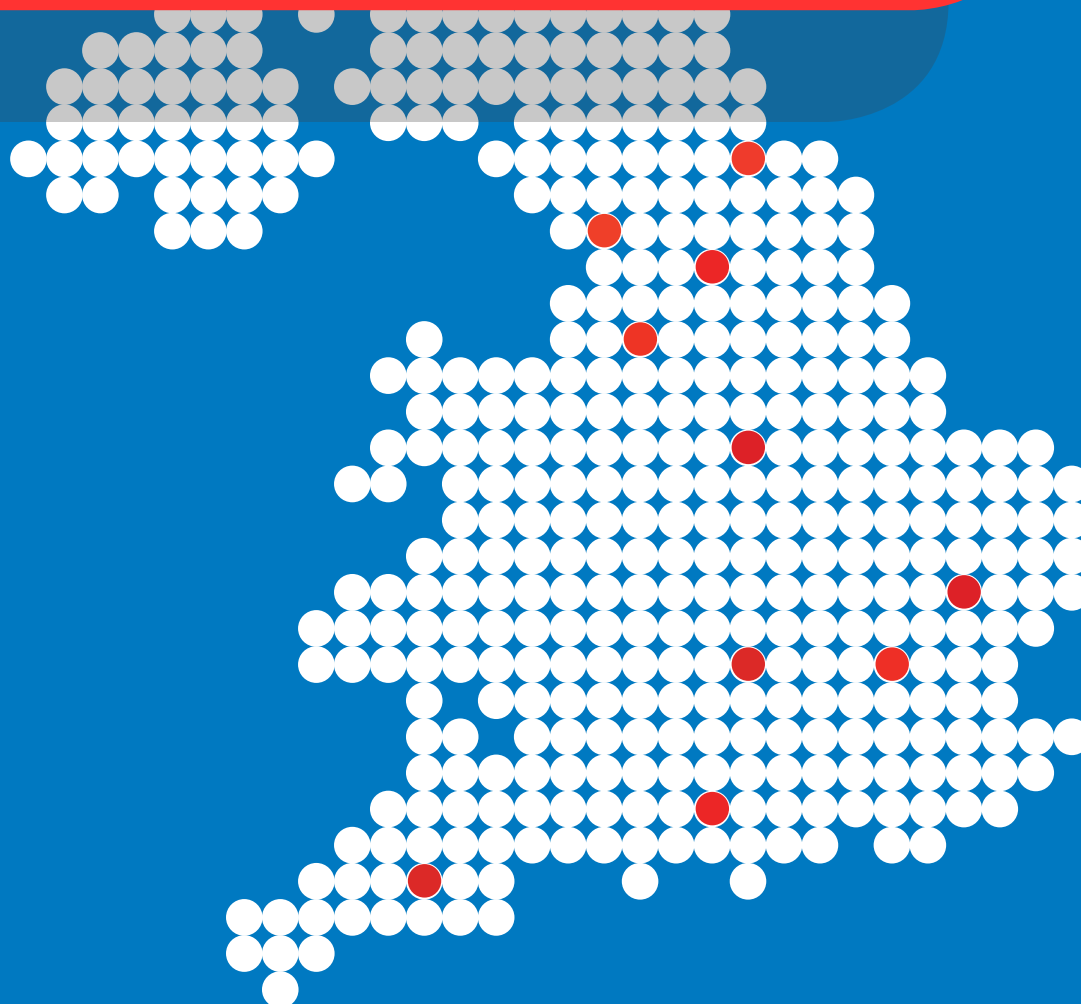


Talking about end of life care:

right conversations, right people, right time





■ *confidence and competence*

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Foreword

Good COMMUNICATION

This report celebrates our work in supporting implementation of the national end of life care strategy for England in what is essentially its most vital aspect - equipping our workforce with the confidence and competence to respectfully and compassionately care for individuals and their families towards the end of life.

Good communication is vital to identify, respond to and meet their needs.

Our pilot site partners have helped us identify the spectrum of communication skills training provision, delivery components and requirements. They have also built new relationships across organisational and professional boundaries and delivered a range of training designed to meet the national core competences.

