TRAINING AND EDUCATION IN END OF LIFE CARE

Recommendations for Health Education England

A report produced by The Democratic Society
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Executive Summary

The history of this report is rooted in the work led by the Leadership Alliance for the Care of Dying People, whose collaboration produced the "Once Chance to Get it Right" report. Health Education England (HEE), as a member of the Alliance, has undertaken a commitment to address the pressing need for more evidence-based education in all settings that care for those who are dying. This report provides recommendations based on a research exercise that was intended to explore how those delivering care to dying patients are supported by education and training.

End of Life Care (EoLC) cuts across specialisms, settings (hospital, care home, community and hospice), workforces (nurses, social care workers, ancillary staff, GPs, specialists) and geographies. Given the breadth of available material and limited time, the focus of this report was to undertake a ‘deep dive’ exercise that prioritised the qualitative views of frontline staff and practitioners. Consequently, it has not been possible to include every suggestion and case study; some suggestions were beyond the remit of HEE, and brevity dictated that we were not able to include many ideas we personally found inspiring. Our aim was to identify what works, and what doesn’t, in EoLC education.

Extending the workforce for delivery of EoLC was a consistent request and can be interpreted in two ways: first, an increase in the number of staff delivering specialist palliative care. The second is to ensure that generalists from across the workforces are able to deliver EoLC to a level commensurate with their role whilst also meeting a basic minimum standard that is universal across the service. Clarification of HEE’s role was also considered important; a significant element of their work should be to strengthen relationships between HEE and other national organisations (national networking); between the LETBs and local equivalents (local networking); and HEE and the LETBs (creating links between the national and local networks).

A very popular idea raised independently by participants at our events was an online hub for knowledge sharing that should be established and managed by HEE in collaboration with its partners. So many interviewees suggested, in one guise or another, a place where resources are collated that we believe this recommendation is a pivotal factor in this report. Our detailed interviews yielded views from commissioners, education providers, employers, frontline staff across sectors and settings as well as LETB representatives, and it is noteworthy that those from different roles could see a value in a hub from their individual perspective. Content could include case studies, educational materials, links to other organisations and/or training courses available nationally and collated by region.
Finding appropriate channels to disseminate funding information also needs to be considered: visibility and adequate timeframe of information release are critical prerequisites for improving planning. In some cases, funds had limited value as they were not known about. In a climate of limited resources, maximising the use of existing budgets is of paramount importance. Clearer overviews of regional spending and identification of successful investment is another way of reinforcing positive training endeavours.

While many parts of the health service deliver excellent EoLC, the risk of an endemic culture of neglect and poor practice in certain environments has devastating consequences for patients: a minimum level of skills in EoLC across all workforces and settings was another consistent theme. Commissioned annual training should focus on upskilling generalists, as appropriate, in the recognition of dying patients, difficult conversations, pain management and personalised care planning. In terms of efficacy, we recognise that a blended learning approach can improve the proficiency of students and qualified staff. Learning that is reinforced through different opportunities and approaches ensures that key ideas are embedded. The most important skill cited by participants was communication and this is a clear focus for any training strategy. Strengthening mandatory training for both EoLC and communication (as a universal skill) early in the clinical learning paradigm was seen as critical, as was focusing subsequent reinforcements of this throughout educational strategies.

In summary, we were able to draw out eight different key themes that correspond to eight recommendations. These are: Extend the workforce for delivery of EoLC; define, develop and disseminate information about the role of HEE and the LETBs; develop relationships and strategic partnerships to support network building in EoLC; create a hub for EoLC education and training resources; improve awareness of and access to funding; focus on communication skills as a universal skill underpinning EoLC; create a baseline of EoLC tools; and support Blended Learning to deepen knowledge in EoLC.

Each over-arching theme has a series of sub-recommendations, the rationale for which is explored in more depth in each chapter. If the recommendations provide the ‘what’, the chapters explain (based on feedback from participants in our research), the ‘why’ and some detail that may be useful in terms of ‘how’.

This report has been based on the generous contributions of time and effort from over 1500 people. We would like to thank everyone who participated in any of our research streams, and acknowledge their contribution of the most precious resource of all: time. We hope our recommendations and summary do justice to their contributions.
Recommendations

1. Extend the workforce for delivery of End of Life Care (EoLC)
   - In workforce planning, HEE should make provision for proactive recruitment and training to increase the number of specialist palliative nurses and doctors able to work in EoLC.
   - HEE should commission the LETBs to support programmes designed to give specialist training to those with a generalist background (nurses, doctors or allied health professionals) who work, or wish to work, in EoLC.
   - HEE should make it clear through its communications and workforce planning that EoLC skills are needed by generalists as well as palliative specialists, and should encourage, through its activities, networks and influence education and training throughout the health workforce.
   - HEE should promote, educate and embed the definition of EoLC as given in One Chance to Get it Right by signposting it, as appropriate, in communications and through networks.

2. Define, develop and disseminate information about the role of HEE and the LETBs
   - HEE should adapt and disseminate current communication materials to ensure that key contacts and connections specific to EoLC can be supported, and to clarify the role of HEE and the LETBs across EoLC networks.
   - HEE should, in partnership with the LETB leads, decide the expectation for any universal requirements expected of the LETBs when delivering EoLC education and training. Discussions should also identify the support needed from HEE to the LETBs in their role.

3. Develop relationships and strategic partnerships to support network building in EoLC
   - The national HEE lead for EoLC should undertake a mapping exercise to identify, join and, where appropriate, create links between other existing End of Life Care Networks for shared education/training learning. This should be undertaken at the national level, with the aim of compiling a national database of contacts to support relationships, knowledge sharing and to ensure adequate links between HEE and other key stakeholders.
   - This national networking exercise should be mirrored at each regional level where it is not already underway. Specifically, HEE should coordinate LETB partnerships with the existing Palliative and End of Life Care Network Leads to support a seamless approach to local delivery of end of life care. This should involve regular meetings to
provide opportunity to engage with the Network Leads on training and education issues.

- HEE should strengthen its relationships with, and relationships between, LETBs by bringing together the LETB leads for an annual knowledge-share workshop in EoLC.
- Through its relationships, EoLC leads at HEE should ensure that they are informed of, and involved in, developments in the field. In this capacity, HEE needs to embed current thinking in their work, and in turn contribute the educational policy perspective as appropriate. These relationships should include, but should not be limited to, the following:
  - HEE should build a positive working partnership with training regulator leads for EoLC.
  - HEE should establish positive partnerships with the voluntary sector and specialist palliative care providers. In particular, joining the Hospice UK initiative for Training and Education would enable a link through which HEE can support, as appropriate, Hospice provided training.
  - HEE should foster and seek representation on key steering groups and committees in other ALBs, stakeholders and third sector organisations relevant to EoLC.
  - HEE should seek to develop a stronger working partnership with Skills for Care and Skills for Health in EoLC through regular meetings, the focus of which could include: clarification of the roles of each organisation in relation to each other; identification of materials that could be usefully shared between partners; collaborative working on programmes with a natural overlap; collaboration for the update of materials useful to each organisation; and support for and between EoLC leads from HEE, Skills for Care and Skills for Health.

4. Create a hub for EoLC education and training resources

- HEE and its national strategic partners should draw on and disseminate the existing, rich knowledge base by collating case studies and programmes used across sectors, geographies and settings. These should be well-organised and easily accessible online with promotion at regional and national levels via LETBs and HEE networks respectively, as well as any strategic partners.

5. Improve awareness of and access to funding

- HEE should, where appropriate, support joint initiatives in EoLC training between the social care workforce and health workforce by opening up access to joint commissioning funds.
- Funding in training and education needs to be consistent, transparent and easy to locate for long-term strategic workforce planning: there needs to be increased clarity around what funds are available and how to access them. This information should be
publicly posted well in advance. The proposed EoLC hub would be one place to do this.

- HEE and the LETBs should provide eight weeks’ notice of funding opportunities and resources.
- HEE should facilitate long-term planning by providing long-term funding pots guaranteed over 2-5 year periods – HEE could work with system partners to set a strategic direction for EoLC on this basis.
- HEE should make EoLC a priority area for funding to link in with the broader NHS strategy.
- Ensure that HEE gets value for funded course placements and course design by exploring, with strategic partners, repercussions for ‘lost’ funding to include consideration of the following measures:
  - Build relationships with providers of qualification-based education courses to ensure that where materials that could be used for in-house training have been put together with HEE funding, as far as possible, these are made freely available and easily accessible. Dissemination through the HEE hub of materials could be one option.
  - Employers need to protect staff training time with forward planning and locum support to avoid last minute drop out and loss of training placements; if an employer designates a place and then pulls out a staff member, the onus is on them to identify another practitioner (not necessarily from their organisation) to take the place or to cover partial costs.
  - The cost of a course may also need, from the employer perspective, to include the cost of a locum or cover for the staff member, and this should be factored into funding.
- LETBs to support cross-sector projects, integrated training and training in primary and community care and third sector training by diversifying their membership to include representatives from these sectors.

6. Focus on communication skills as a universal skill underpinning EoLC

- Communication skills should be reinforced at each stage of learning and a ring-fenced allocation operating across-sectors should be a key priority to support not only EoLC, but other areas of need in the service.
- HEE should formally contribute to discussions with training regulators who are currently developing clinical and qualifications-based curricula. HEE should advocate sign-posting communication as a core competency in which EoLC communications sit as a specific and mandatory component.
- Support training around the use of Personalised Care Planning in every workplace through a package of freely available online resources and guidance linked to CQC and other required standards.
• Commission LETBS to identify effective courses in advanced communication for those working with dying patients on a regular basis, ensuring these meet curriculum and regulatory standards. LETBs should ring-fence a cross-sector budget for shared learning in advanced communication skills as part of mandatory CPD and training.

7. Create a minimum standard of EoLC skills

These sub-recommendations have been grouped thematically but are intended to work holistically to create a minimum level of skill in EoLC.

The role of leadership at Trust level in supporting the development of baseline skills

• HEE should initiate a discussion with NHS Employers and Monitor to consider a new role: a nominated person who would look at education and training at each Trust Board – this role would bring meaningful representation into Trusts supported by HEE, Monitor and NHS Employers.

Formal, qualification-based training

• HEE should maintain dialogue with the GMC, royal colleges and, as appropriate, other training regulators to support the inclusion of EoLC provision in revised curricula in keeping with the principles agreed in “One Chance to Get It Right”. From this perspective, HEE can also support faster feedback and knowledge sharing of policy changes.

• HEE should initiate dialogue with Higher Education Institute representatives with responsibility for interpreting clinical curricula to ensure that the spirit of curricula-based changes and the intentions of “One Chance To Get It Right” are represented in teaching.

• HEE should continue to work with Skills For Care and Skills For Health to promote and develop the Care Certificate

Incorporating EoLC into induction

• Identify, collate and update a suite of tools designed for minimal core training in recognising and responding to a dying patient; these tools should be designed for use as part of the universal induction process for Trusts and Employer Organisations, available through the HEE hub, networks, duplicated on other hubs (Skills For Care, Skills For Life) if appropriate and promoted to employers as part of the integration agenda.

• The finding of this report is that incorporating EoLC into induction as a mandate would be counter-productive at this time; however, given a broader ethos that all nurses and doctors will encounter dying patients, HEE should keep this decision under review and, in collaboration with the CQC and Alliance partnership, should be prepared to support mandatory training in EoLC at the induction stage if it is deemed necessary. A date should be set for August 2016 to review this decision.
Continuing professional development

- Support and commission annual training around recognition of patients approaching the end of their life with a view to ensuring that patients who may benefit from compassionate communication, personalised care planning or any other aspect of EoLC can be identified and treated. This initiative should be targeted towards auxiliary and junior generalist staff who ordinarily have minimal exposure to end of life patients.
- Support an annual training update in EoLC based around Personalised Care Planning for all Trusts and Employer Organisations.
- Support an annual training for GPs in the administration and prescription of pain relief for EoLC patients such that they may be confident and competent in managing pain relief for patients preferring to die at home.
- Identify those staff with responsibility for day-to-day management of dying patients to network a cross-sector working population that could potentially share resources and learning.

8. Support Blended Learning to deepen knowledge in EoLC

Supervision and mentorship

- Supervision and mentorship play a critical role in the training of pre-registration nurses and doctors; HEE should initiate, host and facilitate a discussion with senior clinical leadership (Royal Colleges, GMC) to discuss the expectations of these two critical roles, and to identify the barriers that may undermine supervisors. NHS England, Employer groups and political representatives able to address these barriers should be present and should commit to supporting the supervisor and mentor roles.
- HEE to work with employers and the GMC in their work to accredit Trusts as teaching organisations, and within this framework to explore how best to incorporate intuitive, qualitative feedback from informal mentors into formal appraisal.
- Following on from the above, HEE should initiate and lead a discussion on how, practically, we can build stricter requirements around the support for first experiences of death in collaboration with regulators of supervisory roles, training regulators and with employers.
- Ensure that the role of mentorship / teaching is adequately described in staff job descriptions with allowances for time involved for educational and clinical supervisors; employers must be accountable for enabling staff and trainees sufficient time for education and training.
- Identify and link existing EoLC champions across the country, ensure the EoLC champion role is re-commissioned and supported by LETBs as a well-defined, role for each region funded by HEE.
Online learning

- Clearly sign-post the collated learning tools on the EoLC hub that support role-specific, technical clinical skills, and cross-reference these with linked standards (CQC).
- Increase the visibility of e-ELCA by increasing the number of websites and on-line platforms it is hosted on in different settings, and by disseminating, across networks, a notification of version updates when available.
- Employers requiring their staff to use e-learning as part of their training and development should safe-guard time for this within working hours and ensure access to adequate resources (access to a computer) and should actively seek confirmation that, where required to undertake e-learning courses, staff are suitably supported in doing so.
- E-Learning is recognised as a commonly used tool for supporting education, but much of EoLC involves communication and ‘soft skills’ that require deeper, face-to-face learning to complement theoretical learning; HEE should link e-ELCA components that would benefit from expansion in an offline, face-to-face training with programmes that deepen the learning.

Between sector training:

- HEE should support integrated learning through encouraging programmes that bring different sectors together in a particular setting; work with CCGs, colleges and other key players to explore schemes designed to support integrated training in primary care.
- HEE to explore the role of hospices and third sector education providers in delivering cross-sector education.

In-situ learning

- Liaise with existing national providers to roll-out tools for ‘training the trainers’, designed to support in-house learning and ensure that these programmes are supported properly when the trained lead returns to their working environment.
- Liaise with trusts to support reflective learning as a mechanism for learning and education in situ.
- Commission LETBS to identify effective in-situ courses that would be suitable for environments that may struggle to deliver adequate EoLC where an intensive, ‘culture change’ is needed; ensure these courses meet curricula and regulatory standards. LETBs should support partner organisations with responsibility for improving failing environments by ensuring that funds and commissioned courses that work at this ‘culture change’ level are made available.
- HEE to explore tools that evaluate the translation of education and training to ‘on the ground’ practice (implementation and improvement science, linking with NHSIQ and Academic Health Science Networks, the Kings College research) and to
encourage adoption of these into programmes that involve a heavy investment of time.

- Review and streamline accreditation mechanisms across sectors to ensure clarity of understanding about which bodies accredit in which sectors (e.g., Royal College of Nursing has limited resources to accredit).
- Develop an audit tool to identify training and education needs based around CQC guidelines – this online resource to enable trusts/employer organisations to assess their workforce in advance of an inspection and put appropriate training/education measures in place.
Introduction

There are approximately half a million deaths in England each year, mostly in people aged over 75. For the majority of cases, these deaths can be anticipated: 30% of hospital patients in acute trusts die within 12 months, and many deaths follow a prolonged period of ill health from long-term ailments such as cancer, heart disease or dementia.

While palliative care is often equated with the last few days of life by generalists, planning in advance of this critical period can support consistent, high quality patient care throughout the final months of life. The ‘One Chance To Get It Right’ (OCTGIR) report, on which this work is based on, focuses on the final days of death, but supports a broader definition as given in their glossary (see callout box 1). This considers those approaching the end of life according to a series of factors, one of which is the likelihood of dying within 12 months. This broader timeframe widens the scope of what we conceptualise care and provides scope for advanced and personalised care planning.

Increasingly, surveys of patients, their families and carers tell us what is most important to those approaching the end of their life, informing our perception of what a ‘good death’ looks like. For most, freedom from pain, the care of close family or friends, familiar surroundings and being treated with respect are paramount. Training needs to focus on these critical areas.

While the majority of people would prefer to die at home (75%, although preferences change), in reality, factors such as marital status, access to palliative care and underlying condition are likely to determine the location of death. It is also the case that patient choice may be conflicted; for example, both pain relief and familiar surroundings are important to patients, but a national survey of the bereaved (VOICES) found significantly lower level pain management at home; this may compel patients into making a choice between their priorities.

In terms of where people die, hospital remains the most frequent place of death (48%, although proportionately this represents a slight decline in the last few years), followed by the patient’s home (22%) or a care home (22%) and hospice care at 6%.

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1. [Link](http://www.endolifecare-intelligence.org.uk/resources/publications/what_we_know_now_2014)
3. It is worth noting that although the focus of OCTGIR was on the last two weeks of life, the definition of EoLC promoted in the document is far broader.
4. [Link](http://www.endolifecare-intelligence.org.uk/resources/publications/what_we_know_now_2014)
5. NEoLCIN analysis of ONS Mortality data
determines the relative likelihood of death at home (more likely for men) or a care home (more likely for women).  

**Callout box 1: definitions of end of life and palliative care**

<table>
<thead>
<tr>
<th>End of life</th>
<th>Palliative Care</th>
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<tr>
<td>Patients are ‘approaching the end of life’ when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with: (a) advanced, progressive, incurable conditions (b) general frailty and co-existing conditions that mean they are expected to die within 12 months (c) existing conditions if they are at risk of dying from a sudden acute crisis in their condition (d) life-threatening acute conditions caused by sudden catastrophic events.</td>
<td>Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:  • provides relief from pain and other distressing symptoms; • affirms life and regards dying as a normal process; • intends neither to hasten or postpone death; • integrates the psychological and spiritual aspects of patient care; • offers a support system to help patients live as actively as possible until death; • offers a support system to help the family cope during the patient’s illness and in their own bereavement; • uses a team approach to address the needs of patients and their families; • enhances quality of life and may also positively influence the course of illness; • is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, and includes those investigations needed to better understand and manage clinical complications.</td>
</tr>
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6 NEoLCIN analysis of ONS Mortality data
Different settings incur different challenges and educational strategies must recognise that the learning needs of staff may vary even though the quality of care they deliver should not. Concerningly, the recent Health Select Committee Inquiry into EoLC found inequality in access, diagnosis and quality of care; it is this trend that necessitates consideration of how we can create a minimum standard of EoLC across settings. This is one of the objectives of this report.

“There are unacceptable levels of variation in the care that people receive and this needs to be addressed so that high quality end of life care is available to everyone regardless of their age, medical condition or where they live”
- Dr. Sarah Wollaston, MP
Chair’s comments, Health Select Committee Inquiry into EoLC published March

Health Education England (HEE) has a statutory remit to up-skill the health workforce and is responsible for carrying out the Secretary of State’s functions to secure an effective system for education and training. This role primarily involves providing a national lead on the planning and development, anticipating the changing needs of patients and local communities and ensuring a continuous supply of well-trained staff to deliver the service. At a national level, it ensures that the workforce has the right skills, behaviours and training, and is available in the right numbers, to support the delivery of excellent healthcare and health improvement. It allocates and accounts for National Health Service resources dedicated to education and training. HEE workforce plans are built upon the needs of the 13 Local Education and Training Boards (LETBs) which are employer-led, and informed by the professional expertise of their advisory groups including the Patient Advisory Forum and other stakeholders.

At a local level, each LETB analyses the demographic profile of the current NHS workforce using data from the Electronic Staff Record maintained by employers. This is supplemented by information available from a variety of sources, including but not limited to, information provided directly by other local employers or gathered by national partners such as Skills for Care. Forecast outturn from current education programmes are sourced from LETB-held datasets. LETBs use this data to forecast the available future supply and use these forecasts as the starting point for discussions leading to the development of a region-wide investment plan as part of their five year strategy. Following local ‘review and challenge’ processes engaging with commissioners and other stakeholders, each of the 13 LETB plans are then submitted to HEE nationally.

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7 Taken from the HEE remit and communication materials.
In the context of EoLC, HEE must also liaise with those setting undergraduate and pre-qualification courses, those delivering training courses in situ, and employers. HEE does not have a mandate to set curricula or to manage CPD, but it can liaise with the relevant partners who do to ensure a coherent strategy for education and training is delivered. Similarly, while the social care workforce is beyond the remit of HEE, there is a clear value in ensuring a consistent and complementary approach. In this, collaboration with the Social Care Institute for Excellence and Skills for Care is paramount.

The history of this specific report and piece of research is rooted in the work led by the Leadership Alliance for the Care of Dying People, a coalition of 21 national healthcare organisations, which collaborated throughout last year as part of the system wide response to the Liverpool Care Pathway Review. Their response was detailed in the "Once Chance to Get it Right" (OCTGIR) published in June 2014.  

Since the publication of this document, HEE (which was a member of the Alliance) made a series of commitments to be undertaken in support of the findings. In particular, HEE supports recommendation 35 that highlights the pressing need for more evidence-based education in all settings that care for those who are dying. Embedding End of Life Care priorities across the healthcare workforce was an objective for HEE in its 2014/15 mandate and this work continues as part of its 2015/16 mandated objective.

