Survey to Doctors in England – End of Life Care

Report prepared for
The National Audit Office

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1   Summary of Findings

Confidence in identifying and delivering end of life care

Overall, there was a strong positive association between confidence in identifying the point at which end of life care should begin and confidence in delivering end of life care ($\rho=0.64$, $r^2=0.41$). Doctors who were more confident in identifying the point at which end of life care should begin were also more confident in delivering end of life care.

On average, doctors rated their confidence in **identifying** the point at which end of life care should begin at 6.5 out of 10. The group with the lowest average confidence score was GPs, who rated their confidence as 6.0 out of 10. The highest average score was among Palliative Care Specialists, who rated their confidence on average 8.2 out of 10.

Doctors rated their confidence in **delivering** end of life care on average 6.8 out of 10. Cardiologists had the lowest confidence, with an average rating of 6.3 out of 10, while Palliative Care Specialists had the highest, with an average rating of 8.8 out of 10.

When it came to **discussing** end of life care, doctors rated their confidence on average 6.9 out of 10. The lowest confidence was found in Emergency / Intensive Care Specialists, with an average rating of 6.5 out of 10, while Palliative Care Specialists again had the highest mean rating of confidence, at 8.8 out of 10.

Training in end of life care

Undergraduate Training

29% of respondents report that their undergraduate (or equivalent) training covered the subject of delivering appropriate end of life care, while 39% of respondents report that their undergraduate training covered communication with end of life patients.

On average, respondents rated their undergraduate training as 6.5 out of 10 with regard to how well or poorly it helped them to **discuss** death with patients and families. Palliative Care Specialists rated their training the lowest, at 4.9 out of 10, while Oncologists rated their training the highest, at 7.0 out of 10.

When it comes to **delivering** end of life care, respondents rated the preparation provided by their undergraduate training as 6.0 out of 10 on average. Palliative Care Specialists also had the lowest rating on training for delivering end of life care, at 4.7 out of 10. Oncologists, again, had the highest rating for their training, at 6.6 out of 10.

Post-graduate Training

Overall, the Liverpool Care Pathway training was undertaken by 47% of respondents. The Gold Standards Framework was undertaken by 20%, while the Preferred Priorities of Care was undertaken by 8% of respondents. 17% of respondents have taken other end of life training courses than the aforementioned three.

Palliative Care Specialists took more end of life training than any other specialty, with 95% having taken the Liverpool Care Pathway training, 75% having taken the Gold Standards Framework, 55% having taken the Preferred Priorities of Care training, and 68% having taken other post-graduate training in end of life care.

Support from NHS, Voluntary Sector and Social Services

Patient Support

Overall, respondents gave higher ratings to the voluntary sector than to the NHS for the support it provides.

Doctors gave the NHS' performance mid-range scores for how effectively it meets people's needs at the end of life. 'Management of pain and other symptoms' was given the highest rating (7.1 out of 10), while 'spiritual needs' received the lowest rating (4.6 out of 10).

The voluntary sector was rated in the high-mid range, all around 7 out of 10 in meeting needs of people at the end of life. 'Psychological needs' were given the highest rating (7.3 out of 10), while 'practical needs' and 'social needs' received the lowest rating (6.9 out of 10).

Compared to all other specialties in this study, Palliative Care Specialists rated the NHS the **lowest** for meeting all needs of people at the end of life, with the highest rating 5.4 out of 10 for 'management of pain and other symptoms,' and 'spiritual needs' the lowest at 3.0 out of 10.

Palliative Care Specialists gave voluntary services the **highest** rating of any specialty for meeting the need of 'management of pain and other symptoms' (8.3 out of 10).

Carer Support

We asked doctors to evaluate carer support from NHS commissioned services and local social services during end of life care, as well as NHS' support of carers following bereavement.

On average, respondents rated NHS commissioned services' support of carers during end of life phase as 5.5 out of 10, while local social services' support of carers was rated on average 5.1 out of 10. On average, respondents rated the NHS' support of carers following bereavement as 4.6 out of 10.

Palliative Care Specialists rated the NHS services' support of carers significantly lower than any other specialty, at 4.4 out of 10. Palliative Care Specialists also rated local services' support of carers the lowest of any specialty, at 3.8 out of 10. Finally, Palliative Care Specialists gave the lowest rating of any specialty to NHS support of carers following bereavement (2.9 out of 10).

Barriers

Overall, 'poor co-ordination across health and social care' was most frequently selected as a barrier to high quality end of life care (29% of respondents). Next was 'lack of provision of hospice at home' (25%), followed by 'lack of education and training of generalist staff' (22%).

The most commonly selected first barriers to high-quality delivery of end of life care were 'poor co-ordination across health and social care' (10%), 'the need for more community and acute hospital beds' (9%) and 'Lack of provision of hospice at home (9%).

2 Introduction

The NAO is currently carrying out an investigation into the delivery of end of life care in England. This covers care that helps all those with advanced, progressive, incurable illness to live as well and possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.

The study examines the extent of skills and training of doctors currently practicing in a variety of areas related to end of life care. The study includes General Practitioners, Oncologists, Elderly Medicine Specialists, Cardiologists, Respiratory Specialists, ITU and Emergency Medicine Doctors and Palliative Care Clinicians. As well as local provision, the study will also consider how the national and regional structures of the National Health Service support the delivery of end of life care services.

The study will provide information to help the Department of Health's End of Life Care Initiative better offer choice and access to high quality end of life care to all adult patients nearing the end of life, regardless of diagnosis.

3 Research Objectives and Methodology

The objectives of the Doctors.net.uk study are to investigate specific aspects of doctors' skills and training for end of life care. These include the following specific objectives:

- To examine the extent of training undertaken in end of life care:

    o Undergraduate training;

    o Post-graduate training;

- To explore doctors' confidence in communicating and delivering end of life care;

- To understand doctors' satisfaction with the NHS, social services and voluntary sector in meeting the needs of people at the end of life as well as their carers;

- To identify the perceived barriers that prevent high quality end of life care.

The questionnaire used to collect these data is included in the appendix of this report.

The survey was conducted using an on-line quantitative research methodology with doctors who are members of Doctors.net.uk and registered as practicing in England. All members of Doctors.net.uk are GMC-registered medical practitioners who access the Doctors.net.uk website through a unique user name and password. All those who took part stated that they were currently practicing as doctors in England.

Doctors.net.uk has been contracted to conduct the fieldwork, collect all responses, analyse the information and prepare this report as a summary of the research findings.

3.1 Sample Demographics

The fieldwork for the study took place from 10 April to 28 April 2008.

In total, 901 doctors completed the study.

In order to achieve the 901 completed interviews, 1,629 doctors interacted with the site:

- 728 Hospital Specialists who began the survey screened out for various reasons;

    o 28 unwilling to participate after reading the screen introducing the survey (8 GPs and 20 Specialists);

    o 247 doctors not meeting screening criteria (204 at Specialty, 24 at SHA, 19 at Q1 proportion of patients);

    o 274 quota full (56 GPs and 218 Specialists);

    o 179 incomplete (21 GPs and 158 Specialists).

Quotas were set according to the distribution of GPs by Strategic Health Authority in England. Final recruitment within individual SHAs closely corresponds to the expected regional distribution.
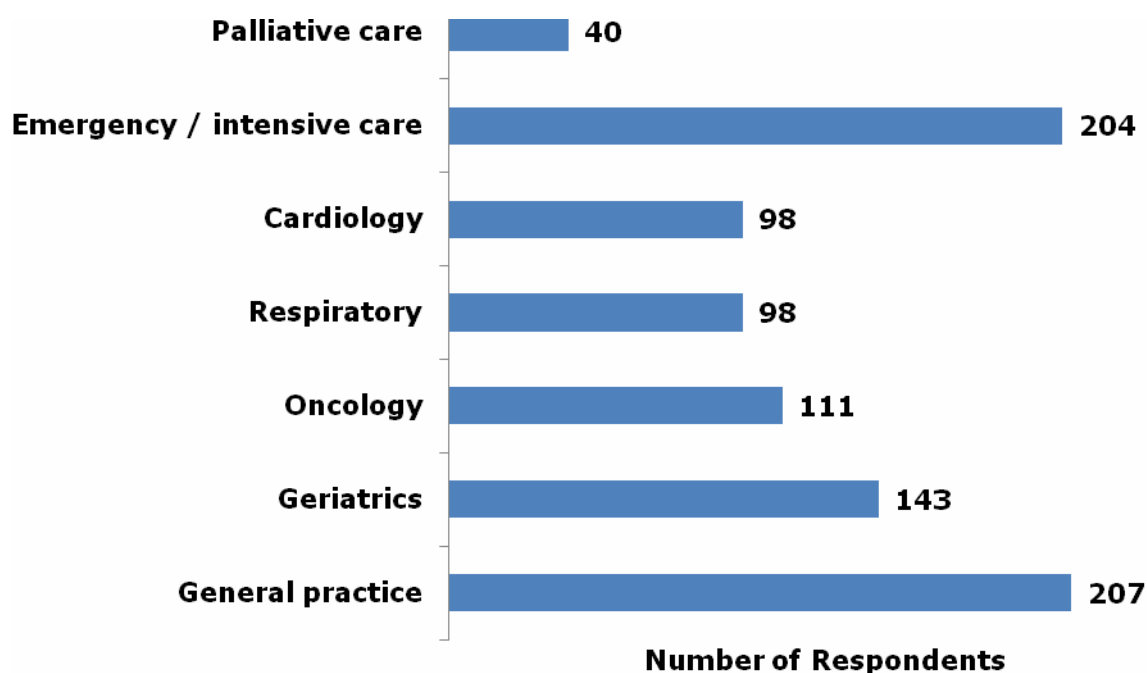
Figure 1: Number of GPs by SHA[1]
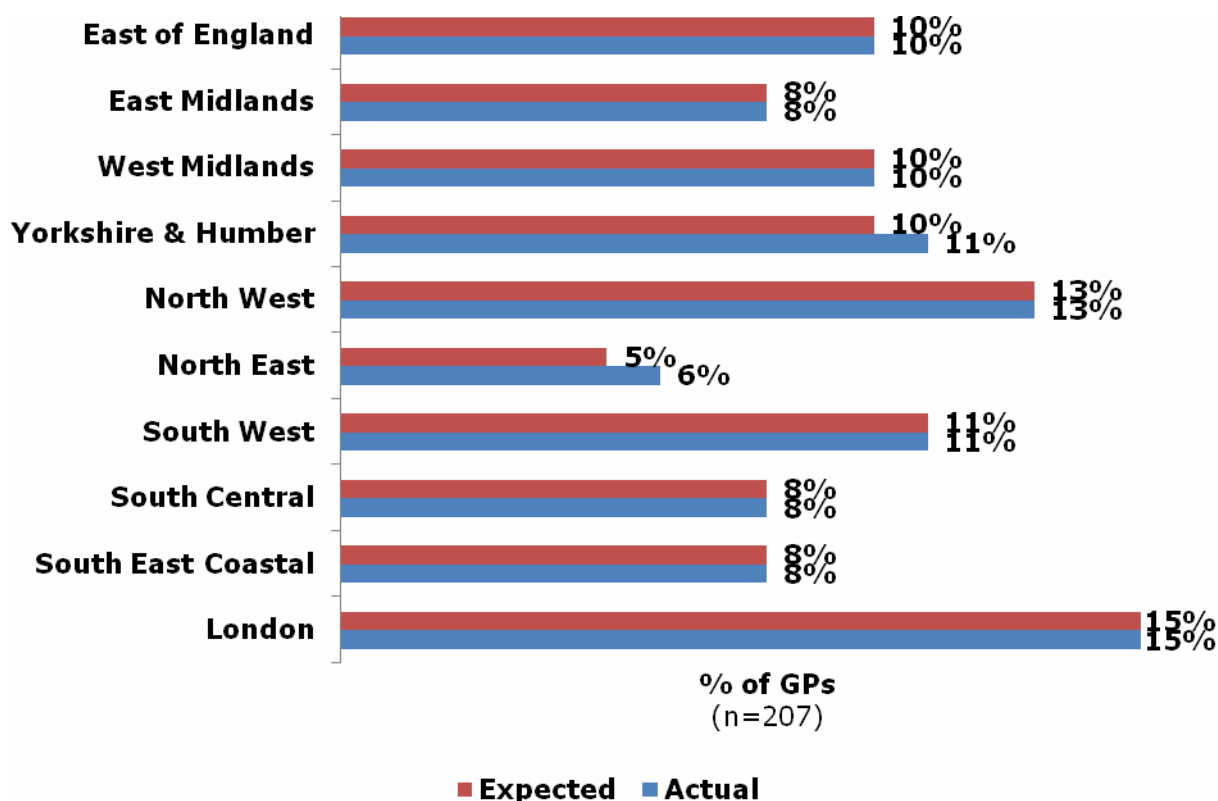
As expected, London was the most represented SHA (15%), followed by the North West (13%) and the South West (11%). The North East had the smallest representation, at 6%.

