Review of the work and impact of the Commission into the Future of Hospice Care

July 2016
About this report

The Commission into the Future of Hospice Care was established in 2011 by Hospice UK (then called Help the Hospices) in order to “provide guidance, information and options for hospices with the aim of informing their strategic position and support in addressing the changing and growing needs of their local communities” (‘Preparing for the future: key operating principles’, Commission into the Future of Hospice Care, 2012). The Commission undertook a two-year work programme and produced 16 different reports and working papers before the publication of its final report, ‘Future ambitions for hospice care: our mission and our opportunity’, in October 2013.

The Commission represented a major piece of work on the part of Hospice UK, with significant financial investment and input on the part of trustees, executive staff and member hospices. Two years after the Commission’s final report, Hospice UK’s Board of Trustees agreed that it would be timely to review the impact for our member hospices of the Commission’s work. The review was conducted for Hospice UK between January and March 2016 by Heather Richardson, working as an independent consultant. This report describes the review and its findings.

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Heather Richardson
This review of the Commission’s reach and impact is a timely and welcome piece of work, and will be of value in assisting Hospice UK as it plans its work in the future. The review drew on a survey, interviews and limited documentary analysis. It focused on five domains, achievement against which has been assessed and is described below:

<table>
<thead>
<tr>
<th>Domain name</th>
<th>Description</th>
<th>Assessment of success</th>
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<tbody>
<tr>
<td>The reach of the Commission</td>
<td>The number of member hospices who were aware of the Commission.</td>
<td>High – 93% of all who responded to the survey confirmed they were aware of the Commission. At least 76% of all member hospices were aware of the Commission when survey results and details of hospices who engaged in the Commission during its lifetime are combined.</td>
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<tr>
<td>Adoption of learning</td>
<td>The proportion of hospices who drew on the publications to inform their work and thinking.</td>
<td>High – 89% of survey respondents who knew of the Commission had referred to Commission publications. Downloads of such publications are over 28,000.</td>
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<tr>
<td>Implementation of recommendations</td>
<td>The extent to which hospices have done things differently in response to Commission intelligence.</td>
<td>Medium/High – 86% of survey respondents who knew of the Commission had used the intelligence to guide their plans and future development. In the main this has focused on guiding their strategic direction.</td>
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<tr>
<td>Maintenance</td>
<td>The extent to which hospices and the hospice sector have sustained interest in the Commission’s learning.</td>
<td>Medium/Poor – Many hospices have “forgotten” the Commission recommendations in the course of the last two years, despite finding them of interest and useful at the time of their publication.</td>
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<tr>
<td>Satisfaction</td>
<td>The extent to which member hospices were pleased with the work of the Commission.</td>
<td>High – Only 14% of all who responded to the survey experienced any disappointment in relation to the Commission. The reasons for the disappointment are variable. Positive feedback and thanks were received from many others who responded.</td>
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A number of key themes emerged:

1. The majority of hospices who engaged in the Commission placed high value on its work.

2. The degree to which hospices engaged in the Commission was variable as a result of a number of different factors.

3. Some hospices who were initially disengaged were encouraged to engage by a third party during the course of the Commission.

4. Some hospices valued the intelligence generated by the Commission but failed to integrate it into their thinking and plans due to local demands and limitations.

5. Many hospices, even those that highly valued the learning of the Commission, have failed to establish or implement long-term plans for change as recommended. Some members feel this outcome would have been different with sustained input from Hospice UK.

6. Some hospices that invested time and effort in planning change demonstrate changes in models of care, behaviours and reach. It is too early, however, to assess the full impact.

7. The opportunities raised by the Commission are still considered to be pertinent by many hospices. They would like Hospice UK to help them re-engage and enact the changes required to take hold of them.

8. Members also identified new areas of work that would benefit from sustained and significant input on the part of Hospice UK, namely performance indicators, new ways of generating income/reducing expenditure and becoming more efficient, and the shape of the workforce in the future.

9. Hospice UK can learn from the experience of the Commission and build on it, particularly around how it draws on expertise and help from its members and partners in the future, the focus and ambition of future projects, and the support required by its members to sustain related interest and change.

10. The highly variable responses to the Commission highlight the significant diversity of the members of Hospice UK. It is clear that, as Hospice UK considers how it serves its members in the future, “one size does not fit all”. Opportunities exist to segment the membership and adjust offerings accordingly.

Many of those who took part in the survey or interviews were grateful for the opportunity to help review the Commission and described an optimism about their future relationship with Hospice UK arising from its new leadership. Hospice UK is invited to respond in a similar vein, giving due consideration about how it reconnects its members to pertinent themes initiated by the Commission and supports them to achieve changes that position hospices well for the future.
This document describes the findings of a piece of work commissioned by Hospice UK to assess the reach and impact of the Commission into the Future of Hospice Care (hereafter referred to as ‘the Commission’). The Commission was initiated in 2011 and, as described in its first publication (‘Preparing for the future, key operating principles’, 2012), set up to “provide guidance, information and options for hospices with the aim of informing their strategic position and support in addressing the changing and growing needs of their local communities”. A comprehensive body of literature was produced which resulted in the final report ‘Future Ambitions for hospice care – our mission and our opportunity’ in October 2013.

The Commission represents a significant piece of work on the part of Hospice UK – demanding significant financial investment and input on the part of trustees, executive staff and member hospices. The detail of the work of the Commission and its outputs has been reported to the board of Hospice UK in the past (board meeting September 2013). Extracts of that paper which describe the scope of the work undertaken and the extent of engagement of hospices up until that time are included in Appendix 1 for ease of reference.
Approach to assessing the reach and impact of the Commission

The following activities were undertaken between January and March 2016 to arrive at the findings described in this report regarding reach and impact of the Commission:

1. An online survey of all member hospices seeking feedback regarding their utilisation of the learning and recommendations of the Commission. Feedback was encouraged from those who did not engage in the Commission or its findings as well as those who confirmed that they did. Feedback was also encouraged from people who were disappointed in the Commission as well as those who were pleased with it, or indifferent to it. In so doing, we hoped to gain a spectrum of views. In total, 181 responses were received. Responses were received from member hospices in three of the four UK nations, and from all 10 regions in England. Northern Ireland was only represented in feedback from national organisations. The returns represented the views of individuals from 109 member hospices (adult and children’s) representing a 50% response rate. They were completed by a mix of trustees, CEOs, and other senior managers including a small number of clinicians. We received responses from more than one person from some hospices. Notably we received no feedback from Marie Curie hospices.

Figures 11, 12, 13 and 14 in Appendix 2 provide details of who completed the surveys. The locations of the hospices that were represented in the survey are identified in the map on page 6 (Figure 1). Appendix 3 provides a list of the questions asked.

2. Ten interviews with individuals who completed the survey and indicated something of interest requiring further investigation and understanding. Efforts were made to speak to people who saw the Commission as highly valuable, plus those who felt it to be of little or no value and those who thought it had been of mixed value, and to ensure a mix of trustees and senior managers (clinical and non-clinical). A list of the interviewees is included in Appendix 4.

3. Seven interviews (telephone or face to face) with leaders in the sector and other stakeholders who could highlight value and areas for further work. These included the National Clinical Director for End of Life Care and other leaders of major charities.

4. Review of documentary evidence that focused on the impact of the Commission. This included a number of related Masters dissertations, ehospice articles and other papers identified through a literature review.

5. A review of the downloads of Commission reports from the Hospice UK website.
Figure 1: Map of 2016 survey respondent hospices
Results and findings

The success of the Commission is considered in this report in relation to the following domains:\(^1\):

**Reach** – defined as the number of member hospices who were aware of the Commission, including those who participated in some of its events or considered its learning.

