

Mapping research activity in hospices in the United Kingdom

Project report

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July 2009

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Executive summary

The End of Life Care Strategy [1] highlights the need for hospices to have a robust evidence base grounded in research to provide a rationale for their services and communicate this to others. This report details the results of a telephone survey that was undertaken in early 2009 to map current research activity in hospices in the United Kingdom. The report draws some conclusions from this exercise and makes recommendations for hospices in relation to research development.

Methods

The Hospice Information Directory [2] was used to identify 179 bedded hospices, all of which were contacted and asked to complete a 5-minute survey over the telephone. The survey consisted of 11 questions about research engagement and infrastructure and seven questions about the hospice and the respondent. One hundred and eighteen responses were received. Because some organisations consist of more than one hospice (for example, the same organisation may comprise an adult and a children's hospice which are listed separately in the Directory), these 118 responses represent 129 hospices, giving a response rate of 72%.

Key findings

Key findings from the mapping exercise can be summarised as follows:

- Over half the respondents (59%) reported that their hospice had been involved in some sort of research activity during the previous year;
- Eighty-four hospices (71%) had collaborated with other organisations on research projects, but only 45 respondents (38%) reported playing an active part in a research network or consortium with other hospices;
- Over two thirds of hospices (69%) reported links with academic departments, but only 29 (25%) had initiated any research of their own during the past year;
- Just under half the hospices (48%) had a journal club and most (88%) had a library;
- A large majority (94%) had subscriptions to academic and professional journals, and all provided computers and internet access to staff;
- Most hospices (71%) had a research policy, but less than half (48%) had a research ethics policy.

Recommendations

This survey provides preliminary evidence that, whilst levels of research activity are reported to be high in some hospices, research is not fully embedded in hospices across the United Kingdom. The report therefore makes the following recommendations:

- More needs be done to encourage and support hospice staff to develop research skills and confidence;
- Further investment in infrastructure and resources is needed;
- Research collaborations and consortia between hospices should be established to promote and support research activity;
- Stronger research links need to be developed between hospices and academic research centres that can provide relevant expertise;

- Further research is needed to explore the factors that facilitate and enable research to flourish in hospices and to identify the barriers that limit research activity and engagement;
- Further research is needed on the roles of staff that have a remit for research within their job;
- A database should be established to record research activity within hospices, which would promote collaboration and reduce redundancy in repeating studies; and
- Research leadership within hospices needs to be strengthened.

Mapping research activity in hospices in the United Kingdom

1. Introduction

This report details the results of a telephone survey that was undertaken in early 2009 to map current research activity in hospices in the United Kingdom (UK). The report draws some conclusions from this exercise and makes recommendations for hospices in relation to research development.

2. Background and aims

The End of Life Care Strategy [1] highlights the need for hospices to have a robust evidence base grounded in research to provide a rationale for their services and communicate this to others. In recent years there has been significant investment in developing capacity within the National Health Service (NHS) to support and promote research, in the form of regional NHS Research and Development Support Units (which since 2008 have been restructured as the Research Design Service). However, in general, staff based in independent hospices have been unable to access and benefit from such initiatives. Independent hospices in the UK are relatively small charitable organisations, whose first priority is to provide patient care, and perhaps not surprisingly research is often much lower down their agendas.

In 2004 the National Cancer Research Institute (NCRI) conducted a review of supportive and palliative care research [3], and identified several areas of concern, including fragmentation of the supportive and palliative care research workforce, a lack of interdisciplinary and interprofessional working, and a lack of collaboration with researchers outside the field of cancer. The recommendations of the report led to the establishment in 2006 of two research collaboratives, the Cancer Experiences Collaborative (CECo) and the Compass Collaborative. Each collaborative has a different focus of work, but both bring together researchers from different universities to form a “critical mass” [4] in order to support and promote research into supportive and palliative care. The Cancer Reform Strategy [5], published in 2007, also emphasises the need for increased support for research in this field.

In 2008 a series of focus groups was conducted with hospice staff to explore the research education needs of staff in hospices. The focus groups were funded jointly by the Cancer Experiences Collaborative and Help the Hospices, and involved 32 participants in five focus groups in London and Manchester. One of the key findings from the focus groups [6] was that although many hospices are engaged in some level of research, most of their studies originate from other organisations or are part of a staff member’s higher degree course. There was reported to be a degree of fear and uncertainty about research amongst hospice staff.

