Research in palliative care: can hospices afford not to be involved?

A report for the Commission into the Future of Hospice Care

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Help the Hospices has changed its name to Hospice UK

This resource was published prior to the change and so still refers to the old name
In 2010 the think tank Demos published a report entitled ‘Dying for Change’ which highlighted some of the challenges facing hospices in the future. Help the Hospices responded to this by setting up the Commission into the Future of Hospice Care to provide guidance, information and options for hospices to inform their strategic position and offerings in the next 10 to 20 years. Opportunities exist across the UK to improve the experience of people who are approaching the end of their life, and that of their families and carers. The Commission is considering how hospices need to develop over the next three to five years to be prepared for the challenges facing them in the future.
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When Dame Cicely Saunders founded St Christopher’s Hospice in 1967, her vision was to create a hospice which combined four important components, all of which were essential for the delivery of excellence in palliative care. These four strands were expert pain and symptom control, compassionate care, teaching and research.

Almost 50 years on, hospices are widespread around the UK, and in terms of quality of care and accessibility to hospice care, the UK rates highly. Whilst hospices around the country have certainly delivered excellent symptom control and compassionate care over the years, and many have pioneered outstanding teaching programmes, the fourth strand, that of research, has not always been present. We find ourselves in a situation today where, despite some notable exceptions, research is not universally welcomed, encouraged, and embedded within hospice care.

The authors of this report highlight some of the reasons why this is so. Despite the pre-eminence of research in Dame Cicely’s original vision, somehow the culture and ethos of hospice has not always been conducive to research. There is limited understanding of the need for research and its implications among the senior hospice leadership. Hospices are at times isolated and do not have productive research partnerships with the NHS or with universities. They lack the ‘know how’ and the resources to make it happen.

Research is something of an investment for the future; without research we cannot sustain high quality hospice care into the future. If we are to understand how to deliver best care in the context of an ageing population, changing patterns of disease, an increasing range of treatment options, and limited resources, we absolutely need research to tell us which hospice based interventions are effective and how they work and which models of care are best, and whether they are both effective and cost-effective. We also need robust measurement of nationally agreed patient-centred outcomes, capturing the difference hospice care makes for patients and families, and providing a foundation for further clinical research.

At present, research is not universally welcomed, encouraged, and embedded within hospice care, but this report comprehensively addresses how it could become so. Hospices are at a cross roads. Will they rise to the challenge and re-invigorate the original vision? It is within our hands to change. I strongly urge every hospice trustee, manager, professional and palliative care academic to read this report, pass it on to their colleagues and managers, debate it within your organisations, and above all, follow its recommendations. Together, we can then reclaim the original vision of expert pain and symptom control, compassionate care, teaching and research.

Fliss Murtagh, Clinical Senior Lecturer and Consultant in Palliative Care at the Cicely Saunders Institute, Kings College London and Commissioner
In recognising the contribution of this timely and strategic report into research in palliative care, it is important to acknowledge the increasing visibility of palliative care within global healthcare practice and policy. Internationally, supported by many agencies including the World Health Organization, palliative care is seen as a driver in the management of complex need, chronic and life limiting illness and a means to address peoples’ experience of suffering and loss. In many countries today, palliative care is moving towards greater integration with statutory healthcare provision and a number of strong European examples (such as Ireland, Spain and Germany) reflect the key messages that this report represents. The findings of this report, based on the study by Professor Sheila Payne and colleagues complements the national strategies already developed in the United Kingdom (Department of Health End-Of-Life Strategy 2008a). It addresses important questions about the need for evidence in hospice care and the challenges faced in that quest.

Hospices remain the bedrock of palliative care practice. They are the genus from which our skills and attributes in the art and science of caring for people at end of life are derived. Hospices offer the framework in which the physical, psychological, social and spiritual dimensions of life are met in a collaborative and caring environment. Hospices demonstrate a societal response to a way of caring which is highly valued by the public and particularly those who avail of its services. They often occupy a role as a societal barometer of how well care is delivered to those most in need. Being able to provide the evidence that supports that care is paramount in the current fiscal climate. Hospices are, and will remain, an important element of healthcare delivery.

People have the right to expect the highest possible standards of care and practice. Without the rigour of investigation and exploration for new ways of knowing what research offers, the strategic direction and thrust of policy and funding is compromised. As this report highlights, investment in research is not only about improving practice. Robust research enquiry sends clear messages to the commissioners, funders and managers of hospice services on how to achieve better outcomes in a more efficient and cost-effective way.

Yet, there are hurdles to overcome and as this report highlights, these are as much to do with changing cultures of hospice practice, capacity building for the future leaders of research and seeking greater collaboration between academic and clinical partners, as the need for significant improvement in financial investment for research in this sector. The recommendation to develop a Research Framework for Hospices and to identify, invest in and support ‘Research Active Hospices’ has the potential to transform the research infrastructure for hospice and palliative care and confirm the leadership role which the United Kingdom holds in the eyes of the international community.

This report is to be welcomed. It offers a genuine opportunity to address gaps, strengthen partnership and enhance engagement in the delivery of quality hospice care which is not only underpinned by rigorous evidence, but is derived and initiated by those at the forefront of care delivery. I wish to thank the authors of this report for having named that challenge. I urge those charged with responsibility for both research and practice to take up that challenge now and derive ways of moving forward collaboratively.

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This report has been commissioned by the Commission into the Future of Hospice Care.

The aims of the study were to:

1. Identify major concerns of national and local importance on the future of research related to hospice care.
2. Provide recommendations to inform the work of the Commission in relation to research and research capacity building.

Three sources of information were drawn upon to produce the report:

1. The outcomes of a study on Research Knowledge Transfer in hospices led by Nancy Preston involving three one-day workshop consultations held in the North West of England (two in Lancashire and one in Cumbria) which included 70 participants consisting of nurses, doctors, chaplains, chief executives of hospices, managers, users, researchers and lecturers.
2. Structured telephone conversations about constraints and opportunities associated with undertaking research by/in/related to hospice care with ten people including: hospice based health and social care practitioners (4); academics (3); commissioners (2); and a service user (1).
3. Scoping of the published literature, including previous research undertaken by Sheila Payne and Mary Turner about research infrastructure and research capacity in hospices.

The following statements and recommendations have been developed from the synthesis of the findings of the three studies above.

Why is research required in hospice care?

1. To provide evidence based treatment and care.
2. To test and improve complex interventions.
3. To provide the best evidence to support negotiations with commissioners and purchasers of hospice services.
4. To provide evidence of cost-effectiveness of hospice care.
5. To create a culture of inquiry.
6. To best understand the changing needs of the community that hospices serve.
7. To involve service users and the public in addressing research questions and defining the research agenda which may be different from professionals and managers.
8. To build practitioners’ expertise in critical appraisal of research and informed analysis of policy recommendations.
9. To attract the best quality staff who wish to undertake research and advance knowledge.

In short the question should be: ‘can hospices afford not to be involved with research?’

What are the barriers to doing research associated with hospice care?

1. The culture and ethos of hospices is not always conducive to research.
2. There is apathy and, in some cases, more overt hostility towards research.
3. Hospices appear to be fairly isolated and do not benefit from optimal research partnerships with the NHS or university sectors.
4. Hospice trustees and senior managers may know very little about research nor understand the implications of, and the need for, research.

5. Lack of research leadership and mentorship within the hospice sector, especially joint appointments of people between the hospice and university sectors.

6. Lack of research awareness, time pressure and expertise in professional staff.

7. Lack of infrastructure and resources to support research.

8. Limited funding to undertake research in hospice, palliative and end of life care.

9. Lack of research capacity means that it is difficult to prepare competitive grant proposals or to conduct studies even if they are funded.

10. Lack of reliable routine data collection means that collective datasets and information may not be available or there are large amounts of missing data.

11. Poor skills in research project management.

12. Poor understanding of the importance of research by staff and lack of skills in recruitment of patients and families into studies and clinical trials.

13. Paternalism and ‘gate keeping’ in relation to inviting patients and families to participate in research.

14. Lack of clarity in ethical research and research governance procedures, especially indemnity insurance (relative to the NHS).

15. Little engagement with service user involvement in research.

16. The nature of undertaking research with patients with advanced diseases and their families is challenging although this is not insurmountable.

17. Competition within the university sector to obtain the very limited funding available.

18. Very few academic research centres, with sufficient critical mass and track record of research leadership, that are able to offer mentorship in research and develop programmes of work within hospices.

19. Lack of concerted effort by medical charities to build programmes of work rather than fund small scale projects.

20. Lack of concerted effort by national organisations representing hospices and palliative care to provide high level leadership and lobbying of research funders.

Failure to offer patients and families the opportunity to participate in research and clinical trials is potentially unethical as it threatens their autonomy.

What are the recommended solutions?

Recommendations are offered in three categories – recommendations for:

- hospices
- universities
- national organisations supporting hospice care

We recommend the adoption of the **Research Framework for Hospices** which provides guidance for the three levels of research-focused participation within hospice care settings (Payne and Turner 2012). These hospices can be designated as ‘**Research Active Hospices**’.