**Adoption** – defined as the proportion of hospices who have drawn on the content of Commission publications to inform their work and thinking.

**Implementation** – defined as the extent to which hospices have done things differently as a result of the outputs of the Commission.

**Maintenance** – defined as the extent to which individual hospices and the sector as a whole have sustained interest in the opportunities and challenges arising from the Commission, and continued to change their ways of operating as a result.

**Satisfaction** – defined as the extent to which members of Hospice UK were pleased with the work of the Commission and felt it to be consistent with their expectations of Hospice UK as a member organisation.

In this piece of work, the **efficacy** of changes and developments is not considered. It is unlikely that the kind of outcomes that could be anticipated arising from the Commission would have been achieved within two years of the final report.

The reach of the Commission

The reach of the Commission has been considered in relation to:

1. The number of hospices that engaged in the learning of the Commission during the course of its lifetime. This means that they either attended one or more events dedicated to exploring the emerging thinking of the Commission, or they participated in one of its activities, such as a postcard campaign to capture the views of people using their hospice.

2. The number of hospices who responded to the survey and confirmed that they were aware of the Commission or its publications.

3. How the composition of both these groups compares to the total number of member hospices of Hospice UK.

In the course of the Commission, 153 hospices engaged in events or activities related to its work\(^2\). As Figure 2 shows, a proportion engaged in more than one activity.

In the subsequent survey, 93% (170/181) of all who responded confirmed that they were aware of the Commission and its publications. Those who responded positively in this regard were drawn from across most of the UK and its different regions. They also represented a mix of children’s and adult hospices. Figures 3 and 4 on pages 8 and 9 describe the proportion of those aware of the work of the Commission as a proportion of the total number who could have responded to the survey.

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\(^1\) These domains reflect an evaluation framework: Reach Effectiveness Adoption Implementation Maintenance (RE-AIM). Glasgow et al 1999. Adapted for the purposes of this piece of work.

\(^2\) These numbers and details exclude events that ran in Wales, Scotland and Ireland at which the Commission findings were discussed. These events were put on by separate organisations, and the Commission executive team and Commission members invited to attend.
Figure 2: Hospice UK member engagement with the work of the Commission

- Participated in at least three Commission related activities
- Participated in at least two Commission related activities
- Participated in at least one Commission related activity

Figure 3: Awareness of the work of the Commission and/or its publications by region (2016 survey)

- Hospice UK members
- Aware
- Unaware
- No response
What is interesting to note is that the vast majority of hospices (84%) who contributed to the 2016 survey had also been involved in the Commission during its lifetime; in fact the survey only draws on the views of an additional 17 hospices. Also interesting to note is that 41% (62/153) of hospices who were involved in the Commission’s work during its lifetime didn’t take part in the survey.

Most importantly, only 53 Hospice UK members out of a possible 223 are not represented in either the survey or the work of the Commission in its lifetime. This means that the work of the Commission was known to at least 76% of all the members of Hospice UK. Figures 5 and 6 on page 10 describe the engagement with the Commission by geography and beneficiary type of Hospice UK members.
Figure 5: Engagement with the work of the Commission and/or its review by geographical location of member hospices (2016 survey)

- Northern Ireland
- Wales
- Scotland
- Yorkshire and Humberside
- West Midlands
- South West of England
- South East of England
- South Central England
- North West of England
- North East of England
- London
- East of England
- East Midlands

Hospice UK members

- Involvement with the work of the Commission and/or its review
- No involvement with the work of the Commission and/or its review

Figure 6: Engagement with the work of the Commission and/or its review by beneficiary group of member hospices (2016 survey)

- Adult
- Children
- Combined

Hospice UK members

- Involvement with the work of the Commission and/or its review
- No involvement with the work of the Commission and/or its review
There is evidence that this level of reach may only have been achieved by the involvement of other organisations who served as a broker for members at risk of being marginalised. By way of example, a tension existed in the early life of the Commission about the degree to which its work would attend to the issues facing children’s hospices. By the same token some children’s hospices expressed scepticism about the degree to which the Commission’s learning would be of relevance to their work and challenges. Efforts were made by the Commission to consider issues pertinent to children’s hospices and to engage them, but involvement by children’s hospices in Commission events was relatively limited until Together for Short Lives and the Commission jointly hosted an event in London towards the end of the Commission at which the Commission’s findings were introduced and discussed.

A high proportion of children’s hospices attended that event at the invitation of Together for Short Lives and were encouraged to apply the learning to their context. The same organisation published a report following the event, which according to some of the interviewees has proved highly valuable.

Another example was an event hosted by Kirkwood Hospice, to which it invited other local hospices and their commissioners. Most of the senior managers who came together for that event were individuals who had previously not attended any other Commission events. This event was identified as the moment where one of the interviewees recognised the value of the Commission for her organisation and new opportunities in response.

Adoption

There can be no doubt that many hospices, as well as a variety of other organisations and individuals, have been interested in the learning and recommendations of the Commission. A total of around 28,000 Commission documents have been downloaded from the Hospice UK website over the course of the last four years. The breakdown of this number by report and also by month over the course of the last four years is described in Figure 7 and Figure 8 on pages 12 and 13.

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3 This figure may not be entirely accurate due to a change in website and related analytics in the course of 2014, but it is a useful indicator.
Figure 7: Total downloads of Commission resources

- The role of hospices in supporting young people in the transition from children’s to adult services: 350 downloads
- Volunteers: vital to the future of hospice care: 436 downloads
- Learning more: patient and family feedback: 457 downloads
- The role of hospices in supporting people with a diagnosis of dementia in the future: 537 downloads
- The future of the clinical nurse specialist delivering end of life care in the community: 597 downloads
- Supporting family carers: 785 downloads
- Research in palliative care: can hospices afford not to be involved?: 819 downloads
- Maximising the contribution of the palliative medicine consultant to meet the future opportunities for hospice care: 829 downloads
- Collaboration toolkit: 1116 downloads
- The future of hospice education and training: 1179 downloads
- Working towards a hospice workforce that is fit for the future: 1322 downloads
- Preparing for the future: key operating principles: 1565 downloads
- Strength in numbers: 1621 downloads
- Future needs and preferences for hospice care: challenges and opportunities for hospices: 2856 downloads
- Future ambitions for hospice care: our mission and our opportunity: 5613 downloads
- Current and future needs for hospice care: an evidence based approach: 7979 downloads
The significant interest in the evidence based report on levels of future need produced by the Cicely Saunders Institute is striking. In the course of the discussion hospices expressed particular pleasure in receiving information from Hospice UK that collates complex data and learning from a variety of sources and describes its implications for hospices in a way that facilitates easy application to local context. This could be one reason why the work of the policy team at Hospice UK was repeatedly praised by interviewees – on the grounds that its outputs clearly describe emerging policy and plans on the part of Government and the implications for hospices.

Figure 8 (above) describes the number of downloads by month in the period during which there was most interest in the Commission. What is interesting to note is the increased but short term interest in particular publications following events or conferences at which details of their content was sought.

During the course of the Commission hard copies of some reports were also distributed by Hospice UK to its members4. The majority of these were sent to hospices as part of a mailing, rather than at the request of the hospice, or distributed at the final conference. As a result we can only speculate on the degree to which they were formally considered by the staff or board of the hospice.

The 2016 survey confirms the value of the publications in disseminating the thinking of the Commission. Of the people who responded to the survey and were aware of the Commission, 89% (n = 149) confirmed that its publications had guided their thinking and work.