This project was undertaken in order to map current research activity within independent bedded hospices. The aims of the project were to:

- Scope the current infrastructure that exists within hospices to support research;
- Scope the extent to which hospices are currently engaged in research activity;
- Identify gaps in research infrastructure and engagement, and propose ways of overcoming these;
- Establish a database of named people with responsibility or a remit for research in hospices; and
- Identify areas for further research.

3. Methods

This study used a telephone survey method to scope the research infrastructure and engagement that currently exists in independent hospices in the UK. Ethical approval was not sought as this study did not require access to patients and family members or staff records.

The sample

The Hospice Information Directory [2] was used to identify hospices to invite to take part in the survey. The Directory lists all hospice and specialist palliative care services in the UK. Our sample was limited to independent, bedded hospices, and all other hospices and specialist palliative care services listed in the Directory were excluded. The reason for selecting these hospices was primarily to reduce the number of variables that might potentially confound the results. For example, the research infrastructure of National Health Service (NHS) hospices may be different from that of independent, charitable hospices, because they have access to NHS research support and funding. For this initial scoping study we decided to focus on bedded hospices because these tend to be larger organisations employing a greater number and variety of staff.

The following inclusion and exclusion criteria were used for the study:

Inclusion criteria:

- Independent adult and children's hospices with in-patient beds.

Exclusion criteria:

- NHS hospices;
- Marie Curie hospices;
- Sue Ryder hospices;
- All hospices and specialist palliative care services without in-patient beds;
- Hospices in the Republic of Ireland.

Recruitment

One hundred and seventy-nine independent, bedded hospices were identified from the Hospice Information Directory [2], and a list of these was compiled together with contact details and, where possible, the name of the Chief Executive or Director of Clinical Services.

Each hospice was contacted by telephone by a member of the project team, who asked to speak to the person responsible for research within the organisation. In some hospices this person was easily identified, but in others it was less straightforward. Where it was unclear, we asked to speak to the Director of Clinical Services or the Chief Executive, on the assumption that they would be of sufficient seniority within the organisation either to be able to answer the survey questions themselves or to identify an appropriate colleague to do so.

In many instances the appropriate person within the hospice was not immediately available to talk to us, so repeated attempts were made to contact them. A small number of hospices asked for the survey to be emailed to them so that they could complete it in their own time. Each of the 179 hospices was contacted at least once, and some were contacted numerous times.

Data collection

A structured survey tool was developed by the project team to be administered via the telephone (see Appendix 1). The initial seven items collected information about the hospice and the name and designation of the respondent. The following 11 questions enquired about research infrastructure and engagement, and dichotomous responses (yes/no) were elicited. In addition, respondents were invited to expand on their responses where necessary, and as far as possible these data were recorded verbatim by the research team member. The questions were deliberately kept simple so that the survey could be completed relatively quickly over the telephone. The survey took around 5 minutes to complete, although if respondents provided additional information this occasionally took longer.

Data analysis

All data from the survey were entered into SPSS 15.0 for Windows. Numerical data were analysed using descriptive statistics, frequencies and percentages. Open ended data were transcribed in to Word and these textual data have been used to illustrate the findings.

4. Results

We start by describing our sample of hospices that responded to the survey, and then describe the findings in relation to two issues, research infrastructure and reported research activity.

One hundred and eighteen responses were received. Because some organisations consist of more than one hospice, these 118 responses represent 129 hospices, giving a response rate of 72%.

The sample

Respondents were asked whether their hospice was for adults, children or both. Table 1 shows the numbers and percentages of respondents who classed themselves in each of these three hospice types. The majority of respondents were from adult hospices, which reflects the predominance of this type of hospice in the UK.

Table 1: Type of hospice (n = 118)

Type of hospice	Number	Percentage
Adults	96	81.4
Children	19	16.1
Adults and children	3	2.5
Total	118	100

Respondents were also asked in which Strategic Health Authority (SHA) or Health Board their hospice was located. Table 2 shows the distribution of hospices across SHAs and Health Boards.