Equity and excellence: liberating the NHS (Department of Health, 2010) now provides an opportunity to place the individual at the centre of their care by acting on this report's findings. In the current financial climate our success will depend on our ability to communicate effectively with both service users and fellow colleagues.

Claire Henry and Anita Hayes, director and deputy director of the National End of Life Care Programme (NEoLCP)

Support for people at the end of their lives has great significance in social care. Domiciliary care and residential home staff often play unique and vital roles working alongside people and their families - sometimes over extended periods of uncertainty and decline. Providing this support in the right way, with an emphasis on dignity in care, can have a positive effect. Social care staff who arrange support services also have a critical role to play.

Our value base, with its strong emphasis on empathy, respect and allowing people to make informed choices, is vital to achieving better end of life care. Mutually supportive working between health and social care is another key ingredient.

Training can have a significant impact on both staff confidence and service standards. The Association of Directors of Adult Social Services welcomes this report, the innovative initiatives it promotes and the opportunity it provides.

Rick O'Brien, end of life care lead, Association of Directors of Adult Social Services

*is vital to identify, respond to
and meet their needs*

Executive summary

Effective communication is essential to deliver quality end of life care. The majority of the health and social care workforce are involved - to some degree - in its delivery, but national reports and patient opinion indicate that not all of them have the competence and confidence required.

The white paper, *Equity and excellence: liberating the NHS* (DH, 2010), urges increased choice - which requires professionals to communicate better. The time is right to tackle the issue.

This is the final report from the communication skills pilot project, which funded 12 pilot sites to explore training need, provision, strategy and sustainability. Service users and other partners also contributed to the project.

The pilots carried out a training needs analysis, reviewed existing provision and benchmarked it against national competences. They then used a needs-based approach to develop new training plans. This report highlights the project's findings and identifies key messages:

Why improve communication skills?

- End of life care conversations are sensitive and staff may actively avoid conversations with people who are dying
- The anticipated rise in the death rate and in the number of deaths taking place outside hospital means a wider range of staff need training
- A range of training and education opportunities are needed to accommodate diverse needs of the health and social care workforce
- Advanced level training, such as that provided to senior cancer staff by Connected©, should be available to other clinical staff when appropriate
- Investment in training will contribute to longer-term cost savings.

How do we do it?

- Select training to match identified need and service users' priorities
- Align learning outcomes with the common core competences and principles for end of life care
- Ensure training builds on existing competences and supports incremental learning
- Introduce standards to assess training quality and evaluate outcomes
- Embed competences in organisational strategies, clinical governance, service commissioning and HR policy to achieve sustainable improvement.

1

The challenge

Death is a taboo subject

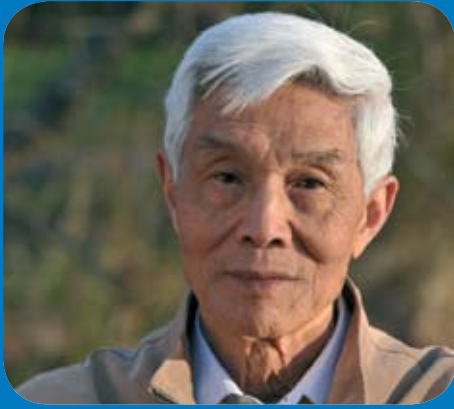
"We had just settled my dad into his new room at the care home - he had motor neurone disease and was in a bad way. Walking down the corridor with my sister, the matron turned to us and said 'Of course, when your father dies, you can have a room to stay in here while he is dying.' Other people could hear this comment. This was the first time that anything had been said to us about my father dying. I felt dreadful and panic stricken." Bereaved relative.

Death is not an easy thing to discuss but quality care depends

on us being able to talk about it. Straightforward, sensitive and open communication between health and social care workers, the individuals they support - and their families and friends - underpins all good services and makes it more likely that people's wishes and needs will be met. There are many examples of staff with excellent communication skills but the need for improvement has been highlighted in several national reports.^{1,2,3}

Death is a taboo subject in our society. A recent survey showed

that while 29 per cent of people had talked about their wishes around dying, only 4 per cent had written advance care plans.⁴ The way staff communicate is affected by these taboos and also by their own beliefs and experiences.⁵ This contributes to the anxiety many feel when communicating with and caring for people approaching the end of life and their families. They may use distancing techniques to avoid the consequences of talking and getting too close to the person's suffering, to ensure their own emotional survival.^{6,7}



While death is inevitable for all of us, it is often seen as a failure in a healthcare system designed to focus on diagnosis, treatment and cure. Staff may deflect debate about death and turn it into the 'vocabulary of saving lives'.⁸ On top of this, it is very hard to predict when someone is going to die. This can result in a failure to discuss end of life care issues until the person may not be well enough to have a meaningful conversation.