- level 1: Research awareness in all professional staff
- level 2: Engagement in research generated by others
- level 3: Engagement in research activities and leadership in developing and undertaking research
Further actions recommended by hospices

At management and strategic level:

1. Development of a culture of inquiry in all aspects of hospice care.
2. Hospices’ trustees and senior managers need to become more aware of the value of research and prioritise it.
3. Regard ‘Research Active Hospices’ as a key quality marker.
4. Earmark a proportion of the overall hospice budget for research and development activities. This is an investment for the future.
5. Investment in staff research training and conference attendance.
6. Develop local hospice research consortia or networks, including links with key academic research centres.
7. In partnership with the university sector, design and offer research training at appropriate levels for the needs of staff.
8. Comply with National Minimum Datasets and other information system requirements.
9. Establish robust data management systems that are compatible with those of other hospices and interface with NHS systems.
10. Ensure there is sufficient access to electronic and digital information systems such as the internet to facilitate scholarship and knowledge transfer to staff.
11. Develop a service user ‘Research Panel’ that can promote awareness of valuing and participation in research.
12. Explore potential roles for volunteers, partnerships with industry, higher education, etc where people can safely and proactively contribute to research in cost effective ways.
13. Support the research training of staff undertaking higher degrees or specialist professional training.
14. Develop more dual/linked clinical/academic roles between universities and hospices to enhance research leadership within hospice settings.

At professional staff level:

1. Identification of research champions and research leaders, with dedicated time in their job description.
2. For those with ‘research’ in their job titles, ensure there is sufficient dedicated time, resources and mentorship to deliver research.
3. For those with ‘research’ in their job titles, ensure that they have sufficient research expertise, or opportunities to develop expertise, to have credibility as a researcher.
4. Encourage a research culture through participation in research meetings such as a journal club.

Further actions recommended by universities:

There are a large number of universities in the United Kingdom, many of them provide professional and academic education but only a very small number have academic research centres that have expertise in hospice and palliative care research. These recommendations largely relate to the latter group.

1. Universities need to develop respectful partnerships with hospices.
2. Universities could identify a ‘hospice research champion’ to liaise effectively with hospices to develop and conduct research.
3. Organise joint events to disseminate research outcomes.
4. Offer mentorship to hospice based researchers.
5. Establish a ‘rising stars’ programme to foster the development and retention of the best early career researchers.

6. Develop posts with a specific remit of working with local hospices to develop research.

Further actions recommended by national organisations supporting hospice care:

1. National organisations supporting hospice care need to adopt and incentivise the ‘Research Active Hospice’ scheme as a key marker of a quality environment of inquiry.

2. National organisations supporting hospice care need to establish regional ‘Hospice Research Hubs’, that draw together research active hospices into consortia or networks that are mutually supportive and provide access to specialist statistical, methodological and research design expertise. These regional ‘Hospice Research Hubs’ need to form partnerships with university academic research centres.

3. Provide resources that signpost hospices to appropriate palliative care research centres, experts or groups, and to Clinical Trials Units.

4. Signpost hospices to appropriate NIHR funded research support such as the national Research Design Service.

5. National organisations supporting hospice care could establish a national forum of senior hospice and academic leaders to advise on strategic direction and monitor processes against an implementation plan.


7. National organisations supporting hospice care could incentivise research by awarding prizes or other markers of national esteem to research leaders within hospices.

8. National organisations supporting hospice care need to form more proactive relationships with the health industry to promote hospices as a research environment.

9. National organisations supporting hospice care need to work with NHS, NIHR, NCRI and other agencies to lobby for the inclusion of hospice and palliative care research and to increase opportunities for researchers.

10. Medical charities and other funders need to be made more aware of hospice and palliative care research and how it can fit within their remit.

11. National organisations supporting hospice care need to lobby NRES for hospices to come under NHS research governance which would include indemnity insurance to conduct research.

Conclusions

There are mutual benefits for hospices and universities to form research partnerships. Currently all organisations appear to work individually on specific initiatives rather than combining as ‘a community of effort’ to more effectively utilise resources, provide leadership on ethical and governance processes, lobby at national level for funding, or to aspire to build the reputation of UK hospice research in the international arena.

Key Priorities

- adopt the Research Framework for Hospices
- implement and incentivise the label ‘Research Active Hospice’
- establish regional ‘Hospice Research Hubs’ with partnership agreements with university academic research centres
This report has been commissioned by the Commission into the Future of Hospice Care. It is estimated that 360,000 people, including patients and their families, receive hospice care in the UK each year (Help the Hospices, 2013, personal communication). These may be as inpatients, outpatients, day therapy patients, or be receiving support from hospice based community teams. Furthermore, since the launch of the National End of Life Care (NEoLC) Programme in 2004, there has been an increasing trend away from death in hospital and towards death at home, in care homes or in a hospice (Gao et al., 2013). As a result, the number of patients and their families receiving hospice care is likely to rise.

A central plank of the NEoLC strategy was the promotion of good practice in end of life care (Gao et al., 2013). While hospice care has emerged strongly over the last 50 years as a valuable and valued method of end of life care, and despite the recognition of the importance of research in palliative care since the outset of the hospice movement (Saunders, 1965), little is known about the effectiveness of different models of care delivery or about the underlying issues of concern that inform policy and service development (Shipman et al., 2008). There have been consistent conclusions from a variety of sources over the last decade that despite the leading position of British hospice care in many of the international comparative reports, such as the Quality of Death Index (The Lien Foundation, 2010), the evidence base for hospice care is weak (National Cancer Research Institute, 2004). More recently, Calanzani et al., (2013: 34) argue that, whilst it is very positive that current evidence ‘shows hospice care being effectively implemented in different settings and making a difference to patients and their families’, more robust research is needed in the area. Moreover, recent public concerns about the effectiveness and application of current end of life care tools such as the Liverpool Care Pathway (Daily Mail, 2013) highlight the need to better define, and justify, models of good practice, and starkly demonstrates where robust evidence is lacking. The latter example highlights the negative impact of failure to invest in research before implementation of new initiatives (Independent Review of the Liverpool Care Pathway 2013).

Alongside this, hospices will need to adapt appropriately to meet the challenges and opportunities of the next 10-15 years (Leadbeater and Garber, 2010). These challenges include:

- an increasingly ageing population.
- the rise in chronic disease and co-morbidities requiring end of life care for different sets of conditions and needs.
- changing social circumstances, including an increasing number of people living alone.
- limited knowledge about patient and family preferences for future care.
- limited evidence regarding the value of hospice care (Help the Hospices, 2013).
The aims of the study were to:

- identify major concerns of national and local importance on the future of research related to hospice care.
- provide recommendations to inform the work of the Commission in relation to research and research capacity building.

**Study Outcomes**

A number of outcomes for the scoping study were identified. These were to:

- enhance understanding of the future of research and evidence generated by hospices.
- provide the Commission with information which will help the integration of research within clinical and organisational practice, and clarify the role of hospices in contributing to new knowledge.
- directly contribute to the evolution and development of a stronger role for research in hospice care, and provide models for implementation.
- contribute recommendations for appropriate and feasible capacity building and research training in hospice personnel and form the basis of further research and evaluation.

**Study Questions**

To meet these outcomes, the following questions were addressed:

- what are the key issues in hospice care research?
  - what should research in relation to hospice care be achieving?
  - what research is needed?
  - what is the role of hospices in relation to research?
- what constrains research in hospice care research?
- what potential solutions could overcome these?
- what is the role of umbrella organisations, such as Help the Hospices and others, in supporting research in hospice care?

The following points are a synthesis of the reasons for hospice research from our data sources.
How was the study undertaken?

To produce the report, data were drawn from three sources:

1) A study on Research Knowledge Transfer in hospices in the North West

Three consultations were held in hospices in the North West of England (two in Lancashire and one in Cumbria) which involved 70 participants including: nurses, doctors, chaplains, chief executives of hospices, managers, service users, researchers, and lecturers. The one-day consultations followed the same format, with presentations in the morning explaining the importance of research in palliative care, followed by group discussions in the afternoon using a nominal group technique. Two questions were addressed:

- how do you think we can encourage palliative care research to take place?
- what are the research priorities in palliative care?

The initial findings were synthesised and used to inform the development of a short set of recommendations. These were sent to all participants who were asked to rank how important they considered them to be. The ranked findings from this study, which have been incorporated into the report, are provided in Appendices 1 and 2.

2) A national consultation with key stakeholders

Telephone consultations were undertaken with 10 national stakeholders to identify barriers and opportunities to undertaking research in hospice care. Stakeholders were identified in liaison with Dr Heather Richardson (Help the Hospices) to ensure a diversity of perspectives was captured. They were selected on the basis of their knowledge, and experience of, undertaking research or building research capacity in hospice care, including their awareness of ethical and governance issues. These stakeholders were: hospice based health and social care practitioners (4); academic researchers (3); commissioners (2); and a service user (1) (see list of names in Appendix 3). Stakeholders gave their verbal permission to be named as contributors to the report.