Table 2: Location of hospices (n = 118)

SHA or Health Board	Number	Percentage
NHS North West	25	21.2
NHS Yorkshire & the Humber	14	11.9
NHS London	12	10.2
NHS West Midlands	12	10.2
NHS East of England	11	9.3
NHS North East	10	8.5
NHS South East Coast	9	7.6
NHS South Central	8	6.8
NHS East Midlands	4	3.4
NHS South West	4	3.4
NHS Greater Glasgow & Clyde	4	3.4
NHS Forth Valley	1	0.8
NHS Highland	1	0.8
NHS Lothian	1	0.8
Eastern Health & Social Services Board	1	0.8
Channel Islands	1	0.8
Total	118	100.0

All ten SHAs in England were represented in the survey, together with four in Scotland, and one Health and Social Services Board in Northern Ireland. Although not actually part of the UK, two hospices in the Channel Islands were also invited to take part in the survey (one of which responded) because they are listed in the Hospice Information Directory and fulfilled the inclusion criteria. The sample is considered to be representative of hospices in both England (77% of those who were invited responded) and Scotland (54% response rate). However, only one out of the four invited hospices in Northern Ireland and none out of the seven in Wales took part in the survey.

Respondents were asked for their job titles and email addresses so that further contact could be made in future; all willingly provided this information. The respondents had a diverse range of job titles, and although it has to be acknowledged that job titles often do

not reflect the actual role, nevertheless it is interesting to note that, despite the hospices being asked by the project team for the person with responsibility for research, only one of the 118 job titles provided actually contained the word “research”. A summary of respondents’ occupational roles is given in Table 3 (a full list of job titles is provided in Appendix 2).

Table 3: Respondents’ occupational roles (n = 118)

Role	Number	Percentage
Patient service managers	32	27.1
Education	31	26.3
Nursing managers	20	16.9
Senior medical role	18	15.3
Other administrative role	6	5.1
Senior managers	5	4.2
Practice development	5	4.2
Research	1	0.9
Total	118	100

Research infrastructure

Respondents were asked a series of questions about the infrastructure that exists within their organisation to support and promote research. These questions included whether the hospice has a journal club, library, journal subscriptions, computers with internet access, and written policies for research and research ethics, and the results are given in Table 4.

Table 4: Research infrastructure (n = 118)

Question	Yes Number (%)	No Number (%)
Journal club	57 (48.3)	61 (51.7)
Library	104 (88.1)	14 (11.9)
Subscriptions to academic and professional journals	111 (94.1)	7 (5.9)
Computers with internet access	118 (100.0)	0 (0.0)
Written research policy	84 (71.2)	34 (28.8)
Written research <i>ethics</i> policy	56 (47.5)	62 (52.5)

The survey provides evidence of significant research infrastructure within hospices, with the majority of organisations having libraries, journal subscriptions and computers (although fewer than half have a journal club). The majority have written research policies to support and promote research, although fewer than half have a research ethics policy.

Research engagement

The survey provided data on the extent to which hospices are engaged with other organisations to promote and conduct research. Table 5 summarises these results.

Table 5: Research engagement (n = 118)