Demographics show that the numbers dying will increase significantly over the next 20 years, so the workforce will be more involved in end of life care.

People approaching the end of their lives need a combination of health and social care services provided in a variety of settings, including the community, hospitals, care homes, hospices, prisons and hostels. The pilot sites' surveys showed that most health and social care staff do, at some point, support someone through the final stages of their life. As choice increases and more people die outside of hospitals, it is therefore extremely important that communication skills training is accessible to a wide range of staff groups and grades, from a variety of cultural backgrounds and beliefs.

There are other challenges. Language barriers and high staff turnover in some areas make it hard to provide training that benefits everyone. Some people - for example, those with dementia, learning or sensory disabilities - have extra difficulty communicating. The competences of the wider workforce in end of life care, such as funeral directors, police and interpreters, need to be recognised. Financial considerations mean funding bodies will want to maximise efficiency on any investment in training.

Research also suggests that communication skills do not reliably improve with experience alone. Additionally, the personal beliefs and values of staff can affect their clinical decisions and willingness to talk about death.⁹

2

Our vision

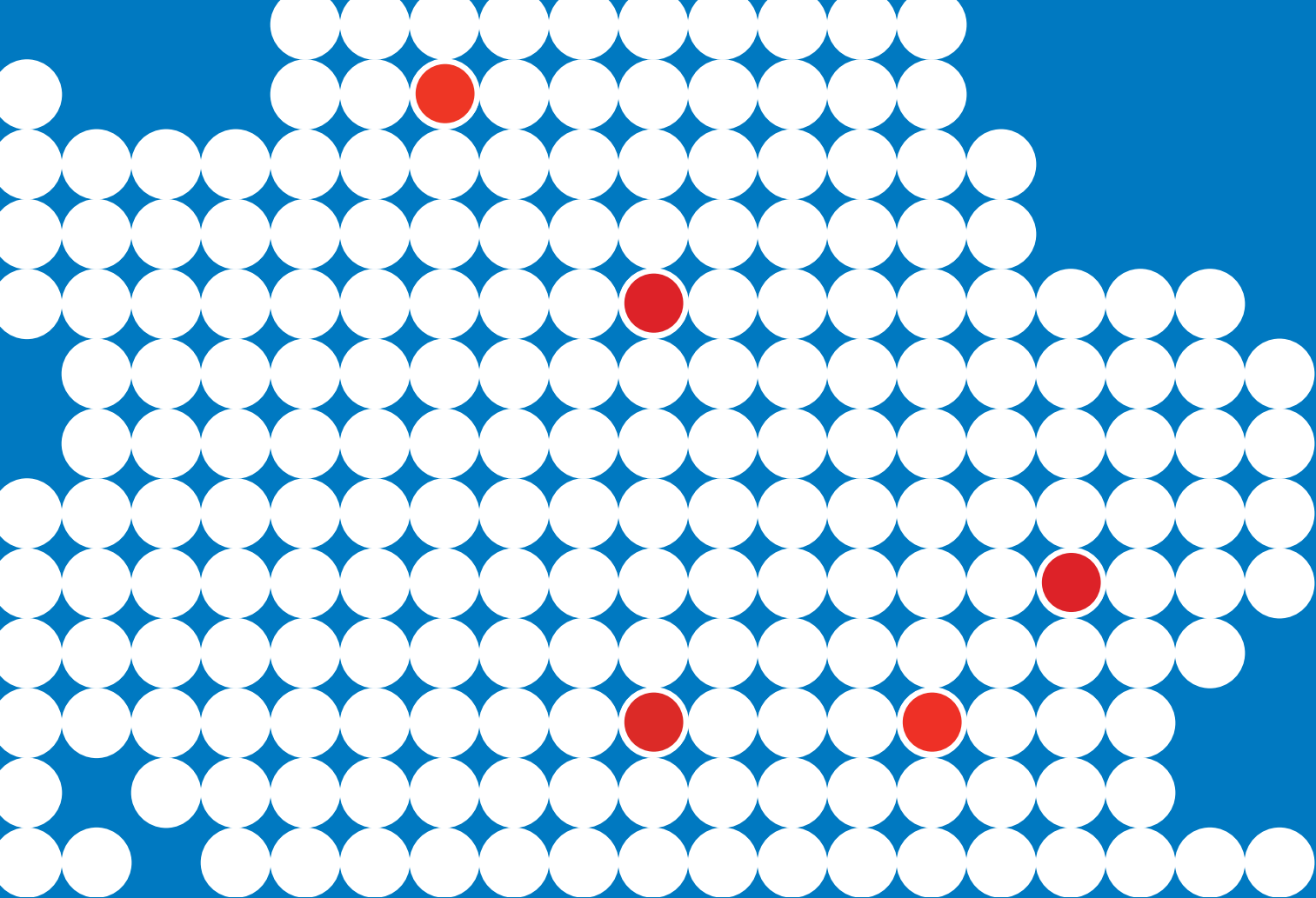
confidence and competence

“Good communication underpins all elements of care and if we can get this right at the end of life, it will make us better communicators all round.” Claire Henry, director, National End of Life Care Programme (NEoLCP)

“Ensuring that health and social care staff at all levels have the necessary knowledge, skills and attitudes related to care for the dying will be critical to the success of improving end of life care.” *End of life care strategy* (DH, 2008)

Our vision is that all staff, in all settings and at all levels - whatever their role - have the confidence and competence to support people at the end of their lives. They will be able to help them to articulate their needs and wishes and to share in planning their care. The key to improving services is conversation: to devise plans and approaches in conjunction with those who receive those services.¹⁰ This gives people more choice and control over their care. Sensitive, effective communication can improve

the overall wellbeing of those who are dying and support their families and friends. It can empower people to express their wishes and help them come to terms with their situation. Care planning has been shown to improve people’s quality of life,¹¹ making it an important tool in helping us achieve our key aims: to support people to live as well as possible until death and to support them to have a ‘good death’.