4 The precise number of hard copies distributed is not known.
For some respondents, the reports were the most valuable component of the Commission:

“I found the reports very beneficial and they made the organisation think about what the future of hospice care will look like.”

“The series of publications were excellent and could be used by clinical, operational and strategic minded staff. I personally used them on a very regular basis. They also represented great value for money when a fee structure was introduced!”

In answer to the question of which publications they found to be most helpful, members identified a broad range – as Figure 15 in Appendix 2 confirms.

In summary, according to the views of 136 respondents to the survey, the five most helpful were:

- The final report: ‘Future ambitions for hospice care’
- The two reports on volunteers and the paid workforce
- Two related reports describing future needs and preferences, and the challenges and opportunities facing hospices to meet them.

The interviews suggested, however, that this assessment was highly variable and some hospices cited the very publications deemed to be least valuable according to the survey as most useful to them. One director of care, for example, cited the report on the role of the clinical nurse specialist as key to the review of their model of community nursing. When asked to comment on this she confirmed it had come at just the right time in their development, identifying key issues to be covered in their plans for the future. By contrast another hospice felt that some of the publications simply didn’t meet their specific requirements:

“A number of the papers were not relevant or detailed enough for our purposes, particularly the ‘Strength in Numbers’ fundraising and data report.”

Paradoxically, the publications were at the heart of some of the disappointment experienced by a small number of members. They described too many reports, some of which they felt were of variable quality. One respondent felt that they had a weak evidence base and a number felt that their examples of best practice were not necessarily the best exemplars. The latter concern had served to be off-putting to organisations who were aware of key flaws in models portrayed as examples of high quality; to avoid this in the future, they urged greater attention on the part of Hospice UK to better indicators of quality in their assessment of good or best practice.

Another criticism to note is the experience of some of the interviewees who were unable to discern which reports were most important to read or attend to, given the high productivity of the Commission.

“There are so many reports coming out of so many organisations that it is difficult to decide which is the most important or the priority of importance.”

This was at the heart of a repeated request for “more specificity and guidance”.

They felt that Hospice UK offered insufficient direction about those that were vital to read, and as a result they failed to read any of them. This sense of being overwhelmed, and of receiving multiple publications with no sense about their relative value was a theme of a number of interviews.

At least one interviewee spoke of the value of refreshing some of the most valued publications, given their ongoing value to hospices now and in the future. She recommended that Hospice UK consult with members about which publications would be of most use.
Implementation

Of the respondents to the survey who were aware of the Commission, 89% confirmed that they had used the outputs of the Commission to guide the plans or development of their organisation.

Those who had drawn on the Commission outputs had used them in a number of ways, as Figure 9 (below) shows. Some respondents saw them as exemplars of what Hospice UK does best for its members:

"The documents have been extremely helpful and exemplify the important strategic role Hospice UK plays in challenging and driving change and quality."

Guidance regarding the strategic direction was identified as the most important function. Interviewees confirmed that even where strategic plans were in place, the Commission informed detail and gaps.

Figure 9: Ways in which respondents used the thinking of the Commission in their organisation (2016 survey)

- To guide service reviews: 43%
- To engage external organisations, including commissioners in planning for end of life care: 44%
- To inform the education and development of staff and volunteers: 46%
- To support trustees in their decisions: 50%
- To inform operational / business plans for the organisation or specific departments: 74%
- To guide the strategic direction of the organisation: 89%

n=131
Response rate = (131/133) = 99% of those who answered they were aware of the Commission
In addition, hospices confirmed that they had also used the thinking of the Commission to (verbatim):

- Plan, organise and facilitate board and staff away days
- Embark on liaison with other independent Scottish hospices regarding national fundraising activities
- Interview new staff
- As part of working with other organisations to develop volunteering
- Benchmark hospice income against the sector
- Serve as an evidence base to support local findings
- Show there is wider back up for own thoughts
- Reference materials underpinning the preparation of a 10 year vision
- Develop a research approach.

It is clear from comments received that hospices used the learning of the Commission in variable ways, depending on their progress and confidence in relation to their future direction.

For some it was something of a map:

“The Commission’s reports provide(d) a useful reference point during deliberations about the future direction of the hospice.”

For others it was a valuable catalyst for change across the organisation:

“As a new CEO and Chair partnership, we found the resources invaluable in helping to persuade others who were happy to continue ‘doing what we’ve always done’ to see that change was needed. Thank you.”

Alternatively it served as an important “sense check” or as a source of evidence to confirm to others that local leaders were on the right track in their efforts to change:

“We used the recommendations as evidence that our thinking was more than a whim on the part of one or two of us cooking up a wild new idea!”

For hospices already committed to a programme of change, it served as an important framework to focus the efforts of staff across the organisation. One chief executive describes how he used it in this way:

“Following the Commission, I led the senior management team in a strategic options think piece for our council of governors to look at in December 2014. We also brought our chairman and one of the vice chairmen to the Bournemouth conference. Following their consideration of the think piece, the council directed that a further 10 in depth studies should be undertaken as an overall strategic review. Quite deliberately these were led by department heads who selected members of staff and volunteers, plus outside partners, as part of their teams. In other words it was a ‘bottom-up’ approach, as suggested by Helen Bevan at Leeds. The senior management team acted as mentors. Supervision of the whole strategy came from a small group of our governors. The final product was taken in December 2015 by our full council which has decided on the major directions of [the hospice] strategy for the next 10 years.”

Other hospices used the learning of the Commission to guide a particular area of development:

“I think the intelligence that was produced by the Commission has been really helpful in reviewing services and stimulating thinking about future service models.”

It was also seen as an important advocate for particular aspects of hospice care:

“The work on volunteering has helped to raise the profile and value of volunteers and whilst there is a long way to go in matching other countries the Commission has sparked change.”

One or two members, already starting to respond to changing needs and preferences, were disappointed that the Commission had failed to be more illuminating about future opportunities, such as technology, particularly in those areas in which hospices have no knowledge thus far. However, where such an introduction had taken place – in the workstream on workforce as an example – some hospices
had found the potential scale and direction of change hard to comprehend and assimilate in their thinking, given the seismic shift described. More support for hospices in these particular areas would have been appreciated. There was also some disappointment about the failure of the Commission to be more inclusive of some professional groups – for example social workers. A masters dissertation focused on leadership of social workers in palliative care cites the lack of reference to social workers in its work as both a cause and consequence of the relatively poor profile of social workers as leaders in the future of hospice care. Where subsequent work was done by Hospice UK to redress similar gaps, for example around the role of allied health professionals, through a publication on rehabilitative palliative care, this was warmly welcomed and deemed to be “one of the best clinical publications delivered by Hospice UK”, stimulating action across the country and a new national grants programme.

Feedback confirms that the Commission offered value for individual leaders as well as organisations:

“The outputs have influenced my own [personal] thinking and work for the future.”

For some the Commission empowered individuals to achieve long held personal ambitions with impact for their organisations. An interview with a director of education and research tells such a story. She described how, as a nurse with a PhD, she was always keen that the hospice in which she worked should become more research active. Prior to the Commission this was seen by the organisation as a personal aspiration and there was little corporate support for her to pursue this agenda. Despite positive feedback from many there was also a sense of frustration described by some about the failure of themselves, their organisations and neighbouring hospices to attend fully to the opportunities afforded by the Commission.

“Sometimes it is hard to persuade other members of the organisation of the importance of the Commission’s work and help them to see that we have to change to survive.”

A chief executive spoke of a gap between her aspiration to use the findings and the capacity of her organisation to do that:

“The publications were great but we simply never got around to doing anything with them. There is so much else to do on a daily basis.”