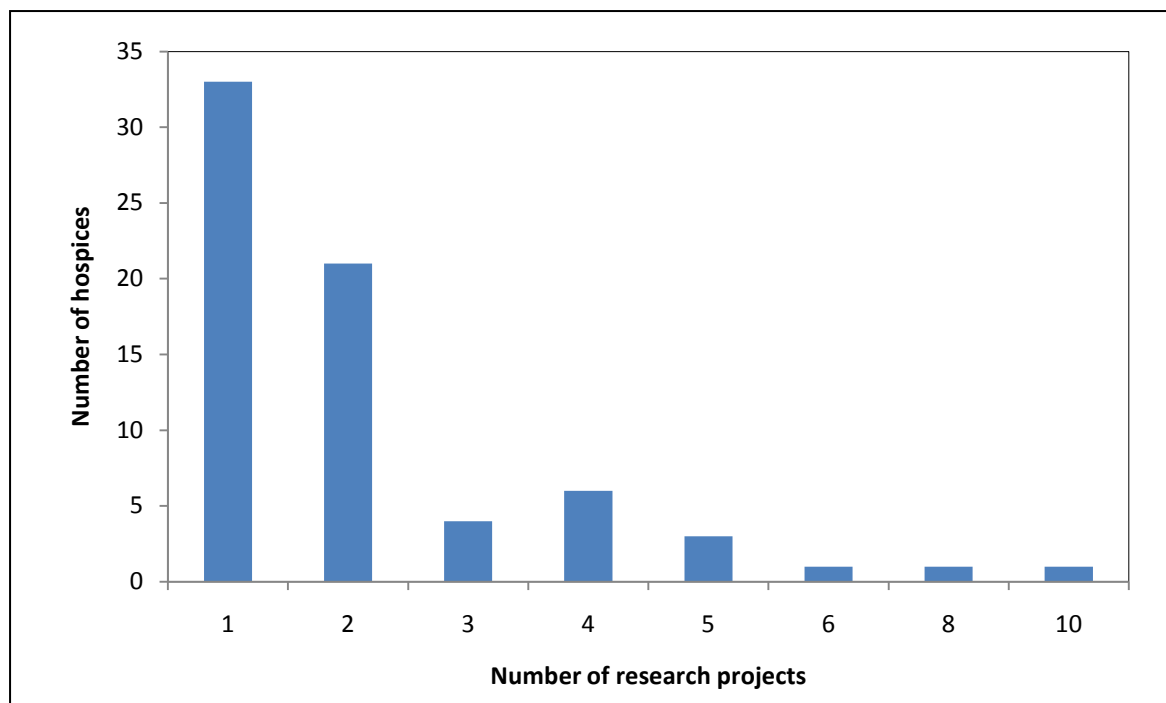
Question	Yes Number (%)	No Number (%)
Involved in any research in the past year	70 (59.3)	48 (40.7)
Collaboration with other organisations on research projects	84 (71.2)	34 (28.8)
Active engagement in a research network or consortium with other hospices	45 (38.1)	73 (61.9)
Links with academic research centres at a university	81 (68.6)	37 (31.4)
Initiation of any research projects during the past year	29 (24.6)	89 (75.4)

Where “yes” answers were provided to these questions, respondents were asked to provide further information, and these findings are summarised below.

Hospices’ involvement in research

Seventy respondents (59.3%) provided details about a total of 150 research projects that their hospices had been involved with during the past year. These projects were very varied in subject matter and scale, and ranged from small studies undertaken by individuals (e.g. for Masters Degrees) to large multicentre drug trials. Figure 1 shows that the number of projects per hospice ranges from 1 to 10, and demonstrates that whilst many hospices were involved with one or two research projects (median = 2), only 16 (13.5% of the total sample) were involved in three or more projects.

Figure 1: Number of research projects per hospice (n = 70)



Of the 150 projects reported, 29 (19.3%) were identified as projects undertaken by individuals for higher degrees or as part of medical training. However, the amount of detail provided about each of the projects was variable, so it is likely that a number of other projects would also be in this category, but were not identified as such.

Collaboration with other organisations

According to respondents, 83 hospices (70.9%) reported collaboration with at least one other organisation, and 41 (34.7%) reported collaboration with two or more organisations. Collaboration with a wide variety of organisations was reported, including Primary Care Trusts (PCTs), Cancer Networks, local and regional palliative care groups, universities and other hospices to develop and promote research, and one hospice even reported collaboration with a hospice in Europe.