Effective communication requires the right conversations by staff with the right skills taking place at the right time. It is important that they recognise and respond to the signs that someone is approaching the end of life and help them start planning their future care. Staff need to create early and repeated opportunities for people to talk about these issues. They should be guided by the person on timing, pace and content, and respect the wishes of those who do not wish to discuss such matters.¹²

Communication and planning will help more people die in the place of their choice. We know that very few people choose to die in hospital but currently over half do so, with less than 20 per cent dying in their own homes.

We want a cultural shift in attitudes across the health and social care workforce, leading to a greater willingness to discuss death and bereavement issues - without staff feeling they have failed because they could not prevent someone from dying.

Staff who are confident and competent will benefit from improved morale, resulting in greater job satisfaction. Insufficient communication training is a major factor contributing to stress, lack of job satisfaction and emotional burnout for healthcare professionals.^{13,14}



A workforce with higher morale will be more efficient, because there will be less costly attrition. Its skills will be transferrable to other areas of care and can also improve working and personal relationships. Patient safety will be improved and risk will be reduced - leading to better clinical governance.

The NHS white paper, *Equity and excellence: liberating the NHS* (DH, 2010),¹⁵ recommends giving people more control over their own care. It follows that service users should also



be more involved in training design, delivery and assessment. We must also remember that different cultures have different views of death and dying. Staff must respect people's values and traditions.

There may be a significant return in any investment we make in communication skills training because it will improve staff productivity as well as the quality of services. The majority of complaints related to end of life care concern communication issues - managing these



complaints has a financial impact. Care planning enables more individuals' needs and preferences to be identified promptly, resulting in the right treatment and preventing unwanted or unnecessary interventions¹⁶ - making best use of staff time and resources. The National Audit Office (NAO) estimates that 40 percent of people dying in hospital are not receiving treatment that requires them to be there.¹⁷ This situation needs to change.

better clinical governance

Investing to save

There is growing interest in the impact of improved communication on the cost of resolving complaints about end of life care.