3) A rapid scoping of the published and grey literature

The evidence from the above sources was interpreted in the context of a rapid scoping of existing published and ‘grey’ literature and evidence from empirical work. The aim of rapid scoping of the literature is to scan recent research in order to identify key issues and highlight gaps (Jackson-Bowers et al., 2013). See Appendix 4 for details of the search strategy.

Integration of data sources

The study questions provided the broad framework through which to examine each of the three conceptually differing sources of data, and to identify the key issues emerging across them. These were synthesised to provide a unified view and to enable reporting in relation to the study aims.
Why is research required in hospice care?

The following points are a synthesis of the reasons for hospice research from our data sources.

1. **Evidence based treatment and care**
   
   The most important reason is to enable practitioners to deliver evidence based treatment and care (Preston et al., 2009; Payne and Turner, 2012). Many of the accepted methods of treatment have no strong evidence base, and some argue that there is little clinical trial data to support the use of new drugs and therapies for patients with advanced disease (Ross and Combleet, 2003). Such research is crucial to the enhancement of future practice in palliative care (Whiting and Vickers, 2010). However, whilst considerable work has been undertaken to identify knowledge gaps in hospice care, many gaps remain. Previous research has been predominantly biomedically driven, with a major focus on physical symptom and pain management, with very little attention to psychosocial and organisational dimensions.

2. **To test and improve complex interventions**
   
   There is a pressing need to draw together the evidence from previous research to identify what is known in hospice and palliative care and highlight gaps in knowledge and, more importantly, gaps in policy and implementation. There is a need to test models and configurations of hospice care as a complex intervention. Little is known about the reasons for the diversity in hospice care. Hospice based research needs not only to develop knowledge that is relevant to practice, but also to optimise the possibility of its integration into practice.

3. **To provide best evidence to support negotiations with commissioners and purchasers of hospice services**
   
   In an increasingly competitive economic climate and with the emergence of commercial competitors, hospice managers need to demonstrate the efficacy and efficiency of their service models.

4. **To provide evidence of cost-effectiveness of hospice care**
   
   In an increasingly competitive economic climate when contracting with the NHS and local organisations, and in generating charitable income, hospice managers need to demonstrate the cost-effectiveness of their service models.

5. **To create a culture of inquiry**
   
   Research in hospice care needs to anticipate cultural changes in attitudes to palliative care and care of the dying in order to make an informed contribution to the debates. For example, on issues such as caring for patients with non-cancer conditions, addressing the needs of people dying in late old age, complex symptom management and in calls for assisted dying.

6. **To best understand the changing needs of the communities that hospices serve**
   
   There is poor consensus on how to develop ways to combat negative perceptions of death, and cultural taboos that requires creative models and techniques to inform social engagement.
7. To involve service users and the public in addressing research questions and defining the research agenda, which may be different from that of professionals and managers

Research needs to include patients’ and families’ experience of care, as this is central to many interventions (Higginson et al., 2013).

8. To build practitioners’ expertise in critical appraisal of research and informed analysis of policy recommendations

There is an urgent need to build research capacity that includes the contribution of hospice based staff, and to ensure that they acquire sufficient knowledge to utilise research findings.

9. To attract the best quality staff who wish to undertake research and advanced knowledge

Hospices need to be in a position to attract high calibre staff who are increasingly seeking to combine research with their clinical roles, especially those in leadership positions.

Conclusions

A key principle of the NHS Constitution is that patients can expect to be informed of approved research that is relevant to their health and care, and ‘commits to innovation and to the promotion and conduct of research to improve the current and future health and care of the population’ (Department of Health, 2010: 3). This is not, as yet, a requirement for hospice care. However, whilst research is not the main focus of hospice care work and not all hospices are actively involved in research activity, some level of engagement is essential. Research should be integral to the organisation – a part of the patient pathway, and part of their care – for three reasons:

1. Hospice care needs research

A key characteristic of a reflective practitioner is their engagement in a process of continuous learning and adherence to professional codes of conduct. The Nursing and Midwifery Council, for example, requires registered nurses and midwives to make use of best available evidence or best practice in the delivery of care, and to keep their knowledge and skills up to date throughout their career (Nursing and Midwifery Council, 2008). Similar expectations are placed on medical, social care and allied health professionals. Having research-aware staff is, therefore, an ethical duty and also benefits the hospice by helping to deliver high quality care.

2. Hospices should play a significant role as the site of palliative care research

There is a scarcity of interdisciplinary collaborative and co-ordinated hospice and palliative care research beyond small scale, fragmented, methodologically flawed and/or non-generalisable studies. More proactive partnership between the academic and hospice sectors is required.

3. Research in palliative care is an identified priority

The Department of Health’s End of Life Care Strategy (2008a) highlights research in palliative care as an identified priority for UK health services (Bennett et al., 2010), and hospice care has an important contribution to make towards this broader agenda.

Hospice care research is crucial for the development of an evidence base for treatment and care. As a result, it needs to develop the evidence base for practice, optimise integration into practice and maintain close links with NHS research. In short the question should be: ‘can hospices afford not to be involved with research?’ To achieve this, a number of supportive structures need to be in place, including research capacity and funding. However, there are a number of barriers that constrain the capacity to undertake good quality hospice care research and these will now be considered.
What are the barriers to doing research associated with hospice care?

There are a number of recognised constraints and barriers in conducting research in hospice care. Although they are inter-related, we make distinctions between constraints that relate to the:

- hospice care settings as the site of research and universities as the sites of research expertise, and
- scientific and methodological aspects of palliative care research which are already widely recognised and have been to some extent addressed within the MRC funded MORECare project (Higginson et al., 2013).

Constraints on research can arise from aspects of the setting in which it takes place. These include collaboration; attitudes to research; infrastructure and resources; and research capacity. Each of these is underpinned by and contributes to a more elusive quality – that of the culture and ethos of the settings.

1. The culture and ethos of hospice is not always conducive to research

Although research is considered important by some hospices, staff attitudes to research and the perceived attitudes of others can result in a lack of appreciation of research (Irish Association for Palliative Care Education and Research Forum, 2013). Research is often regarded as a marginal activity, rather than being seen as central to the remit of hospices (Payne and Turner, 2012).

2. There is apathy, and in some cases, more overt hostility towards research

There may be a lack of understanding and valuing of research by hospice trustees, senior managers and staff. There may be a lack of awareness of research opportunities (Petersen et al., 2009) and no supporting policies for research. Some hospices are reluctant to engage in research participation, perhaps because it can be experienced as threatening or time consuming. This can create difficulties for programmatic work where further research leads on from initial findings. Particular staff groups may find the idea of research daunting. Nurses, for example, may use research to underpin patient care, but few engage personally in generating evidence through their own research (Nyatanga, 2012: 612).

3. Hospices appear to be fairly isolated and do not benefit from optimal research partnerships with the NHS or university sectors

Hospices were originally intended to be, among other things, places of learning and research (Clarke, 2007) in addition to clinical care. Since then, however, there has been a shift in culture; they have largely become passive, failing to develop coherent mechanisms to address research questions, inform policy decisions, or build research capacity (Bennett et al., 2010). Growth in published research is not easily attributable to the hospice sector (Payne and Turner, 2012). Furthermore, we would argue that the application of research findings into practice has been slow and patchy.

4. Hospice trustees and senior managers may know very little about research or understand the implications of research or the need for research

Evidence from a national survey and follow-up interviews with hospice trustees in the UK shows there is little awareness of research (Turner and Payne, 2009).
5. **Lack of research leadership and mentorship within the hospice sector, especially of people with joint appointments between the hospice and university sectors**

There is a lack of good research leadership (strategic and academic), and supportive management structures to help create and sustain a shared vision, develop a research strategy, and build research capacity. These issues are pertinent for collaboration not only between hospices as independent organisations, but also between hospices and academic researchers, and between academic researchers in different institutions.

6. **Lack of research awareness, time pressure, and expertise in professional staff**

Across all hospice settings, as a result of staff shortages and high workloads, a lack of time has been identified (McColl et al., 1998; Kirsch et al., 2004; Petersen et al., 2009; Nyatanga, 2012). In a survey of perceived facilitators and barriers to conducting palliative care research in Ireland (Irish Association for Palliative Care Education and Research Forum, 2013), lack of time was identified as the primary barrier by 63% of provider participants. Linked to lack of time as a resource is the status of staff, because not all staff who work in hospices are employees. In independent hospice care settings, medical staff may be ‘leased’ from the NHS, and where there are shortages of staff, agency staff may be employed (Mackin, et al., 2009). These factors have implications for research governance. Furthermore, staff may not see research as part of their job role, and few staff have ‘research’ in their title or job description (Turner and Payne, 2009). For those nurses who have a designated research role, there may be a lack of guidance on how to carry it out (Dunleavy et al., 2011).