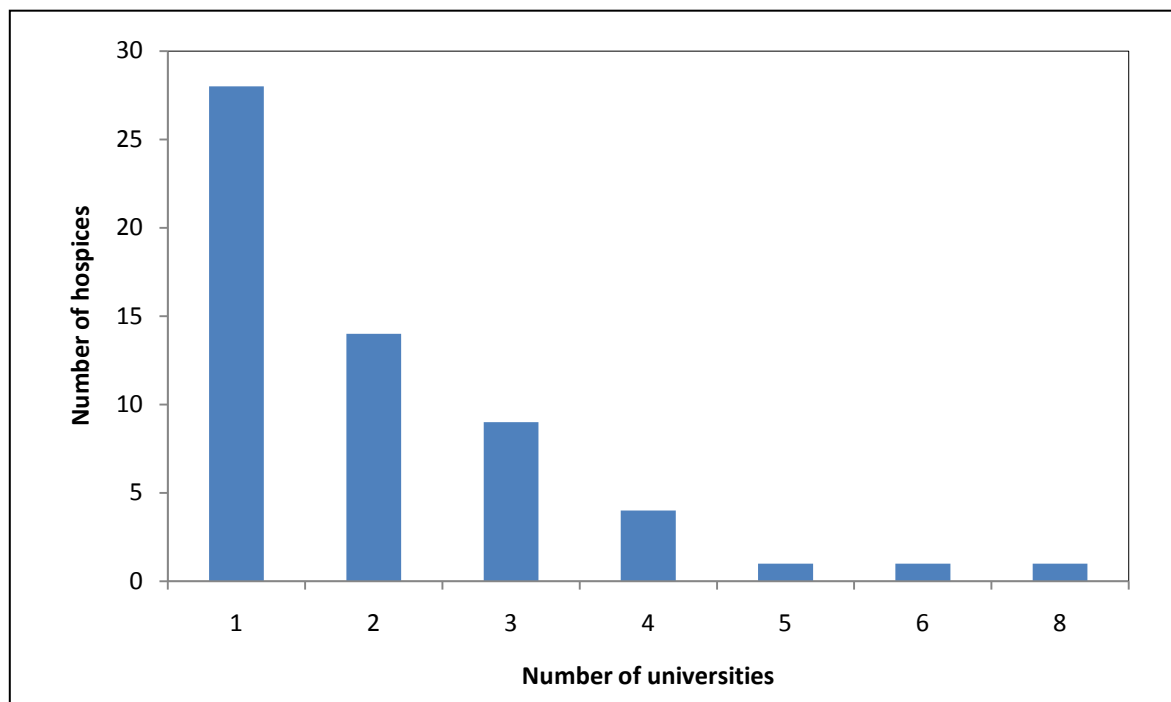
Research networks and consortia

Similarly, respondents reported active participation in a variety of research networks and consortia where they were able to meet with representatives from other hospices. However, the number of respondents engaged in this type of activity was much smaller, with only 45 (38.5%) out of the 118 survey respondents answering yes to this question.

Links with academic research centres

Eighty respondents (68.4%) reported having links with academic research centres at 58 universities. Appendix 3 lists these universities, together with the number of hospices that reported links with each one. It is noteworthy that 28 universities had only one hospice link, and only seven had links with more than three hospices (see Figure 2).

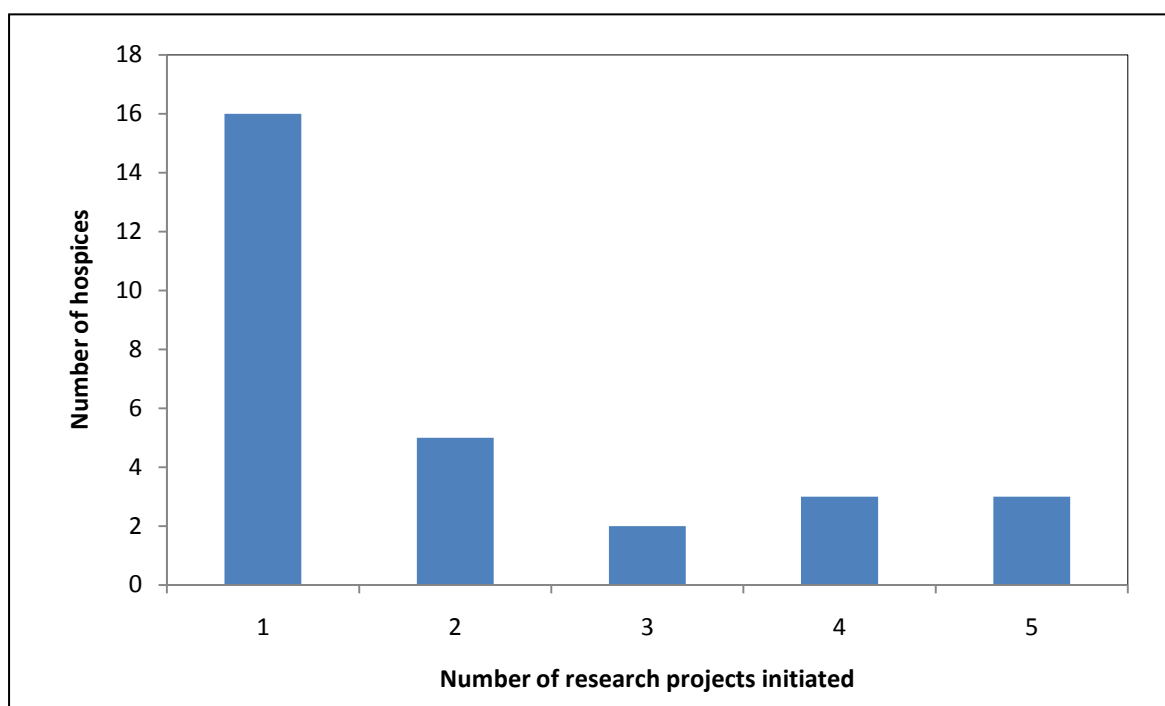
Figure 2: Research links between hospices and universities (n = 58)