Solihull Hospital set up a trial scheme as part of its Bereavement Partnership Project, co-ordinated by the Bereavement Services Association and Cruse Bereavement Care and funded by the Department of Health (DH).

Project lead Dr Dawn Chaplin explains: "Most complaints about end of life care seem to be made about three months after a death - after the relatives had sorted out the funeral and had time to think about what happened. So we decided to offer these people support over the first eight weeks, with the aim of providing better care, avoiding costly complaints and bridging the gap between the acute hospital and voluntary services.

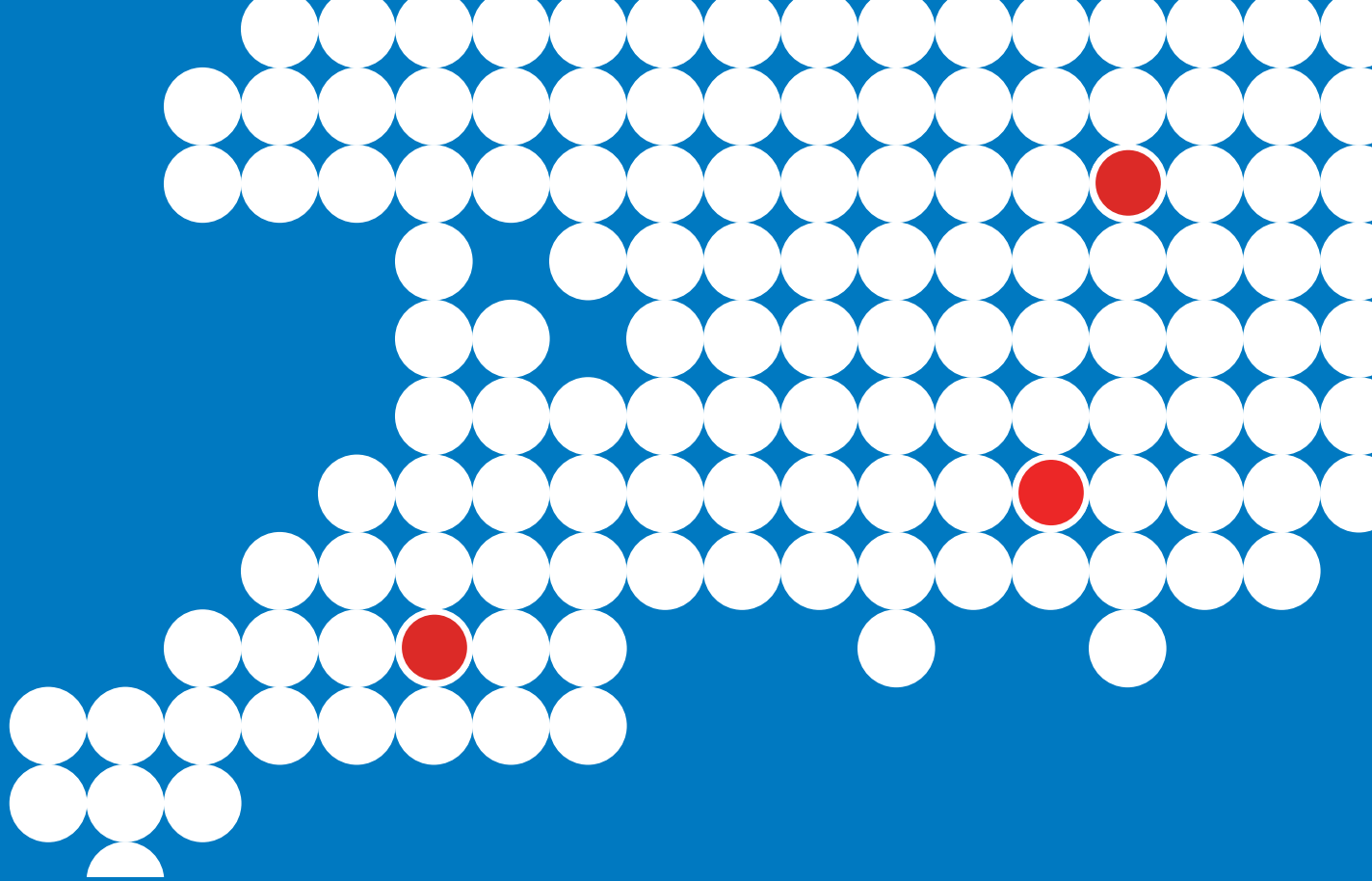
"We recruited volunteers to provide a listening ear and signposting information for those who wanted to receive it. By the end of the pilot we had identified seven people in particular whose situations would probably have led to formal complaints without our intervention. Mostly what these people needed was information.