The challenge of moving beyond attending to the many operational issues, whilst giving sufficient time to new strategic considerations was one reiterated by a number of those interviewed.

Even if time was found, utilisation of the findings was for some hospices relatively superficial. One respondent confirmed that her board had considered the plans of the hospice against the checklist in the final document, but failed to benchmark its performance against any other. Furthermore she indicated that no further discussion had taken place between that
hospice and other local hospices, even though the checklist had identified opportunities for greater collaboration. Her musings were about why this was the case:

“There are so many issues that we need to think about collaboratively; why did we fail to take up that opportunity?”

Her conclusion focused on the reluctance of hospice chief executives to talk openly about the challenges they face. She suggested that such resistance could have been addressed by Hospice UK drawing on the work of the Commission:

“Hospice UK could have made more use of the evidence to inform debates between hospices about key issues raised. The work could be a great platform to spur more national/regional debate about going forward creatively to tackle the challenges.”

A repeated area of frustration on the part of hospices related to their own failure and those of neighbouring hospices to engage in more collaborative relationships, which was a key recommendation of the Commission. Comments made by two different hospices support this:

“We started looking at fundraising initiatives that could be collaborative across the whole sector but it’s gone nowhere.”

“I thought the publications of the Commission were excellent, with an abundance of wise guidance. I am disappointed in some (not all) of neighbouring hospices – in that they have not taken on the underlying message of the document of collaboration and leadership leading to greatest impact.”

In reviewing data collected through the survey and interviews this is the area of least movement, yet arguably one of the most important.

“In terms of disappointment, [the Commission] not been as far reaching in the non-hospice world as we might have liked.”

Failure to engage commissioners across the country to communicate opportunities to work with hospices differently is cited as an opportunity missed in the course of the Commission and a major frustration on the part of hospices.

“The Commission was an excellent piece of work – wide-ranging, grounded and well presented in its findings. Regrettably, local commissioners in the NE paid it no attention because they had no stake in it. Our distance from London may exacerbate this phenomenon, but we find CCGs have no time for anything they haven’t invented/researched themselves. So actual impact was zero locally.”

Hospices are implicated in this failure. A review of quality accounts produced by local hospices suggests that very few hospices made reference to the Commission or their efforts to respond to its recommendations. Out of a sample of 70 hospices, only 10 made reference in 2013/14 and three hospices in the subsequent year.

Where this did happen, either through local or limited national effort, it was seen as valuable.

“I believe the work of the Commission was very valuable in developing a conversation with common themes and goals both internally within the hospice and with external groups.”

It is hard to know whether implementation of the recommendations has resulted in any changes in behaviour or increased awareness of the contribution of hospices in national thinking and policy. A national leader in end of life care described, in her interview, recent work on national guidance that drew on the views of hospices as “enhanced” by the contribution of outward looking, highly collaborative members of the hospice sector. However, it would be impossible to ascribe this to the Commission specifically. According to the director of policy and advocacy at Hospice UK, the detail of the recent Ambitions document produced by NHS England was informed by the Commission. This is seen as encouraging by members.
Maintenance

There is a small body of evidence to suggest that the learning from the Commission has been integrated into the long-term plans of hospices. A review of the abstracts of posters accepted for the most recent Hospice UK annual conference (held in November 2015) reveals areas of development informed by the work of the Commission:

1. Fossilised or future proof? Using Hospice UK Commission resources to conduct a review of governance, leadership and communication. (St John’s Hospice, Lancaster)
2. Magic numbers and deep dives: strengthening data collection to transform clinical evidence and service delivery. (St Richard’s Hospice)
3. Education beyond the walls: three hospices working together. (St Luke’s Cheshire Hospice, East Cheshire Hospice, Hospice of the Good Shepherd)
4. When horses run together: developing collective hospice leadership for the future. (Earl Mountbatten Hospice)
5. The Mill, St Catherine’s Park – community, sustainability, informality. (St Catherine’s Hospice, Preston)
6. Staff care and development. (Martin House Children’s Hospice et al)
7. Namaste care – a compassionate approach to advanced dementia. (St Joseph’s Hospice)

However, there is also evidence that for some people, the learning of the Commission was experienced as valuable in the course of its lifetime but quickly forgotten as an important resource afterwards:

“I personally found the final report very useful and organised an away day with senior leadership team and trustees to consider the impact and importance soon after it was published. However, I think I am probably the only person who has opened the report since then.”

This experience was shared at individual, corporate and national levels. A national leader described, regretfully, her realisation that many of the recent national policy developments around end of life care made no explicit reference to the findings of the Commission, despite its resonance with many of the emerging themes. She and others confirmed the requirement for ongoing reminders of the key messages arising from the Commission to ensure that the learning is not lost. Such efforts will need to be both proactive and reactive, constantly reminding individuals and organisations considering end of life care in the future of the thinking already achieved on the part of the Commission.

At present, documentary evidence (including review of the academic literature) suggests that the main vehicle through which this is achieved is ehospice. As Figure 10 (below) shows, a total of 69 articles were identified, the majority of which were generated via Hospice UK staff.

**Figure 10: Origins of ehospice articles**

October 2012 - November 2015

n=69

- Hospice UK: 85%
- Hospices: 8%
- Other organisations: 7%

ehospice is an online news and information resource which covers the latest news and developments in hospice, palliative and end of life care. Hospice UK runs the UK edition.
Many of those interviewed confirmed that they had enjoyed being encouraged to revisit their memories of the Commission as they undertook the survey or prepared for interviews. One particular interviewee described an intention arising as a result:

“Once I had found the publications, blown the dust off them and reminded myself of their recommendations, I remembered how useful they were. I am going to re-read them and recommend them to [a group of colleagues] as we think about the best way to collaborate in the future.”

A number of member hospices were clear that they continue to need the input of Hospice UK to maintain their interest in implementing necessary changes. For some, a reminder of the findings of the Commission would have been sufficient; for others some help to interpret broad recommendations into local plans would have been much appreciated. By way of example, a hospice in Wales describes the help it would have liked to apply recommendations that described work with local commissioning groups to its context of national funding:

“Feedback workshops on how organisations that have adopted the report have implemented or gone about identifying service models going forward, especially if there is no commissioning processes and the need to engage versus the ease of engagement with the NHS is difficult [would have been helpful].”

Hospices were welcoming of the efforts being undertaken by Hospice UK to review progress related to the Commission and suggested that the findings of the Commission continue to be pertinent, particularly if Hospice UK is willing to support their implementation.

“It is encouraging to see this follow up work being undertaken – important not to lose sight of the work and learning that has emerged as a result of the Commission.”

Many respondents felt that ongoing commitment on the part of Hospice UK was essential:

“It’s really important that Hospice UK continues to prioritise supporting hospices to follow through on the recommendations from the Commission.”

Another said:

“The Commission is seen as history; it could still be current.”

Some members offered advice to Hospice UK about how best to ensure long-term engagement on the outcomes of the Commission:

“I think it is important to map those with responsibilities for strategic planning in hospices (often non-clinicians) and ensure they are included within communication plans.”

A plea was made to remember children’s hospices as well as those serving adults:

“Ensure that all future work continues to engage with both children and adult services to support the change that is required…”

According to members interviewed such communication needs a different style:

“Communication between Hospice UK and member hospices is characterised by its waves of formality. We need more conversations – ongoing and two way”.

A number recommended that Hospice UK critically review the impact of the Commission on its own work, as well as that of its members:

“It would be good for Hospice UK to reflect on the recommendations that applied to them and assess how far they feel that they have taken them forward and/or consider them still to be relevant. I am sure you have done this but would be good to hear your thoughts.”