Hospice initiated research projects

The final question in the survey concerned research projects initiated by hospice staff during the previous year. Figure 3 shows that staff had initiated research in only 29 hospices (24.8%), and of these more than half (16) had only initiated one project.

Figure 3: Research projects initiated by hospice staff (n = 29)



Again the projects appeared to be of very varying scale and focus. Table 6 provides a summary of the additional information about the projects provided by each of these 29 respondents.

Table 6: Hospice initiated research

Hospice	Type of project (if known)	Subject area (if known)
1		Complementary therapies
2		Death rattle
3	Individual academic research	
4		Palliative and supportive care
5		Evaluation of services
6		Experiences of families with a life-limited child; respite and emergency care; needs of grandparents; experiences of Asian mothers; questions life-limited children ask about death and dying
7		Depression and despondency; nature of dying in care homes; palliative care needs in dementia; hypnotherapy in hospice and palliative care
8		Oral care practice in children with palliative care needs
9		Vulnerability in families
10	PhD	Death and dying
11	MSc	

12		Day hospice review; hypnotherapy; communication on the ward; end of life care and dementia
13		Evaluation of psychological programme; end of life competencies in care homes
14		Hospice community services
15		End-stage dementia; palliative care needs of people with dementia; development of palliative care outcomes tool; agitation and distress; dry wound management
16		Mindfulness of stress management
17		Hydration
18	MSc	Lymphoedema; Organisational structure; weblogs in hospices; key components of end of life care
19	PhD 4 Masters studies	
20	SpR project PhD	Patient and staff views on medical student training; Coping and palliative care services
21	MSc	End of life care
22	PhD SpR project	
23	PhD SpR project	Psychological care; Advance care planning; Goal setting in palliative care
24	Observational study RCT	Peripheral neuropathy; Chemotherapy nausea; Evaluation of project to increase access to BME communities
25	PhD	Learning disability and palliative care
26		Technology; dignity
27		Sedation patterns and identification of the dying phase
28		Dimbleby Cancer Care funded study
29		Breathlessness clinics; respite care in palliative care

5. Discussion

The findings of this survey build on the results of the focus groups undertaken in 2008 [6], and provide broad information from a large number of hospices about current research infrastructure and engagement. They raise some significant issues that merit further consideration.

To begin with, these findings indicate that although hospices have clearly invested in providing infrastructure and resources for staff to encourage participation and involvement in research, nevertheless still more could be done in this area. For example, fewer than half the hospices in this sample have a journal club, which can be a relatively simple way of both increasing awareness among staff about research and its application in practice, and encouraging them to develop skills in critically appraising research done by others.

Research ethics policies appear to present hospices with particular challenges, and the relatively low number of hospices with a research ethics policy may reflect a lack of confidence amongst hospice staff about producing such documents. There is clearly scope here for more sharing of policies between hospices to avoid “reinvention of the wheel” and ensure that high quality and relevant policies are produced.

There is little evidence of roles specifically focused on research, as indicated by the list of respondents’ job titles (Appendix 2). Many of the survey respondents carried responsibility for research within their organisation, yet it appears that this is just one part of their much larger portfolios. If a Director of Nursing or Medical Director is given a research role in addition to their clinical role, it is likely that this will not be at the top of their list of priorities. It was also interesting that there were many respondents with an education role who also had responsibility for research, as if research and education are synonymous.