"For example, in one case the coroner had been involved and this had led to the funeral being delayed. The relatives were understandably upset and assumed something untoward had happened. In fact, the patient had undergone an operation shortly before they died. In these cases the coroner must decide whether a doctor can issue a death certificate or whether there should be an inquest. The doctor did issue the certificate but the process itself caused the delay. Once the family realised this, the situation

was resolved."

Eighteen per cent of all complaints referred to the Health Service Ombudsman for England in 2009/10 concerned communication and staff attitudes.¹⁸ It is likely that a similar percentage of locally resolved complaints relate to the same areas. The NEoLCP has reviewed complaints made in the south coast region and estimates the indirect cost of resolving a single complaint, excluding secondary level investigation or compensation, at around £2,500. The Dorset pilot identified 725 complaints that featured communication and staff attitude during 2009. Though only a percentage will be specific to end of life care, cumulatively they indicate that the cost of poor communication places a significant financial burden on the NHS.

improved communication



Talking cure

Mandy Paine was first diagnosed with chronic obstructive pulmonary disease in 1989. In 2001 she was told she was at the end stage of her condition and had only a couple of years to live. "But I'm still here", she says. "Which has made it difficult to get the right kind of care and support. Many people with my condition face the same problem."

Mandy's life improved dramatically when she changed

GPs. "My new doctor is fantastic", she says. "Unlike most of the doctors I've come across over the years, he actually accepts that I know my own condition. He doesn't make presumptions. He even visits me at home so I don't have to go to the surgery, where there's a risk I may pick up an infection.

"I gave him a book called *Difficult conversations* (by the National Council for Palliative Care) and he has used the

examples in it to help him communicate better. Now I can really open up to him - I trust him. It's made such a massive difference to the way I feel. It's given me the strength and confidence to go on. It's such an important thing - letting the patient run the show. More health and social care staff need to understand that. If they worked in conjunction with users and carers it would improve the quality of services and the quality of people's lives no end."

3

Where are we now?

“Conversations have been easier to manage since the course and I can listen for patient cues and explore the answers whilst remaining calm. I am improving and communicating first, rather than being afraid.”

Connected© course participant

The NHS constitution pledges that all staff should receive appropriate training for their jobs, their own personal development plans and the right support from their managers.

Generic communication competences are embedded as a core skill in the NHS Knowledge and Skills Framework (KSF) and common induction standards for social care. This provides a sound base on which to develop additional competences. Those relating to communication in end of life care are specified in the common core competences and principles.¹⁹

The NEOFPC launched a new e-learning package in January

2010: e-End of Life Care for All (see <http://www.e-lfh.org.uk/projects/e-elca/index.html>). It is freely available to all healthcare staff, with some public-facing modules for volunteers/carers, and currently contains several sections on communication skills. It can be used as a stand-alone resource or as part of a blended learning programme, which supports the adult-learner-centred approach.

Connected©

This national training programme was developed in response to the need for better communication skills for staff working in cancer. The Connected© programme offers three-day advanced courses to senior cancer health professionals working in England. It is based on a core model that has been shown in randomised trials to increase confidence and change clinical behaviour.²⁰ Over 7,000 senior cancer professionals have completed the Connected© programme. In response to a national review, it is planning to trial a revised version of the course that involves a blended approach, including e-learning and a shorter face-to-face element. It is using self-reported changes in practice to evaluate the training.



The end of life care pilot projects' training needs analysis (TNA) found that most communication skills training has been developed and delivered locally by palliative care providers, higher education institutes and service providers. A range of organisations offer national training, including Marie Curie Cancer Care, Macmillan Cancer Support, Help the Hospices, the Gold Standards Framework Centre



and the Social Care Institute for Excellence. SAGE & THYME™, an introductory level, three-hour workshop for all grades of health and social care staff, is also available nationally.