A number of members identified work that they would like Hospice UK to consider in the future – either as an extension to the Commission or in a similar style. At least two have talked about help required for hospices on generating income/additional funds in the future. This might be related to statutory funding, new means of raising voluntary income or by increasing productivity and reducing costs. Working with other organisations with a similar ambition, such as Hospice Quality Partnership, could be one way.
One member made a request for some related work to assess whether the income demanded via community fundraising efforts on the part of hospices has reached a point of saturation. Hospices also spoke of their concerns about availability of a relevant workforce in the future and how this is best addressed in their workforce plans. Many interviewees described difficulties recruiting and retaining senior skilled staff and are concerned that this situation won’t change in the future. They need more help to develop a different workforce.

Performance indicators for hospices have been another suggestion for work in the future.

Perceived failure of Hospice UK to reflect on the progress of hospices in implementing changes recommended by the Commission has been identified by some members as a mutual loss:

“I think Hospice UK missed a trick in not formally responding to the [Commission] at the [most recent] conference. It is not clear to me how the Commission has changed Hospice UK’s direction.”

A national leader made a similar comment in a conversation:

“Every opportunity should be taken by Hospice UK to remind hospices of the recommendations, their ongoing pertinence and the failure of the sector to date to achieve what is in its grasp.”
Satisfaction on the part of hospices with the quality of the work

The vast majority of people who responded to the survey or who offered an interview confirmed the value of the work of the Commission:

“Thank you for your leadership on this.”

“Thank you for all the good work; most informative and beneficial for service considerations.”

Other respondents conveyed similar sentiments:

“Keep up the work – it is of huge value.”

“A huge thank you to all those who participated in the work of the Commission to support the future of hospice care.”

Of those who responded to the survey and knew of the Commission 14% (n = 21) identified some disappointment with it. Their reasons for this are varied: some reflective of perceived limitations of the Commission; others more concerned with the limitations of local services, commissioners and other stakeholders. For the purposes of transparency and completeness, the full list of articulated disappointments is listed below, unless utilised elsewhere in the report:

- Some outputs have been a little ‘England centric’. The Hospice sector in Wales is tiny compared with the UK as a whole, so this is perhaps inevitable. Overall, though, the material has been really helpful.
- Hospices need to be allowed to offer their services to major trust hospitals.
- Limited attention to role and contribution of social workers.
- It didn’t feel that the Commission took into account disparity between the regions within the UK. A one sized approach for varying areas doesn’t apply.
- Very poor work so we have not been able to use them.
- Attitude of [statutory] commissioners, difficult to engage.
- Sometimes it is hard to persuade other members of the organisation of the importance of the Commission’s work and help them to see that we have to change to survive.
- Some of the reports seemed to us to be a bit hypothetical/didn’t match our experience.
- Some more statistics would be helpful that we can use in our work. Trying to get localised breakdowns of national figures is very difficult. You are probably best placed to provide.
- Lack of resources in external community services stretches ability to implement changes/develop services.
- Main disappointment has been lack of media coverage and sharing of key messages. These are useful documents but the Commission is largely preaching to the converted.
- I would have liked to have been made more aware of the range of materials available.
- I hoped there would be more momentum to implement the changes suggested in the reports.
There was a sense for some that the Commission failed to seek sufficient difference in views in its assessment of the way forward in the future. One interviewee spoke of the “same old by the same old” implying that Commission membership comprised many of the same people used by Hospice UK for a whole variety of activities. Another interviewee talked about a lack of creativity and transparency about how major contributors to the Commission were chosen:

“The usual suspects were involved with little transparency about how people were chosen and why.”

The input of the (then) executive lead on the Commission as the (now) evaluator of the programme was viewed by at least one person similarly.

Finally, it is important to note the extraordinary range of experience between members who placed high value on the new knowledge offered by the Commission and a small minority who responded who could see no value in the work at all. The different priorities, contexts, sizes and aspirations for individual hospices, and the challenge for Hospice UK in establishing a programme of work such as the Commission to meet highly variable needs, was a recurring theme in many of the interviews.

One person spoke of the sector as “a loose and baggy monster” in which there are more differences than commonalities. Size of hospice, geographical location, local networks and pre-existing relationships and expectations with Hospice UK (for example, a belief that it is London-centric, that its main interest is in “an intellectual adventure for a few”, and that its real interest is to work only with the bigger and more interesting hospices) were factors that affected how much an individual hospice valued the work of the Commission. This was evident in the interviews and also reiterated in work done by others, for example a very comprehensive and detailed masters dissertation by Ashcroft⁵ that explored the efficacy and effectiveness of the Commission literature to shape local hospice strategy, barriers and recommendations drawing on the views of hospice leaders in the Midlands region. In the summary of her results she says:

“Core findings have identified that awareness of the Commission literature is very good and is being used at a local hospice level to underpin local strategy formulation, as an evidence base and to support recruitment processes. However, implementation of the Commission recommended ‘five key steps’ is limited. Barriers identified include that it is not representative of local hospice diversity, it is ambitious, identified nothing new and hospices have limited resources available to support.”

Her recommendations include consideration of market segmentation in the development of any future guidance on the part of Hospice UK. Market segmentation could be defined by geographical regional area and by size (expenditure and/or services provided – inpatient beds/community services). This may prove beneficial with regards to future benchmarking exercises.

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Key themes emerging and proposals for the way forward

1. The majority of hospices who engaged in the Commission placed high value on its work and many saw it as potentially transformational. The nature of this transformation and the degree of impact exerted by the Commission was variable between hospices depending on the presence of a pre-existing vision and programme of development, and the hospice’s appetite to think differently. As a result, the contribution made by the Commission varied between provoking new questions on the part of senior staff and trustees, encouraging different discussions, informing emerging plans and serving as a sense check for hospices already engaged in a comprehensive programme of change.

2. The degree to which hospices engaged in the Commission has been variable. This does not appear to be related to the geography of the hospice or whether it serves children or adults. It relates more to its other pressing priorities and priorities – particularly where operational challenges including staffing and annual budgets predominate. The other significant factor that appears to have affected engagement has been the quality of relationship that individual hospices (or groups) have with Hospice UK. Interviews suggest that where preconceptions were negative, then many of those hospices were disinterested in the learning of the Commission from the start.

3. Some hospices who were initially disengaged were encouraged to start engaging by a third party. There is evidence that the Commission could have done more to promote more third party involvement, possibly from the start of its work.

4. Some hospices recognised the value of the messages arising from the Commission but have struggled to integrate them into their thinking, conversations and plans. In addition to the challenge of managing competing operational priorities, some simply failed to get going, others experienced difficulty in knowing which publications to prioritise in their thinking (including others from Hospice UK), a proportion lacked strategic capacity beyond the chief executive, and still others described a lack of confidence to benchmark their own position against others.

5. This failure to integrate learning into future plans was felt by some to have been exacerbated by gaps in sustained follow-up on the part of Hospice UK. Individuals saw this as a mutual loss – in which Hospice UK failed to capitalise on significant earlier work and maximise on the value of a very high quality piece of work.

6. For those hospices that did engage in learning from the Commission, there is a small but growing body of evidence of changes in models, behaviours and reach on the part of hospices, which can be linked, at least in part, to the work of the Commission. However, even for those hospices which embraced the learning and have invested heavily in implementing its learning, inadequate time has passed since the start of the work to witness its full impact. Many related strategic plans are only one, two or, at best, three years old and changes in models remain embryonic in nature.
7. The opportunities raised by the Commission are still considered highly pertinent by the majority of people interviewed. A high number of survey respondents and interviewees confirmed a value in being relinked to the publications and remain interested in receiving help from Hospice UK to integrate key recommendations into their work to prepare for the future.