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[1] Expected numbers based on NHS Information Centre data from 30 September 2007. http://www.ic.nhs.uk/statistics-and-data-collections/workforce/nhs-staff-numbers/nhs-staff-1997--2007-overview. Last accessed 8 May 2008.

Figure 2a: Specialty

The majority of respondents who completed this survey were General Practitioners (23%), or Emergency / intensive care doctors (23%).

Figure 2b: Specialty as a proportion of the UK population of doctors[2]

	Number in Sample	Number in Population	% Achieved
General Practice	207	36420	**1%**
Accident & Emergency	204	4763	**4%**
Cardiology	98	2067	**5%**
Geriatric medicine	143	2947	**5%**
Clinical & Medical Oncology	111	1669	**7%**
Respiratory medicine	98	1418	**7%**
Palliative medicine	40	444	**9%**

The number of specialists recruited in each group differed according to the number of specialists in the UK population. While a 1% sample of General Practitioners yielded 207 respondents, it required 9% of the 444 Palliative Medicine Specialists to achieve a sample of 40.

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[2] Population numbers based on NHS Information Centre data from 30 September 2007. http://www.ic.nhs.uk/statistics-and-data-collections/workforce/nhs-staff-numbers/nhs-staff-1997--2007-medical-and-dental. Last Accessed 8 May 2008.

Figure 3: GP Type: Grade
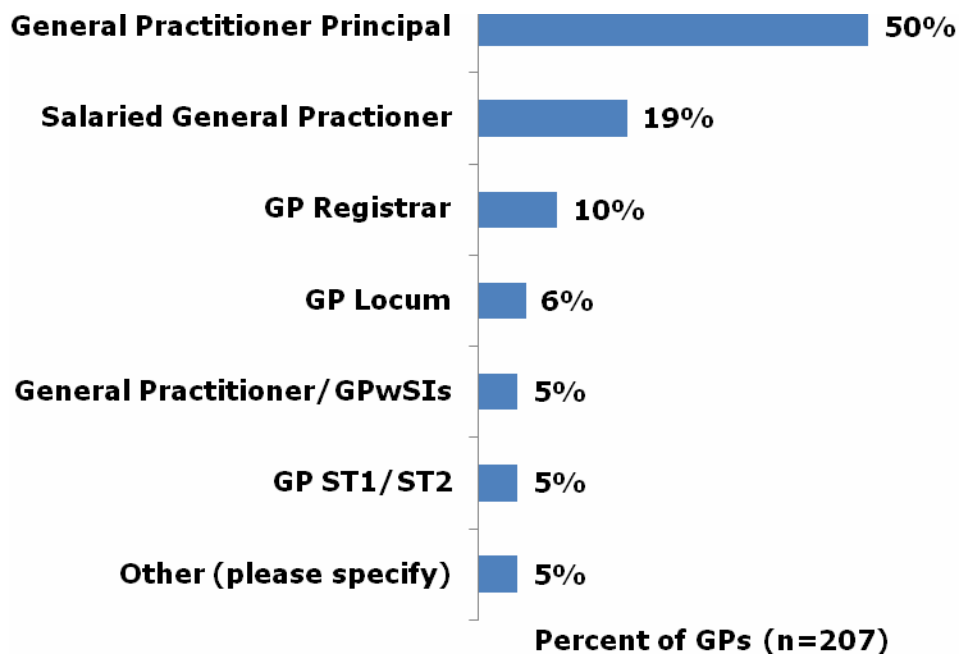
The majority of General Practitioners were GP Principals (50%), and one out of five was a Salaried General Practitioner.
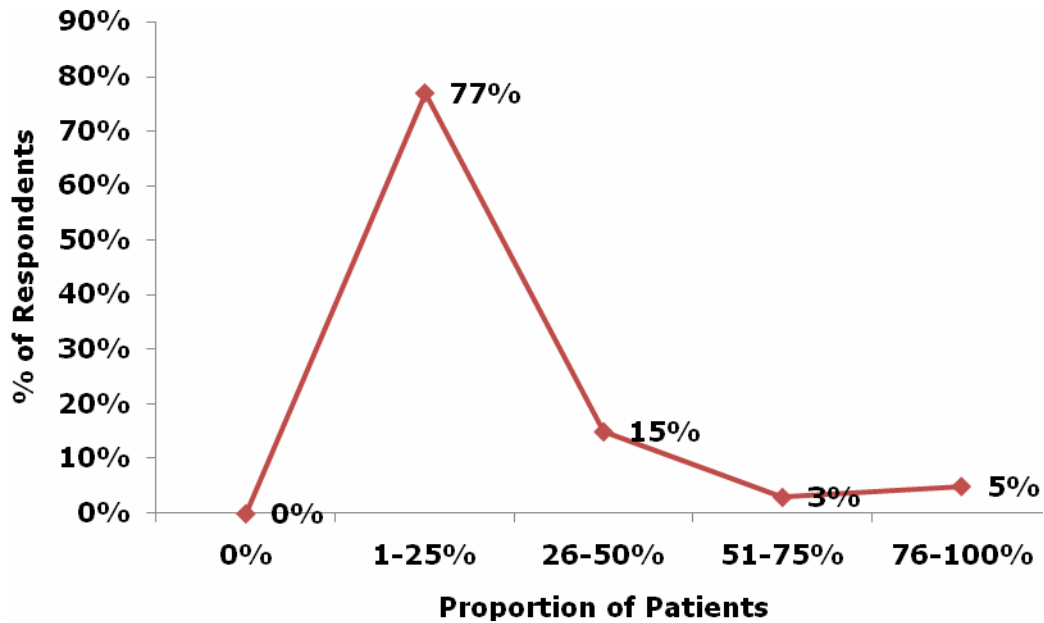
Figure 4: Respondent Gender
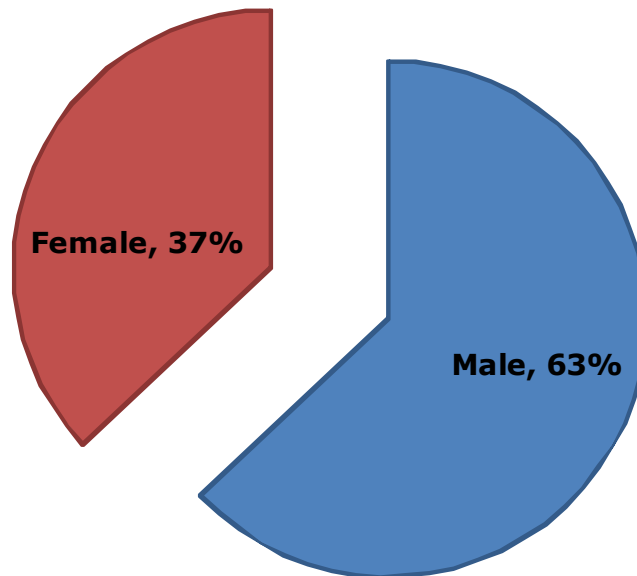
The majority of respondents were male (63%). This split was reversed for Palliative Care specialists, where females dominated (68%).

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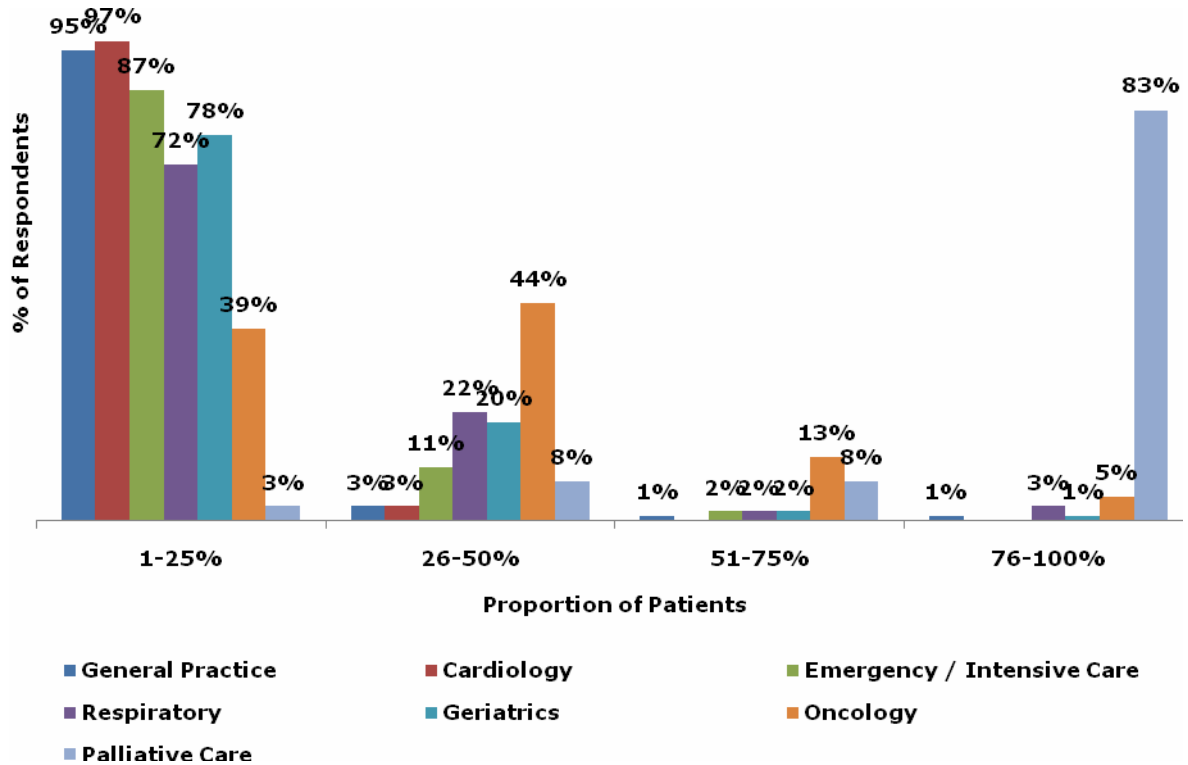
3.2 Practice dynamics

Figure 5a: Proportion of Patients Eligible for End of Life Care in Past 12 Months

Most respondents reported that 1-25% of their patients were eligible for end of life care in the past 12 months.