The TNA also showed that many courses are not relevant to social care staff and there is a need for more advanced level training (such as that provided by Connected©) for staff working outside cancer services.

Unfortunately there are currently no agreed standards for assessing training quality, nor on the levels of training required for different staff roles. This can cause large variations in both the quality and availability of appropriate training and therefore workforce competence - which makes the commissioner's job more difficult.

Two of this project's key successes were the London pilots' outcomes evaluation scheme (see case study 'Demonstrating the value of training' on page 17) and a new benchmarking tool developed by the Plymouth pilot in conjunction with Connected© and the NEoLCP, both of which support commissioners to choose the most effective training.

developed and delivered locally

Benefits of good communication

Research shows that a willingness to listen and explain is considered to be one of the essential attributes of care. We know that effective communication influences wellbeing, pain control, adherence to treatment and psychological health and that timely conversations result in improved care.²¹ Delayed conversations cause late referrals to palliative care, unplanned hospital admissions, emergency respite care,²² more expensive social care packages and inappropriate interventions when crises develop - all of which have cost implications. Delayed planning can also impact on carers, causing higher levels of burnout.

effective communication influences wellbeing

Putting service users first

Service users have been put at the centre of end of life care communication by Berkshire East Community Health Services.

Linda Freeman, project lead, explains: "Listening to people's experiences of end of life care was not easy, but it was invaluable."

One woman with cancer explained how her doctor told her that she couldn't have the life-saving surgery she'd been hoping for. "He just told me the news and then left me to go home", she said. "I felt devastated. He kept looking at his watch and shuffling in his seat, which made me feel I was an inconvenience to him and he needed to get on with some real work. I was given nothing and left with nothing. I left the hospital not even knowing what

way to drive the car. Luckily my husband was with me and we knew we would find a way together."

Linda also interviewed a couple: a man with Parkinson's and his wife, who was his carer. They were fed up with the lack of communication between domiciliary staff, which meant they had to explain their circumstances every time a new person visited. "Why don't they communicate with each other?" asked the woman. "I can always tell when one of them is from an agency. They don't talk or they have an attitude. When a regular carer visits it's much better - not only do I not have to tell them anything but they also listen. Sometimes I get upset and it's nice to have someone just listen, rather than trying to tell me how to fix it."

Linda went on to say "I've now got a much better understanding of what is needed. Involving service users has given us a higher priority with our strategic health authority too - they've just agreed to fund local practice educators who will work collaboratively towards the success of our training programme. I've also been able to look at how communication affects the level of complaints we receive."



4

Leading the way

“What enthused me about this project’s approach was that it was not prescriptive or top-down - it was evolving and exploratory. In the public sector, outcomes are often defined in advance, which constrains creativity and innovation. This project gave pilot sites the freedom to plan according to local circumstance

and it has resulted in a range of tried and tested examples and a firm basis on which to base further policy development.”

Dr Alf Hatton, Institute of Healthcare Management

The communication skills pilot scheme is one of three foundation projects established

by the NEOFPC to progress its workforce development vision. The programme worked in partnership with Connected© on this particular project and benefited from their experience of providing communication skills training to staff who work in cancer services.

How we did it

- Connected© worked in partnership with the NEOFPC, offering its expertise in training delivery and guidance on adapting courses for non-cancer staff
- Recruited 12 pilot sites across England. They identified their training needs and existing training provision, benchmarked it against the national end of life care core competences and developed plans to address those needs
- Set up a series of workshops to support joint working and learning
- Asked pilots to carry out a TNA to help plan future strategy. See the full report at <http://www.endoflifecareforadults.nhs.uk/publications/talking-needs-action>
- Set up service user events to explore experiences of communicating with staff, priorities for change and opportunities for involvement in future training
- Offered pilots the opportunity to help develop training for care home staff that involves service users and to trial the e-ELCA communication skills sessions in a blended learning approach
- Asked the Institute of Healthcare Management to evaluate the project. For a summary of the IHM’s report and details of how to access the full report, see Appendix 1 (page 30).

explore experiences

Demonstrating the value of training



The North East and South East London pilot site has shown that it is possible to assess the effect of training by conducting a post-course evaluation that asked participants how they applied their learning in practice.