“HEE will continue to support End of Life Care by taking forward its actions detailed in the system-wide response One chance to get it right, in particular on developing and influencing education and training on care of the dying, and developing appropriate workforce planning to support good quality end of life care provision. HEE will also contribute to a one year on report scheduled for June 2015”
- Extract from HEE’s mandated objectives for 2015/6

Our report also draws heavily on the NHS England strategy for End of Life Care, and in particular supports the ethos that an increased focus on training generalist staff as well as specialists is needed. Also of particular concern were the observations of the Parliamentary and Health Service Ombudsman summarised in ‘Dying without

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10We refer to the Department of Health (2008) End of Life Care Strategy: Promoting High Quality Care for Adults at the End of their Life: London, DH. Department of Health (2009) End of Life Care Strategy: Quality Markers and Measures for End of Life Care: London DH. The responsibility for this strategy was transferred to NHS England in 2013
Dignity\textsuperscript{11} and the findings of the Health Select Committee Inquiry into EoLC, both published earlier this year.\textsuperscript{12}

However, given the breadth of available material and limited time, the focus of this report was to undertake a ‘deep dive’ exercise that prioritised the qualitative views of frontline staff and practitioners. Consequently, while we acknowledge the available formal research available our findings are largely informed by the voices of those working in End of Life Care and their experience of education and training.

\textbf{Callout box 2: ‘One Chance to Get it Right’, Recommendation 35}

\textit{Health Education England should pay particular attention to the pressing need for more evidence-based education in all settings that care for the dying in its work to improve workforce planning to ensure sufficient staff are trained with the right skills in the right locations to enable healthcare providers to deliver their commissioning plans.}

Our research sought to explore the efficacy of existing education and training resources, and the barriers and enablers to their uptake by the NHS workforce in England; based on the findings within, allowing HEE to frame the current state of play and propose a series of recommendations. During the months of April, May and June, we undertook five research streams (literature search, interviews with stakeholder organisations, a survey, focus groups and workshops) – a detailed breakdown of these activities is given in the Methods chapter.

From our findings, we were able to draw out eight different key themes that correspond to eight recommendations (see callout box 3). Each recommendation is associated with a body of evidence from our research, and a series of ‘sub-recommendations’, and the background thinking is given in more depth in each chapter of this report.

The aim of these recommendations is to improve the quality of care given to patients approaching the end of their life through support of the staff providing that care in the NHS.

This report has been based on the generous contributions of time and effort from over 1500 people. We would like to thank everyone who participated in any of our research streams, and acknowledge their contribution of the most precious resource of all: time. Our greatest regret in delivering this report is that it has not been


\textsuperscript{12} \url{http://www.parliament.uk/business/committees/committees-a-z/commons-select/health-committee/news/report-end-of-life-care/}
possible to include every suggestion and case study; some suggestions were beyond the remit of HEE, and brevity dictated that we were not able to include many ideas we personally found inspiring. We believe that the scale of what this report sets out to achieve was, at times, overwhelming, but we acknowledge with some humility the greater task of those working at the coalface of end of life care: their efforts, compassion and experiences have formed the basis of this report. We hope our recommendations and summary do justice to their contributions.

**Callout box 3: Summary of recommendations**

1. Extend the workforce for delivery of End of Life Care
2. Define, develop and disseminate information about the role of HEE and the LETBs
3. Develop relationships and strategic partnerships to support network building in End of Life Care
4. Create a hub for EoLC education and training resources
5. Improve awareness of and access to funding
6. Focus on communication skills as a universal skill underpinning EoLC
7. Create a baseline of EoLC tools
8. Support Blended Learning to deepen knowledge in EoLC
Methodology

HEE commissioned research support from The Democratic Society, whose role was to interview experts, facilitate focus group discussions and to conduct a desk-based research exercise into End of Life Care. This work culminated in a draft report and series of recommendations delivered to HEE in July 2015. HEE had oversight of the research methodology, guided the work closely and reviewed the recommendations.

Our overall aim was to explore what works, and doesn’t work, as regards effective education and training. If education and training are effective, a worker would have the knowledge and skills to be able to deliver high quality care were all other factors equal (which, we are aware, in real practice is not the case). This may be a clear definition, but it is not a single measurement or easy evaluation.

The first prerequisite for effective training is that it happens at all. We are seeking to identify if training and education (which we measure separately) are available to those delivering end of life care (our survey allows us to consider sectors and regions independently) and what the uptake is - are those delivering care supported (given time out of their duties) to actually go on the courses or take time to learn? These are metrics that we are getting from our questionnaire - in this respect, whether training/education is happening at all is a (relatively) straightforward element of efficacy to assess. The quantitative data is to be complemented by the anecdotal evidence we sought from our interviews, focus groups and workshops.

More problematic is the question of how effective training/education programmes are in supporting a person in delivering high quality care, as this requires us to define high quality care and also to consider a wide range of resources available.

Our working methodology was to learn from the breadth of expert knowledge available, recognising that valuable knowledge could be found across sectors, roles settings. We considered as many different forms of information as we could – from telephone interviews with experts to a review of current guidelines, from web-based identification of providers of national training to focus groups exploring specific questions. In particular, we used an iterative approach: we learned from previous strategies to develop new avenues of exploration, and we refined our research questions based on the feedback we received.

Initial parameters of this review
The parameters listed below were provided by HEE to the Democratic Society and served as a framework for inclusion in our research. The list was amended slightly in the course of the research to ensure inclusion of Allied Health Professionals. The scale of the endeavor lent itself more to identifying over-arching themes and general recommendations than specific ones given that the working experiences of those included in our research varied so greatly. What this broad approach did ensure was that a wide diversity of people were considered in our interviews, focus groups and workshops; participants were able to advise us about a wide range of issues. Given the breadth of material this yielded, it is highly pertinent that so many people shared the same frustrations and hopes.

Parameters of the research:

- Our focus is on the care (*generally described as palliative care*) received by people who are likely to die in the next 12 months, as well as care in the last days and hours of life.
- Education and training resources used by newly qualified and experienced NHS nurses, doctors and other NHS-employed staff (where relevant) working in primary, secondary, community and hospice care settings. HEE does not have a remit over the social care workforce, but does have a responsibility to provide a co-ordinated approach with Skills for Care when delivering education and training with a clear overlap. Allied Health Professionals should be included in the research.
- HEE does not have a remit over CPD for professional staff, but it does have the responsibility to work with employers to explore how CPD can be linked into the broader strategy.
- Consideration is given to the accessibility of resources include all types of accessible and published accredited e-learning/curriculum/guidance material, toolkits and bespoke training programmes which focus on upskilling NHS nurses, doctors and other NHS staff (where relevant) working in primary, secondary, community and hospice care settings to deliver high quality care. We generically refer to all staff delivering end of life care and employed (directly or indirectly) by NHS England as ‘practitioners’.
- Broadly, we interpret ‘education’ to mean formal learning based on a specific, taught course that leads to certification, a qualification or other, similar form of recognition; this can include online programs, theoretical and class-based work. We interpret ‘training’ to mean more practical, in situ learning that may be informal, placement-based or on the job mentoring. Both are important in developing skills.

**Literature report**
A literature review (summarised in appendix 1) revealed a significant bank of research that informed our thinking. However, our strong belief is that this database provides a basis (useful for this report) that needs to be extended. In particular, for completion, we would recommend a systematic review of academic research papers as well as a comprehensive audit from the LETBs of in-house reports that may provide valuable insight into local challenges. In this, HEE as a relatively new organisation should take the initiative to enrich its own understanding of the initial knowledge base we identify in this report, viewing the identification of new thinking as an ongoing task. The people we encountered were passionate and deeply committed to their work and are in themselves a valuable resource able to share wisdom; deepening relationships with experts will be critical for HEE to plan effectively and support the transfer of learning (both experiential and formally researched) to the workforces.

**Online survey**

Following our literature review, we initially drafted a survey\(^\text{13}\) to capture the training and education experiences of frontline staff. The survey was intended for use by any individual delivering End of Life Care working for NHS England. Following the survey launch, we encountered several difficulties that, in our view, limited the value of the information we received.

Primarily, the diversity of viewpoints we sought could not easily be reflected in question design; universal questions and nuanced screening proved challenging given that the survey was intended to work across LETB regions, different sectors and different environments. The changing landscape and diversity of education and training materials could not be incorporated adequately; it was difficult, and perhaps inappropriate, to capture information about specific outdated training (for example, regarding the Liverpool Care Pathway), which might be relevant to an individual’s personal learning history but not relevant to current practice.

Secondly, though as importantly, access to the networks of frontline staff was variable. The survey was disseminated by LETB leads for each region, but it transpired that many of the contacts HEE held at its central offices had moved on, and it took some time to ensure that the survey reached the correct contacts. We had a final respondent number of 1894 – of whom 82.58 % (1, 564 respondents) considered themselves to deliver end of life care, and not all questions were answered. While this is not an inconsiderable number per se, for meaningful analysis we would need to consider replies in terms of subsets. For example, tables 1 and 2 show the breakdown according to working environment and years of qualification:

\(^{13}\) The survey was constructed using [www.surveymonkey.com](http://www.surveymonkey.com).
these groups have very different working experiences, and factoring in regional diversity (table 3), our ‘n’ for the various subset combinations becomes very low and in some cases we have needed to remove groups due to their low response rate. We believe that the survey cannot be considered truly representative of the training and educational experiences across the nation. For this reason, we have used data sparingly and only to quantify learning from other sources.

**Table 1: How long have you been qualified for?**

<table>
<thead>
<tr>
<th>Number of respondents</th>
<th>Percentage of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Over 10 years ago</td>
<td>955</td>
</tr>
<tr>
<td>Between 5 and 10 years ago</td>
<td>168</td>
</tr>
<tr>
<td>Between 1 and 5 years ago</td>
<td>145</td>
</tr>
<tr>
<td>Between 6 months and 1 year ago</td>
<td>19</td>
</tr>
<tr>
<td>Less than 6 months ago</td>
<td>4</td>
</tr>
<tr>
<td>No answer</td>
<td>3</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>1294</strong></td>
</tr>
</tbody>
</table>

**Table 2: Where do you usually work?**

<table>
<thead>
<tr>
<th>Where do you usually work?</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital</td>
<td>618</td>
</tr>
<tr>
<td>Hospice</td>
<td>280</td>
</tr>
<tr>
<td>Community</td>
<td>401</td>
</tr>
<tr>
<td>General practice</td>
<td>53</td>
</tr>
<tr>
<td>Social care setting</td>
<td>35</td>
</tr>
<tr>
<td>No answer</td>
<td>119</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>1506</strong></td>
</tr>
</tbody>
</table>

The feedback we received from LETB leads is that, while some individuals have strong personal networks that enabled them to reach frontline staff, others were unable to forward the survey on to those delivering End of Life Care. Consequently, some regions, such as Yorkshire and the Humber yielded 120 responses (14.11% of the total), whereas others, such as Wessex, reached only 6 (see table 3). In the course of our research, we continued to disseminate the link to the survey to a wider network of experts, practitioners and organisations, and we pushed back the
deadline for survey closure three times. Despite this, as timelines contracted, some people received the link only a few days before the deadline of 20.05.15.

Table 3: Distribution of responses by LETB region

<table>
<thead>
<tr>
<th>Region</th>
<th>Percentage</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>East Midlands</td>
<td>7.46%</td>
<td>111</td>
</tr>
<tr>
<td>East of England</td>
<td>10.22%</td>
<td>152</td>
</tr>
<tr>
<td>Yorkshire and the Humber</td>
<td>14.11%</td>
<td>210</td>
</tr>
<tr>
<td>Wessex</td>
<td>0.40%</td>
<td>6</td>
</tr>
<tr>
<td>Thames Valley</td>
<td>9.21%</td>
<td>137</td>
</tr>
<tr>
<td>North West London</td>
<td>0.54%</td>
<td>8</td>
</tr>
<tr>
<td>South London</td>
<td>1.55%</td>
<td>23</td>
</tr>
<tr>
<td>North Central and East London</td>
<td>1.21%</td>
<td>18</td>
</tr>
<tr>
<td>Kent, Surrey and Sussex</td>
<td>4.97%</td>
<td>74</td>
</tr>
<tr>
<td>North East</td>
<td>3.70%</td>
<td>55</td>
</tr>
<tr>
<td>North West</td>
<td>25.00%</td>
<td>372</td>
</tr>
<tr>
<td>West Midlands</td>
<td>5.91%</td>
<td>88</td>
</tr>
<tr>
<td>South West</td>
<td>15.73%</td>
<td>234</td>
</tr>
<tr>
<td>None of the above (written answer)</td>
<td></td>
<td>13</td>
</tr>
<tr>
<td>None of the above (no answer)</td>
<td></td>
<td>5</td>
</tr>
</tbody>
</table>

answered question | 1488
answered question (including written in) | 1501
skipped question | 5

Total | 1506

While the survey did not provide the information hoped for, the challenges incurred in its distribution, terminology and structure still provide some learning points; notably, we recognise that communication channels between HEE central and the
LETBs in EoLC may need strengthening and this issue was also reported through our interviews.

We learned also that the terminology used by HEE was not comprehensible to many of our survey participants: would a community nurse caring for a wide range of patients which include a minority of terminally ill patients recognise herself as delivering ‘End of Life Care’, or would she see this as a speciality outside of her usual remit? Would a palliative care team recognise the LETB designated region of ‘Wessex’? Finally, several workshop participants observed that key groups were excluded. These included pre-registration nurses and doctors, the allied health professional network and the survey was not disseminated widely in the social care network; in this last example, the reason was that social care is outside of HEE’s remit for training and education, though we acknowledge that the data would have been useful to share with colleagues and to deepen our own understanding.

The relationship between the social care network and the health care network was a key issue in our research. Many participants believed that HEE should have taken greater steps to include more voices from the social care network, and were under the impression that HEE held responsibility for delivering training and education to the social care workforce. HEE may need to clarify the relationship between itself and two key partners, Skills for Care and Skills for Health.

**Focus groups and telephone interviews**

A series of four focus groups held in the North-East, the North-West, the Midlands and Thames Valley yielded richer conversations and input from 50 attendees; we had originally planned a wider spread of focus groups taking place across the regions, but we received strong feedback that staff found it difficult to take the time out of their schedules to participate. We also noted that staff needed a minimum of 6 weeks’ notice to reschedule their workloads to participate; given HEE’s timelines, it was not always possible to provide this. Given how important it is for HEE to ensure that the views of frontline staff are included, we cancelled under-subscribed focus groups and replaced them with telephone interviews.

Health and social care professionals (the latter being a smaller group) from primary, secondary, community, social care, and hospice settings participated in the focus groups and telephone interviews. Expanding the hours allotted for our telephone interview strategy enabled us to reach a wide number of practitioners, and to conduct deeper, more intensive conversations with them. Each interview took between 30 minutes and an hour. In some cases, where it was not possible for a person to come to the phone but where they were keen to input their thoughts, we invited email responses.
For our focus groups and telephone interviews, we had a series of questions that we used to stimulate discussion (see callout box 4). However, the brief given to all facilitators was to not to follow these rigidly, but to be flexible in their use, allowing people to speak about what they personally believed to be the most important issues. In this way, we were able to refine future ‘follow-on’ questions and identify frequently cited issues that translated into themes for the report. Our facilitators did, however, ensure that conversation was focused around areas where HEE has a remit for intervention rather than on the more general circumstances of end of life care delivery in the NHS.

**Callout box 4: focus group questions**

**Warm up question:**
1. What do you think is the most important aspect of End of Life Care training?

**Prompt questions:**
2. How effective do you find the current education and training resources [for End of Life Care]
   a. for trainees? [can’t ask unless people have experienced this]
   b. for experienced staff?
3. How accessible do you feel existing education and training materials are to the health workforce?
4. If members of the group are involved in planning and delivery of training: How do you find the current practice for planning and implementing the resources into education and training methods and programmes?
5. Do you think that there are any systemic barriers to embedding education and training resources across the curriculum in a more streamlined way?
6. What do you think are the most effective ways of embedding end of life care education and training into the system so it can improve the competency levels of healthcare professionals in the field? How can this be improved?
7. How much do education and training resources support better quality of care for the dying?

**Sum up question:**
7. What do you think is the most important thing we should take away from this conversation?
While we were running our focus groups and frontline staff interviews, we also ran a series of interviews with representatives of stakeholder organisations. These were identified by HEE, with interviews conducted by the Democratic Society. In some cases, these interviews identified new organisations or individuals to include in the work. In each case, we used similar opening questions to those developed for our focus groups, but largely found that our interviewees soon raised the issues that they personally considered important, and from these topics, we were able to receive a much richer input of ideas than if we had steered the conversation more rigidly.

We use direct quotes throughout the report, but, as promised to all our participants, we have anonymised contributions and also all contributors. This was done to ensure that people felt able in speaking freely.

**Workshops**

We held two workshops, one in Leeds and one in London, to bring together the research and seek feedback from a series of invited experts. In these workshops, we refined our original research questions with the themes we had identified in our focus groups, telephone interviews and survey information, to generate three simple questions (see callout box 5). These formed the basis of three round-table discussions.

Attendees were initially shown some of the findings from the survey, stakeholder interviews and focus groups by the Democratic Society. These bullet points (shown in table 4) were those raised most consistently, intended for the consideration of attendees rather than a report of the full (and far more comprehensive) list. Attendees were also given an introduction to the work and remit of HEE by Ms. Samina Malik, which helped to clarify what kinds of recommendations HEE would, realistically, be able to implement. In the light of these presentations, and using the three final questions, they were split into smaller groups to explore how these themes could be explored at a deeper level and what recommendations could be drafted in response.

We spoke with representatives from many critical or ganisations, including but not limited to: HEE LETBs, the RCP, RCGP and RCN, NCPC, CQC, NHS Employers, the GMC, NHS IQ, NHS England, ADASS and the Council of Deans.
Callout box 5: iterative development of research questions

Phase 1:

- How effective are existing education and training resources on End of Life Care for both trainee and experienced staff?
- How accessible are existing education and training material to the health workforce?
- What does current practice look like in the planning and implementation of resources into education and training methods and programmes?
- What are the systemic barriers to embedding education and training resources across curricula in a more streamlined way?
- Which system levers are most effective in embedding education and training to improve the competency levels of healthcare professionals delivering high quality care for the dying and how these levers can be improved?
- How much do education and training resources improve and sustain quality of care for the dying?
- What can HEE do to support education and training initiatives for frontline staff?
- What are current practices in the planning and implementation of resources into education and training methods and programmes?
- To what extent do education and training resources, methods and programmes improve and sustain quality of care for the dying?

Phase 2:

- Education and training correspond to two different learning needs: how can we build and strengthen opportunities for both?
- Collaborative working: training across sectors improves working relationships - how can we build these opportunities into existing programmes?
- Navigating a crammed space: how can we share best practice?
- Are commissioners fully aware of all the funding and support they are eligible to receive from HEE?
- How can we support our employers, commissioners and networks to make sure the process works?
- There is a great deal of diversity in practice - how can we respect different working environments but create a working ‘baseline’ of quality?

Phase 3:

- Looking at the existing pathway of learning for nurses, doctors and AHP, where are our opportunities to teach End of Life Care?
- Defining quality in education/training – how can we make sure courses/tools cover the right content?
- How do we know something is working?
Table 4: Slide material shown at workshops for consideration:

<table>
<thead>
<tr>
<th>Points raised during focus groups</th>
<th>Points raised during stakeholder interviews</th>
</tr>
</thead>
<tbody>
<tr>
<td>• EoLC - core care skills (planning, teamwork, communications, person centered)</td>
<td>• Wide diversity of current practice</td>
</tr>
<tr>
<td>• Education and training journey for all staff</td>
<td>• Confusion regarding process, networks and funding</td>
</tr>
<tr>
<td>• Education and training for practice change and assessing that</td>
<td>• Few mandates / formal requirements for EoLC at any stage</td>
</tr>
<tr>
<td>• Consistency and standards vs flexibility and locally tailored delivery</td>
<td>• Service is stretched: difficult to release staff</td>
</tr>
<tr>
<td>• Cross disciplinary vs role based training</td>
<td>• Assumption that staff will ‘learn in their own time’</td>
</tr>
<tr>
<td>• Methods: blended (e-learning, face to face, on the job,)</td>
<td>• Supervised practice year(s) - more scope here?</td>
</tr>
<tr>
<td>• Barriers: funding, time, low priority, variety of providers</td>
<td>• Some excellent programmes designed, but these are not always visible</td>
</tr>
<tr>
<td>• Enablers: CQC/ assessment, role models/ leadership, CPD</td>
<td>• Opportunity for across-sector learning to support collaborative practice</td>
</tr>
<tr>
<td></td>
<td>• Core communication skills for EoLC are valuable throughout practice</td>
</tr>
<tr>
<td></td>
<td>• Placements in other contexts (hospice, community, hospital) valuable</td>
</tr>
<tr>
<td></td>
<td>• Assessment is difficult: peer-to-peer may be the answer?</td>
</tr>
</tbody>
</table>

Case studies

During the course of our interviews, workshops and web-based research, we identified examples of practice that we believed would illustrate the key themes we explore in the report. A series of targeted emails sent to networked contacts enabled us to extend these examples into a series of case studies. These case studies are illustrative only, and in no way represent the depth of available information – time constraints and project scope limited us from a comprehensive review of all the material. What was clear to us is that excellent practice, innovative ideas and transferable working are widely available; HEE has a role in bringing these positive stories to light and ensuring they are shared.