Males reported seeing fewer patients eligible for end of life care, with 83% having caseloads of 1-25% of their patients eligible, versus 67% of females with patients in that band.

**Figure 5b: Proportion of Patients Eligible for End of Life Care in Past 12**

However, 83% of Palliative Care specialists reported seeing a significantly higher proportion of patients eligible for end of life care (76-100%) than did other specialties.

Figure 6a: Proportion of eligible patients with whom subject of approaching death was discussed
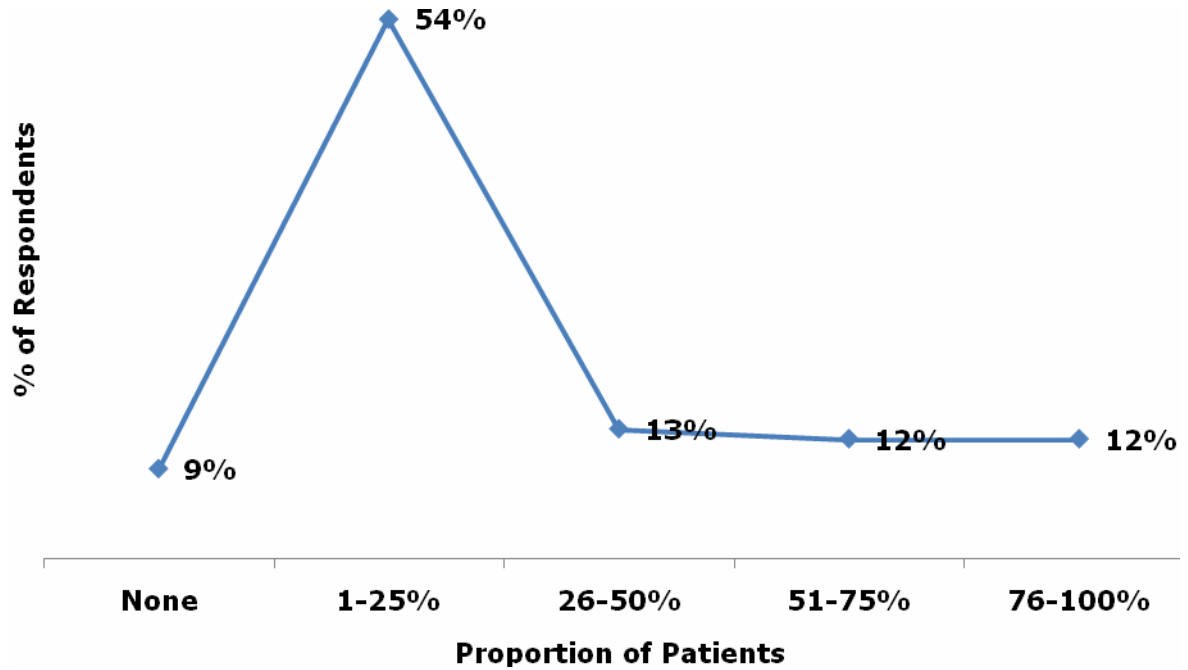
Most respondents discussed end of life care with 1-25% of their eligible patients.

Figure 6b: Proportion of eligible patients with whom subject of approaching death was discussed
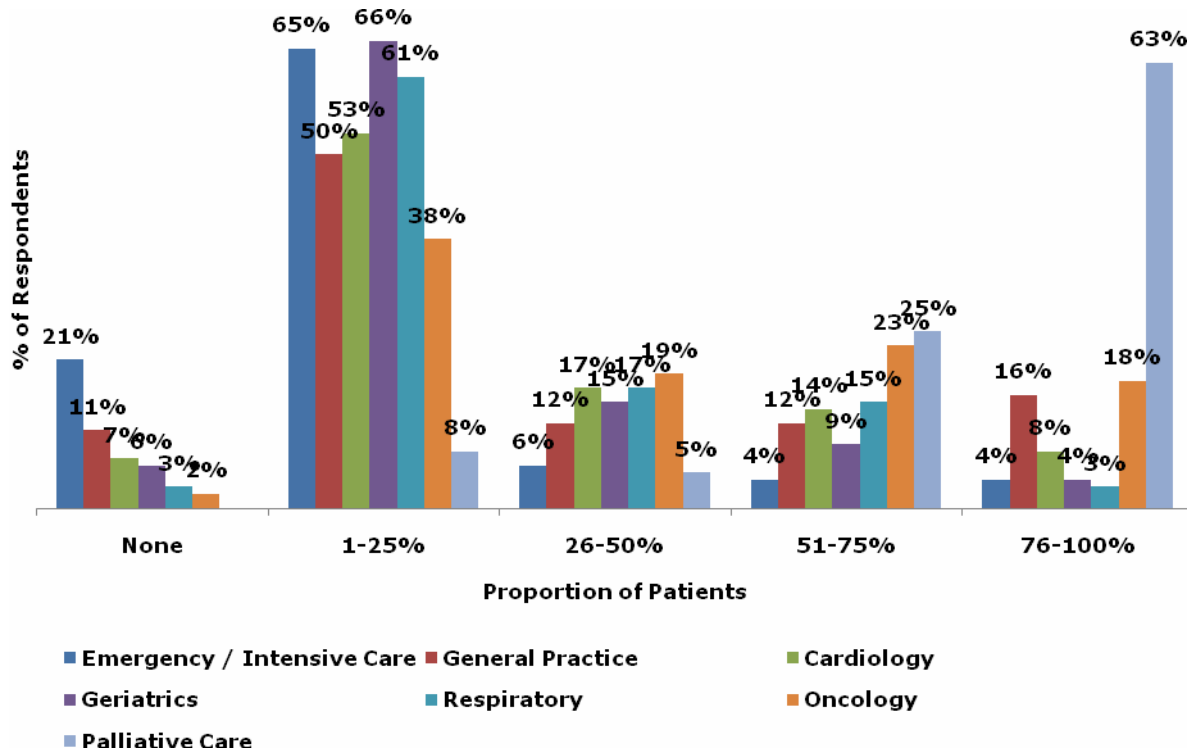
21% of Emergency / Intensive Care Specialists did not discuss end of life care with any patients, while 63% of Palliative Care Specialists discussed end of life care with 76-100% of their patients.

4 Survey Findings

Doctors who completed this survey reported on the skills, training and resources available to them for end of life care. In this section, we explore doctors' undergraduate and post-graduate training and its effectiveness, as well as their confidence in communicating and delivering end of life care. We also examine their opinions for NHS, social services and voluntary services in meeting the needs of people at the end of life as well as their carers. Finally, we report the largest barriers doctors feel they face to delivering high quality end of life care.

We have explored the effects of gender, grade, specialty, SHA and year of qualification on the results, and highlighted any significant differences within these groups.
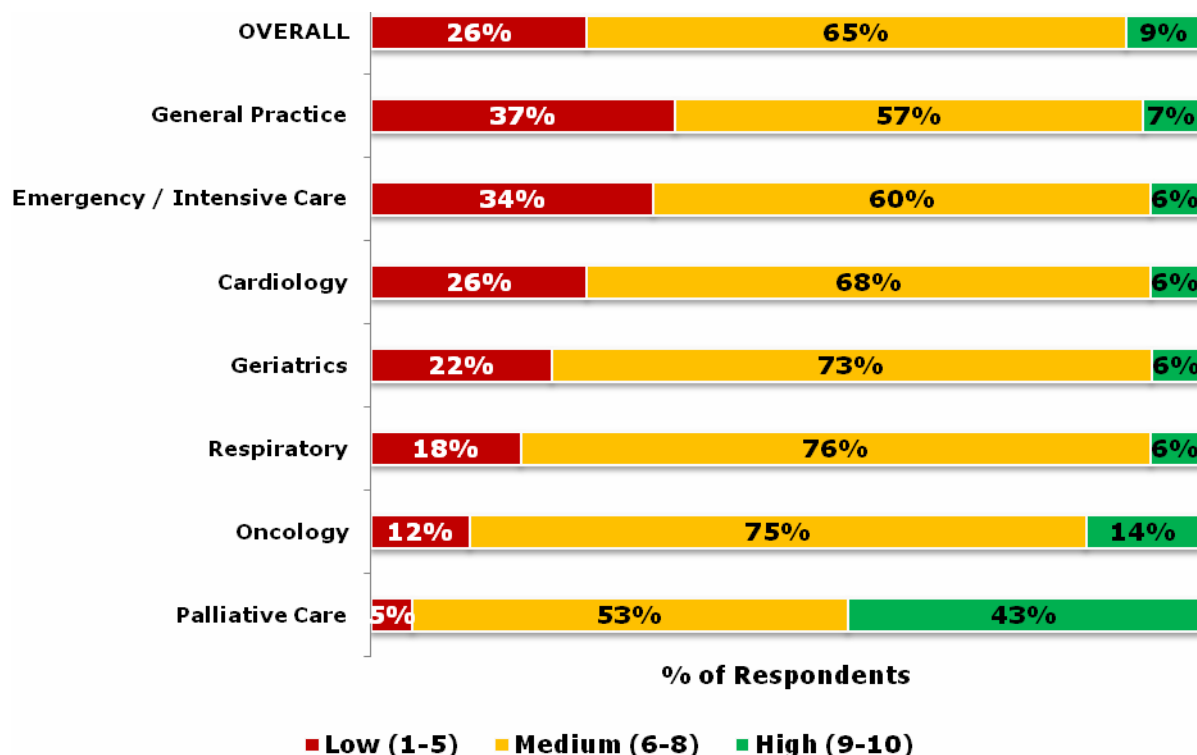
4.1 Confidence in diagnosing and delivering end of life care

Overall, there was a strong positive association between confidence in identifying the point at which end of life care should begin and confidence in delivering end of life care ($\rho=0.64$, $r^2=0.41$). That is to say, doctors who were more confident in identifying the point at which end of life care should begin were also more confident in delivering end of life care.

4.1.1 Confidence in identifying the point at which end of life care should begin

Doctors rated their confidence in identifying the point at which end of life care should begin on a 10 point scale, where 1 is 'not confident at all' and 10 is 'extremely confident'.

Figure 7: Confidence in identifying the point at which end of life care should begin


Specialty	Low (1-5)	Medium (6-8)	High (9-10)
OVERALL	26%	65%	9%
General Practice	37%	57%	7%
Emergency / Intensive Care	34%	60%	6%
Cardiology	26%	68%	6%
Geriatrics	22%	73%	6%
Respiratory	18%	76%	6%
Oncology	12%	75%	14%
Palliative Care	5%	53%	43%

% of Respondents

■ Low (1-5) ■ Medium (6-8) ■ High (9-10)

Overall, respondents rated their confidence in identifying the point at which end of life care should begin at 6.5 out of 10, where 1 is not at all confident and 10 is extremely confident. The mode rating was 7.0 out of 10 (28.2% of respondents).

On average, Palliative Care Specialists rated their confidence in identifying the point at which end of life care should begin as the highest of any specialty (8.2 out of 10). However, GPs and Emergency/Intensive Care Specialists consistently rated their confidence in identifying the point at which end of life care should begin lower than all other specialties included in this survey (on average, 6.0 and 6.1 out of 10).

4.1.2 Confidence in delivering end of life care

Doctors also rated their confidence in delivering end of life care on a scale from 1 to 10, where 1 is 'not confident at all' and 10 is 'extremely confident'.

