will require a leadership cadre that is politically adept, able to influence and comfortable with a high profile within their sphere of influence. This kind of leadership needs to exist at all levels within hospices and it must be evident in the behaviour of trustees, chief executives, clinicians, managers, staff and volunteers.\(^{(5)}\) Specific areas for increased leadership identified by the Commission include fundraising, research and education and training. Strong leadership is also important in the area of risk management, which must be more sophisticated in the future, both in terms of its assessment and its management.

This leadership is also vitally important at national level, within and across national organisations engaged in the support of hospice care. It is essential to establishing a strong and collective voice and one that can influence governments and policymakers. The national leadership of palliative, end of life and hospice care is crowded and somewhat confused. Further discussion is required to confirm how the current national bodies can best work together as well as independently to achieve improved care for patients, their families and carers.

In the meantime effective national leadership is required to bring together and build upon the significant contribution made by many individual hospices working at local level to support greater hospice collaboration and joint learning.

Recommendations for hospices

5.1. Identify potential leaders in the hospice who could benefit from nurture and development within and beyond the organisation.
- Identify individuals within the organisation who would benefit from additional support to become effective leaders. Recognise emerging requirements for strong leaders in areas of fundraising, education and training, research and risk management.
- Encourage the involvement of staff in external meetings and groups in order that they can develop an outward-facing perspective.
- Engage in succession planning with attention to all significant leadership roles within the organisation.

5.2. Invest in leadership training for staff and volunteers.\(^{(5)}\)
Recommendations for other organisations

National organisations supporting hospice care

5.3. Invest in more leadership training – that reaches greater numbers of people and promotes specific skills associated with the challenges and opportunities of the future.\(^{(3)}\)

5.4. Support leaders at local and national levels through coaching, networks and action learning sets.\(^{(3)}\)

5.5. Continue to facilitate a collective voice on issues that confirm the leadership role of hospices. Consider together how this collective voice could be strengthened and identify topics where collective action is likely to produce a greater impact.

5.6. Identify opportunities for streamlining and clarifying the different roles that the various organisations engaged in national leadership of palliative, end of life and hospice care hold in the future.
There are some aspects of the future of hospice care which require further attention; namely the use of technology in the delivery of care, the economics of hospice care, whether there are opportunities for users to pay for hospice care and how leadership of the sector can be shaped to be more effective. The Commission is keen that national hospice organisations take these areas of work forward, with the same energy and vision that has characterised their contributions to the work described in this report.

However, as the Commission’s work draws to a close it is right to reflect on the act of establishing the Commission in the first place. Anyone who works in the care sector knows that processes of inquiry and investigation into different sectors of health and social care system abound. However, such reports are usually imposed or follow close upon the heels of exposed poor practice.

This process of reflection and inquiry was initiated by the sector itself. The Commission has been completely independent of thought and has been encouraged to be challenging in its thinking. The Commission considers this an act of leadership on the part of Help the Hospices which established and have supported the work of the Commission.

This report represents the end of the Commission’s work, and its members are pleased to formally present their conclusions to Help the Hospices, to hospices and to others with a stake in the future of hospice care. The Commission hopes that Help the Hospices, together with other hospice care leaders (individuals and organisations) will work together to further develop and promote its thinking and recommendations.

The Commission urges hospices and others to give thoughtful consideration to the next steps that it proposes. It hopes that its work will catalyse a process of adaptation, energy, and change. The willingness of national organisations and individuals, professional associations and hospices to talk openly and think differently has led the Commission to be optimistic about the future. It urges that this open approach is maintained.

Ensuring the future of hospice care will require innovation and disruption but the Commission is firmly of the belief that the rewards are substantial for hospices, the hospice sector and most importantly for those who deserve the really good care that hospices deliver, with compassion and confidence at the end of people’s lives.
Appendix 1: Preparing for the future: a checklist for Boards and senior management teams

Recognising opportunities and challenges in the local environment

Understanding the local demographics
- Do you know what the current needs of your population are in relation to end of life care?
- Have you considered how these are likely to change in the next 10 years?

Knowing more about your current reach
- How much do you understand about the gap between the needs of your population in relation to end of life care, and the degree to which you meet them?
- How much do you know about those living in your locality who could benefit from your services but don’t currently use them?

Understanding your local systems of care
- How much do you know about your local stakeholders – across health and social care and beyond? What do they know and understand of your service? Do you have shared goals and could you work together to achieve them? Given the changing picture of end of life care in the future, who else needs to be considered as stakeholders?
- How closely do you work with your neighbouring hospices to deliver highly specialist services, share backroom services, market your services to local people and train local providers in aspects of hospice care?

Engaging with local academic networks and centres
- What relationship do you have with your local academic science network or academic centre for the purposes of supporting research?

Understanding your users and engaging them in service development
- What quality of dialogue do you have with current and future users of your service? Do you know what they do and don’t want from you currently and in the future?
- How engaged are they in co-design of services?

Knowing your local communities and engaging them in the support and delivery of care
- How well do you know the make up of your local communities, their leaders and any specific preferences for end of life care?
- How engaged are they in the co-production of services for local people?
- To what degree have you maximised their contribution to your hospice in terms of volunteering, fundraising, participation in care and similar?
- Is there more funding to be found from them given the right ask?
- Are there new sources of local funding currently untapped?

Identifying and galvanising internal capacity and capabilities to respond to future opportunities

Establishing a corporate vision for the future of your service
- To what degree is the vision of the future of your hospice shared by the Board, the hospice staff team and its volunteers?
- How confident would they be to describe the corporate aspirations for care in the future?
- To what degree does the Board, senior managers and wider workforce in your hospice share a vision and clarity about the overall purpose and reason for being of the organisation?
Knowing how prepared you are to meet new needs and preferences

- To what degree are your models of care changing in order that your services are appropriate for emerging groups of new users or existing users with changing needs?
- Is there a live conversation about a different accommodation between quality and quantity in the development of new models of care?