7. **Lack of infrastructure and resources to support research**

As well as poor infrastructure or resources that enable research to take place, a further barrier to hospice care research concerns a lack of access to the resources that support staff engaging with, and in, research require. Two types of infrastructures and resources enable research to take place and underpin it as an activity. The first are those required to enable research to take place, whilst the second type are those that support research as an activity. The lack of either or both of these types has implications for the capacity to actively engage in research (Payne and Turner, 2012). A study of hospice activity identified that 71% of hospices had collaborated with other organisations on research projects, but only 38% reported playing an active part in a research network or consortium with other hospices. Links with other organisations, however, do not necessarily lead to increased research; only 25% had initiated any research of their own during the previous year, even though 69% reported links with academic departments (Turner and Payne, 2009). Researchers require access to a range of information resources, including journals and bibliographic databases via the internet, as well as broader access to the World Wide Web. In addition, they need access to software for data analysis and storage. A recent study identified that the majority of hospices appeared to have a library space (88%), subscriptions to academic and professional journals (94%), and internet/computer access (100%). What is not clear, however, is the extent to which these facilities are used by staff. Nevertheless, less than half of the hospices (48%) organised a journal club (Payne and Turner, 2012) – an activity which, as well as contributing to evidence based practice, helps develop and strengthen research awareness.
8. **Limited funding to undertake research in hospice, palliative and end of life care**

For those working in hospice care and for academic researchers, time and money are central ‘primers’ for research activity, not only through funding an initial research project, but in contributing to the development of a ‘track record’, which provides support towards further applications for funding. One consequence of limited funding is that innovation in study design and methodology is hindered (Evans et al., 2013). In addition, there are concerns about the time-consuming and difficult nature of making grant applications, which are normally highly competitive (Payne and Turner, 2012). There are limited resources for hospice based research and a lack of a national strategy which allocates monies to palliative care research (Kaasa, et al., 2006), in common with other countries. In 2010, only 0·24% (£1,219,349) of the UK research funding awarded for research into cancer by National Cancer Research Institute partners, was allocated to palliative and end of life care research (Sleeman, et al., 2010). More broadly, in a study of 149 UK funding organisations with an annual spend of £260 million, only £3.37 million (1.3%) was spent on palliative and end of life research. This, however, obscures a more complex picture, with statutory bodies spending 0.76% of their budget and charities 2.2% on palliative and end of life research, whilst two charities that specialised in palliative/end of life care had a 40-80% spend (Preston, 2013a). Most respondents indicated that despite palliative and end of life care being within their remit, it was considered too generic since dying happens to everyone not solely those within the charity’s disease of interest. The study, however, had a poor response rate of 13% (38% funders declined to participate and 49% failed to respond), for reasons that are unclear, although a lack of interest in palliative and end of life care may have contributed. Funding for research, thus, remains pitiful. Furthermore, there is intense competition amongst researchers for access to the meagre funding available.

9. **Lack of research capacity means that it is difficult to prepare competitive grant proposals or to conduct studies even if they are funded**

Key dimensions of research capacity include a basic understanding and appreciation of research methods; the promotion of evidence based practice to benefit patient care; and enabling talented individuals to pursue research projects through expert mentorship and research scholarships (Payne et al., 2011). Lack of training about research methods and governance issues, and the subsequent lack of confidence (identified particularly for nurses by Nyatanga, 2012) is a central barrier to generating good quality research in hospice care. Whilst the general level of research education of practitioners is rising in the NHS, many hospice staff still lack basic knowledge about research.

10. **Lack of reliable routine data collection means that collective datasets and information may not be available or there are large amounts of missing data**

There is a lack of standardised infrastructure across hospice care settings that support research, including routine data sets and project management processes (Abernethy et al., 2010). Accurate data are the basis of all research, and information gained through the routine systematic collection of basic data can answer, or contribute to answering, a substantial number of key questions about hospice care. Examples of valuable information include the characteristics of patients dying in different settings, the prevalence of symptoms requiring management, and the outcomes of care.
of service users, and information about their trajectory across the end of life care services with which they have come into contact and the costs associated with delivering different elements of care. UK patient activity in specialist palliative care services in the voluntary sector and the NHS (inpatients, day care, community care, hospital support, bereavement support and outpatients) is collected via the returns of the Minimum Data Set (MDS) for specialist palliative care. Hospices, however, have been slow to identify the need for this and do not always return this data. In 2010, the overall response rate reached 62% but this varied widely by service type (from 75% for home care services to 44% for bereavement and outpatient services) (Calanzani et al., 2013).

In addition, blocks may have been placed on access to data, and databases can be incompatible. As a consequence, data is difficult to access and can be limited and patchy. This results in an inaccurate portrait of the UK hospice care services, and makes comparisons difficult. Furthermore, as information sets and data are not routinely shared between the respective systems involved in end of life care, a broader understanding of the patient’s experience – for example, of the number of clinic visits, or use of social care packages – is not available. Missing research data, whether not collected routinely by the hospice care setting, or because it is not available due to non-response or incomplete collection is also problematic.

11. Poor skills in research project management

Delivery of research studies requires good project management skills. In hospice care research, project management faces many challenges (O’Brien et al., 2010). The complex processes involved in gaining ethical approval and ensuring patient recruitment makes time schedules difficult to maintain. The key tasks of developing relationships, keeping people involved and informed across a variety of groups and settings, setting objectives, managing budgets and resources, organising meetings, and preparing information for different audiences requires particular management styles, capacities and structures to be in place. There are also questions about where overall responsibility lies – with the researcher, or those in the hospice setting – especially when there is cross-organisational collaboration (Payne et al., 2011).

12. Poor understanding of the importance of research by staff, and lack of skills in recruitment of patients and families into studies and clinical trials

Staff attitudes to research and the perceived attitudes of others can result in a lack of appreciation of research (Irish Association for Palliative Care Education and Research Forum, 2013). For those staff with a designated research role, apart from training in relation to the ‘Good Clinical Practice Guide’ (Medicines and Healthcare Products Regulatory Agency, 2012), no formal research induction programme or training may be provided by hospices (Dunleavy et al., 2011). There are also concerns about a perceived lack of skill in introducing a request for research participation; concerns about treatment equipoise, the prioritisation of workloads (Preston, 2013b), and how research might impact on their relationship with patients.

13. Paternalism and ‘gate-keeping’ in relation to inviting patients and families to participate in research

‘Gatekeeping’ – where health professionals, family members or research ethics committees prevent patients being invited to enter research studies – is frequently cited as a major barrier to participation in palliative care clinical trials (White and Hardy, 2008; Hosie et al., 2011).
Preston et al., (2013b) argue that although most staff agreed that patients should have the opportunity to take part if they wish, staff tended to adopt a paternalistic ‘gatekeeping’ role (Preston et al., 2009) that denies patients the potential satisfaction of having contributed to knowledge and care development (Preston et al., 2013c). Specific reasons given for patient exclusion include views about the patient’s physical frailty; their cognitive impairment; communication difficulties; and levels of emotional distress (Ross and Cornbleet, 2003). More broadly, reasons concern staff protection of vulnerable patients from the intrusiveness of research (Casarett et al., 2001) and the desire not to burden the patient with this additional task (Hosie et al., 2011). In practice – perhaps as a result of their traditional caring role to protect patients – there appears to be an unwritten code to only invite those patients fitting the ideal research participant stereotype (Preston et al., 2013c). This is based on the underlying belief that research involving dying patients is inappropriate, and that staff are protecting patients from having to make a difficult decision (Preston et al., 2009).

14. Lack of clarity in research ethical and research governance procedures, especially indemnity insurance (relative to the NHS)

Research governance is a process which sets standards for research, defines mechanisms to deliver standards and describes monitoring and assessment arrangements. For research in health and social care, this is set out in the framework provided by the Department of Health (2005a; 2005b; 2008b). Because of the nature of the hospice care setting, there are additional challenges for governance. For clinical trials that involve medicines, it is a legal requirement that there should be indemnity insurance to cover the liabilities of sponsors and investigators (DOH, 2005a; 2005b). The NHS and universities provide this for their staff. Hospices, however, are classed as non-NHS institutions in the UK, despite adult charitable hospices in England receiving on average 32% of their costs from the government or the NHS (Help the Hospices, 2009). In addition, they only treat NHS patients for whom they provide a variety of free care and services (Dunleavy et al., 2011). This lack of NHS status in the NHS research governance system presents hospices with a number of difficulties. Firstly, research indemnity insurance can be costly. Under the current system, a hospice needs to provide evidence that it has the necessary indemnity arrangements in place to meet the potential legal liability of the principal investigator, the research team, and the organisation in case of harming participants in the conduct of research at the hospice site (Dunleavy et al., 2011). Indemnity cover from the commercial sector can be prohibitively expensive as a result of a failure to understand research in this setting, and the balance of benefits and risks involved (Bennett et al., 2010; Dunleavy et al., 2011). Secondly, as a result of rotating staff, and the use of temporary staff from agencies or staff who are employees of the NHS working in the hospice setting, there can be confusion about which member of staff is covered by NHS or Defence Union indemnity. Thirdly, hospice staff may lack experience in negotiating governance issues, NHS research and development departments may have a lack of knowledge about, and experience of, carrying out clinical trial research in non-NHS hospice sites (Dunleavy et al., 2011), and NHS National Institute for Health Research (NIHR) industry clinical trials managers can be unfamiliar with hospice care research. This results in delays and additional costs to the start of the studies, the duplication of paperwork, and an increase in workload (Dunleavy et al., 2011).
15. Little engagement with service user involvement

While service users are normally involved in NHS research, there is less evidence of this in hospice care.