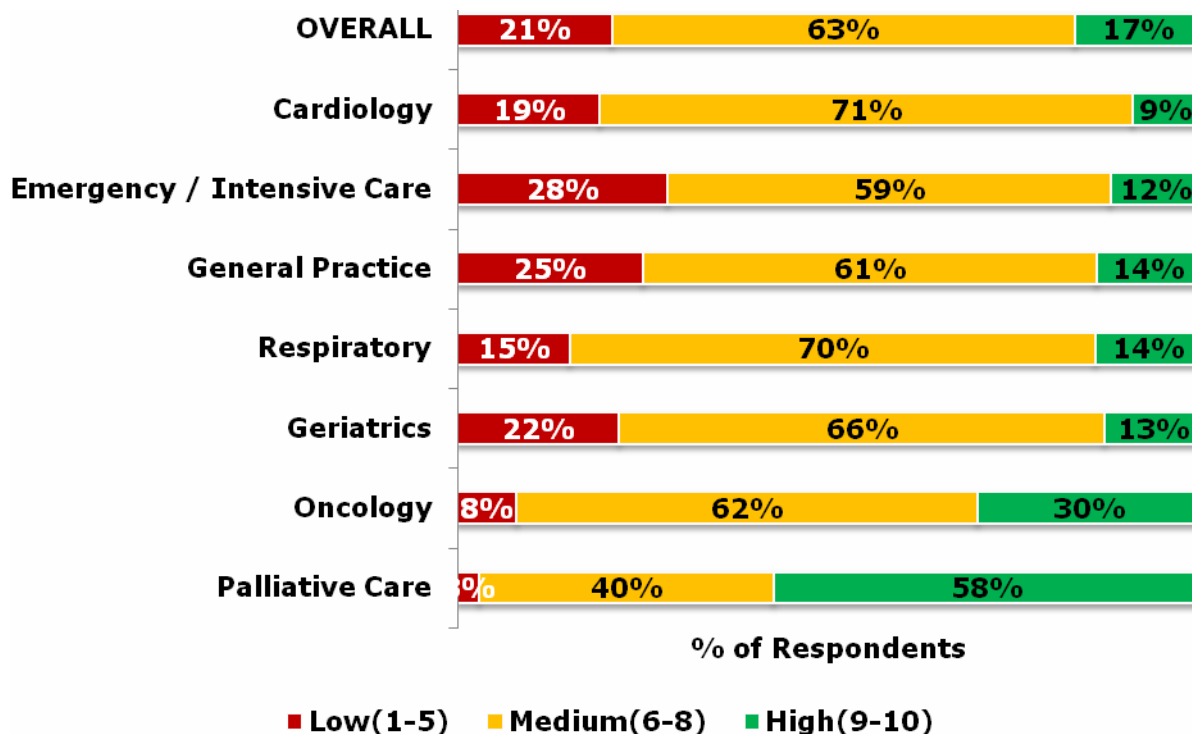**Figure 8: Confidence in delivering end of life care**
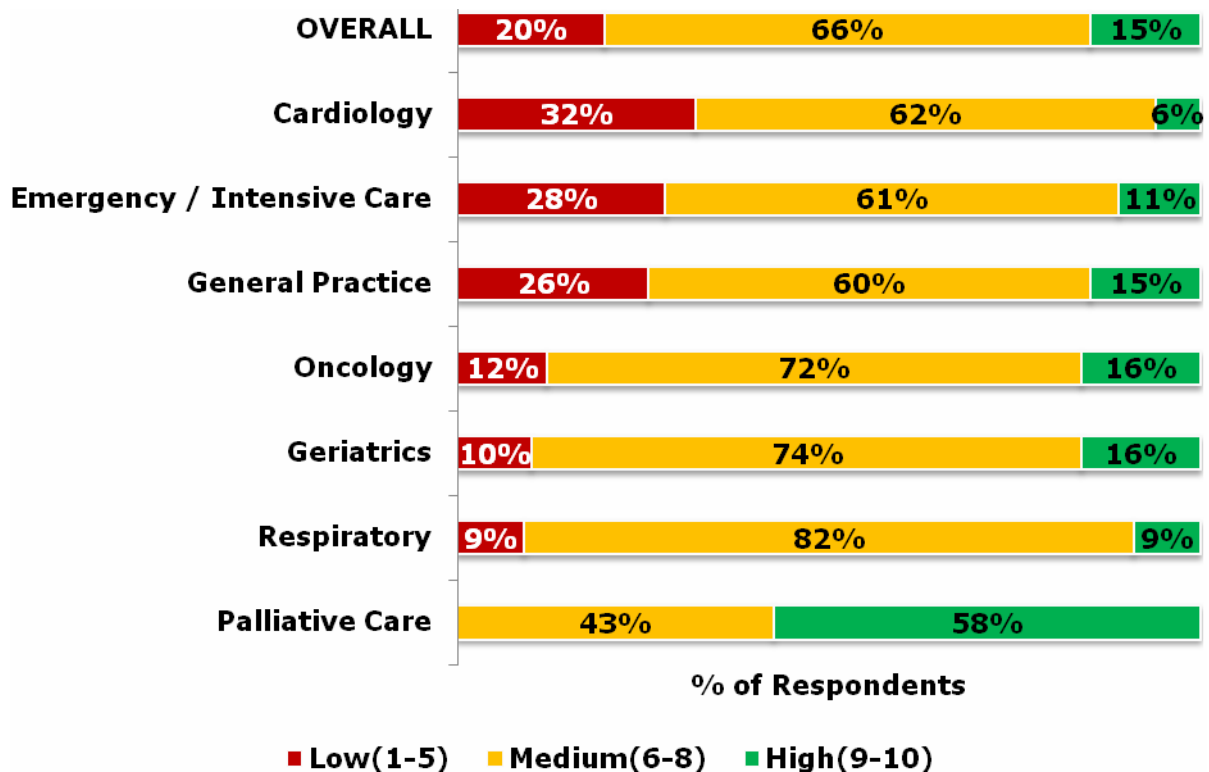
Overall, respondents rated their confidence in delivering end-of-life care as 6.8 out of 10. 26% of respondents rated their confidence in delivering end of life care as 8 out of 10.

Palliative Care Specialists had the highest confidence (8.8 out of 10) and females rated their confidence higher than males (7.0 versus 6.7). Cardiologists had the lowest confidence rating of any specialty (6.3 out of 10).

4.1.3 Confidence in discussing end of life care with those approaching the end of their lives

Doctors were asked to rate their confidence discussing end of life care with those approaching the end of their lives on a scale from 1 to 10, where 1 is 'not confident at all' and 10 is 'extremely confident'. The average rating for all specialties was 6.9 out of 10.

Figure 9: Confidence in discussing end of life care with those approaching the end of their lives

	Low(1-5)	Medium(6-8)	High(9-10)
OVERALL	21%	63%	17%
Cardiology	19%	71%	9%
Emergency / Intensive Care	28%	59%	12%
General Practice	25%	61%	14%
Respiratory	15%	70%	14%
Geriatrics	22%	66%	13%
Oncology	8%	62%	30%
Palliative Care	0%	40%	58%

% of Respondents

■ Low(1-5) ■ Medium(6-8) ■ High(9-10)

While 17% of doctors overall gave high ratings to their confidence in discussing end of life care with those approaching the end of their lives, Palliative care specialists felt significantly more confident, with 58% of them giving a high rating. On the other hand, Emergency / Intensive Care Specialists gave the most low ratings of confidence, with 28% indicating they had a low confidence in discussing end of life care with their patients.

Palliative Care specialists rated their confidence in discussing end of life care as significantly higher than all other specialties (8.8 out of 10).

4.2 Current training in end of life care

We asked respondents to evaluate the undergraduate as well as post-graduate training they have received in end of life care.

4.2.1 Undergraduate training in end of life care

29% of respondents report that their undergraduate (or equivalent) training covered the subject of delivering appropriate end of life care, while 39% of respondents report that their undergraduate training covered communication with end of life patients.
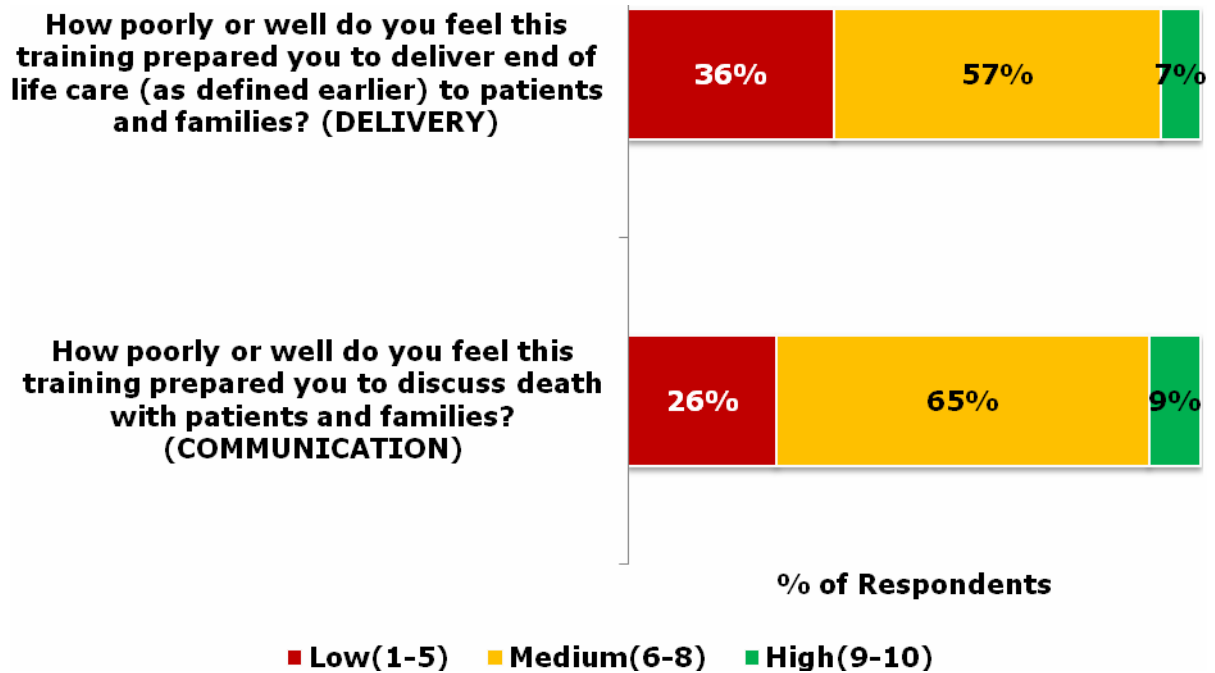
Figure 10: Undergraduate training in delivering and discussing end of life care – By Gender
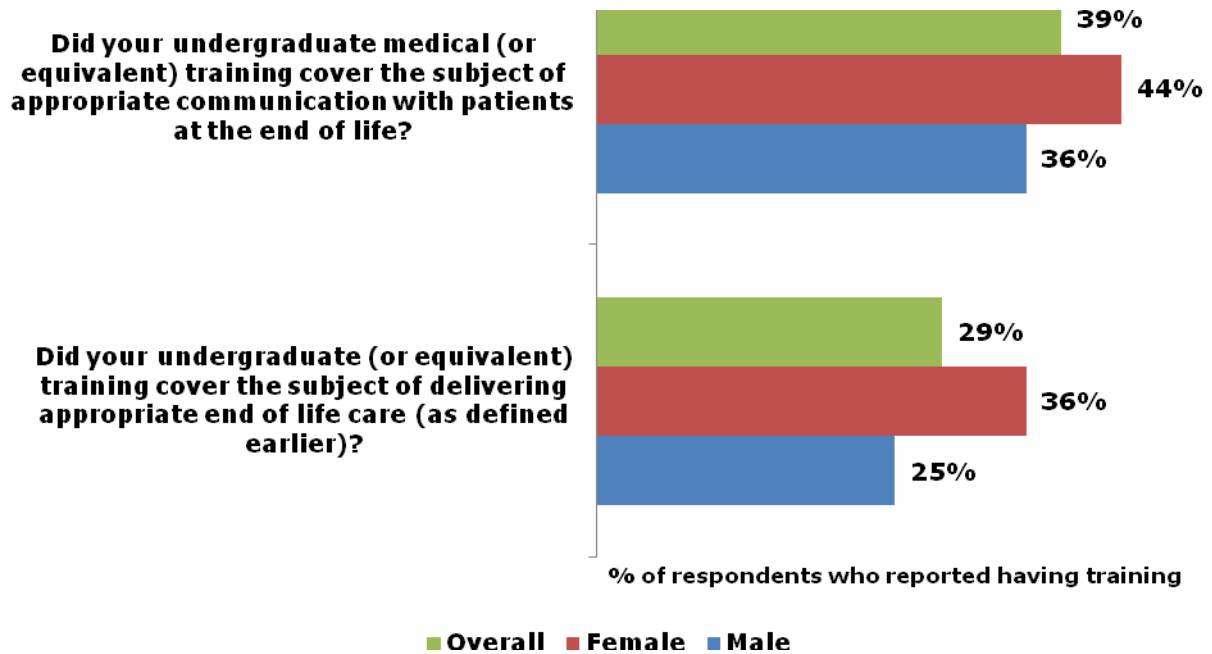
There were no significant differences between specialties in undergraduate training in communication or delivery of end of life care.