Research limitations

We have raised and explored some of the specific limitations appertaining to the survey and focus groups in the relevant sections. A strength of our iterative
methodology was that we were, to some extent, able to learn from and account for these in our final analysis. However, as is often the case in policy-work, timelines were tight and this prohibited a more extensive review of organisations and meetings. Inevitably, many ideas, thoughts and suggestions were beyond the remit of HEE to action through recommendation, because they fell under the purview of different organisations.

These were omitted from the final report, but the thinking has not been lost: the extensive material collated is available to HEE and, as our organisation strengthens its relationships with stakeholders, ALBs and strategic partners, we hope through conversation and influence we will be able to share the insights of our research participants more widely. Finally, although on the same vein, the report is itself of a prescribed length: given an approximate scope of 150 pages, much material has been omitted. What remains are the ideas that were consistently cited, and which fall within the scope of HEE to deliver.
Recommendations
Recommendation 1:

Extend the workforce for delivery of End of Life Care

“End of Life is everyone’s business. We need it at every level”

- Participant at the London workshop

Workforce planning is at the heart of HEE’s work and inherently challenging: with 300 different roles, over 1,000 employers, 1 million staff and 160,000 students\(^\text{14}\) strategic planning to ensure that those employed in the NHS are adequately trained is a complex process. Our first recommendation explores how HEE should ensure that sufficient nurses, doctors and allied health professionals (referred to in combination as ‘practitioners’ in this report) are available and able to care for the dying.

National recommendations, including the research of the NCPC, call for provision of 24/7 coverage in EoLC\(^\text{15}\) – however, according to a national audit of hospitals undertaken by the Royal College of Physicians (2014), only 21% of hospitals currently offer face-to-face access to specialist palliative care services seven days a week.

More generally, there are approximately 110,000 people across the UK who would benefit from palliative care but do not receive it\(^\text{16}\). While most patients prefer to die at home supported by community services, in reality, the majority die in hospital\(^\text{17}\).

For some, the lack of a particular aspect of care, for example, adequate pain relief, may steer their decision. Currently observed service gaps can be linked to under-provision in EoLC\(^\text{18}\). Given an aging demographic profile in the UK, which is likely to increase, the demands placed on the service, active steps need to be taken if this shortfall is to be addressed.

Extending the workforce for delivery of End of Life Care (EoLC) was a consistent request from participants in our focus groups, workshops and interviews. This recommendation can be interpreted in two ways: first, an increase in the number of staff per se delivering specialist palliative care.

\(^{14}\) http://hee.nhs.uk/about/
\(^{17}\) http://www.endoflifecare-intelligence.org.uk/resources/publications/what_we_know_now_2014
The second approach is to ensure that generalists from across the workforces are able to deliver EoLC to a level commensurate with their role, but also meeting a basic minimum standard that is universal across the service. The implications of this for workforce planning cannot be overstated: potentially, every single doctor, nurse, many social care workers and many allied health professionals will encounter a dying person in the course of their working life. Each needs the basic training that will enable them to provide appropriate care.

We make our sub-recommendations with reference to the respective healthcare workforces in terms of the different levels of day-to-day exposure to EoLC; this determines an individual’s baseline of knowledge and learning needs. Figure 1 below is taken from the 2008 National EoLC Strategy.

Figure 1: Stratification of staff involved in care of the dying

Increased recruitment of staff

At the top of this pyramid, we are facing a specialist palliative workforce with low numbers: fo414 consultants in specialist palliative medicine were identified in 2012 in England, 502 throughout the UK; 48% of these worked part-time, and it is predicted that we will see a relative decline in the staff:patient ratio in the future. Anecdotally, we heard from the majority of participants that numbers of specialist palliative nurses and allied health professionals with expert knowledge in palliative services are limited, and there is a risk that, due to the demography of this part of the workforce, generational retirement may have a devastating impact.

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Pressure points for specialist staffing are localised: hence, national data may give a misleading impression and specific, metric feedback from the LETBs is needed to identify areas of current need and predict future need. Local strategies should provide incentives for trainees to specialise in EoLC and/or should explore opportunities for existing, generalist staff to retrain in EoLC. This will require HEE to secure and prioritise funding for areas with an acute workforce shortage.

Investing in the education and training of staff at level B (those with considerable exposure and time spent in EoLC) may support service delivery and ease the pressure on specialists. This learning investment yields a particularly strong return in skill, as training is reinforced through the working environment. Ideally, staff from a generalist background may, through commissioned training opportunities, be incentivised to acquire specialist knowledge in EoLC.

Staff shortages, issues of recruitment and poor staff retention were frequently reported and put pressure on existing teams. Increasing staffing levels per se may be beyond the remit of this particular report, but in deference to the feedback we received from participants, we note that training cannot be divorced from the context in which it occurs: time pressures incurred through staff shortages and the resultant need to safeguard service delivery undermines both formal education and informal training opportunities (such as mentoring). Time pressures also impact on the way learning translates to care: an individual may have learned skills around personal care planning (for example), but may have insufficient time to implement that knowledge. More frontline staff may reduce pressures on existing teams and create an environment more conducive to learning and delivery.

**Upskilling generalists in palliative care**

("Dying is part of caring... should the philosophy be more about putting back that it's everyone’s responsibility for EoLC and should we put it back as a core skill in training?"

– Workshop participant

As stated in the introduction, our definition of EoL is framed by time, qualified in practice by asking practitioners to consider whether they would ‘be surprised if a patient were to die in the next 12 months’. This question, and the philosophy behind it, is used to navigate the uncertainty of knowing patient outcomes; practitioners conceptualise EoLC to include all those who might need it without seeking absolute diagnoses. This increases the number of patients who may be considered to need EoLC, and consequently impacts on the generalists (or specialists outside of palliative care) who provide care for them.
Training generalists in EoLC is critical for holistic assessments and personalised care planning. It also builds complementarity into treatments intended to reverse a given condition while acknowledging that these may prove unsuccessful.

A sensitive dilemma for all practitioners is the fact that outcomes are difficult to predict and a definitive prognosis of the time and circumstances of death may not be possible or even appropriate for every patient. This ambiguity requires adaptation of treatment and care to changing and unpredictable circumstances. In this respect, each situation and patient is unique, creating an obligation for care that addresses the patient’s wishes and best interests. Some fields of medicine benefit from a systematised approach and standardised care; what is certain from our research is that this is not the right approach for a dying patient. Consequently, HEE’s approach to education and training for generalists should reflect this, and be orientated to flexible principles rather than prescriptive practice. This philosophy is difficult to implement, as the onus is on employers and education providers to support and teach qualitative skills deeply and robustly enough that they are of genuine use to a practitioner who may face many different circumstances in the course of their work.

“Palliative care can be provided by a range of health and social care staff and may be done alongside treatment intended to reverse particular conditions”

- World Health Organisation

In this undertaking, HEE are helped by cases of outstanding practice. In a climate where it is understandably important to be aware of negative stories, this report seeks to provide balance by highlighting excellent examples that can be used to support education and training. Here, we are conscious that our case studies are not comprehensive, and later on in the report (see recommendation 4) we advocate a more thorough identification of good practice. It is, from our research, noteworthy that the best outcomes for patients appear to be delivered where relationships are strong between different sectors and settings, and where integrated workforces come together. We note also the contribution that enlightened Trusts, dedicated LETBs and skilled trainers bring.

In considering EoLC as ‘a skill for all’, it is clearly important to explore the level needed relative to any particular role. We understand that training can be burdensome rather than supportive if there is a mismatch between the knowledge imparted and the role of the recipient.

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Specific groups to be incorporated in workforce planning and targeted training

In the course of our discussions with staff, several groups within healthcare were singled out as needing particular support in developing EoLC skills; these were groups who may have been neglected in training strategies, and who should be considered more thoroughly in workforce planning. This is an area to discuss with LETBs on a regional basis, but a summary of the feedback we received is shown on the next page.

“...End of life care was not seen as the sole responsibility of the Specialist Palliative Care Teams (SPC’s) but considered as an integrated service, for which every member of staff was responsible for”

- Extract from a collation of CQC report comments about hospitals delivering outstanding EoLC
Callout box 6: Particular areas of focus for workforce training

- Those who have come to a specialist palliative care role via another specialty: an individual may ‘grow’ into a specialist role through in-house, informal routes – this is particularly true of the AHP sector and nursing sector, where staff shortages and recruitment barriers may require re-training an applicant to a palliative role if no-one with the requisite specialist background is available. This is an important consideration for training, as in effect HEE may need to consider a ‘conversion’ process to meet workforce needs.

- Intensive Care and Acute Situations: Despite the fact that many patients die in the acute setting, EoLC was cited as being particularly difficult to implement here, as the expectation, hope and culture of acute medicine is to save lives. The time frames of acute medicine do not always support personalised care planning given the intensity and pace of the environment. However, upskilling those working in acute medicine to be comfortable with EoL conversations and skills will have a valuable impact.

- General Practice: Given that the majority of deaths do not occur in the community, EoLC is an area that may feel peripheral to a GP’s individual experience unless they have a personal interest. Anecdotally, we heard that encouraging GPs to engage with EoLC training is challenging even where incentives are provided.

- Children’s Care: Many generalists do not see children dying, and many do not feel comfortable thinking or talking about child mortality. This has caused a shortage in the workforce, particularly in paediatric nursing. Ensuring that a wider number of clinicians are able to treat a dying child, and are also able to cope with the emotional consequences, is critical if we are to ensure this age group is not neglected. The role of Children’s Hospices as providing education and insight here may be relevant.

- Carers: Frequent concerns were raised about unregistered staff in care homes. While it is beyond the remit of HEE to steer education and training for the social care workforce, HEE can support education and training for community-based health workforce to work alongside practitioners from social care. Training staff to deliver a joined-up service should support patients should they wish to die at home. The role of unpaid carers, family and community was also raised; HEE has a role in public education and self-care, and to a limited extent may be able to act as a vehicle for providing information about dying. HEE should also support initiatives such as ‘Dying Matters’ that seek to broaden public awareness.

- Other groups that may require greater inclusion:
  - Paramedics
  - Educators and mentors
  - District nurses
  - Consultants who are not palliative care specialists still need EoLC, even if they perceive EoL to be very peripheral in their work: for example, gynaecologists. Engagement in EoLC between different specialisations is significant – EoLC training in cardiology, for example, was cited as a neglected element of the curriculum. This may be mostly historical, based around how different specialities have grown within the NHS framework.
Recommendation 2:

Define, develop and disseminate information about the role of HEE and the LETBs

In our interviews, substantial confusion existed about HEE’s role. This, we believe, is a consequence of history: HEE is a relatively new organisation within the NHS framework (established in April 2013) arising from sequences of service restructure. One repercussion of frequent upheaval has been to disrupt long-standing relationships, another has been the creation of new roles and lines of responsibility that are still incompletely understood.

While most of our study participants knew that HEE delivers training and education, the practicalities of how this translates into practical tasks was less understood. In particular, the boundaries of responsibility between HEE and its strategic partners were considered blurred. For example: the demarcation of responsibility between HEE, Skills for Health and Skills for Care is often unclear. Education providers had, in some regions, been incorrectly informed that their courses could not be commissioned due to restrictions in HEE funding. Some participants wanted to know the extent to which HEE is able to influence Higher Education Institutes (HEI), on the basis that the way the current curriculum is interpreted is a clear avenue for improving education.

There are three potential consequences of this lack of clarity:

1. HEE may be excluded from key discussions because organisations do not perceive the value of HEE as a contributor to strategic debate. For an organisation whose strategic aspirations must often be mediated by other bodies, the importance of influence and strong relationships is critical.

2. Misperceptions about the mechanisms of funding and processes of education delivery in EoLC undermine potential partnerships; cross-sector, cross-environment and cross-regional projects are limited by misunderstandings.

3. Given the multiplicity of organisations with a role in the delivery of education and training, we acknowledge a clear need for leadership, and the need for HEE to develop a stronger role in bringing together the different players.

Recommendation 3 explores how proactive networking and improved relationships will be vital for HEE to define its role, but a prerequisite for this is a clear communication as to what that role is.

The current materials for explaining the role of HEE are provided at the end of this chapter, and may serve as an initial point of clarification to those reading this report.
We believe that there is a value in simplifying this into a 1-2 page primer that details where the boundaries of responsibility lie between organisations responsible for education and training in EoLC. The primer could also be adapted give the named contact leads for EoLC at the national and local organisational levels, and could be disseminated via the LETB networks.

**Stronger leadership**

Participants in our research spoke of a need for leadership in education and training. When we explored what this involves in practice, leadership was interpreted as: holding together the different roles undertaken by the various ALBs, regulatory bodies and partnerships through extensive networking; ensuring that organisations are following the same direction; owning and having oversight of the plethora of tasks learning initiatives to avoid duplicated work; strongly directing the implementation of policy; using relationships and influence to direct shared goals rather than imposing ‘blunt tools’ of tick box action and, finally, leadership involves engaging at the coal-face of delivery whilst also retaining the overall picture.

Leadership must also mediate between the dictates of political directives and the fundamental needs of the clinical and health workforces delivering care. At its most basic level, leadership is inherently personal, requiring individuals to step forward and ‘do whatever needs to be done’. In the absence of leadership, tasks are at risk of duplication or falling through the gaps. We received positive feedback about individual ‘leaders’ in the LETBs, and at HEE: the general message was to increase and share leadership skills across the board.

**Clarifying the role of the LETBs**

LETBs operate very differently according to region in End of Life Care. To some extent, this variation results from historical practices and also from the diversification necessary to meet the specific needs of each region. Yet inevitably there is a balance to be found between responding to regional variation and delivering core function; our findings suggest that, presently, too much diversity in practice has created a ‘postcode lottery’ in EoLC. Some LETB leads suggested that a clarifying discussion of their role would be helpful. This would define a few baseline expectations for EoLC that all LETBs are expected to deliver, whilst still allowing leeway to respond to local needs.

In considering how this recommendation may best be addressed, we are mindful of the dangers inherent in producing standardised requirements that can, in the context of a busy and stretched remit, lose the original intention. Instead, our suggestion is that clarification of the LETB role in EoLC should be facilitated as a
collaborative exercise, bringing together representatives from each LETB region in a collective group. To this end, we suggest that LETB leads play an active role in designing an agenda and activities. The day could culminate in a simple statement describing a series of practical tasks that LETBs perform in EoLC to deliver their agreed role or it could be a less formal, verbal knowledge-sharing exercise or it could generate a living, shared toolkit that can be revised and used however is most useful to participants.

Following on from this, where LETBs are asked to modify or extend their deliverables in EoLC, they should work in partnership with HEE to identify and overcome any barriers to this. HEE should have a responsibility to support the LETBs in their role: for example, some LETB leads identified a need for HEE to tighten communication around funding, provide more notice of events and to support, as appropriate, introductions to contacts where known (addressed in recommendation 5). Bringing LETB leads together may yield further, practical steps HEE could take to improve relationships and underpin the fulfillment of LETB core responsibilities.

The LETBs have already been commissioned via the Directors of Education and Quality DEQs) to feedback their interpretation of ‘One Chance to Get it Right’, but the final analysis of this observed a lack of “quality metrics” that show the link between spending and outcome; the development of an HEE peer network with representatives from each LETB was cited as a key action to develop greater accountability and strong governance in ensuring that the EoLC budget is being directed appropriately at the local level.
During 2013 the NHS transitioned to new structures, including the creation of HEE as the first single national body to lead and co-ordinate investment in the development of the healthcare workforce. The Care Act 2014 established HEE as a non-departmental public body from 1 April 2015 and sets out the functions and constitution of Health Education England and those of its thirteen Local Education and Training Boards.

Purpose of HEE

Health Education England (HEE) exists for one reason only: to help improve the quality of health and healthcare for the patients and public of England by ensuring the workforce of today and tomorrow has the right numbers, skills, values and behaviours, at the right time and in the right place. It receives an allocation of nearly £5bn for investment in the current and future workforce.

Local Education and Training Boards (LETBs) are the regional presence of HEE and have devolved budgets. They lead workforce planning and education commissioning, on behalf of all providers of NHS funded care, within a local geographically defined area; ensuring security of supply of the local health and care workforce and supporting national workforce priorities set by HEE.

Overview of HEE

HEE works with key partners including other arm’s length bodies, higher education institutions, regulators, professional bodies and the Department of Health. HEE’s 13 Local Education and Training Boards (LETBs) include membership of local employers, providers, commissioners, universities, local authorities, patients and other stakeholders responsible for supporting local workforce planning and commissioning of education.

HEE commissions 130 education and training programmes for around 140,000 students at any one time for 110 different roles through contracts with nearly 100 universities. These trainees eventually work in more than 1,000 different health and healthcare organisations across the public, private and voluntary sectors. The vast majority of HEE’s allocation is spent on undergraduate and postgraduate education, clinical placements, bursaries, workforce transformation projects locally and nationally, including those in the HEE Mandate, and paying the salaries of junior doctors. These commissions are set out in our annual Workforce Plan for England, which, along with the Mandate from Government that sets out in-year priorities, form HEE’s work programme. Further information about the Workforce Plan; Mandate and Business Plan can be found at www.hee.nhs.uk.
Continuing Professional Development (CPD) for NHS staff is the primary responsibility of service providers as employers whose duty to provide all staff with personal development, access to appropriate education and training for their jobs, and line management support to enable them to fulfil their potential is set out in the NHS Constitution. HEE sees its role as developing the skills and behaviours of both the current and the future workforce within the resources available, as demonstrated by our proposal to invest in dementia awareness training. A number of LETBs have also prioritised CPD within their 5-year Workforce Skills Development Strategies.

**Workforce Planning**

The annual workforce planning process is a combination of extensive local planning and engagement coupled with national modelling, oversight and engagement with national stakeholders. The role of HEE nationally in regard to workforce planning is three-fold:

- to assure ourselves that a robust local process has taken place
- to ensure that the aggregate position of the 13 LETB plans enable us to deliver our mandate by triangulating it with other evidence
- to lead on a small number of workforce areas where it makes sense to plan nationally.

At a local level each NHS employer produces their assessment of their future needs. Employers and commissioners are responsible for defining service models and thereby identifying current and future workforce requirements (and for ensuring jobs are available for the staff we train); and managing staff retention, recruitment, deployment.

LETBs use these forecasts as the basis of a region wide investment plan as part of their five year strategy. Following local ‘review and challenge’ processes engaging with commissioners and other stakeholders, each of the 13 LETB plans are then submitted to HEE nationally. HEE requires forecasts to include active input from commissioners and link to national strategy and policy to help ensure broad consensus for HEE investment on the systems behalf.

This process produces the ‘Workforce Plan for England’ each December containing the investment and commissioning plans for the following year. The plan provides a transparent statement of the decisions made and the analysis/rationale on which they have been made.
Figure 2: Workforce Planning Process
Recommendation 3:

Develop relationships and strategic partnerships to support network building in End of Life Care

As stated in Recommendation 2, understanding the connections between key organisations in End of Life Care is not always easy; groups co-exist within a complicated framework in a context of political change - agencies theoretically working in partnership find it difficult to collaborate in practice as historical channels of communication break down and ‘tribal knowledge’ is not safeguarded. The simple consequence of a complex situation is that learning may be lost.

Discussions over the fate of NHS IQ revealed concerns that positive resources should remain ‘findable’. Similarly, the much-lauded National End of Life Care Intelligence Network\(^{21}\) provides valuable information, and ensuring its preservation in one form or another throughout future reforms is critical. Our interviews revealed a strong concern that a wealth of valuable education and training materials in End of Life Care is of limited use as it is poorly disseminated, not maintained and/or infrequently updated. Many participants in our research expressed a hope that HEE can develop its role as protector and custodian of such materials and support the various organisations developing these materials.

For HEE to fulfill this element of its remit, improved communication is a vital prerequisite for two reasons: first, HEE needs to be aware of what is ‘out there’ – while appendix 1 provides a basis for this, a more comprehensive, ongoing exercise is needed as new research continually revitalises the knowledge base. Second, perhaps the greatest resource in the EoLC sector is the wisdom and experience of those working within it; insights gained informally through these relationships allow a rich understanding of education and training. Through its partnerships, HEE can identify materials to share openly, but can also develop a more philosophical understanding of the principles at the heart of delivering good care, which may require less formal, more experiential learning.

Relationships can be strengthened across three levels in EoLC:

1. Between HEE and other national organisations (national networking)
2. Between the LETBs and local equivalents (local networking)
3. Between HEE and the LETBs (creating links between the national and local networks).

\(^{21}\) [http://www.endoflifecare-intelligence.org.uk/home](http://www.endoflifecare-intelligence.org.uk/home)
An ideal ‘final result’ would be for the LETB leads for EoLC to act as strong local hubs for EoL networks, and that each of these local hubs should have a clear link to each other and to HEE through which resources can be shared. These networks could support employer organisations, education deliverers and service providers, as well as nurturing productive academic links. The Skills for Care networks currently liaise locally and tie into a national network as well, as does Skills for Health; these two organisations provide an exemplar, and could work collaboratively with HEE to mirror network frameworks across sectors.

National networking

The recommendation here is a prerequisite for subsequent ones. To achieve it, this report suggests an initial audit of existing contact information at HEE to ensure it is up to date, comprehensive and specific to EoLC. A systematic review of all existing, national EoLC networks should be conducted to ensure that the database of contacts and networks is comprehensive. This could include greater use of academic and clinical networks. Where gaps are identified, HEE should take the initiative to open communication channels.