16. The nature of undertaking research with patients with advanced disease and their families is challenging although this is not insurmountable

The principles for ensuring ethical research apply to all clinical domains, including people nearing the end of life (Fine, 2003). These principles are designed to ensure the promotion of the participant’s ethical and legal rights, and that the research does not harm the population or society being researched (McCauley-Elsom, 2009). The particular challenges relating to hospice care are well described by the MORECare project (see Gysels et al., 2013).

17. Competition within the university sector to obtain the very limited funding

This was one of the factors identified by the National Cancer Research Institute (NCRI) in their review of the state of supportive and palliative care research in the UK and influenced the development of the Supportive and Palliative Care Research Collaborates. Unfortunately, the national research funding situation remains difficult and arguably has worsened in the last decade. The NCRI has published data on the amount of funding going in to palliative and end of life care research. This is available as a data package from http://www.ncri.org.uk/default.asp?s=1&p=3&ss=6. They show that still comparatively small amounts are available for palliative and end of life care research.

18. Very few academic research centres, with sufficient critical mass and track record of research leadership, are able to offer mentorship in research and develop programmes of work

Further limitations on the capacity of academic researchers interested in palliative care research to collaborate arise from their potential isolation as ‘lone researchers’ because even though many universities offer palliative and hospice care education, there are only a limited number of UK based palliative care research centres with sufficient critical mass to lead research. The pressures associated with the attainment of academic success based on individual performance and output (for example in the Research Excellence Framework), acts directly against collaborative partnerships as it encourages researchers and institutions to be competitive (Payne et al., 2011). Furthermore, without established structures and people familiar with working across these sectors, an ethos of research in hospices, and lacking supportive links between hospice settings and universities, good ideas may not be seen as research opportunities or as researchable, and little progress can be made. Moreover, individual researchers are often too overwhelmed by their own research and teaching commitments to find time to support others.

19. Lack of concerted effort by medical charities to build programmes of work, rather than fund small scale projects

In 2003, the National Cancer Research Institute (NCRI) identified the need to enhance the value, quality, and productivity of UK research in all aspects of cancer-related supportive and palliative care, and recommended the establishment of interdisciplinary supportive and palliative care research collaboratives to
include academic organisations, researchers, and individuals and groups from different research disciplines and clinical professions. Despite the benefits from the Supportive and Palliative Care Research Collaboratives initiative which were subsequently funded for five years by, for example, bringing together disparate groups, developing good quality research studies that have led to the availability of a significant number of peer-reviewed academic and professional papers, and building research capacity and research leadership – the funding for these have now ceased. Limited resources are placing pressure on the statutory and other funding sources that remain, and changes within the UK university environment increasingly favour inter-institutional competition (Payne et al., 2011).

20. Lack of concerted effort by national organisations representing hospices and palliative care to provide high level leadership and lobbying of research funders

The multi-dimensional complexity of the inter-relationship of the features of hospice care, the nature of palliative care, and the particular needs of this patient and family population, create particular types of constraints on research in hospice care settings. In the UK, in comparison with many other European countries, there is a plethora of organisations working in hospice and palliative care at national level, meaning that there is no consistent ‘voice’ or representation to influence research policy or funding strategies. This is a potential disadvantage to the promotion of hospice research resulting in a lack of strategic direction and prioritisation of research in hospice, palliative and end of life care.

Conclusions

The barriers to hospice care research are found in the settings in which it takes place, as well as in the practical, ethical and methodological challenges that research with this population entails. The need to balance research and clinical roles is a particularly difficult challenge. Nevertheless, the need for research cannot be ignored. Many potential solutions to each of the constraints, in relation to both the settings of research and the scientific aspects of the research process, have been identified, and it is to these that we will now turn our attention.
What are the recommended solutions to increase research activity in hospice care?

Recommendations are offered in three categories – recommendations for:

- hospices
- universities
- other national organisations supporting hospice care

**A Research Framework for Hospices**

We recommend the adoption of the **Research Framework for Hospices** which provides guidance for the three levels of research-focused participation within hospice care settings (Payne and Turner, 2012). These can be designated as 'Research Active Hospices'. Rather than be developed in an 'ad hoc' manner by individual hospices, this framework needs to be enacted by a national, overarching body such as Help the Hospices through whom 'Guidelines for good practice' and supporting governance for each level can be elaborated.

**Level 1: Research awareness in all professional staff**

As ‘critical consumers of research’, all professional staff are aware of research in order to provide evidence based care and services. This awareness strengthens and better informs negotiations with other stakeholders. Research capacity is developed through education and training, service provision is evidenced based and reviewed during multidisciplinary meetings, and staff have access to, and learn how to search, electronic databases to obtain information to support evidence based care.

**Level 2: Engagement in research generated by others**

Level 2 includes the objectives of Level 1 but, in addition, staff develop confidence and skills in research; hospices engage in, or contribute to, research generated by others, collaborating with research studies and trials; and they help increase the number of patients and families who are offered the opportunity to participate in research. There are clear policies governing good research practice, including how to deal with ethical issues and recruitment of patients and families. Staff are helped to understand the issues which enables their confidence and skill level to increase. Each hospice identifies a research leader and research ‘champions’.

**Level 3: Engagement in research activities and leadership in developing and undertaking research**

As well as engagement with Level 1 and 2 activities, the Level 3 hospice actively undertakes research and engages in leadership by developing and undertaking hospice initiated research. Attention is paid to capacity building in research methods training for hospice staff, and there are links with appropriate academic research centres to provide expertise, supervision, mentorship, as well as with other research active hospices in research consortia or networks. Guidelines govern research activities and investment. These levels are outlined in Figure 1.

In this model, all hospice settings could be designated ‘Research-Active’ at one of the three levels in which they are able to engage in research. However, the level of hospice engagement will determine the role responsibilities of members of staff who are designated to actively encourage and support research.

**Figure 1: Features of the setting, tensions that surround research management and the skills required**

Source: Payne and Turner, 2012
Further actions recommended by hospices

At management and strategic level:

1. Development of a culture of inquiry in all aspects of hospice care

There are many practical solutions to some of the constraints and barriers that have been highlighted but, as we have seen, the culture and ethos of the hospice is an important factor affecting on the attitudes and capacity of staff to undertake research, contribute to recruitment into studies, and to support the research efforts of others. It also has an impact on how staff use research evidence in practice. Important strategies, therefore, are those that foster a ‘research-receptive’ culture that values and prioritises research (Payne and Turner, 2012). This means a greater awareness of research, the use of research to solve problems and an involvement in research studies. This type of culture takes a broad view of direct and indirect contributions that can be made to research projects, including staff identifying areas for research; undertaking research; disseminating findings, and applying research to practice (Nyatanga, 2012). For example, St Christopher’s Hospice, London has an international reputation for the quality of its research, education and clinical activities demonstrating the advantage of integrating these elements to improve patient care and engage with its wider community.

2. Hospice trustees and senior managers need to become more aware of the value of research and prioritise it

Changing attitudes of staff to research will be largely influenced by changing the ethos and culture of the hospice setting, and by developing supportive infrastructures and research capacity. Research involvement affects attitudes to research, as those involved are more likely to be confident in their ability to evaluate the quality of research papers and less likely to find applying research to practice difficult (Irish Association for Palliative Care Education and Research Forum, 2013).

3. Regard ‘Research Active Hospices’ as a key quality marker

One of the benefits of declaring the level at which the setting is a ‘Research-Active Hospice’, is that it will inform its users of the value the staff place on research; that it is central in their decisions about care, and implicit in their everyday activities. This, together with collaborative working practices, is likely to increase participation in research (Preston, 2013b). Raising awareness can be undertaken through different media – for example, through posters, leaflets and newsletters in accessible language available in the hospice care environment, as well as through publicity via TV, radio and social media such as ehospice or Facebook. These awareness-raising activities may also help change attitudes to research by reducing the idea that research is ‘academic’ rather than integral to ‘everyday’ practice.

4. Earmark a proportion of the overall hospice budget for research and development activities. This is an investment for the future

Funding is a crucial issue for research and more funding is needed to undertake well designed studies that address priorities. Possible solutions include:

- increasing the skills of making applications for grant funding.
- being alert to funding opportunities that arise, and manoeuvring the focus of the study towards the interests of the funder.
- collaborating with others in order to design more robust studies rather than undertake small-scale studies that will have little impact and may not contribute new knowledge or be publishable.
5. **Investment in staff research training and conference attendance**

There is evidence to support this from the capacity building evaluation undertaken by the Cancer Experiences Collaborative (Payne et al., 2012).