8. A number of hospices mentioned areas of work in which they would value help from Hospice UK in the future, undertaken in a similar way to the Commission. These focus primarily on performance indicators and new ways of generating new income/reducing expenditure and becoming more efficient in the use of resources. The shape of the workforce in the future is another recurrent theme.

9. Hospice UK has a real opportunity to learn from its investment and work around the Commission to shape programmes of work in the future. Opportunities to do things differently include:
   a. Seeking a diversity of views and representation on fora such as the Commission in the future; being transparent about how membership is agreed and inviting members to nominate themselves.
   b. Being more ambitious in its efforts to anticipate the future.
   c. Bringing in partners who can help extend the reach and potential impact from the start, and building their involvement into the programme.
   d. Being clear about what represents good or best practice and encouraging members to identify models/practice which meet particular criteria.
   e. Confirming key messages and publications which are essential for members to consider.
   f. Establishing a programme of support for implementation of any recommendations following publication, in recognition that change is difficult to prioritise and do, and takes considerable time.
   g. Recognising the diversity of its members and their varying needs. Remembering that one size is not likely to fit all. A number of hospices spoke of the value of segmenting the membership and its work.
Final thoughts

The efforts of Hospice UK to review the work of the Commission and its impact have been applauded by many of the hospices represented in the survey and the subsequent interviews. The timing of the review is also good. Many spoke of a belief that new opportunities exist to build a different relationship and dialogue with Hospice UK as a result of its new leadership. Their willingness to appraise the Commission and contribute ideas for the future reflect that optimism. Hospice UK is invited to respond in a similar vein – considering its work in the future with reference to the Commission recommendations and thinking further on how it ensures that its members are ready and ideally positioned for the future.
Appendix 1: The Commission process and outputs

Process

The Commission was formally established in November 2011.

Its original members were:

<table>
<thead>
<tr>
<th>Commissioners</th>
<th>Role (at time of Commission final report)</th>
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<tbody>
<tr>
<td>Dame Clare Tickell (chair)</td>
<td>Chief Executive, Action for Children</td>
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<tr>
<td>Dame Barbara Monroe (vice chair)</td>
<td>Chief Executive, St Christopher’s Group</td>
</tr>
<tr>
<td>Harry Cayton OBE</td>
<td>Chief Executive, Professional Standards Authority</td>
</tr>
<tr>
<td>Dr Mayur Lakhani</td>
<td>Chairman, National Council for Palliative Care, general practitioner and a clinical commissioning group (CCG) board member</td>
</tr>
<tr>
<td>Jonathan Ellis</td>
<td>Director of Policy and Advocacy, Help the Hospices (now Hospice UK)</td>
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<tr>
<td>Baroness Ilora Finlay</td>
<td>Doctor, Professor of Palliative Medicine, and independent crossbench member of the House of Lords</td>
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<tr>
<td>Penny Hansford</td>
<td>Director of Nursing, St Christopher’s Hospice</td>
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<tr>
<td>Claire Henry MBE</td>
<td>Head of Programmes for Long Term Conditions and End of Life Care, NHS Improving Quality</td>
</tr>
<tr>
<td>Peter Holliday</td>
<td>Group Chief Executive, St Giles Hospice, West Midlands</td>
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<tr>
<td>Robin Knowles CBE, QC</td>
<td>Chair, Richard House Children’s Hospice and Chair, Together for Short Lives</td>
</tr>
<tr>
<td>Dr Jonathan Koffman</td>
<td>Senior Lecturer in Palliative Care, Cicely Saunders Institute, King’s College London</td>
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<tr>
<td>Dr Fliss Murtagh</td>
<td>Clinical Senior Lecturer and Consultant in Palliative Care, Cicely Saunders Institute, King’s College London</td>
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<tr>
<td>David Praill</td>
<td>Chief Executive, Help the Hospices, Co-Chair of the Worldwide Palliative Care Alliance and chair of ehospice</td>
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<tr>
<td>Joe Saxton</td>
<td>Founder and driver of ideas at nfpSynergy</td>
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<tr>
<td>Professor Jane Seymour</td>
<td>Professor at Sue Ryder Palliative Care Centre, University of Nottingham</td>
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<tr>
<td>Dr Teresa Tate OBE</td>
<td>Consultant in Palliative Medicine and former medical adviser to Marie Curie Cancer Care</td>
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<tr>
<td>Sarah Whitfield</td>
<td>Former Chief Executive of Dorothy House Hospice, Bath</td>
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<td>Charlie Leadbeater</td>
<td>Author, Dying for Change</td>
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Outputs

In total, the Commission developed:

- 16 reports regarding aspects of future care provision
- a final report
- a toolkit to guide the development of partnerships to help hospices be better positioned in the future
- a workbook to guide consideration regarding the future of volunteering in hospices.

<table>
<thead>
<tr>
<th>Title of report</th>
<th>Author</th>
<th>Publication date</th>
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<tbody>
<tr>
<td>Volunteers: vital to the future of hospice care</td>
<td>Commission support team</td>
<td>November 2012</td>
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<tr>
<td>Preparing for the future: key operating principles</td>
<td>Greg Parston and Harry Kippin</td>
<td>November 2012</td>
</tr>
<tr>
<td>Future needs and preferences for hospice care: challenges and opportunities</td>
<td>Commission support team</td>
<td>April 2013</td>
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<tr>
<td>The collaboration toolkit</td>
<td>Saffron Steer</td>
<td>June 2013</td>
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<tr>
<td>Strength in numbers: how independent hospices can raise more income from</td>
<td>nfpSynergy</td>
<td>July 2013</td>
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<td>donated sources to fund their work</td>
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<td>The role of hospices in supporting young people in transition from children’s</td>
<td>Dr Victoria Lidstone</td>
<td>September 2013</td>
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<td>to adult services</td>
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<td>Supporting family carers: report on the evidence of how to work with and</td>
<td>International Observatory on End of Life Care, Lancaster University</td>
<td>September 2013</td>
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<td>support family carers to inform the work of the Commission into the Future</td>
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<td>of Hospice Care</td>
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<td>Learning more – a report of user views received by the Commission</td>
<td>Commission support team</td>
<td>September 2013</td>
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<tr>
<td>Research in palliative care: can hospices afford not to be involved?</td>
<td>International Observatory on End of Life Care, Lancaster University</td>
<td>October 2013</td>
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<td>Working towards a hospice care workforce that is fit for the future</td>
<td>Skills for Health</td>
<td>October 2013</td>
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<tr>
<td>The future of hospice education and training</td>
<td>Commission Support Team and National Association of Palliative Care</td>
<td>October 2013</td>
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<tr>
<td>Have your say – a report of a conversation with the general public and</td>
<td>Commission Support Team</td>
<td>October 2013</td>
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<td>users of hospice care</td>
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<td>The future of clinical nurse specialists delivering end of life care in the</td>
<td>Penny Hansford</td>
<td>October 2013</td>
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<td>community</td>
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<td>Maximising the contribution of the palliative medicine consultant to meet</td>
<td>Dr Teresa Tate</td>
<td>October 2013</td>
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<td>the future opportunities for hospice care</td>
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<tr>
<td>The role of hospices in supporting people with a diagnosis of dementia in</td>
<td>Dr Jo Hockley</td>
<td>October 2013</td>
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The final report, ‘Future ambitions for hospice care: our mission and our opportunity’, was published in October 2013 and launched at the (then) Help the Hospices conference. Where hard copies of these reports have been produced, two copies were sent to every hospice – one to the Chair of the Board and one to the chief executive.