All contacts should be stored in a comprehensive database or similar tool with a named HEE lead(s) / adequate staff resourcing and support to manage the network. LETB leads should also have access to this national network database. Clearly defined roles and responsibilities are needed within the EoLC team at HEE, and one of these roles should be to orchestrate regular contact with key stakeholder organisations. In this respect, HEE should practice a ‘networking the networks’ approach – that is, the EoLC lead at HEE should join existing networks and create, if needed, links between these.

Once HEE has undertaken this mapping exercise and established a robust portfolio of relationships, a proactive exploration of current key developments, projects and initiatives ongoing in the sector at each contact organisation is needed. An evaluation of whether HEE needs to be aware of, or actively contributing to these initiatives should be made by the EoLC lead at HEE. Conversations that are not specific to EoLC but which will have a profound influence (such as current changes to the medical curricula) already have input from HEE representatives, but not necessarily those with a specific interest in EoLC; the EoLC lead needs to co-ordinate internally at HEE to ensure that EoLC policy is represented and that the developments are fed back.

As far as possible given resources, this report recommends that HEE should join the regular meetings of partner organisations discussing EoLC. Ensuring excellent communication channels between HEE and its contacts is an intuitive process,
requiring consideration of the frequency, best mode of contact and content of dialogue.

**Regional networking**

Joining up employers, education providers, staff, commissioners and other key players at a local level is a critical prerequisite for delivering excellent training and education. We observed a high level of diversity in the breadth and functioning of networks held by the regional LETBs in EoLC. These networks should, as far as possible, operate across strata and reach to service delivery to get direct feedback from staff. Healthcare staff within NHS England are ideally placed to raise awareness of outstanding courses, trainers and programmes, broadening the network and informing the decision-making of the LETB leads.

Local networks also provide a strong basis for knowledge exchange beyond the conventional routes of education and training. Our focus groups provided insights into valuable, informal learning from funeral companies; carers service; charities supporting unpaid carers; council and public health representatives; bereavement support (such as CRUISE); and NGOs (such as AGE UK). In particular it was noted that good relationships with local third sector organisations can bring together different strands of training, enabling a wide range of those with potential informal learning to share. We therefore recommend that the national networking research exercise be mirrored at the local level if it is not being done so already; several examples exist of LETBs with exceptionally strong networks as exemplified by our case studies.

**Linking national and local networks**

HEE has a responsibility to ensure that local networks join up with each to share information with each other, and to benefit from national overviews and/or nationally available resources.

This report also recommends that HEE should seek to establish stronger and more comprehensive lateral communication links between the LETBs, facilitated by HEE. In this respect, the details are important. Some LETB leads in the course of this project observed that due notice (a minimum of 8 weeks) is a necessary prerequisite for ensuring events are well-attended; communication strategies may fail purely because of logistics. Identifying the best way for HEE to bring LETB leads in EoLC together requires identification of the best communication channel, be it email group, regular teleconference or a face to face meeting operating on an ad-hoc basis. It is likely this will involve optimising and making better use of existing channels.
To develop, support and embed communications channels through personal relationships, we recommend that an annual knowledge-share workshop should be created. Initially, the first workshop could be structured to allow exploration of the LETB role (as outlined in recommendation 2), and this could be supported by knowledge sharing from LETBs already practicing some of these tasks (see our case studies). Workshops could also provide LETB leads with the opportunity to present their interpretation of OCTGiR and to identify where HEE needs to provide support.
**Case study: Nottinghamshire County Council hub**

Nottinghamshire County Council was one of a number of areas which have kept their End of Life Care Networks and an End of Life Care Strategy Group going after the end of funding. Driven by one individual, this is a network across health and social care to support the delivery of the objectives of the National End of Life Care Strategy in the county. It spreads information through a website and regular newsletter updates and provides a range of education and training provided for staff working in health and social care and refreshed regularly. Approaches used include the Gold Standards Framework.


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**Case study: Cheshire and Merseyside Strategic Networks**

Cheshire and Merseyside have used HEE funding to keep their Strategic Network for Palliative care. This network coordinates between Work with 3 education partners and hospices – and work with specialist palliative care teams delivering education. But this year they received 40% less funding.

Recommendation 4:

Create a hub for EoLC education and training resources

A universal comment across all interviews, focus groups and workshops was the plea that we should ‘not reinvent the wheel’. HEE should not create new tools while existing ones have been proven effective. Allowing regional ‘resurrection’ of training materials that had been popular in the past could, subject to updates, provide consolidation of past learning. For example, the EoLC skills programme was cited as a valuable resource that is in danger of being reinvented.

“I don’t really know where we’re at right now, thought we’d agreed [all this] with EoLC skills programme four years ago”

- Focus group participant

The focus should be on the practical support HEE can provide to increase the visibility and reach of existing material. Innovation in education or training currently occurring in silos could be made more accessible. Supporting this is a positive contribution that HEE can make.

Deeper exploration of this role identified two core strands of work: first, ensuring that HEE supports networks and builds relationships through which it can interact with learning initiatives from other organisations – this was discussed in recommendation 3, and should be considered as a primary task that underpins all later recommendations. The second area of focus is how shared knowledge, collated through these networks, can be preserved, updated and disseminated. This chapter is concerned with the practicalities of making this happen.

Creating a cross-sector, cross-environment ‘hub’ for training and education

A very popular idea raised independently by participants at our events was an online hub for knowledge sharing that should be managed by HEE. So many interviewees suggested, in one guise or another, a place where resources are collated that we believe this recommendation should be a pivotal element of HEE’s future work. Potentially, such a hub can support dissemination of the existing, rich knowledge base in EoLC by providing a central place where different, freely available resources can be found easily. The success of this ‘hub’ rests on its visibility and the quality and breadth of content; strong networks are needed to advertise, create and update the hub.

The heterogeneity of practice across regions is often discussed in relation to bad news stories, yet many ‘good news’ stories exist. Specifically, discussion revolved
around informal learning through shared case studies. Delegates at our events wanted the opportunity to share their good practice and positive experiences where education and training had been highly successful. One source of inspiration for this idea came from the pan-London initiative, where a collation of case studies has already been produced. These were linked to a series of over-arching principles for learning and delivering training which set a strong, positive ethos which HEE supports – these principles of connecting learning to practice are consistent with and have informed our thinking in this report (see the pan-London case study).

**A baseline hub to collate case studies**

At the simplest level, HEE could interpret this recommendation by supporting each lead to follow the same process as the pan-London team in their regions. Each region’s case study collection could be made available on local websites (and disseminated through local networks), but HEE would provide a central online space for each suite to be hosted. Effectively, grouped regional case studies are brought together on a national space for comparison and sharing. The use of networks (building on recommendations 2-3) to seek nominations for excellent case studies and programmes could form the basis of each build. This may also encourage providers, staff and agencies to pro-actively make links by providing a clear focus for an initial communication.

It is tempting to suggest creating a simple portal that provides no more than a list of case studies, to be downloaded in PDF format – certainly at the local level, the pan-London Initiative is impressive – the idea works because of its context. In the different landscape of a national database, while this option is likely to be low-cost and relatively low-effort, it is also likely to have a comparatively low impact.

For the hub to address the need identified by our research, there’s a real and complex user experience issue to understand how to get all the different actors to buy into and adopt such a resource. An interactive, social element to the site generates more interest, traffic and creates a living tool that people have an incentive to visit, actively update and share. The danger is that localised material without a search tool provides a limited experience for the end user seeking material from outside their region; it also leaves them with the job of evaluating the relative merits of different training options.

**Collating programmes at the local and national level**

There is an argument for investing more effort to create a richer resource that will be of value to different stakeholders. Our detailed interviews yielded views from commissioners, education providers, employers, frontline staff across sectors and
settings as well as LETB representatives. It is noteworthy that those from different roles could see a value in a hub from their individual perspective.

A hub that holds more detailed information about courses and programmes available from a variety of different education providers, as well as exemplars of in-house or very specific, commissioned work that might be proposed as a case study would have a universal benefit. HEE recognise that it does not have the sufficient resources or remit to undertake a comprehensive exercise to collate all the material, nor would it likely be possible to include everything. Instead, an automated function on the site itself could enable outsiders to send in their suggestions.

Practitioners could propose a particular course that they had attended and enjoyed. LETB leads could propose case studies of a successful intervention. Education providers could provide links to their programmes. These three avenues for bringing in details would ameliorate the need for HEE to run a comprehensive analysis of all available courses, which we believe would be beyond the scope of the organisation. The idea would be that the hub should specifically hold details of post-qualification and ‘on the job’ training programmes. If successful, there should be scope to broaden into earlier, pre-qualification training. A collection of programmes will help employers to purchase from a catalogue of options mediated by course attendees reviews.

The hub could, therefore, become a place where commissioners, trainers and individuals can search for education and training resources by:

- **Content**
  - Content descriptors could incorporate specific learning outcomes, the level intended and/or specific role-related tasks. Consideration would need to be given to achieve the balance between set, tagged terms (to enable easy searching) and qualitative description.
  - This could be cross-referenced by existing guidelines, standards or principles, for example, employers or commissioners may wish to consider how a course helps their workforce to achieve CQC standards in preparation for an audit.
  - A standardised template could be used to describe a course or programme, and within this template, there could be scope to cross-reference national or local standards as appropriate.

- **Region**
  - Primarily, commissioners and local HEE representatives will wish to search by region; however, search functions should also include national programmes available across regions.
All programmes, regardless of regional designation, should be viewable; commissioners or those designing education tools see a value in being able to identify what’s worked in other places that could be adapted, or providers used.

- Accreditation or kite-mark
  - It is considered beyond the resources or remit of HEE to undertake an accreditation or kite-mark exercise for all included programmes. However, existing accreditation processes already exist; some focus group members raised the example of the ‘Skills for Health quality mark’. Existing accreditation, quality marks or kite-marks should be clearly explained.
  - Where accreditation has been awarded, this should be clearly visible and it should be possible to for commissioners to search for accredited programmes.
  - A summary or roadmap for gaining accreditation should available on the hub for education providers – this may be valuable for smaller organisations and those designing programmes for multiple workforces, where the accreditation may be complicated by cross-sector requirements.
  - It was not considered that accreditation (of any kind) should be a prerequisite for posting on the hub as this might unfairly disadvantage smaller providers.
  - It was noted that the Royal College of Nurses has limited resources for accreditation; while beyond the remit of HEE to address per se, discussions of how partnership working might support accreditation of programmes for nurses would be valuable.

- Feedback from frontline staff
  - A popular idea was that the hub should incorporate a facility for allowing those who had attended the course to feedback their views. This would reduce the need for HEE to review or moderate what goes on the site and would provide a complementary means to accreditation for assessing quality.
  - In practical terms, this feedback would function as a standard online review (similar to Amazon or Trip Advisor) that enables those who have been on the course to (anonymously) provide a rating and, depending on the budget for the tech, qualitative comment.
  - There are several advantages here: smaller providers may become more visible, exceptional trainers or programmes gain recognition and, conversely, courses that receive poor reviews can be removed from the hub. This latter intervention would require a site administrator to follow a prescribed moderation and update process.
• Workforce
  o Many programmes currently offer training across sectors and roles, focusing on universal skills and promoting integrated training. The hub could enable searchers to proactively seek out such training out to support integrated learning (see recommendation 8), but would also provide scope for users to identify role specific programmes.
  o The social care workforce is under the purview of Skills for Care, and programmes targeted solely at this sector should not be included. However, many education providers are training the healthcare and social care workforces together in EoLC, and in recognition of this we recommend close partnership working with the EoLC leads there, and at Skills for Health, to ensure that integrated courses can, as appropriate, be shared across the respective platforms. Duplication of material may increase visibility, and a reciprocal arrangement whereby all three organisations share knowledge of excellent programmes with shared learning across sectors would be useful.

• Setting
  o This report recognises that EoLC happens in a variety of settings; primarily, hospitals, hospices, communities (to include care for those dying at home) and care homes. There may be a number of similar skills that are ‘required’ or ‘essential’ in each of these areas, but in some cases learning and skill development may need to be tailored towards the specific needs of one environment. It would be helpful to have the option to search for programmes by the setting in which it is provided, and for which it is intended in order to make it easier to search for courses.

• Evidence of impact in the workplace
  o Increasingly, models for evaluating the impact of an educational intervention are based on the resulting behaviour, care or practice of an individual are becoming more sophisticated. Incorporating this kind of evidence, or a link to where more information can be obtained, could be a valuable measure for commissioners.

• Time investment
  o One of the most important considerations for employers and staff will be how long the course takes – an investment of an hour, a day or a week. Courses may also incur other time burdens, such as reflection or follow-up after completion.
• Pilot work
  o Given strong lateral communication between LETBs, the hub could also provide an opportunity for LETB leads to share pilot work addressing specific training and education needs; for example, if a series of LETBs wished to explore programmes designed to improve leadership in EoLC, they could share pilot case studies of different approaches. A single region need not take on the full scope of problem solving if other regions share similar issues and can co-ordinate a strategy.

Providing the national overview

Implicit in the lists above is that nationally available education and training programmes will be posted; in some cases, these programmes may be identified regionally but accessible nationally. In exceptional cases, an outstanding local pilot may be a good target for funding to develop into a national programme. The existence of the hub itself may encourage national providers to self-identify and open constructive dialogue with HEE, and to some extent, HEE may wish to identify excellent programmes that closely reflect educational priorities.

One potential risk of the hub is, therefore, that programmes that are posted (whether they are available by region or nationally) will be perceived as formally endorsed by HEE as opposed to those that do not appear on the hub. One suggestion is that HEE should consider a series of minimal criteria for programmes that are not already formally accredited or reviewed by another body. These criteria could be embedded in the mechanism for uploading programme information. There may be scope for HEE to identify and explicitly endorse a limited number of national providers where outstanding and evidence-based training is apparent, but this is a different undertaking that we would recommend should only be considered with other EoLC partners.

Digital considerations

A critical consideration for HEE is whether this is a solution that they should lead, and/or host the site, or propose to another body to do this on the proviso that HEE will support development. Regardless of where the hub sits, linking in and out of other EoLC sites and networks (possibly a networking area could be incorporated as a sub-page) will increase traffic and build connections. We note that the Skills for Health website\(^{22}\), which already has an EoLC resource, lists some excellent tools.

\(^{22}\)http://www.skillsforhealth.org.uk/projects/item/147-end-of-life-care

The site architecture is based around javascript, using some commercial libraries has the potential to be enhanced
The Skills for Care website has yet more information and resources, and structurally may provide some inspiration as well as useful materials that, in some cases, are relevant for the healthcare workforce.

To be effective a national portal needs to understand the needs and user experience of the target audience. In this case, training providers, employers, manager as well as staff. Current popular digital tools offer of us some insights that include flexibility (using tagged data to ensure that filters and searches can be provided flexible to encompass a range of learning styles and requirements), looking at introducing user-engagement tools so that ratings and comments can be provided. These tools are not just popular but they work because we trust people who are like us - in a professional learning setting this is enormously valuable. It’s also important that a potential learner can be guided to the right course, not just content but level and delivery method. A data-driven portal would make this very easy to do.

To establish what the core functionality would look like would require a more detailed scoping exercise, but we would suggest, as a minimum, a standardised input form that allows the person submitting the material to describe basic information on what it is and how to get at it, and to select certain options. These selected options could then be used for tagging case studies and courses by some of the criteria listed above (subject, region, level, discipline). User-rating is more complex, but a simple 5-star rating may be easiest to create in the short term. Looking at existing government digital websites, such as gov.uk, and exploring the philosophy provided by the GDS23 we can see that relatively simple digital solutions that are build around user needs provide strong solutions.

**Broadening accessibility to materials and tools for download**

As discussed earlier, the concern that ‘tribal knowledge’ is being lost needs to be addressed and the hub could act as an additional mechanism for increasing the visibility of existing materials and resources in EoLC.

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23 This blogpost from GDS, we believe, outlines the remit of the service which is what this particular project calls for. [https://gds.blog.gov.uk/about/](https://gds.blog.gov.uk/about/)
This may involve a conscious duplication of EoLC materials; the value of increasing visibility must be balanced against the duplication of effort involved in terms of sharing, updating and keeping track of materials in EoL. Consequently, this should be undertaken in close partnership with Skills for Care, Skills for Health, NHSIQ and other EoLC networks where existing tools are already posted, and should maximise the utility of links in and out of these sites.

One option is to design a database of existing, comprehensive resources that could be updated each year and reviewed for use, feedback (including feedback about visibility/accessibility) and linked to standards/CQC would provide the basis for this. HEE could designate the task of creating the database (and therefore the links with other organisations) as a responsibility of an existing staff member, but could then organise a meeting between the relevant agencies and organisations to identify who would be best placed to hold responsibility for the various updates (based on expertise rather than funding) and from there, cost a pooled annual update fund and identify how it would be divided accordingly. The fund itself would still need allocation (the alternative being to ‘find’ the pot first) but possibly if the exact breakdown is negotiated, it could be easier to identify.

While it may seem premature to consider updating and archiving a resource library not yet created, the fate of out-dated educational resources was a consistent source of concern. The potential wastage and loss of creating tools that have a short shelf-life seems untenable in a climate where finances are limited. A priority for updating materials seems wise, as does an archive library of past courses where elements could be extracted and used as a foundation for newer designs would be useful.

**Funding**

Elsewhere in this report (recommendation 5), we explore the need for more visibility surrounding funding opportunities for EoLC. Depending on where the hub is held, funding pots could be advertised here (as well as on the HEE main site) to raise awareness of what is available.

**Inclusion of national standards and guidelines**

Many participants observed that plurality of standards, guidance and guidelines appertaining to EoLC are overwhelming; ensuring clarity about which of these are relevant in EoLC education would help. This could be a simple table, review piece or short introductory guide with links to the relevant documents, disseminated via the hub.
Many delegates also proposed their own local standards, competency framework and guidance as the basis of a putative national model — the balance here may be to ensure that the best of these are available for areas which have not developed these local resources. This must, at present, be an optional venture as we do not recommend running the risk of disrupting existing, good practice where it exists.
Case study: The Hub - Overarching principles for end of life care - London End of Life Care Clinical Network

London faces a number of unique challenges from a higher than average number of patients dying in hospital, to inequality of service provision by borough or locality, and an end of life care network was established to support a coordinated regional approach.

The skills and training of the London workforce were considered a priority and a subgroup of clinicians from across the capital and from a diverse range of professions formed to take a studied look. This included representation from the three HEE areas in London. It was clear much was going on in the capital, but guidance to provide a focus was needed.

The overarching principles were developed to support commissioners and providers, both of care and training, to understand why a focus on end of life care is important. It covers the key principles that drive how such training can be delivered effectively and the key elements it is likely to contain. It is for all staff working in health and social care settings, whether in a clinical or other role. The amount and type of training will vary according to the role they have, and the level of contact they have with individuals requiring end of life care.

Alongside this, the group have been collating case studies of end of life care training from across the region, which is starting to demonstrate the volume and diversity of provision underway. The case studies are intended to inspire and inform those who are in the process of developing new training to meet the overarching principles, and encourage learning to be shared amongst professionals.

The principles are available here: http://www.londonscn.nhs.uk/publication/overarching-principles-for-end-of-life-care-training/ and the case studies will be available shortly.
Recommendation 5:
Improve awareness of and access to funding

“If we can get the funding right, and not rely on these pots here and there, we could solve some of these issues”

- Focus group comment

Funding is, invariably, a significant driver of change; what we had not fully appreciated is that this is not simply about the amount of money available, but also its accessibility, visibility and the predictability. While the majority of our research explored the content, structure and delivery of learning, the importance of financial provision merits its own chapter. The potential benefits of an easier funding structure are, for LETBs, commissioners, employer organisations and, ultimately, individual staff members, profound enough to address many of the more cultural issues underpinning EoLC.

Allocation of funds

In any dialogue about funding, cuts are cited as having a direct impact on provision, and our research conforms to that pattern. The principle concerns are that essential training does not happen at all, or that the default position is that training comes from ‘the cheapest provider that gets the work done – not necessarily the best’.

There is an enduring issue about the interpretation of what is ‘cost effective’, which we believe should not be the cheapest option but the one that provides the best value for money in terms of outcomes. With this in mind, looking at feedback tools that can assess the impact of training on practice would be valuable.

HEE devolved £9.58m of funding for End of Life Care to LETBs in this financial year, with a directive to ensure that the five priorities for care detailed in ‘One Chance to Get it Right’, June 2014, were embedded across the LETB regions. The LETB leads were asked to provide information on how they had implemented the directive, but HEE did not request feedback on the breakdown of financial spending decisions or their relative impact; the lack of this information makes tracking the efficacy of different strategies across the regions more challenging. Given funding pressures, it may be valuable for HEE to seek more specific information about spending decisions to ensure adequate governance of funding allocation. More concerningly, the feedback we received anecdotally suggests that several key partners were not

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24 Information taken from the HEE internal report: End of Life Care: Summary of HEE LETB Activity 2014/15
aware of funding – without knowing what was/is available, local spending may be severely impaired.

During our work, we discovered several different research programmes\(^{25}\) for designing tools that evaluate the impact a course has on behaviours and care provision. One of our recommended sub-points is that HEE should follow the development of these and similar branches of research and, as far as possible, use it as a tool for LETBs to identify courses that offer real value.

In terms of funds per se, while it was recognised that HEE has no control over government spending plans, a need for stronger advocacy for EoLC relative to other spending priorities within in HEE was raised. This can be linked to, CQC findings to strengthen the case.