6. **Develop local hospice research consortia or networks, including links with key academic research centres**

Collaboration requires a collegiate approach. Although it can be time consuming, collaboration brings many benefits. For hospice care staff, this includes research capacity building through access to research expertise, advice and guidance and the potential for supervision and mentorship based in university academic centres. For researchers, collaboration increases the support of hospice staff in the research design, the ethical review processes, enables access to research participants, and enhances understanding of the setting and the clinical expertise of the staff. For research studies, access to multi-site consortia or networks means there is likely to be an increase in eligible populations for recruitment and therefore increased sample sizes, increased likelihood of successful recruitment (Daniels and Exley, 2001) and, therefore, more robust and generalizable outputs. For example, a research network of three hospices established in north Lancashire benefited from academic medical leadership, investment of NHS resources to fund part time research nurses based in each hospice and enabled it to host university and industry led-research (Dunleavy et al., 2010).

7. **In partnership with the university sector, design and offer research training at appropriate levels for the needs of staff**

Different levels of formal and informal research-focused education and training need to be available. Short courses on specific issues such as: research awareness; methodological and ethical issues in research; skills for data retrieval; recruiting participants to studies; and budgeting and financial reporting can enable staff to both select a course of relevance and enable them to develop skills over time. Examples of informal, practice-based opportunities include developing the critical appraisal capacity of staff, for example through journal clubs (Payne and Turner, 2012), and developing evidence based practice, for example through discussing the evidence base of treatment decisions in team meetings.

8. **Comply with National Minimum Datasets and other information system requirements**

The infrastructure for collection of the Minimum Data Sets is already in existence. However, to ensure that an accurate picture of hospice care can be made, strategies need to be in place that encourage accurate completion and maximises response rates. Discussions within the sector could be helpful in identifying barriers to completion, and the use of incentives may encourage higher response rates.

9. **Establish robust data management systems that are compatible with those of other hospices and interface with NHS systems**

Current hospice data management systems may be unhelpful if they do not readily ‘communicate’ with local NHS systems.

10. **Ensure there is sufficient access to electronic and digital information systems such as the internet to facilitate scholarship and knowledge transfer to staff**

The Hospice Information Service offers good resources. An example of this is an accessible web based resource to support research activity in hospices such as the one hosted on the International Observatory on End of Life Care Website and the St Catherine’s Hospice Website (Preston et al., 2013b).
11. Develop a service user ‘Research Panel’ that can promote awareness of valuing and participation in research

Service users are often both the subject of research and participants in it. Patients’ experience of care is central to many interventions (Higginson et al., 2013) and is, therefore, at the heart of improving practice. Involvement can occur at different phases in the research, offering a number of benefits to studies and to the work of the hospice care setting, including:

- ensuring that research questions, methods and recruitment strategies have utility and relevance
- identifying issues that may be overlooked by ‘professional researchers’
- assisting in the dissemination of findings.

12. Explore potential roles for volunteers, partnerships with industry, higher education, etc where people can safely and proactively contribute to research in cost-effective ways

There are already examples where volunteers have been used to support research by transporting trial medication (Dunleavy et al., 2013), or have been recruited with specific research skills or experience such as statistics at St Christopher’s Hospice, London. For example, Age UK has structures that operate across the UK where older people volunteer their time and expertise to assist with research projects.

13. Support the research training of staff undertaking higher degrees or specialist professional training

There is evidence of a diversity of support for hospice staff in building their research capacity (Payne et al., 2012). For example, we are aware of research ‘Master Classes’ provided by the Palliative Care Research Society which are available in different parts of the UK.

14. Develop more dual/linked clinical/academic roles between universities and hospices to enhance research leadership within hospice settings

Collaboration between hospice care staff and researchers enhances understanding of their respective roles. It enables staff to recognise the ways in which practice has informed the research, and also the applicability of research to practice. Greater development of roles that combine clinical and researcher activities supports the research–practice interface (Gysels et al., 2013). Good leadership contributes to achieving stability and managing change. In the context of a research-active hospice, leadership entails activities that are relationship-focused, and others that are research-focused.

At professional staff level:

1. Identification of research champions and research leaders, with dedicated time in their job description

A member of staff is designated to encourage and support research within their setting, beyond the narrow focus of primarily recruiting patients, collecting data for the researcher, and undertaking administration duties for a research project (Nyatanga, 2012).

2. For those with ‘research’ in their job titles, ensure there is sufficient dedicated time, resources and mentorship to deliver research

It is essential to have protected time to enable staff to participate in research (Irish Association for Palliative Care Education and Research Forum, 2013).

3. For those with ‘research’ in their job titles, ensure that they have sufficient research expertise, or opportunities to develop expertise, to have credibility as a researcher

For those working in designated research posts, being assigned a supervisor or mentor is also a
helpful strategy to develop skills and confidence (Irish Association for Palliative Care Education and Research Forum, 2013). Spending time with someone who has experience of designing and initiating studies and recruiting patients to clinical studies is useful, especially for those undertaking a more specialist research role (Dunleavy et al., 2011).

4. **Encourage a research culture through participation in research meetings such as a journal club**

All professional staff are encouraged to engage in promoting research, both in their practice and as an essential activity in building evidence of best practice. This reflects the idea that staff contribute to the research culture, and can give patients the opportunity to decide about involvement in research studies for themselves, and help relatives to understand that the research may be beneficial to the patient (Preston et al., 2009).

**Further actions recommended by universities:**

There are a large number of universities in the United Kingdom, many of which provide professional and academic education, but only a very small number have academic research centres that have expertise in hospice and palliative care research. These recommendations largely relate to the latter group.

1. **Universities need to develop respectful partnerships with hospices**

   Universities should be reaching out to hospices who are geographically isolated in terms of access to research expertise, to offer advice and support on overcoming the challenges in undertaking research in hospice care.

2. **Universities could identify a ‘hospice research champion’ to liaise effectively to develop and conduct research**

   University based research should undertake feasibility consultations with hospices and service users to ensure their research design and methods are appropriate. This can be facilitated by a dedicated person who can both understand ‘cultural’ environments and communicate effectively in the language of health care and in research/academia.

3. **Organise joint events to disseminate research outcomes**

   This recommendation arises out of our Knowledge Transfer project (see Appendix 1).

4. **Offer mentorship to hospice based researchers**

   For those staff who are research active, being assigned a supervisor and mentor is also a helpful strategy to develop skills and confidence (Irish Association for Palliative Care Education and Research Forum, 2013). Spending time with someone who has experience of designing and initiating studies and recruiting patients to clinical studies is useful, especially for those undertaking a more specialist research role (Dunleavy et al., 2011).

5. **Establish a ‘rising stars’ programme to foster the development and retention of the best early career researchers**

   There are benefits to identifying those staff with the potential to become research leaders in hospices (Payne et al., 2011). For example, in public health a ‘rising stars’ programme provides enhanced mentorship and international opportunities to accelerate the development of high quality junior researchers to enable them to be internationally competitive.
6. Develop posts with a specific remit for working with local hospices to develop research

The Supportive and Palliative Care Research Collaboratives (the Cancer Experiences Collaborative [CECo] and COMPASS) did much to promote partnership working across universities in the UK and other organisations including NHS cancer centres, Third Sector organisations and helped to develop research in hospices (Payne et al., 2011). In particular there are models of research capacity building pioneered within CECo that focused specifically on those working in hospices (Payne et al., 2012). For example, offering short term scholarship funding for clinicians to undertake research within CECo institutions and providing access to free mentorship and research methods training as potentially transferable models which have been built upon by the All Ireland Institute for Hospice and Palliative Care.

Further actions recommended by other national organisations supporting hospice care:

Many national organisations constitute the wider environment that influences hospice care research, and these include:

- hospice related organisations, such as Help the Hospices, National Council for Palliative Care, Together for Short Lives
- statutory sector organisations, including the NHS and social care providers
- professional bodies, such as the Royal College of Physicians and the Nursing and Midwifery Council
- professional organisations, such as the Association of Palliative Medicine
- medical charities and philanthropic organisations, such as Marie Curie Cancer Care, Motor Neurone Disease Association, Sue Ryder Foundation, Dimbleby Cancer Care, Macmillan Cancer Support, AgeUK and many others.

Each of these groups has a different remit and set of priorities, as well as a different relationship to hospice care settings. Nevertheless, they share a keen interest in the work of hospice care settings and in the research on which disease-specific and wider forms of care are based. They have an important role in improving the research environment and enabling hospice care research to take place through strategic vision, advocacy, lobbying and support. Their contribution is helpful to gain consensus and consistency in relation to good practice, and to reduce duplication of effort.

1. National organisations supporting hospice care need to adopt and incentivise the ‘Research Active Hospice’ scheme as a key marker of a quality environment of inquiry

See Figure 1 on page 19.

2. National organisations supporting hospice care need to establish regional ‘Hospice Research Hubs’

The ‘Hubs’ could draw together research active hospices into consortia or networks that are mutually supportive and provide access to specialist statistical, methodological and research design expertise. The regional ‘Hospice Research Hubs’ need to form partnerships with university academic research centres to provide specialist expertise.
3. **Provide resources that direct hospices to appropriate palliative care research centres, experts or groups, and to Clinical Trials Units**

Strategies for improving access to research related resources include:

- improving the capacity of staff to access and use bibliographic and data analysis technologies appropriately and effectively.
- creating access to abstracting journals or blogs that direct staff to the publication of key papers and articles.
- creating ideas and prompts for journal club discussion.
- developing and maintaining an accessible database of hospice-based research activity (Turner and Payne, 2009).
- alerts to calls for funding for research proposals and other funding opportunities, specifically applicable to those working in hospices.