Establishing systems to strengthen the evidence base for what you do

- To what degree are you confident that you are collecting the right data about the care patients receive to enable you to assess reach and impact?
- How research active are you as an organisation? Would you like to be participating more in research and to what degree?
- How confident are you that what you are doing works? To what degree is your care evidence-based? Could the evidence base be stronger and how could you be contributing to it?

Establishing systems to critically review the care that you receive

- How confident are you in measuring outcomes and impact?

Knowing where you could find savings to invest in new services?

- Do you know how much your specific services cost per person using them? How do these costs compare to others?
- How much consideration have you given to services you might reduce or close to free up resources to meet more pressing needs?
- Are there opportunities to work in partnership with other hospices or local organisations to share costs or invest jointly in new services?

Understanding your human resources

- How flexible is your workforce in response to new needs and preferences? To what degree are they able to focus on tasks, rather than roles in the future?
- To what degree does the skill base of staff reflect new opportunities to deliver care and run the business of hospice care differently?
- To what degree are your volunteers engaged in the direct delivery of care?
- Is the training you provide for staff and volunteers preparing them to work differently in the future?

Understanding the capacity for leadership and innovation in your organisation

- How confident are you that the leaders of the future are being developed in your teams currently? Who will be able to drive forward significant developments in the care and business of hospice care?
- Is leadership and leadership development undertaken at all levels in the hospice, to increase strategic awareness and flexibility?
- Does your process of resource allocation allow for investment in innovation?
Appendix 2: Members of the Commission

**Chair**

**Dame Clare Tickell**  
Chief executive, Action for Children

**Harry Cayton OBE**  
Chief executive, Professional Standards Authority

**Jonathan Ellis**  
Director of policy and advocacy, Help the Hospices

**Baroness Ilora Finlay**  
Doctor, professor of palliative medicine, and an independent crossbench member of the House of Lords

**Penny Hansford**  
Director of nursing, St Christopher’s Hospice

**Claire Henry MBE**  
Head of programmes for long term conditions and end of life care NHS Improving Quality

**Peter Holliday**  
Group chief executive, St Giles Hospice

**Robin Knowles CBE, QC**  
Chair, Richard House Children’s Hospice Chair, Together for Short Lives

**Dr Jonathan Koffman**  
Senior lecturer in palliative care, Cicely Saunders Institute, King’s College London

**Vice-chair**

**Dame Barbara Monroe**  
Chief executive, St Christopher’s Group

**Dr Mayur Lakhani**  
Chairman, National Council for Palliative Care, general practitioner and a clinical commissioning group (CCG) board member

**Dr Fliss Murtagh**  
Clinical senior lecturer and consultant in palliative care, Cicely Saunders Institute, King’s College London

**David Praill**  
Chief executive, Help the Hospices, co-chair of the Worldwide Palliative Care Alliance and chair of ehospice

**Joe Saxton**  
Driver of ideas at nfpSynergy and founder

**Professor Jane Seymour**  
Professor at Sue Ryder Palliative Care Centre, University of Nottingham

**Dr Teresa Tate OBE**  
Consultant in palliative medicine and former medical adviser to Marie Curie Cancer Care

**Sarah Whitfield**  
Former chief executive of Dorothy House Hospice
The members of the Commission and Help the Hospices offer thanks to members of the Commission Support Team: Heather Richardson, Steve Dewar and Laura Hamblin for their work over the last two years. The team, led by Heather, has been responsible for the organisation of the Commission’s activities, publications and considerations. They have provided a programme of events for hospices and other stakeholders. In addition they have produced an array of publications, culminating in this final report, written by Heather and Steve. Their productivity and commitment is to be commended.

We extend thanks to all the hospices which participated in our campaign to capture the experience of hospice users in December 2012 and to those hospices and organisations who have hosted events on our behalf to help disseminate our learning.

We appreciate the participation of the many hospices and hospice staff in the events conducted by the Commission as well as the engagement of representative organisations across the four nations that has enabled the Commission to hear important messages from a wide variety of individuals and groups with a stake in hospice care: the All Ireland Institute of Hospice and Palliative Care, The Scottish Hospice Forum, Together for Short Lives, The Association of Day Care Leaders, the Association of Palliative Medicine, the Executive Clinical Leads in Hospice and Palliative Care, the Association of Volunteer Services Managers, the National End of Life Care Programme Facilitators, Hospices Cymru, Marie Cure Cancer Care, Sue Ryder, the National Association of Palliative Care Educators and many independent and NHS hospices.

The Commission has only be made possible through the generous funding on the part of supporters of Help the Hospices: The National Garden Scheme, Allianz Insurance, Towergate Charitable Foundation, Clydesdale Bank and Yorkshire Bank, and Hope for Home.

The support and wisdom provided by Barbara Monroe as vice-chair has been invaluable to both of us. We are, of course, indebted to all of the other members of the Commission, also, who have generously given of their time and have brought intelligence, integrity and commitment to the table.

Dame Clare Tickell,
Chair of the Commission

The Rt. Hon. Lord Howard of Lympne, CH, QC, Chair of Help the Hospices
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“I hope our work will remind all hospice leaders of this mission, persuade them to reinstate their ambition and encourage them to grasp opportunities that lie ahead.”

Dame Clare Tickell,
Chair of the Commission
Help the hospices is the charity for hospice care representing local hospices across the UK and supporting the development of hospice and palliative care worldwide.