More females than males reported having undergraduate training in communication (44% versus 36%) and delivery (36% versus 25%) of end of life care.
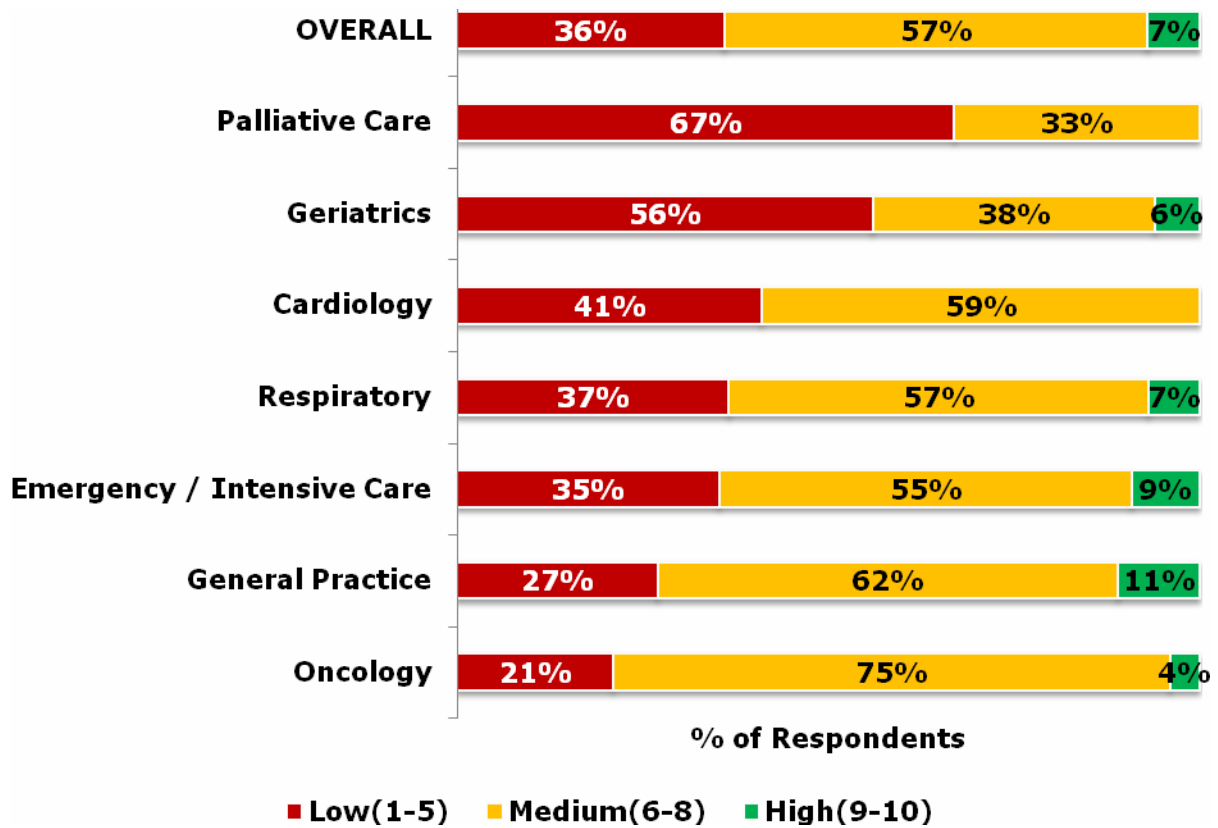
Figure 11a: How well or poorly undergraduate training prepared doctors for delivering and communicating end of life care

On average, respondents rated their undergraduate training as 6.5 out of 10 with regard to how well or poorly it helped them to **discuss** death with patients and families.

When it comes to **delivering** end of life care, respondents rated the preparation provided by their undergraduate training as 6.0 out of 10 on average.

Figure 11b: Delivering end of life care – By Specialty

Specialty	Low(1-5)	Medium(6-8)	High(9-10)
OVERALL	36%	57%	7%
Palliative Care	67%	33%	
Geriatrics	56%	38%	6%
Cardiology	41%	59%	
Respiratory	37%	57%	7%
Emergency / Intensive Care	35%	55%	9%
General Practice	27%	62%	11%
Oncology	21%	75%	4%

% of Respondents

■ Low(1-5) ■ Medium(6-8) ■ High(9-10)

Palliative Care Specialists rated their undergraduate training in delivering end of life care the lowest of all specialties, at 4.7 out of 10 on average. No Palliative Care Specialists or Cardiologists gave top box ratings to their undergraduate training in end of life care.

Figure 11c: Discussing end of life care – By specialty
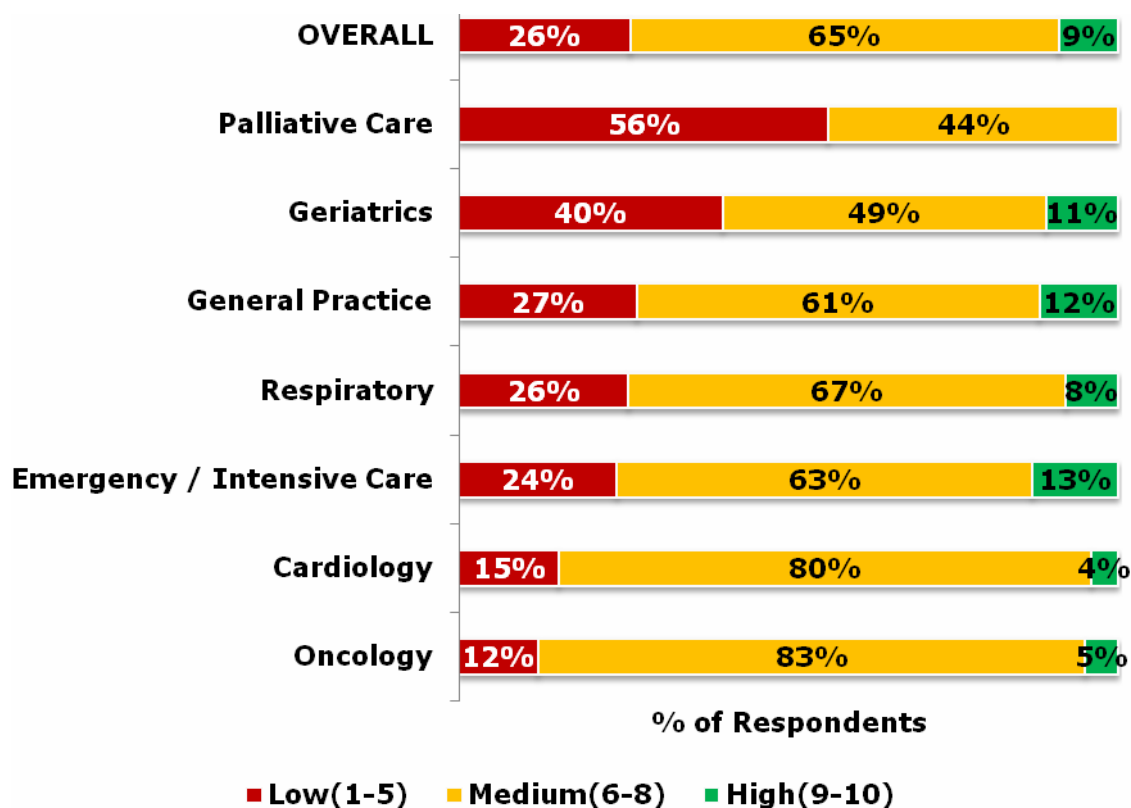
Overall, 9% of respondents gave a high rating to undergraduate training in discussing end of life care, while one quarter gave a low rating. Palliative Care Specialists rated their undergraduate training in discussing end of life care as lower than any other specialty (4.9 out of 10). No Palliative Care Specialists gave a top box rating to undergraduate training in end of life care, and over half gave a low rating.

4.2.2 Post-graduate training in end of life care

The Liverpool Care Pathway was developed in the late 1990s and became part of the National Cancer Plan after receiving the Beacon Award in 2000. In 2004, the Liverpool Care Pathway was recommended in NICE guidance in Supportive and Palliative Care Strategy. It is described on the Marie Curie Palliative Institute website as providing,

"an evidence based framework for the delivery of appropriate care for dying patients and their relatives in a variety of care settings. It encourages a multi-professional approach to the delivery of care that focuses on the physical, psychological and spiritual comfort of patients and their relatives that has also been shown to empower generic staff in the delivery of care.[3]"

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[3] The Marie Curie Palliative Institute, accessed 7 May, 2008.
http://www.mcpcil.org.uk/liverpool_care_pathway/overview

The Gold Standards Framework was developed in 2001, and in 2004 was rolled out to programmes in primary care, care homes and other related end of life care areas. It is described by the NHS as,

> *"a systematic evidence based approach to optimising the care for patients nearing the end of life in the community. It is concerned with helping people to live well until the end of life and includes care in the final year of life for people with any end stage illness... The aim of the Gold Standards Framework (GSF) is to develop a locally-based system to improve and optimise the organisation and quality of care for patients and their carers in the last year of life."[4]*

The Preferred Priorities of Care was developed in 2000 as part of the Palliative Care Education Programme. In 2004, it was included in NICE Guidance on Supportive and Palliative Care for Adults with Cancer. It is described by the End of Life Care Programme as,

> *"a document that individuals hold themselves and take with them if they receive care in different places. It has space for the individual's thoughts about their care and the choices they would like to make, including saying where, if possible, they would want to be when they die. Information about choices and who might be involved in their care can also be recorded so any care staff can read about what matters to the individual, thereby ensuring continuity of care."*

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[4] The Gold Standards Framework website, accessed 7 May 2008. http://www.goldstandardsframework.nhs.uk/