4. **Signpost hospices to appropriate NIHR funded research support such as the national Research Design Service**

The Research Design Service is available free of charge to support research design and development of proposals for competitive funding and currently have an ‘It’s OK to Ask’ campaign to encourage more people to seek support.

5. **National organisations supporting hospice care could establish a national forum of senior hospice and academic leaders to advise on strategic direction and monitor outcomes against an implementation plan**

The possible benefits of establishing such a group outweigh the modest costs of convening it.

6. **National organisations supporting hospice care could establish a directory of hospice care research**

Promoting high quality research in hospice care settings would benefit from a centralised pooled resource such as the Toolkit for Care Home Research developed by the Dementia and Neurodegenerative Diseases Research Network (DeNDRoN) (available at http://www.enrich.dendron.nihr.ac.uk). It draws on work from the NIHR School for Social Care Research to provide information, tools, case studies and further resources for facilitating research. Whilst it is focused on research in care homes, it is being designed to be applicable to other disease areas, and to support the promotion of all high-quality research. It may not be necessary to duplicate this. However, this type of overarching website could provide a strong basis for meeting the particular needs and constraints of hospice care research.

7. **National organisations supporting hospice care could incentivise research by awarding prizes or other markers of national esteem to research leaders within hospices**

There is little national recognition of hospice research leaders and therefore few role models for junior staff to aspire to. For example, the European Association for Palliative Care awards three annual prizes to early stage researchers. These are seen as highly prestigious and enhance career opportunities for the winners (see EAPC blogs and the European Journal for Palliative Care for evidence of the impact of these awards on winners) and may reflect well on organisations which they are associated with.
8. *National organisations supporting hospice care need to form more proactive relationships with the health industry (pharmaceutical and non-pharmaceutics commercial companies) to promote hospices as a research environment*

This suggests that more proactive pathways can be established to highlight the opportunities in hospices for clinical trials. For example, the North West hospice research network supports drug trials.

9. *National organisations supporting hospice care need to work with NHS, NIHR, NCRI and other agencies to lobby for the inclusion of hospice and palliative care research and to increase opportunities for researchers*

Some research funders may have little understanding of hospice and palliative care.

10. *Medical charities and other funders need to be made more aware of hospice and palliative care research and how it can fit within their remit*

National efforts are needed to influence funders to increase the percentage of their budgets that is spent on hospice care research and for funding themes to reflect the priorities in hospice care. For example, we are aware that the NCRI have organised a number of meetings with funders to foster better relationships. NCRI also did the NCRI Rapid Review published in November 2010 because of the need to align what all the funders were doing and get funders behind supporting this research area more. Since that meeting NCRI have held further funder meetings and developed the UK end of life care Research Interest Group that has grown to 29 members. This is a strong indication of the importance of the research area and the increasing recognition of that by the funders.

11. *National organisations supporting hospice care need to lobby NRES for hospices to come under NHS research governance which would include indemnity insurance to conduct research*

Potential solutions to the lack of indemnity for hospice related research include:

- hospices to be considered as equivalent to NHS sites

For NIHR research purposes, hospices need to be recognised as NHS sites providing NHS services, and the NHS litigation authority needs to be extended to the named patients, staff and hospices involved in the study (Bennett et al., 2010). Alternatively, hospices could be treated as independent treatment centres. NHS indemnity is extended into private premises, but to apply in hospices, they would have to be recognised as treating NHS rather than private patients, and NHS indemnity would then apply. Senior researchers have been in discussion with NIHR, and it is hoped a solution will shortly be found.

- hospices seek indemnity from commercial sources

An alternative is for hospices to seek indemnity from commercial insurance companies. Based on actuarial terms of harm, most palliative care research is considered low risk. Some hospices have found that if the type and range of research to be undertaken in any one year is fully explained to the insurance company, they will provide low cost cover linked to the hospice’s existing insurance. Continued cover is negotiated following a report to the insurance company on what research has been done.
Many of the issues that cause concern in relation to research governance and ethics can be addressed by strengthening and consolidating hospice-based processes. A key strategy is to convene a Research Governance Committee, whose responsibility is to ensure the research governance of any studies undertaken within the setting is scrutinised and approved. This can be achieved either by the hospice setting up its own committee or core group of members with relevant expertise, or by outsourcing responsibility for some or all aspects of research governance within hospice research consortia or networks. There are many activities that a hospice-based ‘research governance committee’ can usefully undertake, depending on their level of research engagement.

Conclusions

There are a significant number of potential solutions to the constraints in hospice care research. Enhancing the culture and ethos of the hospice care setting is of particular importance as this has an impact on other factors that constrain or enable research to take place successfully.

Collaboration within and between hospices, between hospices and academic researchers, and between academic institutions is also a significant influence on hospice care research – on recruitment to studies, the types of studies that can be undertaken, and on research capacity building. In addition, it supports research close to practice enhancing the possibility of its integration into practice (Payne et al., 2012). Collaboration depends on academic leadership and good management skills.

Key solutions include capacity building and leadership development through education and training, and supervision and mentorship; and funding to support collaborative activities and undertake collaborative research. Crucially, patient and family issues need to be at the centre of all aspects of the research enterprise. Many solutions can be achieved through the attention to individual issues, but many require strategic action such as influencing policies, lobbying for appropriate funding and providing direction. National organisations have a crucial role to play in providing this form of leadership and strategic direction.

There are mutual benefits for hospices and universities to form research partnerships. Currently, all organisations appear to work individually on specific initiatives rather than combining as ‘a community of effort’ to utilise resources more effectively, provide leadership on ethical and governance processes, lobby at national level for funding, or to aspire to build the reputation of UK hospice research in the international arena.

Key Priorities

- adopt the Research Framework for Hospices
- implement and incentivise the label ‘Research Active Hospice’
- establish regional ‘Hospice Research Hubs’ with partnership agreements with university academic research centres.
International Observatory on End of Life Care, Lancaster University

Lancaster University is approaching its 50th anniversary with a world class reputation as a centre for excellence in teaching, scholarship and research. Established in 2008, the Faculty of Health and Medicine brings together a critical mass of expertise in teaching, research and outreach from four established departments and their associated centres: Biomedical and Life Sciences; Centre for Training and Development (CETAD); Health Research; and Lancaster Medical School.

Situated within the Division for Health Research, the International Observatory on End of Life Care (IOELC) aims to undertake high quality research, evaluation, education, advocacy and consultancy to improve palliative and end of life care for patients and their family carers. Established in 2003, the IOELC is a globally recognised centre of excellence for research in palliative and end of life care. Since the early days the range of work undertaken at the Observatory has expanded dramatically and the numbers of staff, students, honorary members and associates have increased commensurately. The IOELC works closely with the local health and social care community in the North West, as well as nationally and internationally. They offer a range of methodological and theoretical expertise drawn from clinical and social science perspectives. Their aims are to improve palliative and end of life care for patients and carers, and they include:

- to provide research based evidence on end of life care provision – locally, nationally and internationally – through primary research studies and reviews;
- to disseminate results in order to make a practical and academic impact;
- to provide appropriate programmes of education and training, as well as consultancy services;
- to work in partnership with key organisations and individuals as a ‘community of effort’ for the global improvement of end of life care.

Authors of the report:

Professor Sheila Payne is Director of the International Observatory on End of Life Care and President of the European Association for Palliative Care. Dr Nancy Preston is a Lecturer in Palliative Care with a research expertise in clinical symptom management. Dr Mary Turner is a Senior Research Fellow with research expertise in family carers experiences of home based palliative care and end of life care in prisons. Dr Liz Rolls holds an Honorary Research Fellowship with IOELC and has expertise in childhood bereavement and service evaluation.


Gysels, M., Evans, C., Lewis, P. et al., (2013) MORECare research methods guidance development: Recommendations for ethical issues in palliative and end-of-life care research. Available at: http://pmj.sagepub.com/content/early/2013/05/03/0269216313486952


Irish Association for Palliative Care Education and Research Forum (2013) Survey of perceived facilitators and barriers to conducting palliative care research in Ireland. Dublin: Irish Association for Palliative Care.

Accessed 28.5.13.