The Commission ran eight major events to engage hospices in giving due consideration to future challenges and opportunities. These events were concerned with:

- The future of volunteering – April 2012
- Establishing the context of the future and related key operating principles – Sept 2012
- The future of fundraising and income generation – October 2012
- An event to pilot the partnerships toolkit – March 2013
- The paid workforce required in the future – April 2013
- The future of education and training as delivered by hospices – April 2013
- Listening to members of the general public and users of hospice care – July 2013

All were fully booked and well attended.

The Commission support team engaged with a wide variety of organisations and associations across the UK to describe the work of the Commission and learn more about the priorities of those engaged in hospice and end of life care. These included dedicated events with:

- The All Ireland Institute of Palliative Care
- Together for Short Lives
- The Scottish Partnership for Palliative Care
- Hospices Cymru
- Marie Curie Cancer Care
- The National End of Life Care Programme

It also made presentations to the national associations supporting day care leaders, hospice at home, executive clinical leads, the Association of Palliative Medicine and volunteer service managers. A number of hospices hosted their own events around the Commission to which the Commission support team was invited to attend.

It took oral evidence from 16 individuals and received written submissions from 10 organisations or individuals.

The Commission executive lead provided presentations regarding the Commission to eight hospice boards and management teams and delivered a further 14 conference presentations drawing on Commission generated information. She also presented emerging findings from the Commission at the 2013 (then) Help the Hospices roadshows for senior staff and trustees.

The (then) Help the Hospices conference in October 2013 drew heavily in its themes on the learning of the Commission and served as the launch of the Commission final report.
# Appendix 2: Data from the survey

**Figure 11: List of hospices who contributed to the survey**

<table>
<thead>
<tr>
<th>Hospice Name</th>
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<tr>
<td>ACCORD Hospice, Paisley, Scotland</td>
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<td>Acorns Children's Hospice, Birmingham</td>
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<td>Alexander Devine Children's Hospice Service, Maidenhead</td>
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<td>Arthur Rank Hospice Charity, Cambridge</td>
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<td>Ayrshire Hospice, Ayrshire</td>
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<td>Bethesda Hospice, Stornoway, Isle of Lewis</td>
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<td>Bluebell Wood Children's Hospice, Sheffield</td>
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<td>Bolton Hospice, Bolton</td>
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<td>Children's Hospice Association Scotland, Edinburgh</td>
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<td>Compton Hospice, Wolverhampton</td>
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<td>Cornwall Hospice Care, Cornwall</td>
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<td>Countess Mountbatten Hospice Charity, Southampton</td>
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<td>Dove Cottage Day Hospice, Melton Mowbray</td>
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<td>Earl Mountbatten Hospice, Isle of Wight</td>
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<td>Eden Valley Hospice, Carlisle</td>
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<td>ellenor, Gravesend</td>
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<td>Farleigh Hospice, Chelmsford</td>
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<td>Garden House Hospice, Letchworth</td>
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<td>George Thomas Hospice Care, Cardiff</td>
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<td>Greenwich &amp; Bexley Community Hospice, London</td>
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<td>Hartlepool Hospice, Hartlepool</td>
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<td>Haven House Children's Hospice, Woodford, London</td>
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<td>Havens Hospices, Essex</td>
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<td>Heart of Kent Hospice, Aylesford</td>
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<td>Hope House, Oswestry</td>
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<td>Hospice in the Weald, Tunbridge Wells</td>
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<td>Hospice Isle of Man, Isle of Man</td>
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<td>Hospiscare, Exeter</td>
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<td>Isabel Hospice, Welwyn Garden City</td>
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<td>Katharine House Hospicare, Banbury</td>
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<td>Katharine House Hospice, Stafford</td>
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<td>KEMP Hospice, Kidderminster</td>
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<td>Kirkwood Hospice, Kirklees</td>
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<td>Lindsey Lodge Hospice, Scunthorpe</td>
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<td>Longfield, Minchinhampton</td>
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<td>LOROS, Leicester</td>
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<td>Martin House, Boston Spa</td>
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<td>Martlets Hospice, Brighton</td>
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<td>Mary Ann Evans Hospice, Nuneaton</td>
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<td>Mary Stevens Hospice, Stourbridge</td>
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<td>Michael Sobell Hospice Charity, Northwood</td>
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<td>Nightingale House, Wrexham</td>
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<td>North London Hospice</td>
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<td>Nottinghamshire Hospice, Nottingham</td>
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<td>Oakhaven Hospice, Lymington</td>
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<td>Overgate Hospice, Elland</td>
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<td>Paul Sartori Foundation, Pembrokeshire</td>
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<td>Peace Hospice Care, Watford</td>
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<td>Pendleside Hospice, Burnley</td>
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<td>Phyllis Tuckwell Hospice, Farnham and Guildford</td>
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<td>Pilgrims Hospices, East Kent</td>
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<td>Primrose Hospice, Bromsgrove</td>
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<td>Princess Alice Hospice, Esher</td>
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<td>Prospect Hospice, Wroughton, Swindon</td>
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<td>Rainbows Hospice for Children and Young People, Loughborough</td>
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<td>Rennie Grove Hospice Care, West Herts and Bucks</td>
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<td>Richard House Children's Hospice, London</td>
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<td>Rossendale Hospice, Rawtenstall, Rossendale</td>
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<td>Rotherham Hospice, Rotherham</td>
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<td>Rowcroft Hospice, Torquay</td>
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<td>Royal Trinity Hospice, London</td>
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<td>Saint Catherine’s Hospice, Scarborough</td>
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<td>Saint Francis Hospice, Romford</td>
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<td>Saint Michael's, Harrogate</td>
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<td>Severn Hospice, Shropshire and Mid Wales</td>
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<td>South Bucks Hospice, High Wycombe</td>
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<td>St Andrew’s Hospice, Grimsby</td>
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<td>St Ann’s Hospice, Manchester</td>
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<td>St Barnabas, Worthing</td>
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<td>St Barnabas Lincolnshire Hospice, Lincolnshire</td>
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<td>St Cuthbert’s Hospice, Durham</td>
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<td>St David’s Hospice, Llandudno</td>
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Figure 11 continued:
St Gemma’s Hospice, Leeds
St Giles Hospice, Lichfield
St Helena Hospice, Colchester
St Johns Hospice, Lancaster
St Joseph’s Hospice, London
St Joseph’s Hospice Association, Liverpool
St Luke’s Cheshire Hospice and End of Life Partnership, Winsford
St Luke’s Hospice, Harrow and Brent
St Margaret’s, Somerset
St Mary’s Hospice, Ulverston
St Michael’s Hospice, Basingstoke
St Nicholas Hospice Care, Bury St Edmunds
St Oswald’s Hospice, Newcastle upon Tyne
St Peter and St James Hospice and Continuing Care, East Sussex
St Peter’s Hospice, Bristol
St Richard’s Hospice, Worcestershire
St Vincent’s Hospice, Renfrewshire
St Wilfrid’s Hospice, Eastbourne
St Wilfrid’s Hospice, Chichester
Strathcarron Hospice, Denny
Sue Ryder Manorlands Hospice, Keighley
Thames Hospice, Windsor
The Myton Hospices, Coventry and Warwickshire
The Rowans Hospice, Portsmouth
Treetops Hospice, Derby
Trinity Hospice Blackpool
Weldmar Hospicecare Trust, Dorset
Wigan and Leigh Hospice, Wigan
Willen Hospice, Milton Keynes
Willowbrook Hospice, St Helens
Wirral Hospice
Zoe’s Place, Coventry