“When I look at all of the CQC reports, EoLC and dementia are the two [areas of concern] that come up”

- Comment from telephone interview

Those who have worked in palliative care for decades observe that cultural taboos often restrict open discussion of dying, and potentially this can undermine the way resources are allocated. Given that mortality is absolute, funding for EoLC training should, perhaps, be closer to funding allocation for diseases of old age that are increasingly prioritised in response to the UK’s changing demography.

Participants at our London workshop discussed the impact increased spending prioritisation on dementia had made – for example, the dementia awareness week successfully raised awareness across clinical and non-clinical boundaries, and a similar initiative might work for EoLC.\(^{26}\) It was felt that if commissioners, Trusts and providers could see a visible drive from HEE to push EoLC to the forefront of the educational agenda, they would respond by supporting this in their work. The desire to see EoLC education promoted widely was balanced by a cynicism that education policy is subject to ‘fashions’ and that a topic can become highly (but briefly) publicised before interest (and funding) wanes. One workshop participant spoke of ‘shelves of leaflets’ that remain unused, representing years of transient initiatives that were never updated or embedded in practice.

\(^{25}\) In particular, a new framework for evaluation is being developed at Kings. We recommend that HEE should initiate conversations exploring this work, and also proactively seek out other research that can allow the LETBs to structure training appraisal feedback and review the efficacy of their training investment.

\(^{26}\) http://www.ruh.nhs.uk/media/media_releases/2015_05_18_RUH_marks_Dementia_Awareness_Week.asp
A solution is to take a longer-term perspective, and commissioners in particular wish to see this reflected in workforce planning at both the national and local levels. Successful learning strategies require an investment of time and sustained effort to reach a critical mass in order to affect real culture change across different care environments. It is not sufficient to train a single generation (although that is an admirable start), particularly when a high staff turnover means consistent renewal of knowledge is required within any given work team.

Participants at our focus groups and workshops discussed at length the impact of the identification and allocation of funding pots, describing severe limitations current practice imposes on education and training. The most significant (and solvable) issues concern tight deadlines (in some cases, participants claimed they had only 48 hours to submit a proposal) that undermine the bidding process. Short-term funding pots that undermine the strategic planning needed to cement learning into practice are another solvable problem.

“To develop we need a bit of stability in the way we organise our programmes. It feels like we’re always trying to catch up, rather than planning things”

- Comment from participant at the London Workshop

A bid written ‘at the last minute’ is likely to be of lower quality than one that has been thoughtfully planned and developed in collaboration with experts over a longer time frame. Short deadlines undermine the ability of a bid-writer to bring on board partners, develop cross-sector initiatives or mine ‘deeper’ training ideas.

“We have an issue with the call for bids and the short amount of time to submit after announcement”

- Comment from telephone interview

Tight deadlines are in part a product of poor advertisement and low visibility of available funding. Several of our interviewees stated that unless you ‘know someone on the LETB’ it’s difficult to know where money is available. Likewise, LETB representatives claimed that funding allocation from HEE central was poorly sign-posted, and this has an inevitable knock-on effect. A solution would be to ensure there is a named responsible officer situated nationally at HEE central, who would co-ordinate HEE bids and know, and advertise, in good time the available funding opportunities. This individual would hold budget information across the board but work closely with EoLC colleagues at HEE central and regionally, or the HEE named
lead for EoLC could proactively seek out information about budgeting to disseminate out.

Finding appropriate channels to disseminate funding information is also needs to be considered: communication channels (mail groups, regular meetings) are one avenue, but it was further suggested that information should be posted more clearly online – this could be facilitated through the HEE EoLC hub (depending on how this is developed) or another HEE sub-site that LETBs (and other interested parties) could be made aware of.

“Funding is year on year so you can’t plan long term, and then rush to get it in as there’s short notice; it’s very disjointed.”
- Comment from telephone interview

If short deadlines are one problem, short ‘lifespan’ of funding pots are another. This creates a poor rate of return: frequent bids for fast turnover projects are more time consuming than bids that allow training to be delivered over a long time frame, and funding needs to be longer-term to allow sustainability of teaching systems. Courses happen when money becomes available. Where funding pots are unpredictable and subject to re-allocation, organisations struggle to reprioritise and to maintain their plans. Commissioned educational plans are sometimes abandoned or diluted in response to unexpected shifts in budget. These changes, we believe, are often preventable.

“We need to have confidence that what we start doing we keep doing”

“It puzzles me to become so dependent on funds becoming available. Why can’t we have them to forward plan these things? They’re essential”

“I probably spend 30% of my time writing bids – stability and funding would be marvellous. You can’t get people with calibre and quality you want on such short-term contracts”
- Discussion points from the London Workshop

Addressing these issues represents a clear, achievable positive move HEE can take. Therefore, the recommendations and sub-recommendations of this chapter call for a simplification of the way funds are distributed.
Assessing the wider funding landscape

One avenue for an HEE lead in EoLC is to explore the broader landscape, outside of HEE, where providers are receiving funding. This can be done through improved communication with commissioning partners and cross-sector work and, through this, it may be possible to learn more about the destination of the various allocated funds for EoLC. Do other agencies face difficulties in ensuring that funding is visible, fairly distributed and ‘taken up’? The EoLC lead with responsibility for funding should map how budgets are used more widely, and whether there are some resources that are not currently being accessed.

If one concern is that funds are not being applied for, another is that as various funding pots ‘dry up’. The knock-on effect of reduced learning provision will impact on the workforce, and needs to be reflected in HEE’s workforce planning. A recurrent theme was that staff members in palliative care are paying for their own education and are doing it in their own time. Essentially, this is a subsidy to healthcare provision, and HEE needs to consider whether it is appropriate for professionals to fund their own education. Senior staff members in our discussions believed that once staff members have reached a higher salary band it is not unreasonable for enthusiastic specialists to wish to deepen their own practice, but there is a concern that this is potentially being expected of more junior and less well-paid staff.

Covering staff leave for training

Our telephone interviews with frontline staff showed that, across roles and in different environments, people are struggling to protect training time. A common complaint was that individuals sign up to courses, but then have to cancel at the last minute to prioritise service delivery. It was noted that employers must factor in the additional cost (sometimes substantial) and/or practicalities of hiring locum cover to safeguard staff training. This latter point is critical for enabling staff to attend courses as, without planned cover within a stretched workforce, day-to-day fluctuations in job requirement and availability can make it impossible to predict if a pre-booked course can actually be attended. CCGs report difficulty in arranging and committing to courses due to availability issues.

For our allied health professionals, and some nurse interviewees working specifically in palliative care, a different but related problem was raised: recruitment is so stretched in some areas of the workforce, that even if employers are prepared to cover the cost of a locum, it is not always possible to find one. For example, physiotherapists specialising in palliative care are now so reduced in number that finding adequate cover, either in-house or externally, can prove impossible for employers. In this respect, the circumstances necessary for education and training
cannot easily be met. For CCGs the struggle to ensure minimum viability for courses to operate was a significant issue.

A further issue was the amount of study leave staff members are permitted to take each year. Notably, the increased mandatory training requirements combined with staff shortages in some parts of the sector make it challenging for employers to release staff for study leave. EoLC leads need to be aware of the challenges and to recognise these in strategic planning.

“Because mandatory training is so arduous, as a consequence paid for study leave has become more scarce”

- Focus group participant

One result of this trend is that a significant number of staff that attend EoLC courses in their own time; on the positive side, this suggests there is a desire to learn and a clear need to provide programmes but, on the other, staff who don’t have that impetus to learn may not receive the training they need.

**Callout box 9**

*A focus group attendee spoke of a funded an EoLC course for ambulance staff, that put out through network, and the staff came in their own time.*

Trusts need an incentive to allow staff away from delivery for training – examples of this include linking courses to CPD points or payment to trusts. The payment strategy may be one for HEE to discuss with LETB representatives; consideration of this may need to be circumstantial and subject to certain criteria. Paying trusts indiscriminately would stretch funding and, arguably, implies that Trusts don’t already have a mandate to support the training and education of their staff. However, in certain circumstances where resources are particularly tight, payment to cover the cost of locum support could be a prerequisite for training.

**Improve flexibility of funding allocation to support partnerships**

A balance that HEE needs to find, in collaboration with the LETB leads and other strategic partners, is the extent to which ring fencing money undermines collaborative work. We received very mixed views in this respect, and to some extent, it may never be possible to find an ideal solution. However, some concerns seem worthy of further investigation.
The following points were raised during our focus groups and workshops:

- Sometimes courses that are fundamentally the same content-wise are being delivered to the social care workforce and the health care workforce separately; if we want to support cross-sector working, we need cross-sector training and that needs to be better supported by cross-sector funding.

- It was reported that organisations will often refuse to support attendance at a programme that falls outside of their Trust; if the individual or an individual’s line manager has identified a suitable course that falls outside of the boundary, then payment cannot be funded; in this respect, organisational ring-fencing of funds from HEE limits access to places. Linked to this point, some attendees observed that we are starting to see a postcode lottery in terms of care that reflects, to some extent, a postcode lottery in the way that regions deliver education and training. In a positive light, this gives us anecdotal evidence to support the real impact that a strong strategy can have on service delivery and care to patients; more worryingly, at the borders of regions, we heard there are stark contrasts in quality.

- One of the most exciting outcomes of local commissioning is where an education programme develops within a particular region, and has such a profoundly positive effect that those further afield wish to benefit. In this respect, flexibility that allows a local education provider to attract a wider group of staff is beneficial, but there is also logic in HEE identifying, supporting and funding the expansion of such provision at the national level. The current funding structure does not make this easy, particularly for in-house providers whose expertise arises from coalface experience and/or cross-sector learning. We suggest that HEE reviews the current process by which outstanding programmes developed at a local level can be supported as national programmes, regardless of the size or provenance of the course provider.

These are anecdotal reports and therefore difficult to quantify or substantiate. However, subject to further consideration during workforce planning meetings, we suggest that there should be some scope for flexibility around reciprocal training and co-working between regions where there is a will, need and logic to do so. Establishing the most efficient way of allowing this to happen would involve HEE removing some of the restrictions surrounding funding allocation to improve flexibility and increased communication.

**Broadening the scope of funding**

There was a general plea that funding should cover more than courses but should incorporate different modes of learning and information sharing. Suggestions
included an education fellow for each region, the re-introduction of EoLC champions for regions who had lost the funding to support the role, and peer-to-peer support meetings for reflective learning that encourages institutional memory and provides personal support for staff.

“If we’re not looking after our staff, our staff will not look after our patients”

It was also recognised that networks discussed in recommendation 3 need funding for development and sustainability: strategic clinical networks and academic networks can bring support, particularly if their insights can be cross-linked through HEE at the national level.

One criticism was that funding always goes to the same places: hospitals were seen to take the majority of funds in terms of environment, and HEIs in terms of education providers. HEE recognizes the value in broadening funding recipients. In particular, we note that community-based practice may need more support, and we acknowledge the contribution of Hospice-provided education to the EoLC sector. HEE should clarify the wider range of funding choices are available to LETBs, and should ensure that LETBs are empowered to take innovative decisions that address local needs.
Recommendation 6:

Focus on communication skills as a universal skill underpinning EoLC

“Our communication underpins everything. That’s the thing to try and get right”

“We don’t need to label communication skills as end of life skills”

If, as is argued in recommendation 1, we envisage a scenario in which End of Life Care training needs to be embedded in the training of all healthcare professionals, we need to differentiate between (1) skills that should be encompassed in basic training and that are relevant to a broad range of healthcare experiences and (2) skills that should be taught to generalists as part of dedicated End of Life training.

Universal skills refer to those that have value for different workforces, services and specialisms. They are skills that can be developed all the way through a person’s career and which can be updated in light of research or other developments. The most important universal skill cited by participants during this research was communication. It is worth noting that existing reports already propose improving communication is a core issue for training; for example, The Shape of Training Report27 and The Shape of Caring Report.28 Our findings reinforce the rationale expressed in these and other research pieces.

Positive communication supports a culture able to deliver high quality EoLC. Thinking about the way we communicate creates a virtual circle in which language reveals attitudes, which can then be explored to raise awareness. Increased awareness in turn influences behaviours, the delivery of care and the way we communicate. Embedding strong communication skills could be achieved through education programmes and core competency frameworks at every stage of professional development. Good communication also takes time: time not only to learn the skills, but to implement them in the day to day working environment. In some respects, as one of our experts observed, ‘good communication is a casualty of deficiencies in workforce numbers.’

This chapter focuses on the communication between staff and patients, as well as with the families and friends of patients. Communication between staff, teams and different parts of the healthcare sector is also critical, and is considered in the next chapter in the context of shared learning.

27 http://www.shapeoftraining.co.uk/static/documents/content/Shape_of_training_FINAL_Report.pdf
Current practice in education and training

At a time when clinical curricula are being reformed, it is perhaps unhelpful to run an extensive critique of the existing structures; nevertheless, in its workforce planning and discussions with education regulators, HEE should be aware of some of the feedback we received regarding current education and training for communication skills.

 Concerns were raised communication skills are in some educational settings ‘niched’ in EoLC education and often only reinforced in specialist context. This raises a risk that only palliative care nurses and doctors are able to speak about dying with confidence. The danger is that a very small, increasingly stretched part of the service (palliative care) is being directed to hold tasks based around patient conversation that could be undertaken by generalists. This would ease the pressure, provide more support and, arguably, improve job satisfaction.

 Including communication in training strategies per se may not necessarily be enough; an audit of acute hospitals undertaken by the Royal College of Physicians (RCP) in collaboration with the Marie Curie Palliative Care Institute Liverpool found that, between 2013-14, communication was extremely variable and broke down in several critical areas (see call out box 11 for data). This is despite the fact that acute hospital trusts had specifically included End of Life Care training with a communications element for doctors (61% of trusts) and nurses (69% of trusts). These data suggest that whether the training is happening or not is only part of the story; not all courses are created equal, and the impact that a course has on changing behaviours should be a critical factor in commissioning. Communication is one area where evidence-based interventions, accreditation and positive feedback

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are critical in commissioning choice. Some of our interviewees noted that few courses focus on the deeper levels of communication because of a limited number of facilitators and capacity – this shortage represents a target for HEE and the LETBs to address.

One consistent comment we received was that communication cannot be adequately learned online – the value, if any, of online courses in communication is only to stimulate an initial interest or preliminary understanding of the topic, but this

“Connected to the requirement to have face to face, communication skills courses are often expensive in terms of time and money (3 days out of practise)”

- Telephone interview

Callout box 11: Communication at End of Life in acute hospitals with patients who were capable of participating in a discussion about their wishes and care.

- Patients dying with documented recognition that they were in the last hours or days of life (87%) only received communication of this in 46% of cases.
- The need for clinically assisted hydration was assessed in 59% of dying patients, and discussed with only 17% of patients.
- The need for clinically assisted nutrition was assessed in 45% of dying patients, and discussed with only 17% of patients.
- Bereaved relatives of people dying in hospital felt that they were not at all involved in decisions regarding the care and treatment of their family member in 24% of cases, and only 47% of acute hospital trusts reported having a formal system in place to record the views of bereaved relatives. However, 63% of bereaved relatives reported the level of emotional support given to them by healthcare staff as good or excellent.

must be followed up by a more comprehensive offline experience.
How should we consider communication in EoLC?

While we posit communication as a universal, core skill, we also note that within this there are specific requirements in EoLC. We heard diverse, but complementary, opinions exploring what is meant by communication in EoLC and where the most successful training strategies focus. A summary of these points is given below.

- The communication between team members responsible for delivering care to a patient: teamwork rests on good communication between staff.
- The communication between individuals working across sectors to provide ‘joined up’ care – understanding and connecting with those in a different working culture is critical if the patient is to receive seamless care.
- We need to be aware that many doctors and nurses in the UK are from overseas; not only is language per se sometimes a barrier, but cultural assumptions about dying can cause problems where the expectation of appropriate behavior surrounding death differs significantly from the patient’s wishes. This is inextricably linked with how comfortable a practitioner feels in holding a conversation with a dying patient.
- While different cultures may evoke different behaviours around death, we need to be aware of English cultural taboos surrounding communication about mortality – these are often strong and an individual staff member may need to consciously recognise their own perceptions and feelings around the subject before they can engage with a patient.
- Communication is not just about the words used; it is also about knowing the context, timing and circumstances that best suit a conversation. And sometimes it is about knowing when not to speak, when to hold back information and when to bring in a third party to mediate.
The most frequent term cited in communication was ‘difficult conversations’ – it was recognised that a conversation about dying may be one of the most difficult, but breaking bad news or discussing painful decisions about treatment are also challenging, and not limited to EoLC. Difficult conversations need also to consider how we communicate uncertainty and enter into a therapeutic conversation where outcomes are not easily predicted.

Recognising that patients may have specific communication needs is important – some patients may have learning difficulties, language difficulties, disabilities such as deafness, mental conditions such as dementia that limit their understanding – responding to these needs should be part of communication training. Currently, people with learning disabilities are less likely to have access to specialist palliative care, to receive opioid analgesia and are more likely to have deaths described as ‘poorly managed’.

Communication may also incorporate a psychological element – this involves assessment of psychological distress in the patient, but also awareness of the staff members’ own feelings, responses and beliefs, which may be brought into the dialogue at a subtle level.

Communication may involve confronting conflicted perspectives of death, and ensuring that the notion of a ‘good death’ is acknowledged. Medical staff in particular may strongly subscribe to the pressure of wanting to heal, rescue and save patients – this is admirable, but can create feelings of failure around the death of a patient, or where death is unexpected.

Students don’t always get the chances they need to talk about death and dying. It is not necessarily the case that students (or qualified practitioners of any of the healthcare workforces) do not wish to talk about death; it is that

“Some staff say: “in our culture, we don’t talk about death” – we have no particular conclusion about how to address that, other than we need to embed talking about death for all those likely to work with dying patients. Arguably English culture is not comfortable talking about death – although we are getting better”

- Workshop participant
they need, sometimes, the opportunity to do so and a genuinely innovative, transformative way of learning the necessary communication skills.

- We should not be afraid to use art and creativity to engage with the dying, to break down barriers and to help people see this area of work in a more positive light.
- The environment and role of the practitioner is important and training needs to address the specific practicalities of a role as well as the universal principles: a GP may recognise a professional responsibility to hold an EoL conversation, but time pressures are a significant barrier. Consideration of this limitation needs to be factored into their training. For some practitioners, particularly in primary or community care, conversations may happen over the phone and this again is a specific aspect to address within communication training.
- Communication skills need to be taught appropriately for the individual. Some people have, through previous learning or innate ability, excellent skills already and repeating familiar material can be counterproductive for them; assessing the level of skill, confidence and need is a necessary prerequisite for identifying a suitable course.

Communications training in EoLC for all generalist staff

A patient may choose to initiate a conversation about their prognosis with whoever they personally feel drawn to – they may choose to reach out to a student nurse or doctor, a carer they are familiar with, a therapist or any available staff member regardless of role. In this, the human need to connect with another person, and the personal choice that drives that, will take precedence over professional role. A dying patient may not wish to wait to speak to a specialist palliative care member of staff – and in terms of workforce development, HEE needs to ensure that any practitioner who may be asked, unpredictably, to give bad news or console a distressed patient will be prepared and able to do so. Many generalist physiotherapists, for example, break bad news to patients or are sought out by a patient for consolation.

“Very often a person will ask a student nurse, healthcare assistant or a junior “am I dying?””

“You don’t want to tell people they’re on a palliative or end of life care register. How do you tell them?”

- Comments from focus group discussions

www.ncbi.nlm.nih.gov/pubmed/24152480
Palliative care specialists we spoke with commented that by the time a patient enters their care, they will already have received news about their diagnosis and prognosis from another member of staff. If this has been a traumatic experience, the subsequent care may be shadowed.

Of particular relevance here is the gap between the medical terminology used around EoLC. As a prerequisite for building good communication, this should be mediated by the needs of the patient and their loved ones. The Social Care Institute for Excellence and the National Council for Palliative Care have produced excellent materials to support a universal terminology around terms used in End of Life and Palliative Care that are inclusive for all – this report recommends that HEE links in with this work and acts supportively to disseminate the resulting documents to education providers. Materials include a new film that supports good communication based around language in a way that is inclusive for patients and families and provides a useful resource for supporting positive communication. This could be used as part of an induction, in taught courses or circulated by employers for in-house training updates.

Can we teach compassionate communication?

One of the most challenging areas of communication surrounded the need for compassion in EoLC. This fundamental human response to a dying person is mediated through, but not entirely covered by, strong communication skills. It is perhaps a semantic exploration to define whether compassion is a prerequisite of good communication in EoLC, or whether it is a distinct response that cannot be taught. Either way, many of our interviewees were advocates of encouraging staff to explore their own attitudes and behaviours, and the value of shared personal experience both in professional and personal life. Notably, the strongest arguments in favour of encouraging compassionate care came from those with a long-standing history of professional work in palliative care. They sought to promote the value and importance of just caring in an increasingly busy working environment where ‘soft skills’ are sometimes deprioritised.

“It doesn’t matter what rank you are, how busy you are or what profession you are – the fact you attend to somebody and your heart is there with them matters to family more than anything else”.

- Focus group participant

It was noted that HEE, in workforce planning, may be considering how students and staff are increasingly recruited into the service on the basis of high academic achievement, but there is a sense that evaluation of an individual needs to reflect their caring abilities. This observation was made with the caveat that more academically trained people are not necessarily less caring; this is an erroneous assumption that has increasingly infiltrated reports – the emphasis is on an ‘and’ rather than two mutually exclusive qualities.