## Findings: Research knowledge transfer in hospices in the north west

### Research questions

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<th>IQR Range</th>
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<thead>
<tr>
<th>Question</th>
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<tr>
<td>What are patient/carer experiences of ‘out of hours’ palliative care?</td>
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<tr>
<td>Is palliative care cost-effective in the UK?</td>
<td>8</td>
<td>2.75</td>
</tr>
<tr>
<td>Why is there so much variation in palliative care provision (across different disease types etc) – and how do we address these inequalities?</td>
<td>8</td>
<td>3.75</td>
</tr>
<tr>
<td>What are the gaps in end of life care provision in the community?</td>
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<td>3</td>
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<tr>
<td>How do we improve our assessment of prognosis, so that we know when to initiate end of life care (especially in patients with non-cancer conditions)?</td>
<td>8</td>
<td>3</td>
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<tr>
<td>How do we prevent palliative care patients dying in Hospital Accident and Emergency Departments?</td>
<td>8</td>
<td>3</td>
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<tr>
<td>What is the impact on end of life care for patients who lack local support from family and friends?</td>
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<tr>
<td>What are the experiences of parents caring for children at the end of life?</td>
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<tr>
<td>What is the role of advance care planning in end of life care?</td>
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<td>3</td>
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<tr>
<td>What is the impact upon organisations of trying to achieve the preferred place of death?</td>
<td>7.5</td>
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<tr>
<td>Do relatives sometimes feel under pressure from health care professionals to provide informal care to patients at the end of life?</td>
<td>7.5</td>
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<tr>
<td>What are patients’ expectations of palliative care?</td>
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<tr>
<td>Is a hospital death bad?</td>
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<td>3</td>
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<tr>
<td>Would patients held records improve palliative care?</td>
<td>7</td>
<td>4</td>
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<tr>
<td>How do we prepare carers better for the imminent death of their loved one?</td>
<td>7</td>
<td>3</td>
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<tr>
<td>What constitutes good bereavement care?</td>
<td>7</td>
<td>3</td>
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<tr>
<td>What is the effectiveness of specialist versus generalist interventions for palliative care for patients with Motor Neurone Disease?</td>
<td>7</td>
<td>3</td>
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<tr>
<td>Are patients treated with dignity and care in different palliative care settings?</td>
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<tr>
<td>Should all hospice patients be asked if they want to be informed about any relevant research studies? This information could then be displayed on their notes to make it easier for staff to approach them.</td>
<td>7</td>
<td>3.75</td>
</tr>
<tr>
<td>How do we measure a good death?</td>
<td>6.5</td>
<td>3.75</td>
</tr>
<tr>
<td>What is the ideal format of the multi-disciplinary team in palliative care?</td>
<td>6</td>
<td>3.75</td>
</tr>
<tr>
<td>What do professional carers (including health care assistants) understand by spirituality in relation to end of life care?</td>
<td>6</td>
<td>4</td>
</tr>
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</table>
## Findings: Research knowledge transfer in hospices in the north west

### Barriers to research

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<tr>
<th>Question</th>
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<th>IQR</th>
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<tbody>
<tr>
<td>1. Hospices should collaborate with each other on research projects, and share information and best practice (for example through an online database).</td>
<td>9</td>
<td>0.25</td>
</tr>
<tr>
<td>2. Service users (patients and their families/friends) need to be made more aware of the benefits of palliative care research, for example through posters, leaflets and newsletters in accessible language, as well as through TV, radio and social media such as Facebook.</td>
<td>9</td>
<td>2.25</td>
</tr>
<tr>
<td>3. A 'research culture' should be encouraged in hospices, with staff having access to research training, and to education materials such as journals, and receiving support to undertake their own projects.</td>
<td>9</td>
<td>1</td>
</tr>
<tr>
<td>4. The findings from research need to be fed back to staff, patients and carers, and incorporated into patient care.</td>
<td>9</td>
<td>1</td>
</tr>
<tr>
<td>5. Hospice staff should receive training in how to approach patients about research, and to explain what is involved so that they can make an informed decision.</td>
<td>9</td>
<td>2</td>
</tr>
<tr>
<td>6. There is a need for national research management and governance standards for hospices.</td>
<td>8.5</td>
<td>1</td>
</tr>
<tr>
<td>7. We need to improve the training of Research Ethics Committees, to increase awareness of the need for palliative care research, and the challenges of undertaking this kind of research.</td>
<td>8.5</td>
<td>1.5</td>
</tr>
<tr>
<td>8. A 'research champion' should be identified in each hospice/palliative care unit (a member of staff with a particular interest in research).</td>
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<tr>
<td>9. There needs to be greater collaboration between clinical staff in hospices, and those who work in universities. (For example, more staff should be appointed in joint clinical/academic roles, and there should be more palliative care research interest groups where clinical and academic staff can meet to discuss issues.)</td>
<td>8</td>
<td>2</td>
</tr>
<tr>
<td>10. A researcher/research champion should be present at multidisciplinary team meetings within the hospice/palliative care unit.</td>
<td>7</td>
<td>4</td>
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<tr>
<td>11. Part of the funds raised by hospices should be spent on research.</td>
<td>6</td>
<td>4.25</td>
</tr>
<tr>
<td>12. Staff should be employed in every hospice/palliative care unit to carry out research.</td>
<td>6.5</td>
<td>3</td>
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</table>
# Appendix 3

## Stakeholder interview participants

<table>
<thead>
<tr>
<th>Name</th>
<th>Designation</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Professor Mike Bennett</strong></td>
<td>St Gemma’s Professor of Palliative Medicine</td>
</tr>
<tr>
<td></td>
<td>University of Leeds</td>
</tr>
<tr>
<td><strong>Tony Bonser</strong></td>
<td>Dying Matters Champion</td>
</tr>
<tr>
<td></td>
<td>National Council for Palliative Care</td>
</tr>
<tr>
<td><strong>Dr Claire Butler</strong></td>
<td>Director of Medicine and Research</td>
</tr>
<tr>
<td></td>
<td>Pilgrims Hospice, Kent</td>
</tr>
<tr>
<td><strong>Wendy Fisher</strong></td>
<td>Independent Advisor, Research Governance</td>
</tr>
<tr>
<td></td>
<td>Wendy Fisher Consulting</td>
</tr>
<tr>
<td><strong>Professor Irene Higginson</strong></td>
<td>Professor of Palliative Care Policy and Rehabilitation</td>
</tr>
<tr>
<td></td>
<td>King’s College London</td>
</tr>
<tr>
<td><strong>Lesley Hutt</strong></td>
<td>NHS NIHR Industry Clinical Trials Manager</td>
</tr>
<tr>
<td></td>
<td>Cumbria and Lancashire CLRN</td>
</tr>
<tr>
<td><strong>Dame Professor Barbara Monroe</strong></td>
<td>Chief Executive, St Christopher’s Hospice</td>
</tr>
<tr>
<td></td>
<td>Honorary Professor, International Observatory on End of Life Care, Lancaster University</td>
</tr>
<tr>
<td><strong>Dr Joy Ross</strong></td>
<td>Consultant Palliative Medicine</td>
</tr>
<tr>
<td></td>
<td>Royal Marsden Hospital</td>
</tr>
<tr>
<td><strong>Professor Jane Seymour</strong></td>
<td>Sue Ryder Care Professor in Palliative and End of Life Studies, University of Nottingham</td>
</tr>
<tr>
<td><strong>Dr Teresa Tate</strong></td>
<td>Consultant in Palliative Care, Barts and The London NHS Trust</td>
</tr>
<tr>
<td></td>
<td>Medical Director, Marie Curie Cancer Care</td>
</tr>
</tbody>
</table>
Search strategy for scoping of the literature

A defined search strategy was adopted, and the search was conducted using electronic databases, which comprised of Cinahl; Medline; PsychArt; PsychInfo and SocioIndex. Papers from the grey literature, including those ‘In Review’, ‘In Press’ and ‘Working Papers’ were also identified.

It predominantly, but not exclusively, drew upon studies investigating research capacity in hospices in the United Kingdom since 2000. The search strategy included the following terms: Hospice [and] Research; Hospice [and] Research Capacity; Research [and] Capacity building; Research [and] Capacity building [and] Hospice; Research [and] Palliative care; Capacity building [and] Palliative care research; Recruitment [and] Palliative care research. Fifty six papers of relevance were identified, although later scrutiny of relevance reduced this number considerably. Further papers were consulted as particular issues emerged.
Note 1: Hospice Care

Throughout the document we use Help the Hospices definitions of hospice care which states that ‘A hospice is not just a building, it is a way of caring for people. Hospice care aims to improve the lives of people whose illness may not be curable’ (Help the Hospices, 2009:2). ‘Hospices provide care in a number of different places including in people’s own homes, in day therapy units and in inpatient units. Palliative care can also be provided in hospitals and care homes’ (Help the Hospices, 2009:2).

Note 2: Families and carers

We recognise that there are many forms of informal carers including those who are not family members. In this report we only use the term ‘family’. This is not to diminish the significant contribution that informal carers make to the well-being of patients but, rather, for ease of reading.
We would like to acknowledge, with gratitude, the contribution of those who have made a contribution to this study: the 10 key stakeholders listed in Appendix 2, and the participants of the Study on Research Knowledge Transfer in Hospices in the North West.

Help the Hospices is very grateful to The National Gardens Scheme for supporting the Commission and its publications.

The National Gardens Scheme has been supporting Help the Hospices since 1996 by opening gardens of quality, character and interest to the public, helping to raise over £2.6 million for hospice care. They publish the ‘Yellow Book’, an annual best seller listing gardens that open for the scheme.

www.ngs.org.uk

Registered charity number 1112664
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.