Our survey demonstrates that overall there is limited research activity in hospices, and that hospices in general are at an early stage of development in terms of research. Although the majority of respondents reported research involvement during the previous year, much of this was on a relatively small scale, and most hospices had only been involved in one or two studies. In addition, many of these studies were conducted by people from outside the hospices, although there are a few notable exceptions of (mainly larger) research active hospices where multiple studies are in progress and are being initiated by staff in the hospices themselves. Arguably it is of concern that one fifth of research activity forms part of a higher degree. This type of research activity should be regarded as research training and cannot be expected to be of a scale or quality to contribute to the evidence base on hospice care. It bodes well for the future that some hospice staff are undertaking master’s and doctoral level research training, and this needs to be followed up by post-doctoral training opportunities to ensure that research becomes embedded in hospice culture. It is to be hoped that the future clinical research leaders in palliative care will be linked to hospices.

A large proportion of the respondents in hospices reported links with a total of 58 different universities. However, it was not always clear whether the link was for research purposes or whether it was an educational link. In addition the type of academic department that was linked to the hospices was not clear, nor the extent to which its staff are engaged in palliative care research. Very few of the universities cited have dedicated palliative care groups with a high level of palliative care research activity, so the nature and quality of these links and what the hospices can gain from them might be questioned. This finding mirrors the review of supportive and palliative care research capacity that was undertaken in 2004 [3] and indicates that there has been little development during the past five years.

The limitations of this survey must also be acknowledged. Its purpose was to provide a broad picture of the current situation in relation to hospice research, and in some respects it has raised more questions than it has answered. There was also a degree of difficulty for some respondents in interpreting some of the questions, even though they were deliberately constructed as simply as possible. An example of this is the question “Does your hospice have a library?” Although this appears to be a straightforward question, some respondents were unsure as to exactly what constitutes a library, and whether or not their simple shelf of books could be classed as such. Similarly, all 118 respondents stated that their staff had the use of computers with internet access to information databases; however, whether or not the staff had the skills required for database searching is not known. Further in-depth research is needed using site visits and interviews with a number of informants at each hospice to explore these and other issues, to ensure a more comprehensive mapping of hospice research.

6. Conclusion and recommendations

This survey has provided evidence of the current level of research infrastructure and engagement in UK hospices, and indicates that whilst levels of research activity are reported to be high in some hospices, research is not fully embedded in the majority of hospices across the United Kingdom. Despite the inroads that have been made through the establishment of the two supportive and palliative care research collaboratives CECo and Compass, our conclusions raise major concerns about the quantity and quality of research currently generated by hospice staff:

- Although there is evidence of increasing numbers of hospice staff undertaking higher degrees, the proportion of small scale descriptive studies that do not contribute to the palliative care evidence base is still too great;
- There is little evidence of research collaborations between hospices;
- Although hospices report links with many university centres, very few of these are recognised as having sufficient critical mass in palliative care research; and
- Research appears to be a low priority in hospices, as evidenced by the very few research-specific roles that currently exist.

Recommendations

In the light of our conclusions we make the following recommendations for hospices, further research and Help the Hospices.

Practice development within hospices

- More needs be done to encourage and support hospice staff to develop research skills and confidence;
- Further investment in infrastructure and resources is needed;
- Research collaborations and consortia between hospices should be established to promote and support research activity; and
- Stronger research links need to be developed between hospices and academic research centres that can provide relevant expertise.

Further research

- Further research is needed to explore the factors that facilitate and enable research to flourish in hospices and to identify the barriers that limit research activity and engagement; and
- Further research is needed on the roles of staff that have a remit for research within their job.

National development for Help the Hospices

- A database should be established to record research activity within hospices, which would promote collaboration and reduce redundancy in repeating studies; and
- Research leadership within hospices needs to be strengthened.

Acknowledgements

We would like to thank all the respondents who gave so generously of their time to provide information about research in their hospice.