**Strategies and resources to embed communication**

Within HEE, communication is identified across many therapeutic areas as a prerequisite for good care, and persuasive arguments regarding cost, practicality and synergy suggest we need to combine strategies that promote this skill. It should be noted that the deeper, encompassing communication learning envisaged in our research requires HEE to invest and commission, through the Local Education and Training Boards (LETBs), genuinely effective training and the supported development of education curricula. The former requirement may involve initial ring-fenced costs that are significant, but we believe that in the long-term, it is a more cost-effective solution.

“Feels like we’re all trying to get to the same goal with different pots of money”

- Workshop comment

Our research suggests that the strongest model is one in which advanced communication skills are taught in some depth and that the spectrum of compulsory learning must include specific consideration of difficult conversations, breaking bad news and discussing death.

A nuanced argument is the extent to which the ethos and practice of good communication is exemplified by End of Life Care – as one interviewee put it, ‘if a person can ‘do’ communication in End of Life, they can do it anywhere’ – and the extent to which conversation regarding death sits as a subtopic. To improve the quality of interactions and experiences of those in End of Life Care, HEE advocates a combined effort – between educators, trainers and colleagues in social care - to universally embed strong communication skills, achieved through a route of well-supported, blended education and training. This would be beneficial for all professionals interacting with EoLC, but ultimately it would serve to improve the experience for patients and those supporting them.
Recommendation 7:
Create a minimum standard of EoLC skills for generalists

“A care of the dying is delivered by many people – and if we only educate a few then it’s not possible”

A consistent theme that emerged throughout our research was the need to create a minimum level of ability in EoLC across all workforces and settings. Consequently, this chapter explores a minimum standard in EoLC and how best to inculcate the requisite skills, attitudes and behaviours across healthcare workforces. A challenge we face is that, for many clinicians, EoLC is not their direct focus – for some, care for the dying features only peripherally in their work and so their need for training in this area is not considered a priority. As training in EoLC is often optional following qualification and registration, voluntary courses are attended by people who are either interested in the subject or who have the self-awareness and self-motivation to address a perceived deficit in a skill they value.

“EoLC is let down by people that have it as part of their overall job but not their focus.”
- Focus group participant

It is not realistic to expect people to choose to educate themselves in things that aren’t their passions; part of our thinking must be to explore natural opportunities to build on existing training, as well as finding motivations for staff that can overcome existing barriers, resistance and lack of awareness.

“People don’t see that End of Life Care is part of their work - people from all parts of the health service need to participate in training but they don’t see end of life as part of their job description, despite the fact that every patient has the potential to be at ‘end of life’.”
- Workshop participant

Before considering, as HEE must, the complexity around addressing this recommendation, it is worth reflecting on its origin. The real anxiety that we heard from our interviewees is that, while many parts of the health service deliver excellent EoLC, some environments have an endemic culture of neglect and poor
practice that has devastating consequences for patients. The findings of the Keogh review,33 Francis Inquiry,34 and subsequent publication of the Cavendish review35 and Berwick review36 demonstrate that this concern is well founded.

The role of leadership in supporting a minimum standard

It is not, we believe, a lack of educational resources or guidelines that undermines EoLC across teams, but the fact that in some environments, these are interpreted and implemented at a sub-standard level.37 Here, leadership plays a role. The Francis Inquiry found that at Mid Staffordshire NHS Foundation Trust the culture of tolerating poor quality of care was in part related to a disengagement from responsibilities at the management level. Poor leadership affects not only practice, but it is also a clear causal factor in how education and training are embedded: the absence of strong leadership was frequently cited in our research as an underlying barrier to learning. We note that in our survey, while the majority of respondents could identify a senior, named lead for monitoring EoLC in their Trust or their employer organisation (83%, n=652) a significant minority could not (16%, n=129). Every member of staff should be able to name a senior person with clear responsibility.38

We recommend developing leadership as a prerequisite of embedding a stronger culture for EoLC. Practically, we advocate linking in with leadership training strategies, developing the leadership of HEE (recommendation 2) and in recommendation 8, we explore leadership in the context of mentorship and supervision. A further suggestion is for HEE to mediate with a representative on each Trust board. Leadership plays a role in ensuring that all staff interacting with dying patients - in whatever capacity, setting or level of seniority - have a strong grasp of EoLC.

33 www.nhs.uk/NHSEngland/bruce-keogh-review
34 www.midstaffspublicinquiry.com
38 These figures, when broken down by setting are as follows, where (yes, no) answers are provided for staff ability to identify a named lead: Community (197, 44), Hospital (263, 59), Hospice (117, 10). It should be noted that the staff indicating ‘no’ for the hospice setting gave responses that indicated in their environment, this specific role may not exist but equivalent leadership has a different nomenclature)
What does our minimum skill set in EoLC look like?

A primary question for us is what a baseline should look like, and this line of enquiry itself opened up several new ones: do we expect a single baseline for all staff, regardless of their role in the healthcare workforce, or do we wish to take into account different amounts of time spent with dying patients? Do we need to ensure specialists have this minimum, or should we consider that they will have acquired the skills as an inherent part of their role? How does our baseline requirement relate to our universal skill of communication, covered in recommendation 6?

In the course of our research, we reviewed many different documents that explored the absolute, critical skills needed. While presentation, structure and weighting differed, there was remarkable congruity between the materials. In fact, one confusing element for those managing training and education is that there are, perhaps, too many sources saying similar things in slightly different ways: our aim, therefore, was to look at simplification rather than additional guidelines or guidance.

Our starting point was to focus on the NHS strategic priorities around End of Life Care, which suggest that staff should be trained at: a. recognising when the individual is approaching the last year(s) of life and in communicating about this and other difficult issues in a sensitive manner; b. using skills of shared decision-making to engage and empower those for whom they care in coming to decisions about health and social care that best fit with the person’s needs and preferences; c. using evidence-based principles of medicines optimisation to improve clinical outcomes and patient experience and d. assessing and addressing the needs of carers, including in bereavement.

Next, we considered the work of the CQC, and the points auditors will look for in their analysis of a care setting. In the aftermath of the More Care, Less Pathway review, the CQC was tasked with including EoLC as one of eight core services to focus on. Tying in a concept of minimum proficiency to regulatory requirements will ensure that training receives due weight, and here again, the principles were consistent with the NHS Strategy.

We note in particular the CQC’s focussed research, currently underway, in exploring why end of life care has so much variation, and why some groups in particular are more vulnerable to receiving poorer care. These groups are: people with a diagnosis other than cancer; people aged over 75; people with dementia; people from BAME

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groups and other groups of people who may have specific needs, such as those with mental health needs, people with learning disabilities, people who identify as LGBT, people who are homeless, prisoners, travellers and gypsies.\textsuperscript{41} Our recommendation is that there needs to be an increased focus on these groups in training strategies and that HEE should continue to liaise with CQC to ensure that any findings are reflected in a minimum skill set for EoLC.

We also note the findings of the Parliamentary and Health Service Ombudsman, ‘Dying without dignity’, which identified a further list of areas where poor practice has a particularly negative impact on EoLC: not recognising that people are dying or responding to their needs; poor symptom control; poor communication; inadequate out-of-hours services; poor care planning and delays in diagnosis and referrals for treatment.\textsuperscript{42} The Health Select Committee into EoLC similarly noted that recognising end of life is a primary prerequisite for staff to respond with appropriate care.

\begin{quote}
“The situation on end of life care is unlikely to improve unless clinicians feel confident to identify people who may be near the end of life and to start conversations with their patients about their wishes. Too often, however, staff feel that they lack the confidence, skills and training needed to raise end of life issues with patients, let alone understanding the mechanisms available to patients and carers under the Mental Capacity Act 2005 which allow people to make their wishes clear”

- Health Select Committee: summary comments 2015\textsuperscript{1}
\end{quote}

Any minimum skill set should respond in particular, to these weaknesses in service delivery. Most of our reviewed materials also align with the principles of OCTGIR. The five core principles (see callout box 12), which, while specifying the last days of life, are still relevant in philosophy for the final year. We believe that awareness of, and ability in each of these should be at the heart of training.

Most significantly, education priorities in EoLC should incorporate those that patients themselves consider important; while we have devoted a whole chapter to communication as a critical precursor to caring, there are clearly technical skills that are as important as compassionate dialogue. Patients themselves cite pain relief being one of the most important in the final days.\textsuperscript{43}

\begin{footnotes}
\footnotetext{41}{http://www.cqc.org.uk/content/identifying-variation-end-life-care-commissioning}
\footnotetext{43}{Source: Sue Ryder, A time and a place: what people want at the end of life, July 2013.}
\end{footnotes}
The ‘Every Moment Counts’ narrative, a collaborative exercise undertaken by the National Council for Palliative Care, NHS England and National Voices advocates coordinated, patient-centered care. The five principles of good EoLC can be summed up by the following statement:

“I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s)”

- Every Moment Counts

We note that the principles are often universal, and our recommendation for conceptualising a minimum standard that reflects the different sectors and roles in EoLC is to create a tool that refers to these principles (see the pan-London LETB initiative case study later in this chapter). The challenge is how do we do this in such a way that over-arching principles and core skills are made appropriate to each workforce?

To address this, we believe a roadmap of learning outcomes that identifies where there is an overlap of required skills and which delineates the different sectors and

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career stages can be of vital use in scoping the best opportunities for shared learning. Health Education Yorkshire and the Humber have produced a series of EoLC Learning Outcomes, which use themes of practices to map specific competencies against different workforce sectors (see case study). This roadmap allows planners to observe how different educational outcomes match to different roles, references the skillset priorities and also allows for specific consideration of technical skills that may be critical for generalists caring for EoLC patients. It also joins up the various principles that underpin EoLC.

The great strength of this approach is that it allows principles and guidelines to be broken down into very specific, measurable skills – this provides a useful tool for supervisors, commissioners and those running an audit of education and training needs in a staff group. We believe, therefore, that a similar approach (possibly using this tool itself) on a national level would help clarify the expectation of the basic skill set that any given member of staff needs to have. This should be achieved by first collaborating with LETB leads to identify what similar strategies are already in use, and then to work with strategic partners to finalise national learning outcomes for a national minimum standard of EoLC.

We acknowledge that skills in themselves are not enough; as discussed in recommendation 6, awareness and an attitude of caring are a prerequisite for good care. Achieving a balance between the priority to nurture appropriate behaviours and the specific skills needed is not trivial. The roadmap created must be complemented by tools that take on board the philosophy that we wish to embed, and here recommendation 8 supports a blended learning approach with elements that encourage reflection and awareness as well as skills.

Our rationale for seeking to define and deliver a minimum standard is that the CQC’s analysis of variability in service delivery needs to be addressed – it is, of course, not solely the impact of training that leads to that variability, but HEE needs to address this factor to contribute to the overall effort. We fully appreciate that each region must be free to interpret how it delivers education and training; the aim of developing learning outcomes is not to prescribe how they are achieved, but to provide clarity about the minimum skillset required. We also stress that the emphasis is on ‘minimum’ – the learning outcomes should not be considered limiting and should not prohibit the existing activities of the LETBs. Rather, these should set the basic threshold for EoLC that LETBs can build on, exceed and fulfil however makes sense in the context of their region.
**Mandated training**

An absolute lever for ensuring training in a specific area happens is to create a mandate for it, and this was a source of deep contention in our discussions. Mandated training enables us to reach those who currently are either not interested in EoLC or who don’t believe it is relevant to their role. A concern raised by many participants was that as education and training in EoLC is often voluntary, those who may need to learn the skills the most aren’t necessarily the ones who sign up. As this issue was raised in many different contexts and interviews, several potential areas for mandate were identified, the most common of which were:

1. A mandate for Trusts to teach EoLC at induction for all staff.
2. A mandate for annual GP ‘shutdown’, where cross-sector training could enable GPs, district nurses and other healthcare professionals working in the community to learn together. As appropriate, training could made available to the social care workforce on a voluntary basis.
3. A mandate for annual CPD to cover EoLC for those caring for the dying as a part of their daily work regardless of whether or not they are considered palliative care specialists. Advanced communication skills were considered the priority here.

There were strong arguments in favour of each of these; given the universality of caring for the dying in the hospital setting, (1) was considered clinically relevant for most staff. Significant difficulties in persuading GPs to attend EoLC training was the impetus for (2), and for (3), the observation that palliative care could comprise a significant proportion of a practitioner’s work (particularly in nursing) without any obligation for the necessary training. Mandates were considered unnecessary for hospices and, while there were strong calls to impose mandates or tighter regulation of training in care homes and nursing homes, this falls outside the remit of HEE.

A worrying argument was that some Trusts would not action training that is not considered compulsory. This was considered to be due to the pressures of safeguarding service delivery. If true, this presents an impossible operational dilemma: if only mandatory training is implemented, there comes a point where training models become unsustainable – we cannot mandate every topic needed in clinical practice without placing an untenable burden on staff. This is a broader issue that requires deeper consideration of the working context in which training is delivered. In particular, the observation that is of most concern is the proportion of mandated training that clinicians are required to undertake that does not relate to clinical practice (for example, fire regulations) but which reduces the overall training time available.
The critical issue for HEE is the extent to which a mandate for EoLC training would genuinely build knowledge and have the power to improve patient outcomes. If used judiciously in a context where employers and staff have sufficient time to take on board the additional requirements, a mandate can ring-fence time for staff to engage with the material and be a valuable tool in up-skilling a neglected area of expertise. Mandates direct attention and target funding. Yet mandates incur a significant burden of time and cost on staff and employers; we need to consider the benefits in the light of the available resources.

In the course of our research, we identified many cases of excellent practice, dedicated expertise and compassionate working. Placing additional mandatory requirements on these groups would be unnecessary and overly prescriptive; as importantly, we do not believe that a mandate would necessarily address failing environments. Mandates, although powerful, are a blunt instrument, ensuring that some form of training happens but with no guarantee as to the quality – the inherent danger that concerns us is of creating a ‘tick box’ approach to training, which satisfies the minimum compulsory requirement yet leaves the deeper learning needs unaddressed.

Our hope is that it is not necessary to introduce a mandate for EoLC training if all the recommendations suggested are implemented and if HEE is able to work with training regulators to strengthen delivery of the existing measures. We suggest that the LETBs, and each employer organisation, should retain the power to respond to the individual needs of their region and environment; EoLC training can be mandated by Trusts – 19% of acute hospital trusts already mandate training for doctors, and 28% for nurses.45

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45 Source: National Care of the Dying Audit - Hospitals England 2013/14
www.rcplondon.ac.uk/sites/default/files/ncdah_national_report.pdf
However, we do heed, and are sensitive to, the views we received; we have tried to incorporate the ethos of these by reinforcing existing mandates and levers for education and training in this chapter, and in the next, exploring more creative ways to change the culture surrounding EoLC learning. These positive measures, we hope, will mitigate the need for additional regulation. We also recommend that HEE support, observe and consider the impact of changes to the clinical curriculum, and the GMC’s current work in accrediting Trusts as education providers before imposing mandates into a changing landscape.

This report recommends, therefore, that HEE should monitor the efficacy of our current recommendations and other work in the field and set a date to review the issue of training mandates. HEE could do this in collaboration with our partners from the Leadership Alliance for the Care of Dying People, and to include LETB leads, SfC, SfH and representatives of NHS Employers in discussion.

Callout box 13

Completing a DNR has become compulsory in many settings, and needs to be completed by patients. This has led to difficult and distressed conversations, where the patient was given no warning or counseling around the decision. These cases originate from an insensitive introduction of a well-intentioned idea that was cascaded down without the sensitivity of communication needed to go with it. This is where a tick box exercise fails; we need to have awareness and caution of KPI’s and tasks that are delegated.

- Based on an amalgamation of focus group participants

“We mandated EoLC training in our foundation trust (Newcastle hospitals) and are redesigning a lot of the mandatory training programme. Day in day out people are avoiding difficult conversations so we’re bringing that into the training arena of other training areas (role specific). Based on that model we also have online EoLC session. It is likely that the first wave of comms training will led by palliative care teams and then move onto train-the-trainer model”

- Focus group delegate
Embedding basic EoLC skills along the learning pathway

We asked expert stakeholders representing different workforces in health to talk us through practitioner career paths and to identify the opportunities for introducing and reinforcing EoLC education and training. Although the NHS website publishes a framework which we have modified to illustrate learning pathways for nurses, doctors and AHPs (see figures 3a-c), there is no such thing as a ‘typical’ pathway.

We cannot, unfortunately, predict with accuracy fixed places where we can guarantee all generalists will receive EoLC training. Given the significant number of clinicians entering the service from overseas, we cannot assume that a qualified nurse or doctor has received EoLC in their undergraduate degree under the UK system and, depending on what role overseas staff take up, their opportunities for subsequent training are difficult to predict. Continual reinforcement of EoLC training is the only way to address these uncertainties.
Figure 3: education and training pathway for nurses (a); doctors (b) and allied health professionals (c)
Our survey showed that 70% of respondents had received training or education within the past year. With the caveats that survey responders tend to be more engaged in the topic and we cannot measure the quality or nature of that training or education, this is broadly positive news. While the small sample sizes within regions cannot be statistical significant they indicate that most areas have delivered training in the last six months to approximately 50% of staff. More worryingly, our survey identified 72 people delivering EoLC who considered that they had never received training or education in the subject (see table 6).

**Table 6: If you have qualified - when did you last receive training or education in end of life care?**

<table>
<thead>
<tr>
<th></th>
<th>Number of Respondents</th>
<th>Percentage of Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 6 months ago</td>
<td>646</td>
<td>49.92</td>
</tr>
<tr>
<td>Between 6 and 12 months ago</td>
<td>258</td>
<td>19.94</td>
</tr>
<tr>
<td>Between 12 and 24 months ago</td>
<td>172</td>
<td>13.29</td>
</tr>
<tr>
<td>Over 25 months ago</td>
<td>115</td>
<td>8.89</td>
</tr>
<tr>
<td>Following my qualification</td>
<td>31</td>
<td>2.40</td>
</tr>
<tr>
<td>I have not received any end of life education and I have not received any training</td>
<td>72</td>
<td>5.56</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>1294</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

As might be expected, frequency of post-qualification training varies in setting, as shown in table 7. Again, our data are limited by resolution in that sub-sets of role and region render sample sizes too small, but generally the trend we observe is consistent with our qualitative findings. Hospices train staff the most frequently, followed by the hospital then primary care.

**Table 7: Frequency of training by setting**

<table>
<thead>
<tr>
<th>Setting</th>
<th>More frequently than twice a year</th>
<th>Every six months</th>
<th>Annually</th>
<th>Every 2 years</th>
<th>No Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
<td>N</td>
</tr>
<tr>
<td>Community</td>
<td>112</td>
<td>36.01</td>
<td>25</td>
<td>8.04</td>
<td>85</td>
</tr>
<tr>
<td>General practice</td>
<td>15</td>
<td>40.45</td>
<td>3</td>
<td>8.11</td>
<td>13</td>
</tr>
<tr>
<td>Hospice</td>
<td>92</td>
<td>49.73</td>
<td>20</td>
<td>10.81</td>
<td>47</td>
</tr>
<tr>
<td>Hospital</td>
<td>121</td>
<td>26.95</td>
<td>32</td>
<td>7.13</td>
<td>114</td>
</tr>
</tbody>
</table>

Of these, 43 would loosely be considered nurses, and most of the remainder would be a variety of therapists, including speech therapists and physiotherapists.

Social care workforce excluded due to low numbers of respondents
This leaves us with a dilemma: it is our strong belief that HEE should invest, as far as possible, in building a strong bedrock of EoLC awareness and training in the earliest stages of education. However, it seems clear that these efforts will need to be repeated throughout different strata and stages of career development if they are to reach all staff. One important finding, evidenced through published research and anecdotal evidence is the point that classroom-based education must be reinforced by actual, practical experience.\textsuperscript{48}

We identify three key opportunities for HEE to make a specific intervention: in achieving formal qualifications, at induction, and through continuing professional development. Accordingly, our recommendations are structured around these discreet areas: formal qualification in the early years of learning; induction and continuing professional development. Given its remit, HEE cannot directly steer these areas, but must work cooperatively with its partners to effect change and to ensure a consistent approach.

**Formal qualification in the early years of learning**

One of the frequent issues in EoLC is the variability of training, and for nurses and doctors, this starts at the undergraduate degree level. EoLC is already mandated in undergraduate curriculum for nurses and doctors, and elsewhere we advise engaging in dialogue with the royal colleges and GMC to understand what the revised curriculum will cover for both EoLC and communication skills. A further topic to address with these stakeholders is how HEE can support a high standard of delivery in degree teaching.

We heard anecdotal discussion of some universities offering medical degrees for doctors that included placements in EoLC and guest lectures from frontline specialist palliative care workers. In other settings, only 30 minutes are devoted to teaching EoLC, and in some cases the topic was incorporated into other subject areas. Given its role as a funding body for HEIs, it may be a valuable exercise for HEE to strengthen its direct links with the sector to explore how the degree curriculum for doctors and nurses is being interpreted in different universities. These conversations may not only provide more robust evidence of teaching variation but will also provide opportunity for HEE to encourage HEIs to develop a strong foundation level of teaching for nurses and doctors in EoLC.