Figure 12: Breakdown of 2016 survey respondents by country and region

Northern Ireland | 2
Wales | 3
Scotland | 7
Yorkshire and Humberside | 9
West Midlands | 10
South West of England | 7
South East of England | 10
South Central England | 8
North West of England | 13
North East of England | 2
London | 11
East of England | 8
East Midlands | 6

n=122
Response rate = (122/126) = 97% of organisations which responded to the survey
### Figure 13: 2016 survey respondents by hospice type

<table>
<thead>
<tr>
<th>Breakdown by beneficiaries</th>
<th>Individual respondents</th>
<th>Organisational responses</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>%</td>
</tr>
<tr>
<td>Adults hospice</td>
<td>137</td>
<td>76</td>
</tr>
<tr>
<td>Children’s hospice</td>
<td>14</td>
<td>8</td>
</tr>
<tr>
<td>Adults and children’s hospice</td>
<td>18</td>
<td>10</td>
</tr>
<tr>
<td>Not applicable (other organisation)</td>
<td>8</td>
<td>4</td>
</tr>
<tr>
<td>Unknown</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td><strong>Totals</strong></td>
<td><strong>181</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

### Figure 14: Source of completed 2016 surveys according to the role of respondents

<table>
<thead>
<tr>
<th>Role</th>
<th>Number</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Senior Manager</td>
<td>69</td>
<td>38</td>
</tr>
<tr>
<td>Acting Patient Services Director, Care Director, Charity Manager, Clinical Services Director, Commercial Director, Community Services Lead, Deputy CEO, Director for Children and Families, Director of Human Resources and Engagement, Director of Adult Nursing, Director of Care, Director of Clinical Services, Director of Clinical Services/Acting CEO, Director of Corporate Services and Company Secretary, Director of Fundraising, Director of Income Generation and Communications, Director of Income Generation and Marketing, Director of Knowledge Exchange Services, Director of Nursing, Director of Nursing and Care Services, Director of Nursing and Education, Director of Nursing and Patient Services, Director of Patient Care, Director of Patient Care and Strategic Development, Director of Patient Services, Director of Practice and Service Development, Director of Strategy and Development, Director of Strategy and Information, Director of Strategy and Engagement, Group Medical Director, Head of Business and Operations, Head of Care, Head of Clinical Services, Head of Clinical Services and CEO for National Association of Hospice at Home (NAHH), Head of Community Services, Head of Development and Quality, Head of Finance, Head of Fundraising, Head of Fundraising and Marketing, Head of HR and Volunteering, Head of Income Generation, Head of Marketing and Communications, Head of Nursing, Head of Nursing and Clinical Care, Head of Nursing and Quality, Head of Research, Head of Supportive Care, Head of Voluntary Services, Head of Wellbeing Services, Hospice Director, HR Director, Medical Director.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CEO</td>
<td>67</td>
<td>37</td>
</tr>
<tr>
<td>Trustee</td>
<td>21</td>
<td>12</td>
</tr>
<tr>
<td>Chairman, Executive Trustee, President, Treasurer, Trustee.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>12</td>
<td>7</td>
</tr>
<tr>
<td>Care Education Coordinator, Corporate fundraiser, Day Care Leader, External Service Development Lead, Individual Giving Manager, IPU Manager, Practice Development Nurse/Lead, Project and Business Development Researcher, Trust Fundraiser, Voluntary Sector Consultant and Researcher.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Senior Clinician</td>
<td>8</td>
<td>4</td>
</tr>
<tr>
<td>Senior Nurse, Senior Sister, Consultant, Lead Consultant, Matron.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unknown</td>
<td>4</td>
<td>2</td>
</tr>
</tbody>
</table>

Review of the work and impact of the Commission into the Future of Hospice Care | 32
Figure 15: Tools and publications that respondents deemed most helpful (2016 survey)

- Maximising the contribution of the palliative medicine consultant to meet the future opportunities for hospice care: 14%
- Learning more: patient and family feedback on care: 18%
- Supporting family carers: 20%
- Collaboration toolkit: 25%
- The role of hospices in supporting young people in the transition from children’s to adult services: 26%
- The future of the clinical nurse specialist delivering end of life care in the community: 28%
- Research in palliative care: can hospices afford not to be involved?: 39%
- The future of hospice education and training: 41%
- The role of hospices in supporting people with a diagnosis of dementia in the future: 45%
- Strength in numbers: how independent hospices can raise more income from voluntary and donated sources to fund their work: 50%
- Preparing for the future: key operating principles: 53%
- Working towards a hospice workforce that is fit for the future: 65%
- Volunteers: vital to the future of hospice care: 66%
- Future needs and preferences for hospice care: challenges and opportunities for hospices: 69%
- Current and future needs for hospice care: an evidence based report: 78%
- Future ambitions for hospice care: our mission and our opportunity: 87%
Appendix 3: Questions asked in the survey

1. Please provide your details below. Name, role, organisation, town / location of organisation

2. Are you aware of the work of the Commission into the Future of Hospice Care and/or its publications? Yes / no

3. Have you or your organisation used the publications in any way to guide your work and thinking? Yes / no

4. Which tools/publications have you found particularly helpful? (Full list was given for respondents to select from)

5. Have you used the thinking of the Commission to guide your organisation’s plans/development in any way? Yes / no

6. In what ways have you used the thinking of the Commission in your organisation?
   a. To support trustees in their decisions
   b. To guide the strategic direction of your organisation
   c. To engage external organisations, including commissioners in planning for end of life care
   d. To inform operational/business plans for the organisation or specific departments
   e. To guide service reviews
   f. To inform the education and development of staff and volunteers
   g. Other (please specify)

7. Have you or your organisation experienced any disappointment in relation to the work and outputs of the Commission? Yes / no

8. Please say more about how and why you experienced disappointment in relation to the work and outputs of the Commission. Open answer

9. How would you rate the overall value of the Commission in your work?
   a. Not valuable
   b. Limited value
   c. Average value
   d. Valuable
   e. Very valuable

10. Would you be prepared to take part in an interview about your experience/views as part of this review of the impact of the Commission? Yes / no

11. Please enter your details below so that we can contact you for an interview. Email address, phone number

12. Is there anyone else in your organisation we should approach for their comments regarding the Commission and its value? Yes / no

13. Please provide their contact details below. Name, role, email address, phone number

14. Is there anything further you would like to comment on or mention? Open answer
Appendix 4: List of interviewees

1. As follow up to the survey:
   - Rob Woolley, Chief Executive, Hospice in the Weald
   - Gill Horne, Director of Care, Rowcroft Hospice
   - Kate Heaps, Chief Executive, Greenwich and Bexley Community Hospice
   - Shaun O’Leary, Joint Chief Executive, St Christopher’s Hospice
   - Tony Collins, Chief Executive, St Michael’s Hospice, Harrogate
   - Lesley Spencer, Director of Care, Princess Alice Hospice
   - Stuart Evans, Chairman, Arthur Rank Hospice
   - Karen Ashcroft, Director of Strategy, Loros Hospice
   - David Brown, Chairman, Pendleside Hospice
   - Colin Burgess, Chief Executive, St Peter and St James Hospice

2. Other leaders/stakeholders:
   - Dr Bee Wee, National Clinical Director, NHS England
   - Barbara Gelb, Chief Executive, Together for Short Lives
   - Judith Parks, Deputy Chief Executive, St Luke’s Hospice, Sheffield
   - Peter Ellis, Chief Executive, Richard House and Chair, CHAL
   - Claire Henry, Chief Executive, National Council for Palliative Care
   - Erna Haraldsdottir, Head of Education and Research, St Columba Hospice
   - Jason Davidson, Head of Supportive Care, Marie Curie Hospice Hampstead