Figure 12: Participation in post-graduate training in end of life care
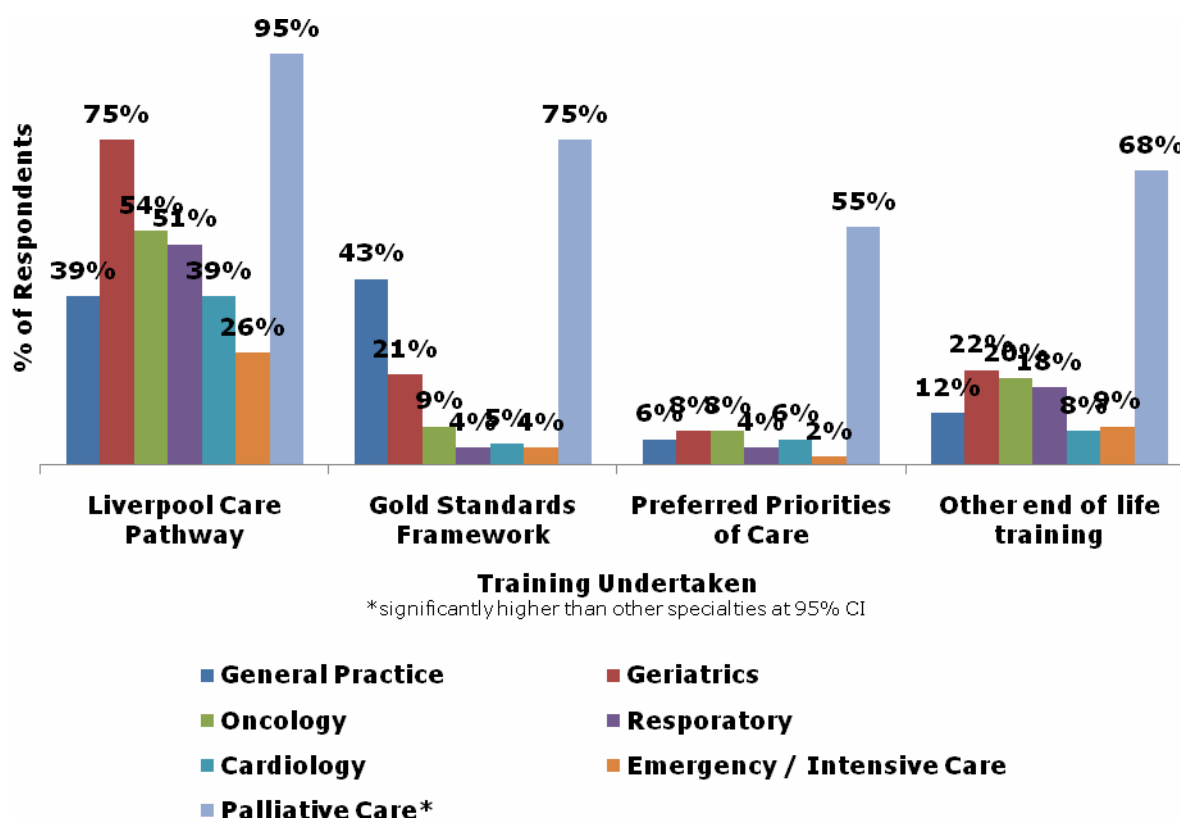
*significantly higher than other specialties at 95% CI

Overall, the Liverpool Care Pathway training was undertaken by 47% of respondents. The Gold Standards Framework was undertaken by 20%, while the Preferred Priorities of Care was undertaken by 8% of respondents. 17% of respondents have taken other end of life training courses than the aforementioned three.

The other postgraduate courses taken by respondents included: Specialist Palliative Care training (23 respondents), Work experience / on-the-job training in palliative care (18 respondents), Local/Regional training (17 respondents), or In-house training (11 respondents).

Female doctors tended to undertake more post-graduate training in end of life care than did males, specifically the Liverpool Care Pathway (55% versus 43%), the Gold Standards Framework (25% versus 17%) and other end of life training (22% versus 14%).

Palliative Care Specialists took more end of life training than any other specialty, with 95% having taken the Liverpool Care Pathway training, 75% having taken the Gold Standards Framework, 55% having taken the Preferred Priorities of Care training, and 68% having taken any other post-graduate training in end of life care.

61% of doctors who qualified after 2000 have undertaken the Liverpool Care Pathway that those who qualified earlier, which is significantly more than those who qualified in 1991-2000 (45%) and before 1991 (38%). However, the Gold Stardards Framework was undertaken significantly more by those who qualified before 1991 (27%) than those who qualified from 1991-2000 (16%) or after 2000 (19%). Those who qualified after 2000 were the least likely to have taken other post-graduate training in end of life care (9%) versus those who qualified from 1991-2000 (17%) or before 1991 (23%).

Figure 13: Impact of training on confidence when communicating with people at the end of life
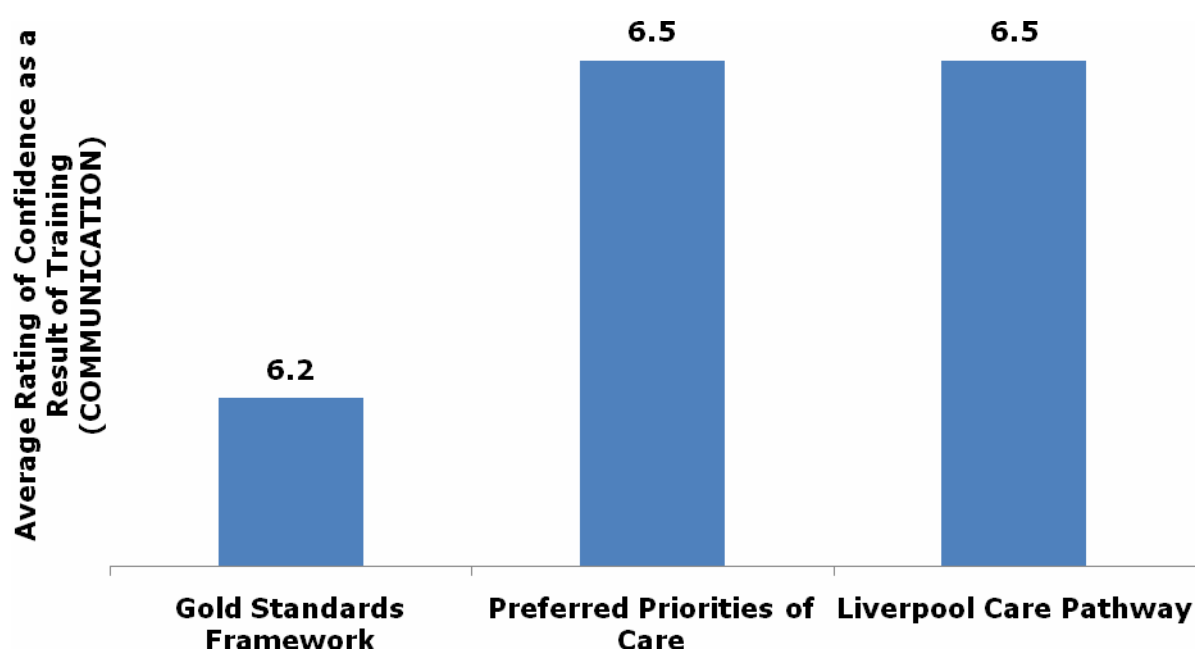
The Liverpool Care Pathway, Preferred Priorities of Care and Gold Standards Framework all had a similar impact on confidence of doctors in communicating with people at the end of life.

Doctors' rating of confidence in discussing end of life care as a result of training did not differ significantly by specialty, or by SHA, gender or grade.

Figure 14: Impact on confidence when delivering end of life care
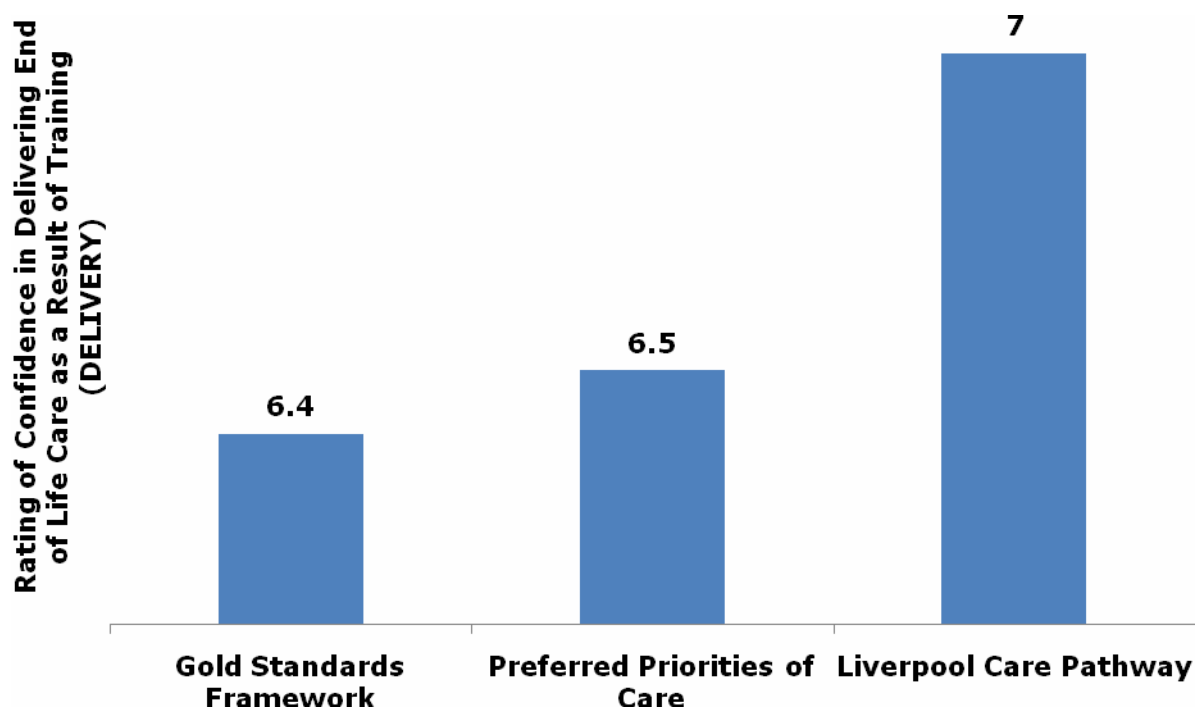
The Liverpool Care Pathway training had the highest rating for giving confidence to doctors in their delivery of end of life care (7.0 out of 10).

Doctors' rating of confidence in delivering end of life care as a result of training did not differ significantly by specialty, or by SHA, gender, or grade.

4.3 NHS and Voluntary Sector performance in meeting needs of people at the end of life

The Voluntary Sector plays a large role in providing end of life care as well as training for practitioners. According to a BBC report, two-thirds of hospice programmes in the UK are run by the voluntary sector[5]. Funding for voluntary sector hospices is primarily sourced by the charities themselves, with about one-third of funding coming from the NHS. The Voluntary Sector services are seeking more funding from the NHS to offset the high demands for their services,[6] thus highlighting the importance of ensuring quality delivery of services from these sources. We asked doctors to report their views of how effectively the NHS and voluntary services are addressing the needs of patients at the end of life.

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[5] BBC News. Hospices 'face funding struggle'. Published 23 July 2007.
http://news.bbc.co.uk/1/low/health/6912260.stm Accessed 7 May 2008.
[6] BBC News. Call to end 'distressing deaths'. Published 30 Aug 2007.
http://news.bbc.co.uk/1/hi/uk/6970054.stm Accessed 7 May 2008.