The diversity of AHP roles is substantial and without a universal starting point. Professionals complete specific courses, but there is no guarantee that these include

\textsuperscript{48} Source: Classroom-based and distance learning education and training courses in end of life care for health and social care staff: A systematic review. Palliative Medicine 2013 March; Vol. 27 (3), pp. 221-35. Pulsford, David; Jackson, Georgina; O'Brien, Terri; Yates, Sue; Duxbury, Joy www.ncbi.nlm.nih.gov/pubmed/22126845
an EoLC component. In considering a foundation education that would enable a professional to care for a dying patient, we looked for an existing qualification that could cut across these different roles.

The Care Certificate is an opportunity for healthcare staff to acquire caring skills and, following development with SfC, SfH and HEE, the certificate represents a comprehensive tool that teaches a set of care standards universally appropriate for patients. It is easily accessible, has well-structured, evidence-based materials to support in-house training and provides a single, standardised qualification. Critically, the certificate (intended for both the healthcare and social care workforces) does not include a standard on EoLC; yet the standards it does include underpin a philosophy of care that, if embraced, would go a long way to inculcating the necessary skills.

We suggest that a meeting with the Leadership Alliance for the Care for Dying, SfC and SfH should be set up to audit the extent to which the Care Certificate, as is, covers the skills required for carers looking after dying patients. Where there are gaps, one suggestion (made by some of our experts) is to incorporate additional material or a standard for EoLC, but those from a social care background noted that this would be irrelevant for many of their staff. We would suggest, therefore, looking to see how adjunct resources could be linked to the certificate to support its relevance for AHPs and other healthcare staff working with dying patients who may not have had EoLC in other learning contexts. One option might be to link the certificate to an optional component or specific e-ELCA module for staff who are likely to have an EoLC role. Further dialogue on supporting the uptake of the care certificate by employer organisations and review on its reception amongst staff would also be valuable.

In our own research, the principle and content of the care certificate was applauded, but the four points below were raised in discussion that HEE should explore further with SfC and SfH when considering the utility of the care certificate in EoLC. These concerns are:

1. Without external verification, some employers may not invest the requisite time and thought into the evaluation of staff needed to make the certificate a meaningful reflection of ability.
2. We should review statistics for/seek to measure the current uptake of the Care Certificate – do these reflect the intentions and hopes of the partner organisations, or do employers need additional incentives to implement it? If so, would emphasising the link to CQC requirements more strongly on the
HEE/SfH websites have a value in ensuring that certain staff who have not received any other formal training in caring have the basic skills they need?

3. Presentation of the Care Certificate, its materials and structure are much clearer and easier to access (for free) on the Skills for Care website than elsewhere; on Skills for Health, the user is directed to a paid link. It would be best to mirror the presentation of SfC as this is simpler to navigate.

4. What is the demographic of participants on the Care Certificate course? What is the overlap in material for nurses and doctors – do they see a value in the material? Participants at one of our workshops felt this was worth exploring as a way of reviewing the reach of the certificate.

**Induction**

We acknowledge that induction is the purview of employer organisations, and it is up to them to tailor the experience in such a way that is of maximum benefit to their teams. We believe induction is a logical opportunity to raise awareness of dying patients for staff and wish promote the practice of devoting a short time to EoLC as part of this process. To this effect, HEE should identify, collate and update a suite of tools suitable for use as part of the universal induction for Trusts and Employer Organisations – these should be made available on the hub described in recommendation 4.

These tools should be designed to provide core training in recognising and responding to a dying patient, and should reflect the minimum level that is appropriate for generalists throughout the healthcare workforce, clinical and non-clinical. We appreciate that given placement rotations, junior staff may experience repetition of material within a relatively short time-frame, as may other staff moving roles; ideally, this may serve to: re-enforce material; orientate staff as to the specific procedures used in that team; introduce systems for collaborative working with palliative care specialists and make new staff aware of the named individual with responsibility for personalised care planning.

Many Trusts already use excellent and creative in-house tools for EoLC training at induction – one example, ‘Darkness in the Afternoon/Barbara’s story’ uses a video to explore a patient’s story; although brief enough for use in induction, the film is deeply moving. Other creative examples we were made aware of included Patient Voices and linked in with the material from Dying Matters. We advocate seeking the input of LETBs to identify successful case studies and using the proposed HEE

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49 This was true at the time of writing, July 2015.
hub to share some of these. Looking at the Skills for Care website, there is a section for employers within EoLC focusing on induction, usefully linked to both the care certificate and also the relevant CQC requirements. This kind of sign-posting may be helpful, particularly the cross-referencing with CQC inspection standards to illustrate how a learning intervention can be used to meet a requirement.

We note that, in addition to materials posted on the SfC and SfH websites, most of the Leadership Alliance for the Care for Dying partners have excellent introductory resources on their sites which could be reviewed and collated to build this induction library. We advocate cross-referencing and cross-linking between sites to increase visibility as far as possible. Comments from our survey suggest that e-ELCA has some basic introductory components that might be suitable in some induction settings for junior staff.

Brevity may be the key to success here – material that can be viewed as a video, short collaborative discussion exercise, interactive tool or even a powerfully visual leaflet is more likely to be used in induction than a more comprehensive but time-expensive course. Universal training, no matter how minimal, will get staff thinking and talking about death – this in itself is a significant barrier to break for some. Members of staff are also members of the public, and publicising initiatives such as ‘Dying Matters’ can provide a topical in-road to the subject.

For HEE, the task will be to collate what’s already out there suitable for induction in one place, and sign-post the information.

Continuing professional development

CPD represents a wide target for intervention and we aim to increase the visibility, motivation and impetus for staff to engage in EoLC courses following their initial training. As CPD is outside the remit of HEE, it will require collaborative working in partnership to promote this strategy. Key contextual barriers were explored and considered alongside levers that may be used to increase provision and uptake of CPD in EoLC. In brief, core barriers to training included:

1. Time – staff are “too busy fire-fighting” to take time out to train
2. Support – leaders don’t see EoLC as important, so it is not prioritised in training and education, exacerbating (1)
3. Funding – commission funding is usually directed to mandatory training – and EoLC is not usually mandated

We discuss funding in recommendation 5, but the two other critical barriers, time and support, are linked to priorities. A shortage of time is a perennial problem, and
ensuring that EoLC is valued highly enough that if HEE, with partners, seek to increase the opportunities for staff to learn, these course placements are taken. While HEE cannot influence the (invariably stretched) hours in a day, it can vocally and publically raise the EoLC as a key area - for EoLC to become more embedded in training strategies, it needs to be a benchmarked priority. This also needs to be a long-term, enduring commitment rather than a finite trend.

“There used to be lots at training but there has been a change over time – number of people coming to our courses has dropped off – 10-15 instead of 50-60 – the quality of training not changed, but people can’t get time off (especially ward workers and community nurses)”

- Comment from focus group participant

There are several avenues that HEE could explore in order to increase the motivation for learning EoLC skills. The first is to commission training that links to CPD points; a caveat here is that this should not default to online learning which, although valuable (and discussed in more detail in recommendation 8), does not, in isolation, always provide the depth of skill needed. A potential barrier in CPD, given time constraints, is a lack of consistency in the quality of training – given that time is precious, accreditation and validation of learning material is useful not only to ensure quality but also to indicate value and relevance to potential participants. Skills for Health offer national occupational standards – HEE could explore the possibility of introducing such a measure for aspects of end of life care to strengthen training around a particular area of need.

We note that the NMC has introduced revalidation and, as with the GMC, this process may provide an opportunity to link CPD with a compulsory requirement; as revalidation itself is subject to change, HEE should discuss with both organisations what scope there may be to strengthen the requirements for EoLC skills as a prerequisite to practice.

Annual training initiatives that are focused and consistently rolled out across organisations may be more successful in implementing a culture change as they attract a critical mass of attendees. These rely on a clear issue to explore, funding and visibility. Numerous possibilities exist for EoLC; our survey, for example, cited ‘bereavement, communication and symptom management’ as the three aspects of EoLC where additional training support is most needed53. We also note that a skills audit locally may identify technical training as the priority – for example, clinical

53 Small sample size for this question (n=250) reduces validity.
decisions regarding starting or stopping artificial hydration or nutrition are particularly challenging, and may represent a clear target for organisational training.\textsuperscript{54} Below we list three commonly cited priorities which we believe would provide a positive intervention if considered as part of an annual widespread strategy.

**Focus for annual training 1: Recognising that a patient is nearing the End of Life**

Many interviewees observed that (across different settings) staff do not always notice when a person is dying; at the very least, a member of staff without the requisite skills to act as the principle carer throughout the dying process must be able to recognise when and how to bring in the additional support a patient needs.

**Focus for annual training 2: Responding to a patient’s need to talk**

Some of our participants observed that a dying patient may choose to talk about their prognosis, illness or death with any member of staff caring for them, regardless of whether that person is a dedicated expert. All staff should, therefore, feel able to conduct a difficult and unpredictable conversation (see also recommendation 6).

> “There are a lot of healthcare professionals who for various reasons have zero education on end of life”

> “We don’t have a national health service but loads of little local health services... There is no place in this country where people don’t die so it should be fundamental foundational core competency for everyone”

> “EoLC doesn’t just take place in a hospice or ward specifically designed for EoL patients, it happens on every ward”.

Everyone gets CPR training – but so many people never have to deal with cardiac arrests. But people doing End of Life Care every day have no training.

- Statements from our focus groups

**Focus for annual training 3: Personalised Care Planning**

A fundamental aim is to increase generalists’ confidence in EoLC by providing a framework for them to conceptualise some of the more ephemeral conversations, behaviours and emotions that can feel challenging. Many of our interviewees

believed that the value of a personalised care plan is that it is a potential
communication tool that can be used to stimulate discussion with a patient about
their wishes and needs. An agreed personalised care plan, subject to regular review,
is a specific element of the NHS End of Life Care Strategy. Several examples of good
practice focused on using personalised care plans were cited, and represent
opportunities for shared learning (see case studies).

### Callout box 14: personalised Care Planning

A frequent comparison we heard was that a personalised care plan should
operate similarly to a birth plan; it acts as a guideline that everyone should have
and a named person (equivalent to a midwife, but designated from a variety of
different sectors/settings) oversees this and co-ordinates care. It allows
healthcare staff to capture the wishes and treatment plan for the individual. It
can be shared with carers, friends and family, and it can also be changed as often
as needed to reflect any changes in circumstance and patient choice. The plan
should be a critical focus for communication, caring and practice around EoLC.
This is also supported by the findings of the Health Select Committee.

HEE supports the use of a personalised care plan as a tool for communication and
advocates training in its use, which has shown to increase the proportion of patients
offered planning and may also support difficult conversations. We do so,
however, with the caveat that it should not become a proxy replacement for the
Liverpool Care Pathway. It was observed that in some cases, the original ethos and
rationale for the LCP had been upheld and used to instigate compassionate
decisions, shared responsibility with relatives and to manage death compassionately.
In other cases, the reverse was true.

There is a danger that any replacement strategy becomes vulnerable to the same
diversity of interpretation and culture of managerialism if the emphasis becomes
placed on a standardised approach where practitioners are, under extreme pressure,
defaulting to an automated process rather than a responsive, reactive treatment

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spcare.bmj.com/content/3/2/227.3.abstract
plan. This is particularly important given that patients change their minds regarding preferences. The challenge for HEE is to support intelligent, responsive practice that can be adapted to meet the needs of a situation not a form, but which is still robust enough to ensure that a minimum level of high quality care is available to all dying patients.

“Generic protocols are not the right approach to caring for dying people: care should be individualised and reflect the needs and preferences of the dying person and those who are important to them.”

- Once Chance to Get it Right

Focus for annual training 4: pain relief training for GPs

One area we feel is worthy of particular exploration is the role of the GP in prescribing stronger pain relief for those dying at home and/or in another community setting. Given the pressures on palliative specialists and also in pain management, the benefits of GPs managing pain relief in EoLC are significant. Pain relief is not well supported in the home environment compared with, for example, a hospice setting (pain is relieved completely, and all of the time, in 18% versus 62% of cases respectively according to VOICES survey data). Upskilling GPs in pain relief may support more patients in realising their preference to die at home. We recommend that pharmacological intervention at EoL to manage pain adequately should be a priority in the community setting.

Training for generalists working in EoLC

Our emphasis in this chapter has been to explore the process by which generalists can be upskilled; we recognise that for specialists, the continuing professional development aspect is the most relevant, and this should of course operate at a more advanced level of training. One grey area to address is the population of nurses and doctors who do not hold a ‘palliative specialist’ job title, but who spend a significant proportion of their time treating dying patients – should these individuals receive an increased quota of CPD analogous to their responsibilities? It is a judgment call for employers and line managers, and staff themselves, to recognise

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58 A survey of patient wishes found more people preferred to be in a hospice as they approached death, but conversely, fewer people wanted to be at home – the proportion dropped from 91% in the final year to 63% in the final days. www.sueryder.org/About-us/Policy-and-campaigns/Our-campaigns/Dying-isnt-working/A-time-and-a-place

when a peripheral involvement in end of life care (as might be experienced by a GP) becomes a central component of a person’s role (as may be the case for a physiotherapist working in a care home). In this respect, CPD needs to be applied fluidly, with a proportionate increase in continuing learning relative to the role.

Following on from this point, while there are, as explored already, universal skills that cut across different roles, in CPD the focus will need to shift to the individual needs of the staff member, taking into account their knowledge base, previous learning, years of experience and day to day role.

“There needs to be a practical element. Having some core training that is multi-disciplinary and acknowledges huge overlap in skills needed to be used with patients, there’s also need for something role specific”

- Focus group participant

The final chapter of this report promotes opportunities for blended learning, which may suit different individuals’ approaches and, ideally, provide scope for more creative ways to engage staff imaginations.
Case study: EoLC Learning Outcomes – developed for Health Education Yorkshire and the Humber by Dr. Vanessa Taylor.

The End of Life Care Learning Outcomes (EoLC LOs) has been supported and developed in part by Health Education Yorkshire and the Humber (HEYH). It is primarily aimed as “ensuring that health and social care staff at all levels have the necessary knowledge, skills and attitudes related to care of the dying” (The End of Life Care Strategy 2008). The initiative supports the view that ‘EoLC should be included in induction programmes, continuing professional development and in appraisal system’ (The Royal College of Physicians 2014).

The EoLC LOs work focuses on four staff groups:
2. Pre-qualifying health and social work students at the point of registration.
3. Registrants providing palliative care approach/general palliative care.
4. Registrants providing specialist palliative care.

The EoLC LOs were developed using a framework that was informed by the national policy context for palliative and EoLC. This also included published guidelines for the educational and clinical standards of pre-qualifying students and registrants to deliver EoLC, alongside career structures and guidance for advanced level practice.

The EoLC LOs incorporates:
- Feedback from Higher Education Institutes across Y&H who deliver pre-qualifying programmes for Nursing, Medicine, Allied Health and Social care.
- Feedback from a consensus group of registrants providing general and specialist palliative care across HEYH.

The EoLC LOs which are currently being piloted are focused on; unregistered support workers, registrants providing general or palliative care, incorporating; specialist palliative care practitioner; specialist palliative care and advanced specialist palliative care practitioner.

HEYH is of the view that the EoLC LOs with the support and recommendation of our major stakeholders e.g. NHS England, National Council of Palliative Care, Hospice UK, Royal College of Nursing, Royal College of Physicians, have the potential to be used in the following ways;
- Support the commissioning of education and training required for EoLC in pre and post registration programmes.
- Support clinical staff and their managers to identify professional development needs and demonstrate learning that has been undertaken and well as supporting career development.
- A framework to support revalidation nurses and other health professionals.
Case study: Worcester hospital and Coventry hospital – ‘green sleeves’

These are built from the patient notes. The care plan and patient’s wishes are incorporated, and the patient can take the Green Sleeves to hospital with them so that at all times people can see their wishes are. National Transform programme – fabulous resources and heaps of work on measures – the data is being collected there.
Recommendation 8:

Support Blended Learning to deepen knowledge in EoLC

Blended learning has various definitions (see call out box 15), but for the purposes of this chapter, we are referring to the practice of mixing the approaches used to teach a topic in order to improve proficiency. Our interpretation is based on feedback from our interviewees, and starts from the belief that a practitioner, in the course of their career, should be exposed to different types of learning experiences. A diversity of teaching methods can reinforce core material, expose staff to new ways of interpreting their existing knowledge and support the fact that people have different preferences for the way they learn. The suggestions in this chapter should work in combination not isolation; the exact blend will depend on resources and regional considerations.

**Callout box 15**: What is blended learning?

1. To combine or mix modes of web-based technology (e.g., live virtual classroom, self-paced instruction, collaborative learning, streaming video, audio, and text) to accomplish an educational goal.
2. To combine various pedagogical approaches (e.g., constructivism, behaviorism, cognitivism) to produce an optimal learning outcome with or without instructional technology.
3. To combine any form of instructional technology (e.g., videotape, CD-ROM, web-based training, film) with face-to-face instructor-led training.
4. To mix or combine instructional technology with actual job tasks in order to create a harmonious effect of learning and working.

**Blending learning experiences throughout the career pathway through placement**

Initially, we considered ‘blended learning’ in the light of an individual’s career pathway – we conceived a general progression from theoretical, text-based learning in a traditional educational setting to experiential ‘on-the-job’ learning. Feedback from students suggests that ‘blending’ can and should happen at every stage within a career, rather than in progression: an undergraduate nurse may benefit tremendously from a placement in a hospice. A doctor wishing to deepen their knowledge and develop their specialism in palliative care may benefit from going back into a class-room environment to take stock of new evidence. Pragmatically, the model we discussed with senior trainers was one that allows students who had not yet qualified a ‘taste of the coal-face’ to enrich their course
material. Conversely, we also need a model that periodically brings specialists out of their clinical environment through continuing professional development.

We suggest that HEE should proactively build relationships that help HEIs offer student placements. We believe that, provided the setting has a positive culture and strong practice, undergraduate placements may bring a new dimension to EoLC learning in these critical early years. Recognising that high calibre EoLC may be delivered in care homes, hospice, community, primary care or hospital, placements should follow the best opportunities available; this strategy is ultimately dependent on the good will, vision and resources of the institutions involved. An alternative is to support a ‘guest lecturer’ role in which an experienced palliative care practitioner delivers modules or elements of the EoLC course. Hospice representatives in our interviews had experience of doing this and spoke of positive relationships with universities who valued the frontline perspective.

HEE also has a role in supporting institutional ‘link ups’ to support placement opportunities as part of a blended learning experience. The QUELCA programme, described briefly in our earlier case study, exemplifies how hospice placements in particular can positively improve nursing practice in EoLC in the hospital setting. This type of national initiative creates a successful framework for hospice placements, would seem to be a good way of maximising the benefits of this type of learning.

The different pace of practice may offer an advantage for learning certain technical skills: one nurse spoke passionately about the experience of learning how to use syringes for pain relief. Having spent a half-day of training in the theory, the frenetic pace of her hospital ward setting made her feel unable to put into practice the newly acquired skill. The increased supervision, calmer environment and ability to practice at a slower pace (if needed) made a hospice placement invaluable for building confidence in skills that could then be transferred back to the ward setting. It may well be that the value of a placement is the transferrable skills it helps embed, but these are not always predictable.

A caveat to these advantages was made by attendees at our London course, who cautioned that the environments of a hospital, hospice or GP surgery are often too different for EoLC experiences to translate easily. In particular, ward staff seconded to a hospice for learning may prefer the pace, culture and treatment of patients, but on attempting to bring back those principles to their own working environment, they may face a strong culture clash. What makes the difference is the support and follow-up strategy that frames the placement.
In this respect, we believe that there are several options to support placement style programmes: first, if possible, encouraging small group placements may help any learning from a different culture to be reinforced by more than one member of staff; the group works collectively to consider their experience can be translated into their own environment. Second, building strong relationships between different institutions to develop more frequent placements and exchanges of staff can support shared-learning and peer-to-peer communication. Finally, as with the role of a ‘guest lecturer’ in HEI, taking a representative of a different sector into various environments for short talks or practice audits can build further on relationships between institutions. The role of the LETBs in sharing the processes and building local relationships to support a culture of placement learning will be vital, and this is an area that HEE should discuss further with LETB leads.

**Supervision and mentorship**

Supervision and mentorship play a critical part in the training of pre-registration nurses and doctors. In general, mentorship consists of knowledge sharing through the mentor’s demonstration of good practice, observation by the mentor and, where necessary, correction of mentee’s practice. Psychological support as needed, encouragement and the identification of the specific learning needs of the individual are further elements. Mentorship usually occurs over a prolonged period of time and develops through the relationship between individuals – this may be more difficult to achieve given an environment in which people undertake brief placements during the foundation years, during which mentorship is most needed. However, we heard from our contributors that even short periods of good mentorship can have a strong impact.

Staff members we spoke to recalled their own experiences of learning from a role model whom they were able to emulate. Those who had received thoughtful mentoring believed that this informal, continuous learning was a powerful contributing factor to their personal development. This hands-on teaching is critical to emergent independent work and also critical for supporting the transitional jump students must make from their initial qualifications and theoretical learning to delivering healthcare.

This transition is particularly stark in End of Life Care, where an individual’s first experience of someone they have cared for dying may be profoundly moving, shocking or even traumatic. This is true whether the person in question is a newly qualified physiotherapist tending a hospice resident, a trainee nurse on a community placement or a pre-registration doctor on a ward round. This first occurrence of death may influence, positively or negatively, subsequent clinical practice and as far
as possible, EoLC training should recognise this by framing the experience with supportive mentorship. One interviewee commented that “medical students are required to attend births; how many have ever had to attend a death?” Consideration of death as a fundamental experience of medicine deserves specific attention.