7. References

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Appendix 1: The survey

An Investigation of Research Activity in Hospices
Proforma for telephone interviews

1. Name of hospice	
2. Town or city	
3. Postcode of hospice	
4. SHA / Health Board	
5. Name of person providing information	
6. Job title	
7. Email address	

	YES	NO
8. Has your hospice been involved in any research in the past year? If yes please specify:		
9. Does your hospice have a journal club?		
10. Does your hospice have a library?		
11. Does your hospice subscribe to any academic and professional journals?		
12. Does your hospice have one or more computers with internet access to information databases for the use of staff?		
13. Does your hospice have a written research policy?		
14. Does your hospice have a written research <i>ethics</i> policy?		

	YES	NO
<p>15. Does your hospice collaborate with other organisations on research projects? If yes, please tell us which organisations</p>		
<p>16. Does your hospice play an active part in a research network or consortium with other hospices? (e.g. Attending meetings, initiating proposals) Please tell us which other hospices/organisations</p>		
<p>17. Does your hospice have links with academic research centres at a university? If yes, please give name of centre and university</p>		
<p>18. Has your hospice initiated any research projects during the past year? If yes, please tell us what projects</p>		

Appendix 2: Job titles of respondents

GROUP	JOB TITLE	NUMBER
CEO	Chief executive	3
	Deputy chief executive	1
	Hospice director	1
	Total	5
Patient services	Director of care / care services	10
	Director of patient services	4
	Head of patient services	1
	Clinical services manager	5
	Director of clinical services	5
	Care manager	1
	Head of care / patient care	2
	Clinical services lead/matron	1
	Clinical director	1
	Patient services manager	1
	Team leader – care team	1
	Total	32
Nursing	Director of nursing / nursing services 6	6
	Director of nursing and patient care services 1	1
	Matron 3	3
	Deputy matron 1	1
	Clinical nurse manager / nurse manager 3	3
	Deputy clinical nurse manager 1	1
	Ward manager 2	2
	Senior nurse manager 1	1
	Senior sister 1	1
	Staff nurse 1	1
	Total	20
Medical	Medical director	7
	Deputy medical director	1
	Head of medical services	1
	Consultant / consultant in palliative medicine	8
	Hospice doctor	1
Total	18	
Education	Director of education	1
	Head of education	9
	Education manager	2
	Head of education and development	1
	Education and clinical services director	1
	Education co-ordinator	1
	Education facilitator	2
	Senior lecturer / manager education department	1
	Lecturer	1
	Nurse lecturer	1
Lecturer practitioner	4	

	Lecturer practitioner and researcher	1
	Learning development manager	1
	Allied health professional lecturer in palliative care	1
	Education and training co-ordinator	1
	Tutor	1
	Education administrator	1
	Palliative care educator	1
	Total	31
Practice development	Practice development facilitator	1
	Practice development co-ordinator	1
	Practice development and quality nurse	1
	Quality and practice development facilitator	1
	Professional development and quality facilitator	1
	Total	5
Research	Head of research and development of care	1
	Total	1
Other	Project director	1
	Clinical governance manager	1
	Director of non-clinical services	1
	Secretary to nurse consultant	1
	Clinical assurance manager	1
	Quality co-ordinator	1
	Total	6
TOTAL		118

Appendix 3: Universities linked with hospices

University	Number of hospices with links
Anglia Ruskin	3
Bangor	1
Bath	1
Bedfordshire	1
Birmingham	3
Bolton	1
Bournemouth	1
Brighton	2
Cardiff	1
Central Lancashire	2
Christ Church Canterbury	1
Coventry	1
Dundee	1
East Anglia	2
Edge Hill	2
Edinburgh	1
Glasgow	2
Glasgow Caledonian	1
Greenwich	1
Hertfordshire	3
Huddersfield	2
Hull	2
John Moores	1
Keele	2
Kent	3
King's London	4
Kingston	1
Lancaster	8
Leeds	2
Leeds Metropolitan	1
Liverpool	5
Manchester	2
Manchester Metropolitan	2
Middlesbrough	1
Northumbria	4
Nottingham	1
Oxford	1
Oxford Brookes	2
Plymouth	3
Queen Margaret, Edinburgh	1
Queen's, Belfast	1
Sheffield	4
Sheffield Hallam	1

Southampton	3
Southbank	1
St George's London	1
Staffordshire	3
Stirling	3
Suffolk	1
Surrey	4
Sussex	1
Swansea	1
Teesside	6
Ulster	1
Warwick	2
West of Scotland	3
Worcester	1
York	2