Figure 15: NHS and Voluntary Sector performance in meeting needs of people at the end of life
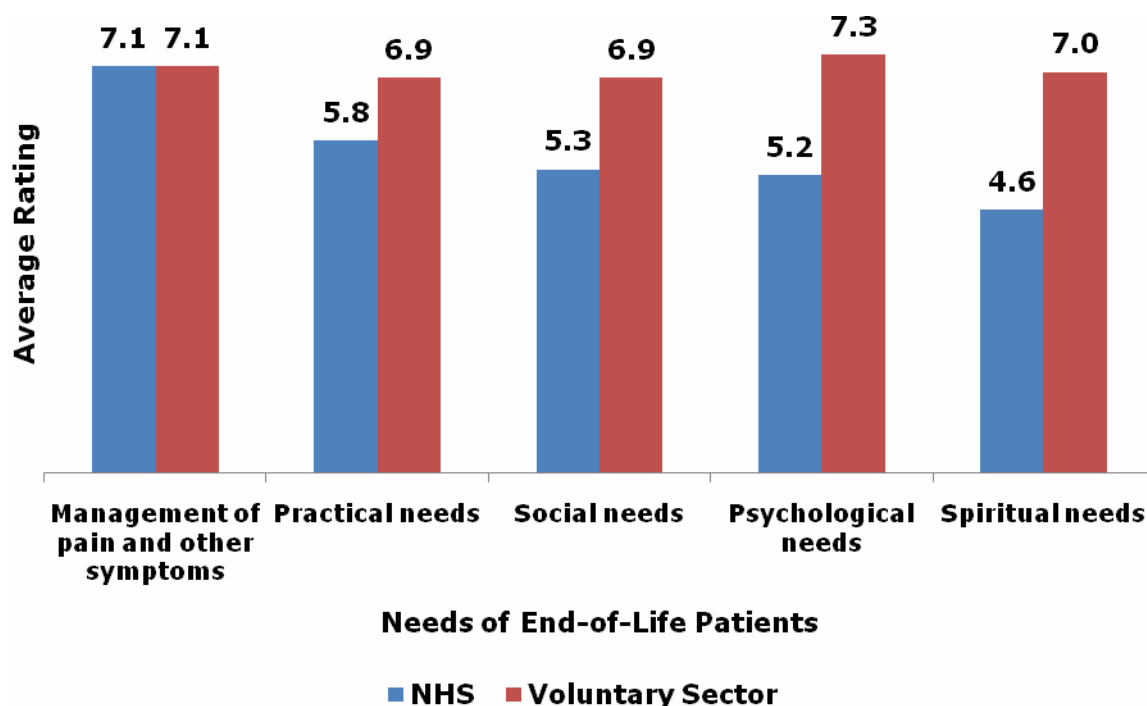
Overall, respondents gave the NHS' performance in meeting needs of people at the end of life mid-range scores. 'Management of pain and other symptoms' was given the highest rating (7.1 out of 10), while 'spiritual needs' received the lowest rating (4.6 out of 10).

Compared to all other specialties in this study, Palliative Care Specialists rated the NHS the lowest for meeting all needs of people at the end of life, with the highest rating 5.4 out of 10 for 'management of pain and other symptoms,' and 'spiritual needs' the lowest at 3.0 out of 10.

Voluntary sector were rated in the high-mid range, all around 7 out of 10 in meeting needs of people at the end of life. 'Psychological needs' were given the highest rating (7.3 out of 10), while 'practical needs' and 'social needs' received the lowest rating (6.9 out of 10).

Females rated voluntary sector performance higher than did males for meeting all needs they were asked about. The largest difference was in rating 'management of pain and other symptoms,' where females rated voluntary services half a point higher than did males (7.5 versus 6.8 out of 10).

Palliative Care Specialists gave the highest rating of any specialty to voluntary services for meeting the need of 'management of pain and other symptoms' (8.3 out of 10).

4.4 Support of carers during the end of life phase

Figure 16: NHS commissioned services' support of carers during the end of life phase
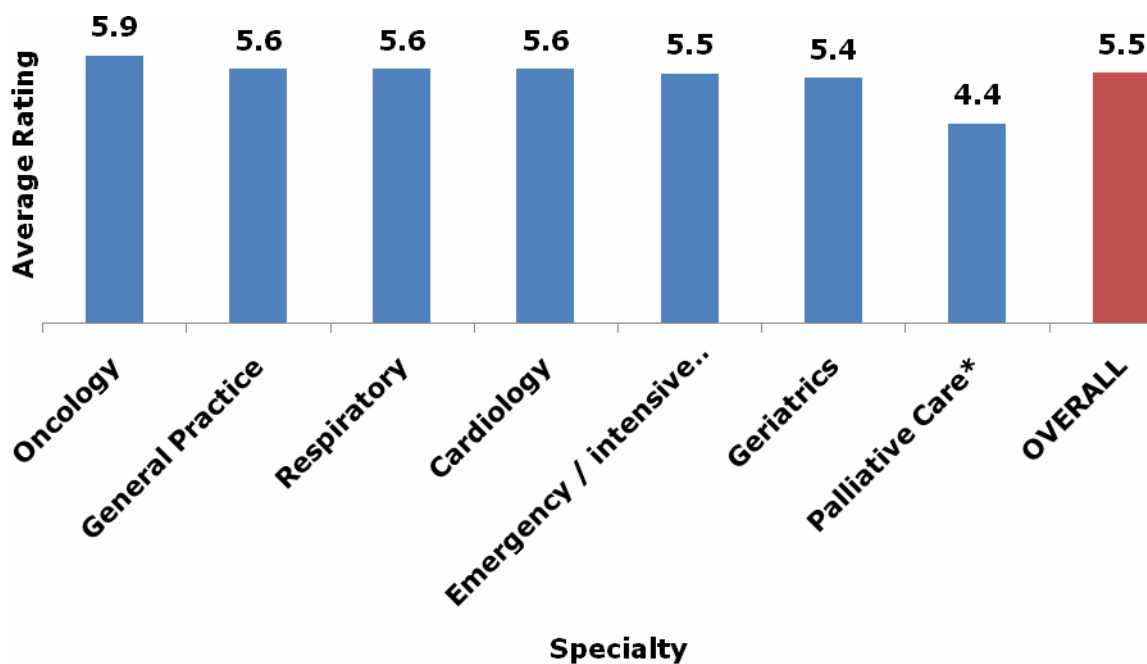
*Significantly lower than other specialties, at 95% CI

On average, respondents rated NHS commissioned services' support of carers during end of life phase as 5.5 out of 10.

The mean ratings provided by Palliative Care Specialists regarding the NHS services' support of carers were lower than any other specialty, at 4.4 out of 10.

Figure 17: Local Social Services' support of carers during the end of life phase

Bar chart showing Average Rating by Specialty:
- Oncology: 5.5
- Cardiology: 5.3
- General Practice: 5.2
- Respiratory: 5.2
- Emergency / intensive care: 5
- Geriatrics: 4.8
- Palliative Care*: 3.8
- OVERALL: 5.1

Specialty
*Significantly lower than other specialties, at 95% CI

Local social services' support of carers was rated on average 5.1 out of 10.

Palliative Care Specialists rated local services' support of carers the lowest of any specialty, at 3.8 out of 10.

Figure 18: NHS services' support of carers following bereavement

On average, respondents rated the NHS' support of carers following bereavement as 4.6 out of 10.

Palliative Care Specialists gave the lowest rating to NHS support of carers following bereavement (2.9 out of 10).

Males rated the NHS support of carers following bereavement higher than did females (4.8 versus 4.2).

4.5 Barriers faced in dealing with end of life care

Respondents were asked to identify the first, second and third largest barriers to high quality end of life care. The largest barrier selected overall was 'poor co-ordination across health and social care', which was selected by 29% of respondents as the first, second or third largest barrier.

Figure 19: Barriers that prevent the delivery of high quality end of life care services

Barrier	First	Second	Third
Poor co-ordination across health and social care	10%	11%	8%
The need for more community and acute hospital beds	9%	5%	5%
Lack of provision of hospice at home	9%	9%	7%
Lack of education and training of generalist staff	8%	6%	8%
Lack of integrated palliative care service	7%	6%	5%
Lack of 24/7 District Nursing	7%	8%	7%
Low numbers of patients achieving preferred place of care and death	6%	4%	5%
Lack of provision of social care	6%	6%	6%
Poor development of non-cancer services	6%	6%	7%
Lack of specialist rapid response	5%	4%	3%
Poor communication between providers	4%	7%	7%
Lack of dedicated end of life staff at senior level	4%	6%	5%
Lack of carer support, including respite and bereavement services	4%	6%	8%
Lack of education and training in care homes	3%	5%	3%
Insufficient implementation of end of life care tools (e.g. GSF, LCP, PPC etc)	3%	3%	4%
Lack of a local end of life care strategy	3%	3%	4%

% of Respondents
(n.b. only >10% endorsement shown)

■ First ■ Second ■ Third

Overall, 'poor co-ordination across health and social care' was most frequently selected as a barrier to high quality end of life care (29% of respondents). Next was 'lack of provision of hospice at home' (25%), followed by 'lack of education and training of generalist staff' (22%).

The most commonly selected first barriers to high-quality delivery of end of life care were 'poor co-ordination across health and social care' (10%), 'the need for more community and acute hospital beds' (9%) and 'Lack of provision of hospice at home (9%).

5 Appendix

5.1 Questionnaire

Doctors.net.uk invites you to participate in a survey commissioned by the National Audit Office regarding end of life care.

Please read the following text, which explains the intent of this research:

- I understand that this research is commissioned by the National Audit Office and is being carried out within the code of conduct of the Market Research Society and the British Healthcare Business Intelligence Association.

- The identity of respondents is confidential: no details of respondents are passed to any 3rd party· Results are aggregated to provide an overall picture of attitudes to the areas being discussed.

- Respondents have the right to withdraw from the interview at any time during the interview process and to withhold information as they see fit

SHOW GPs

The survey will take about twenty minutes to complete and all members completing the survey will be entered for a prize draw with three opportunities to win 50,000 eSR points. All results will be anonymised in accordance with Doctors.net.uk's zero-tolerance privacy policy and the Market Research Society Code of Practice.

SHOW HOSPITAL DOCTORS

The survey will take about fifteen minutes to complete and all members completing the survey will be entered for a prize draw with four opportunities to win 40,000 eSR points. All results will be anonymised in accordance with Doctors.net.uk's zero-tolerance privacy policy and the Market Research Society Code of Practice.

Please confirm that you have read and understood this information, and you agree to proceed with this survey.

- ❍ Yes
- ❍ No

[NEW SCREEN]

Survey - Definitions

Where the following terms are used in the questionnaire, the following definitions[7] should be applied:

End of life

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[7] Department of Health (2007) *Operating Framework 2007/08: PCT Baseline Review of Services for End of Life Care*

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The phase "end of life" ends in death. Definition of its beginning is variable according to individual patient and professional perspectives. In some cases it may be the patient who first recognises its beginning. In other cases the principal factor may be the judgement of the health/social care professional/team responsible for the care of the patient. In all cases, subject to patient consent, the beginning is marked by a comprehensive assessment of supportive and palliative care needs.

Professional judgement may be informed by use of a range of indicators. They include:
1. The surprise question. Would you be surprised if this patient were to die in the next 12 months?
2. Choice. The patient with advanced disease makes a choice for comfort care only.
3. Need. The patient with advanced disease is in special need of supportive/palliative care.
4. Clinical indicators. Specific indicators of advanced disease for each of the three main groups – people with cancer, organ failure, elderly frail/dementia.