While mentorship is usually associated with the early stages of career, we heard from our interviewees that should not be limited to the foundation years but should be available to any member of staff for as long as they need it. In particular, experienced doctors and nurses working outside of palliative care, for example in primary care, felt they would benefit from mentorship from a palliative care specialist – in this respect, the opportunity to debrief and discuss potentially stressful EoLC cases provides not only learning but also emotional support.

We frequently heard that in hospitals, the time given to this mentorship is under constant attrition due to the pressures of service delivery – this was true across the sectors. Mentorship, while universally recognised as valuable, was sporadic and frequently disrupted, particularly for younger staff. A frequently expressed opinion was that mentorship is in danger of becoming a ‘tick box’ exercise – trainees may be apprehensive about expressing their insecurities or lack of knowledge, and, in turn, mentors are motivated to hurry training to release new members of staff for unsupervised service delivery. The challenge for HEE is how best to support this very personal relationship, so critical for learning, without imposing increased monitoring or requirements which may add barriers rather than support the practice.

The supervisory role is more formally described than mentorship in clinical medicine, but in practice it is interpreted variably across regions, sectors and environments. In some cases, a supervisor is also a mentor. In others, the roles are distinct. While the aspiration must be that staff members each have a supervisor, in reality, from our interviews, this is not always the case in hospital settings. A named supervisor, as identified by a Trust, often does not correspond with the person who in practice holds a clinical supervisory role.

We suggest that HEE needs to explore with training regulators how best to embed the role of supervisors and mentorship in the curriculum at pre-registration level. Our proposed recommendation is that HEE should initiate, host and facilitate a discussion with senior clinical leadership (Royal Colleges, GMC) to discuss their expectations of these two critical roles. Collaboratively, HEE needs to identify the barriers that currently prevent or undermine supervisors from fulfilling these expectations. Representatives from NHS England, Employer groups and political representatives able to address these barriers should be present and willing to
commit to the changes needed to support the supervisory role. Supervision and mentorship is no less important for AHPs, where the structures in place for these roles are highly variable as well. The same principles apply, and we recommend a separate sequence of discussions to address the differing barriers that AHP staff face.

While the lead for this work must come from training regulators, in practice supervisors can only meet their obligations if given support from employers in a culture where sufficient time and resources are available for them and their trainees to focus on learning. This is a deeper, systemic issue that will need broader support, hence HEE has a role in mediating the discussion to ensure that the barriers to supervision that are connected with service culture can be heard by the relevant organisations and responded to.

EoLC champions are logical mentors and, where used, have proven successful; currently, the NHSIQ network of EoLC\textsuperscript{60} facilitators and social work champions, mediated by Hull University incorporates 700 volunteers. HEE should, though the work of the LETBs, proactively review the existing provision of EoLC champions across the country (many trusts support the role already) and ensure funding for new champions where needed. Part of the challenge will be to ensure that there are sufficient numbers of champions to make mentorship a genuine opportunity for all staff delivering EoLC. The role itself should sit in hospitals, primary care and community-based care, such that each setting (and each member of staff) has access to an EoLC champion. It is, we believe, unlikely that a Hospice would need an EoLC champion to the same degree, although a Hospice member of staff might be an appropriate choice of Champion.

LETBs may be best placed to consider the number, distribution and set-up of local EoLC champions. HEE should take an active role in defining the expectation of the informal mentorship the Champion is to provide, and also any desired outcomes. This basic set of principles may also be augmented by additional requirements from the LETBs, for example, the mentor may have a valuable role in supporting local learning outcomes or objectives.

**Online learning**

Overwhelmingly, the feedback we received was that “experiential learning is invaluable” in EoLC. There was a strong backlash against an increasingly perennial

\textsuperscript{60} \url{http://www.nhsiq.nhs.uk/7935.aspx} and \url{http://www2.hull.ac.uk/fass/centre-for-end-of-life-studies.aspx}
view that the digital environment solves training and education issues – not everyone learns in the same way, and HEE acknowledges in this report that the emphasis of EoLC learning should not be through e-learning.

There was a perception that s-learning is chosen as a cheap alternative to real life training. If used inappropriately it can cause, paradoxically, both over-confidence (through a misplaced belief in competency that is only theoretical) and a lack of confidence (some staff lose confidence because they are expected to deliver skilled practice that they have not had practical experience of). With e-learning, there is no way to query what a member of staff has really learned – workshop participants in particular noted the ease with which it was possible to ‘cheat’ on an e-learning course. Yet, despite these drawbacks, the participants in our research acknowledged that for CPD, online courses provide an ‘intense, concise hit’ of knowledge that is undeniably convenient. For HEE, the important question is what is the value of e-learning and where does it fit in with a blended learning approach?

E-learning can provide a technical sum-up of specific pieces of information that, if complemented with ‘on the job’ guidance, provide a useful introduction to EoLC that can be tailored to role. Tailored learning can be supported through well catalogued, well sign-posted modular based programmes in which a practitioner selects only those modules that specifically relate to their role. The value of e-learning does, however, rest strongly on a user’s ability to identify modules that are genuinely appropriate to their role and baseline knowledge.

The e-ELCA online learning programme (see call out box 16) is continually updated; HEE should liaise with, and support this process.

This report contributes to that exercise by bringing together some key barriers to its use that can and should be addressed (see call out box 17). These were primarily identified through our discussion groups and interviews as, notably, our survey yielded very little information on e-ELCA – 13% of respondents claimed it had little or no positive impact and 14% claimed it had some positive impact – the majority of respondents (72%) did not answer. This may reflect a lack of awareness or knowledge of the e-ELCA.

This report suggests that, in the context of e-learning, HEE should provide full support for improving, disseminating and supporting e-ELCA rather than investing time or funds in other digital tools.
Callout box 16: description of the E-ELCA online learning programme

Overview
e-Learning for Healthcare (e-LfH) is a Health Education England Programme in partnership with the NHS and Professional Bodies providing high quality content free of charge for the training of the NHS workforce across the UK. e-ELCA (end of life café for all) is one of many free online training resources that aims to enhance the training and education of all those involved in delivering end of life care. Commissioned by the Department of Health (DH) to support the National End of Life Care Strategy (2008), e-ELCA has been developed by the Association for Palliative Medicine of Great Britain and Ireland in partnership with e-LfH. It offers around 150 easy to use and interactive e-learning sessions covering all aspects of end of life care such as assessment, advance care planning, symptom management and communication skills to all NHS staff and social care staff via their employer NMDS-SC (National Minimum Data Set for Social Care) registration code. The code will enable each individual employee to self-register for access to e-ELCA.

Access
For health care workers, e-ELCA is available to access through a number of different ways depending on an individual’s role.

- **Existing e-LfH users and GPs** Those health care workers currently accessing another e-LfH e-learning project and GPs should email elca.support@e-lfh.org.uk to arrange access.

- **NHS health care staff (excluding doctors)** NHS health care staff, excluding doctors, should contact their internal trust training and development lead about accessing e-ELCA via the National Learning Management System (NLMS). The NLMS is the e-learning platform fully integrated with the Electronic Staff Record which means activity from e-ELCA learning will be recorded against an employee portable training record.

- **New e-LfH users (doctors - except GPs)** Those doctors, except GPs, new to e-LfH e-learning should complete the registration form at www.e-elca.org.uk. A username and password will then be issued.

Evidence of learning
The sessions will each result in a certificate as proof of completion. While the sessions might or might not contribute to registration requirements such as continuing professional development depending on the profession, the certificates will be evidence of learning activity.
Callout box 17: e-ELCA revisions suggested by our research

- The technical infrastructure it uses can’t be easily imported; nursing homes, for example, are not able to access it.
- e-ELCA was not easy to find in all settings; hospice, community, care homes and GPs surgeries should all be able to access it. Many practitioners we spoke with had never heard of e-ELCA. Those outside of the hospital environment in non-clinical roles in particular didn’t know the social care workforce, Hospice workforce and care home workforce could access e-ELCA for free.
- Improved sign-posting and an indication of the level of training would be helpful; several of our survey participants commented that some of the material was very basic and should be targeted at induction level or very junior staff, whereas other elements were suitable for CPD.
- EoLC components should be fit for purpose and cross-referenced with CQC requirements, standards and guidelines so that employers and supervisors can see clearly which outcomes are addressed.
Successful e-learning rests on the culture that surrounds it. It was noted that e-learning is used as a means by which staff can be expected to ‘learn in their own time’. While most people we spoke with at a senior grade felt it was not unreasonable for them to use an e-learning course in their own time for CPD, and that many staff actively choose to do so, it is a problem if less experienced, junior staff are required to train in their own time. Expecting junior staff, especially those under intense pressure working long shifts, to learn in their free-time was considered inappropriate. Working environments that do not offer access to computers limited the feasibility of e-learning further.

Where e-learning is seen as a desirable educational tool, time for that training must still be safe-guarded for staff as a taught offline course would be and staff should have access to computers if the expectation is that e-learning will form a significant part of their personal development.

**Getting the most out of formal courses**

When we asked practitioners, in our survey, to comment on the quality of the education they had received in EoLC, the feedback was broadly positive (see table 8). However, this kind of question is a fairly blunt instrument, and it was in the qualitative responses (where we sought to define the reason for the rating) that we learned more.

**Table 8: Feedback on the quality of EoLC**

<table>
<thead>
<tr>
<th>How would you describe the quality of the education in end of life care that you have received over the past two years?</th>
<th>Absolute Numbers</th>
<th>Percentages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Excellent</td>
<td>358</td>
<td>33.36</td>
</tr>
<tr>
<td>Very Good</td>
<td>308</td>
<td>28.70</td>
</tr>
<tr>
<td>Good</td>
<td>171</td>
<td>15.94</td>
</tr>
<tr>
<td>Adequate</td>
<td>103</td>
<td>9.60</td>
</tr>
<tr>
<td>Poor</td>
<td>44</td>
<td>4.10</td>
</tr>
<tr>
<td>No Answer</td>
<td>89</td>
<td>8.29</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>1073</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

Positive responses specifically mentioned courses and providers that had made a specific impact: Six Steps, Sage and Thyme, GSF, MacMillan (End of Life Academy) and Hospice education were frequently lauded. Notably, not only did these providers/courses receive attention in our survey, but they were also discussed at length by focus group and workshop attendees, who also referred frequently to the Amber Care Bundle and the Advanced Communication course.
Several national education providers explore, as we did in recommendation 7, the concept of a baseline that cuts across sectors and have developed succinct overviews or tools that can be used within to up-skill to a minimum standard. Looking at these are useful for exploring how principles are translated into learning tools. The GSF prognostication tool\(^{61}\) and basic course are two examples that work to a universal baseline.\(^{62}\) We also received much positive feedback for the AMBER care bundle, which builds on recognition of a potentially dying patient to trigger care planning.\(^{63}\) We suggest reviewing, collating and clearly sign-posting these to enable employers to identify materials that best fit their workforce. While it may not be the place of HEE to promote specific, private sector providers over others, it maybe useful for employers, commissioners and LETB leads to know nationally available courses that cover the needed material and which have consistently received significant positive feedback.

Popular topics that survey respondents felt had made a significant difference included: symptoms management; advanced communications skills; Mental Capacity Act training and Care of the Dying. There was also an emphasis on self-directed learning, suggesting that a staff member’s ability to identify their personal learning needs and proactively undertake a course had a positive impact.

A common criticism we heard about courses in EoLC was that material can feel stale and that senior staff felt that they’d ‘heard it all before’. This may be a reflection on individual courses, but it may also suggest the need for a more sensitive appraisal system that is specific to a practitioner’s individual needs. Courses were seen as more successful when they were targeted to knowledge gaps. In terms of how this is done, we heard a strong call for employers to move away from tick box appraisals and focus instead on qualitative assessment that engages supervisors more deeply. Appraisal to identify EoLC training needs should also recognise the considerable depth of knowledge that comes simply from experience; retraining staff who are experienced and also who are performing well is a redundant exercise. While we accept that staff may not always be aware of their own limitations and may have misplaced confidence in their abilities, we also recognise that there is not necessarily a correlation between training and knowledge. The role of a supervisor in identifying where training is necessary and what specific areas it should target is critical.

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\(^{62}\) (http://www.goldstandardsframework.org.uk/library-tools-amp-resources)

\(^{63}\) http://www.ambercarebundle.org/homepage.aspx
Good supervision and assessment recognises not only the technical skills that a practitioner needs, but also individual, character-based needs, which may elude the formal, structured process. For example, a person may have been taught the pharmacological tools for pain management, but lack confidence in using them and require more support. Another individual may have had only very basic communication training but have naturally strong abilities. HEE should initiate, host and facilitate a discussion with NHS Employers, Trusts and NHS confederation to explore how peer-reviewed (and other) appraisal tools can be further developed to identify individual, specific training needs more sensitively – this should be part of the previously described conversation about the role of supervision per se..

Assessment can operate at different strata, and scoping a regional workforce can provide valuable insight into localised practices within a LETB area – specifically, the best way to identify the best local courses and activities may be to run a scoping exercise specific to the region (see case study). This is another way to get the most out of formal courses.

**Training the different sectors of the healthcare workforce together:**

HEE should support integrated learning through encouraging programmes that bring different sectors together. Learning together ensures that overlap between roles can be recognised which in turn supports, as recommended by the Shape of Training Report, a more flexible workforce. Challenging the culture of expectation about fixed roles and responsibilities through shared training may increase staff willingness to assume responsibility for EoLC tasks they might previously have considered out of their domain.

“One of the barriers is that we stick to the old-fashioned hierarchy of “you’re a doc you do this, you’re a nurse you do this”. There’s a lot of cross-over in terms of educational requirements. Training shouldn’t be defined by the role but by your contact with the issue.”

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64http://www.shapeoftraining.co.uk/static/documents/content/Shape_of_training_FINAL_Report.pdf

“I feel completely confident in raising end of life issues, however this is due to clinical experience and exposure, rather than any training that I have received”
- Survey respondent
It is, however, a necessary prerequisite of the course design that it be formulated around areas of learning that are genuinely transferable and applicable to each participating workforce; recognising that individuals from a team will have very different knowledge basis and daily roles is vital, and ensuring that content is a good match for all attendees should be a first stage.

Courses focusing on communication, caring skills, the spiritual aspects of EoLC and psychosocial factors but which do so to a substantial depth may be the most successful here, rather than those which appertain to technical skills.

We see a particular value for training across the healthcare and social care workforces for patients who prefer to die at home (79% express this preference in the National Survey of Bereaved People – VOICES) and/or who are cared for in the community. Here, several different staff roles must work together to provide seamless care. Transitions between care settings are compromised by ‘gaps’ between services. Similarly, poor co-ordination of care can be a challenge for UK generalist clinical settings yet this is a critical factor for improving palliative care provision in the community. The relationships and insights developed through shared learning, we believe, can address this problem and help patients follow their preference to die at home with an integrated care team supporting them. Some evidence suggests that training can directly affect practice: GSF accredited practices

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“*There’s a danger generic becomes too generic*”

- Focus group attendee
increased the proportion of patients dying in their preferred location from 43% to 72%, with deaths in hospital halved in some practices.69

There may be considerable value in bringing together community carers (for example, ambulatory care, social care staff, nursing palliative care, district nurses and GPs) in the same physical setting. One option for CCGs to consider is a surgery shut-down, on the basis that this requires GPs to focus their role in co-ordinating EoLC in the community, as well as introducing into the network specialist palliative staff who support the region. This option has high time-costs and it effectively mandates EoLC training in primary care – we suggest that this decision should be made regionally and collaboratively by Trusts, CCGs and LETBs where local leaders have identified a significant problem in practice due to a lack of joined up care. It may also be a way of exploring whether it is possible to increase the quality of EoLC care in the community through cross-sector training, and, in doing so, support a greater number of patients to die at home if that is their wish.

Other strategies specifically targeted to primary care include the use of (paid) locally commissioned services (LCS) arranged by the local CCG. An LCS for EoLC could use a variety of approaches, including shared training, participation in audits and quarterly meetings with the local palliative care team. This combination of elements provides opportunity for primary care staff to deepen their knowledge, reflect on specific cases and receive mentorship from specialists. This may be particularly relevant for GPs who are aware of the theory of EoLC, but do not have the day-to-day experience that embeds the practice.

These suggestions, made by our participants, should primarily be driven at the local level. For HEE, in practical terms, this equates to a directive in support of cross-sector learning which focuses on community-based EoLC. The indirect benefit will be to upskill the community based generalist workforce in developing the skills needed to support an individual who wishes to die at home.

In-house learning methods

In-house training was generally considered an organic way of up-skilling staff that is appropriate to their daily working experience. It also negates the resource implications of taking a staff member out of situ for a taught course. The greatest strength, and weakness, of this approach is that it relies heavily on the prevalent culture.

69 Source: 2. GSF Accredited practices receiving Quality Hallmark award 2012-3 Key outcome ratios. Available through: www.goldstandardsframework.org.uk/
The method of ‘training the trainers’ was referred to in our interviews and had mixed reviews. While studies suggest this model can improve practice and patient care,70 the expectation that knowledge ‘trickles down the system’ from an investment of only a few trainers sometimes proves erroneous. This was, our interviewees suggested, particularly the case where the training was not further supported by scheduled opportunities for the trainer to disseminate their knowledge and where follow-up was poorly orchestrated. The most successful strategies involved an education provider using a highly specified, rigorous protocol (for example, the SAGE programme).

We recommend therefore that HEE commissions the LETBs to identify courses that have a strong follow-up component if they involve this method. These courses should cover content that clearly addresses the skillset(s) needed by a community or defined team and which can successfully navigate the diverse knowledge bases of the intended audience. Further discussion with SfC and SfH to explore how tools for trainers can be further strengthened for specific issues in EoLC would also be helpful – for example, HEE could consider, with SfH, adapting and extending existing training materials to address some of the clinical, technical training needs in EoLC.

A frequently cited barrier was that people don't have the time to cover everything, and we need to consider different approaches to learning that get the message across but which are more deeply integrated with daily working practice. One interesting idea, cited in different case studies, was to incorporate reflective learning into regular working practice. This involves a more open interpretation of education and training, right on the boundary with practice, but for EoLC in particular it maybe a particularly important tool with great potential to support peer-to-peer learning and team working.

Reflective learning can take several different forms, but shares the general principle that staff need to take stock of existing patient cases to consider how they can learn from their own, and others’, experiences. This has a strongly supportive, therapeutic angle as well, and may be particularly appropriate for staff who find EoLC emotionally challenging, for those who engage strongly with the philosophical aspects, those who wish to work positively around the notion of what a ‘good death’ should be and in cases where particularly good or particularly bad outcomes are deserving of further attention.

This type of learning can cover diarised commitments for sharing practice reflection in a team group – the Schwartz ward review system\(^1\) was cited as a good case study for how reflective learning ties directly into practice. Another suggestion was that a system events panel for deaths that were poorly managed or difficult in some way – in effect, a serious events audit - could be used to help staff consider what could have been done differently. In practical terms, this would require HEE and LETB leads to liaise with Trusts to explore the usefulness of this practice; where reflective training techniques are already employed, sharing the practice (as through the HEE hub) might offer inspiration to other Trusts.

Failing environments, as identified by CQC, need urgently to demonstrate an in-situ, long-term transformative training approach. This is difficult to achieve if training is largely completed online or in-house – in a setting where the practice is poor, there is a significant risk that the in-house training will transmit a negative skillset to the trainee nurses and doctors who receive placements. The GMC’s current initiative to accredit Trusts as training providers will clarify and regulate this and HEE will strongly support this work. In the meantime, enabling employers to assess their environment according to CQC measures prior to formal assessment would provide a helpful tool. A poor internal assessment would signpost the fact that in-house training may be insufficient.

A successful approach, and one able to address issues of endemic, poor culture, is to use accredited, proven trainers to go in situ and work with staff across all roles to build a stronger culture in EoLC. This intervention is based on a specific assessment of learning needs targeted to prescribed learning outcomes followed by a tailored training approach. This is the strategy used by GFS and, we believe, a short-list of providers able to offer this service could be commissioned by the LETBs for use where needed. Environments that have demonstrably been found to have a poor EoLC culture should receive funding for this intensive type of training. In this respect, a helpful distinction needs to be made between ‘in-house’ (where training is based on internal expertise) and ‘in-situ’ (where an external provider may be brought in). This type of training intervention is cost-heavy, and so in these circumstances, HEE advocates the use of courses that show a demonstrable effect on practice.

Case study: The QUELCA Initiative

The national rollout and evaluation of the QUELCA programme (Quality End of Life Care for All) was designed by St Christopher’s Hospice. A detailed description of the programme and its positive effects is described in a BMJ Publication. In brief, the programme supports health professionals from acute NHS Trusts to learn how EoLC is delivered in a hospice; they are then supported in taking the knowledge back to their own practice setting. This was an intensive learning, in which 137 nurses took 5 days of learning in the hospice followed by 6 months of learning sets. Outcomes and improvements in patient care were monitored through examples given by the nurses; the majority believed that QUELCA had changed their working practice. 17 acute NHS trusts participated and liaised with 21 local hospices.

Case study: Scoping exercise into end of life care education and training supported by Health Education West Midlands

The report from this exercise, kindly provided in draft form to inform HEE research, was based on an online survey of those with responsibility for progressing the end of life care agenda and also interviews. The report explores the impact of HEWM’s investment in EoLC, reviewing commissioned projects and their impact, scoping the activities of specific Trusts and employer organisations. The outcome is a tool for informing HEWM’s future decisions around training strategy.
Appendix:

Bibliographic Database