End of life care

End of life care is care that helps all those with advanced, progressive, incurable illness to live a well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.

End of life care is underpinned by:
- An active and compassionate approach to care that ensures respect for and dignity of the patient and family
- Partnership in care between patient, family and health and social care professionals
- Regular and systematic assessment of patient/carer needs incorporating patient consent at all times
- Anticipation and management of deterioration in the patient's state of health and well-being
- Advance care planning in accordance with patient preferences
- Patient choice about place of care and death
- Effective coordination of care across all teams and providers of care (statutory, voluntary and independent sectors) who are involved in the care of patient and family.

Demographic section D1-6

1. What is your speciality?

   - General practice
   - Geriatrics
   - Oncology
   - Respiratory
   - Cardiology
   - Emergency /intensive care
   - Palliative care
   - Other   THANK AND CLOSE

2. What is your grade?
   - Consultant
   - Associate Specialist
   - Staff Grade
   - Hospital Practitioner/Clinical Assistant
   - Registrar
   - Specialist Registrar
   - StR
   - Flexible Trainees – StR
   - GP ST1/ST2
   - Flexible Training Specialty ST1/ST2
   - Foundation Year FY1
   - Foundation Year FY2
   - Flexible Training Foundation Year FY1
   - Flexible Training Foundation Year FY2
   - Trust Grade Doctors
   - General Practitioner/GPwSIs
   - General Practitioner Principal
   - Salaried General Practioner
   - GP Registrar
   - GP Locum
   - Other (please specify)

3. In which SHA do you currently practice?

   - London
   - South East Coastal
   - South Central
   - South West
   - North East
   - North West
   - Yorkshire & Humber
   - West Midlands
   - East Midlands
   - East of England
   - Retired   THANK AND CLOSE
   - Not practicing in England   THANK AND CLOSE

4. What is your year of qualification?
   Please write in the year.

5. What is your gender?

  ❍ Male
  ❍ Female

ASK ALL RESPONDENTS NOT CODING 1 AT D1

6. Is your centre?

  ❍ A teaching hospital
  ❍ A District General Hospital
  ❍ A tertiary centre
  ❍ Other

Survey - Questions

1. Please estimate the proportion of patients whose care you were involved with in the last 12 months who would have been eligible for end-of-life care?

  1. ☐ None
  2. ☐ 1-25%
  3. ☐ 26-50%
  4. ☐ 51-75%
  5. ☐ 76-100%

2. With how many of these patients at the end of life did you discuss the subject of their approaching death?

  1. ☐ None
  2. ☐ 1-25%
  3. ☐ 26-50%
  4. ☐ 51-75%
  5. ☐ 76-100%

3. How would you rate your confidence in identifying the point at which end of life care should begin for a patient?
Please rate your confidence on a scale of 1-10, where 1 is not confident at all and 10 is extremely confident. [1-10]

1	2	3	4	5	6	7	8	9	10

4. In general, how would you rate your confidence in delivering end of life care (as defined above)?
Please rate your confidence on a scale of 1-10, where 1 is not confident at all and 10 is extremely confident. [1-10]

1	2	3	4	5	6	7	8	9	10

5. Did your undergraduate (or equivalent) training cover the subject of delivering appropriate end of life care (as defined above)? *[Yes/No]*

- ❍ Yes
- ❍ No

ASK Q6 IF Q5 CODED YES

6. How poorly or well do you feel this training prepared you to deliver end of life care (as defined above) to patients and families?
Please how well prepared you were on a scale of 1-10, where 1 is not at all well prepared and 10 is extremely well prepared. [1-10]

1	2	3	4	5	6	7	8	9	10

7. In general, how would you rate your confidence in discussing end of life care with those who are approaching the end of their lives?
Please rate your confidence on a scale of 1-10, where 1 is not confident at all and 10 is extremely confident. [1-10]

1	2	3	4	5	6	7	8	9	10

8. Did your undergraduate medical (or equivalent) training cover the subject of appropriate communication with patients at the end of life? *[Yes/No]*

- ❍ Yes
- ❍ No

ASK Q9 IF Q8 CODED YES
9. How poorly or well do you feel this training prepared you to discuss death with patients and families?
Please rate how well prepared you were on a scale of 1-10, where 1 is not at all well prepared and 10 is extremely well prepared. [1-10]

1	2	3	4	5	6	7	8	9	10

10. Which, if any, of the following have you undertaken as post-grad training?

	Yes	No
Liverpool Care Pathway		
Gold Standards Framework		
Preferred Priorities of Care		
Other end of life training (please specify) _____		

11. How do you rate the impact on your own confidence when **communicating** with people at the end of life as a result of being trained in each of the following tools?

Please rate the improvement on a scale of 1-10, where 1 is no improvement at all and 10 is a significant improvement. If you have not been trained on a particular tool, please select Not applicable, or if you feel that as a result of your training your confidence in delivering end of life care has deteriorated, please select 'Negative impact'.

	Negative impact	1 = No improvement at all	2	3	4	5	6	7	8	9	10 = A significant impact	Not applicable
Liverpool Care Pathway	❏	❏	❏	❏	❏	❏	❏	❏	❏	❏	❏	❏
Gold Standards Framework	❏	❏	❏	❏	❏	❏	❏	❏	❏	❏	❏	❏
Preferred Priorities of Care	❏	❏	❏	❏	❏	❏	❏	❏	❏	❏	❏	❏
Other end of life training (please specify _____)	❏	❏	❏	❏	❏	❏	❏	❏	❏	❏	❏	❏

12. How do you rate the impact on your own confidence when **delivering** end of life care as a result of being trained in each of the following tools?

Please rate the improvement on a scale of 1-10, where 1 is no improvement at all and 10 is a significant improvement. If you have not been trained on a particular tool, please select Not applicable, or if you feel that as a result of your training your confidence in delivering end of life care has deteriorated, please select 'Negative impact'.

	Negative impact	1 = No improvement at all	2	3	4	5	6	7	8	9	10 = A significant impact	Not applicable
Liverpool Care Pathway	❏	❏	❏	❏	❏	❏	❏	❏	❏	❏	❏	❏
Gold Standards Framework	❏	❏	❏	❏	❏	❏	❏	❏	❏	❏	❏	❏
Preferred Priorities of Care	❏	❏	❏	❏	❏	❏	❏	❏	❏	❏	❏	❏
Other end of life training (please specify _____)	❏	❏	❏	❏	❏	❏	❏	❏	❏	❏	❏	❏

13. To what extent do you agree or disagree that people at the end of life and their families generally are sufficiently and appropriately involved in decisions about their care?
Please use the scale shown below.

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
❏	❏	❏	❏	❏

14. In general, how poorly or well do you feel the NHS meets the following needs of people at the end of life?

Please rate how well it meets each need on a scale of 1-10, where 1 is not at all well and 10 is extremely well. If you don't know, please select DK. [1-10 or DK]

	1 = Not at all well	2	3	4	5	6	7	8	9	10 = Extremely well	DK
Management of pain and other symptoms	❏	❏	❏	❏	❏	❏	❏	❏	❏	❏	❏
Psychological needs	❏	❏	❏	❏	❏	❏	❏	❏	❏	❏	❏
Social needs	❏	❏	❏	❏	❏	❏	❏	❏	❏	❏	❏
Spiritual needs	❏	❏	❏	❏	❏	❏	❏	❏	❏	❏	❏
Practical needs	❏	❏	❏	❏	❏	❏	❏	❏	❏	❏	❏

15. In general, how poorly or well do you feel the voluntary sector (e.g. services provided by voluntary hospices in the community and via in-patient care) meets the following needs of people at the end of life?

Please rate how well it meets each need on a scale of 1-10, where 1 is not at all well and 10 is extremely well. If you don't know, please select DK. [1-10 or DK]

	1 = Not at all well	2	3	4	5	6	7	8	9	10 = Extremely well	DK
Management of pain and other symptoms	❏	❏	❏	❏	❏	❏	❏	❏	❏	❏	❏
Psychological needs	❏	❏	❏	❏	❏	❏	❏	❏	❏	❏	❏
Social needs	❏	❏	❏	❏	❏	❏	❏	❏	❏	❏	❏
Spiritual needs	❏	❏	❏	❏	❏	❏	❏	❏	❏	❏	❏
Practical needs	❏	❏	❏	❏	❏	❏	❏	❏	❏	❏	❏

16. In general, how poorly or well do services commissioned by the NHS support carers during the end of life phase?

Please rate how well on a scale of 1-10, where 1 is not at all well and 10 is extremely well. If you don't know, please select DK. [1-10 or DK]

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1	2	3	4	5	6	7	8	9	10	DK
❑	❑	❑	❑	❑	❑	❑	❑	❑	❑	❑

17. In general, how poorly or well do local Social Services support carers during the end of life phase?
Please rate how well on a scale of 1-10, where 1 is not at all well and 10 is extremely well. If you don't know, please select DK. [1-10 or DK]

1	2	3	4	5	6	7	8	9	10	DK
❑	❑	❑	❑	❑	❑	❑	❑	❑	❑	❑

18. In general, how poorly or well do services commissioned by the NHS support carers following bereavement?
Please rate how well on a scale of 1-10, where 1 is not at all well and 10 is extremely well. If you don't know, please select DK. [1-10 or N/k]

1	2	3	4	5	6	7	8	9	10	DK
❑	❑	❑	❑	❑	❑	❑	❑	❑	❑	❑

ROTATE ORDER OF BARRIERS IN Q19

19. From the list below please select the top 3 barriers that you feel prevent the delivery of high quality end-of-life care services to all patients in your local area. Please rank the barriers in order of importance where 1 is the largest barrier you experience

Barrier	Largest barrier	Second largest barrier	Third largest barrier
Insufficient implementation of end of life care tools (e.g. GSF, LCP, PPC etc)	❏	❏	❏
Lack of 24/7 District Nursing	❏	❏	❏
Poor co-ordination across health and social care	❏	❏	❏
Lack of education and training of generalist staff	❏	❏	❏
Lack of education and training in care homes	❏	❏	❏
Poor development of non-cancer services	❏	❏	❏
Lack of timely access to equipment	❏	❏	❏
Lack of timely access to medication	❏	❏	❏
Low numbers of patients achieving preferred place of care and death	❏	❏	❏
Lack of provision of hospice at home	❏	❏	❏
Lack of provision of social care	❏	❏	❏
Lack of carer support, including respite and bereavement services	❏	❏	❏
Lack of specialist rapid response	❏	❏	❏
Insufficient transport services	❏	❏	❏
Patient choice	❏	❏	❏
Poor communication between providers	❏	❏	❏
Lack of integrated palliative care service	❏	❏	❏
The need for more community and acute hospital beds	❏	❏	❏
Lack of dedicated end of life staff at senior level	❏	❏	❏
Lack of a local end of life care strategy	❏	❏	❏
Other (please specify)	❏	❏	❏

24. Thinking back over the last year, please estimate the total number of patients you have seen overall?
    Please write in the number

_____

25. Which of the following best describes your centre or practice?

    Please choose the one that best applies.

    1. ☐ District General Hospital
    2. ☐ Teaching Hospital
    3. ☐ Private hospital
    4. ☐ Private nursing home
    5. ☐ Private care home
    6. ☐ Hospice
    7. ☐ GMS Primary Care Practice
    8. ☐ PMS Primary Care Practice
    9. ☐ Other (please specify) _____

THANK AND CLOSE