This is crucial because it enables educators to demonstrate the value of communication skills training in end of life care to

both service providers and commissioners.

Evaluations were completed for 19 courses, covering different staff groups working in different settings, different training formats and different training providers. Methods include face-to-face interviews, focus groups, telephone interviews and questionnaires.

Three factors relating to course participants have been identified which reduce the effectiveness of the training: lack of opportunity to apply skills in practice, training which is not relevant to participants' roles and training which does not match the prior knowledge and skills of the participants.

Commissioners should take these into account when looking to target specific groups of staff.

Training providers who participated in this project have reported that the experience was positive and beneficial, that they have used the evaluation results for their work in a variety of ways, and that they would be prepared to take part in similar evaluations in the future.

"I think it gave all of us involved a real boost to our confidence", says one trainer. "Everyone has taken the feedback seriously and addressed the issues arising from it. It has also strengthened my resolve to involve service users in training more often because this was so well evaluated."

5

Project achievements

"We have recently trained in the Human Givens psychotherapy technique that is improving our communication with people following trauma. The impact has been phenomenal. It has

meant getting people home quicker, them being able to stay at home, reducing anxiety and the need for support services - and for high cost hospital beds. It has enabled us to get

both staff and service users to function normally quicker. The economic benefits are obvious." Judith Hodgson, social work lecturer, University of Hull/Dove House Hospice

learning network

Regional impact of the project

- East Midlands SHA is now piloting a training evaluation toolkit based on the common core competences for end of life care
- It is also mapping the end of life care pathway to identify the tasks that take place and developing a new model that identifies the communication competences required
- South Central SHA plans to roll-out SAGE & THYMETM and is working on a project to test blended learning using the e-ELCA learning modules
- West Midlands SHA has developed a learning network that will roll out e-ELCA training and a second project to deliver basic and intermediate level training in areas of most need.

Local impact of the project

- Improved partnership working across organisations and sectors including strategic health authorities, Skills for Care, education providers, the NHS, local authorities, voluntary organisations and the private sector
- Improved communication and understanding between the health and social care sectors
- Identification of gaps in staff competences and training provision, which enabled the development of new, needs-led training strategies
- Raised awareness of end of life care and enthusiasm for communication and training
- Improved commissioning arrangements and relationships
- Pilot sites benefited from each other's experiences and shared learning
- Evaluation has led to higher quality training that is better targeted at the needs of all staff groups, resulting in more tailored and flexible approaches
- Evidence gathered by the TNA and integration with workforce development and clinical governance has led to better organisational and business strategies.

Pilot site achievements

- Dorset Cancer Network has developed a foundation level train-the-trainer resource for local health and social care organisations and embedded communication skills across its quality and complaints frameworks
- Berkshire East Community Health Services identified a group of end of life care champions and created a new training directory
- Teesside University set up a 360-degree evaluation tool to help pre-registration students enhance their interpersonal skills
- Dorset Cancer Network, Berkshire East Community Health Services and St Luke's Hospice, Plymouth are now involving service users in training
- Lancashire and South Cumbria Cancer Network found SAGE & THYME™ effective in building the skills and confidence of health and social care staff
- North East and South East London Cancer Networks, East of England Cancer Networks and the Leeds Partnership delivered advanced training for staff outside cancer services.

Focus on social care

The importance of social care staff - and the challenges they face - was recognised by several of the pilots.

The East of England pilot set up an e-learning programme for residential homes that is being rolled out across Anglia, Bedfordshire, Hertfordshire and Essex.

"We developed a blended programme that involves a mixture of e-learning and face-to-face work", explains Sarah Russell, project lead for Bedfordshire and Hertfordshire. "This increases its availability for staff who are either not confident with computers or don't have regular access to them."

The blended learning programme includes a pre- and post-course questionnaire and workbook. It covers six core modules: care principles, communication, comfort and wellbeing, assessment and care planning, advance care planning and an end of life toolkit.

Each of these consists of three elements: learn (using text, animation and quizzes), listen (listening to case studies and real life conversations) and practice (deciding how to deal with everyday situations).

"Our team of end of life care educators go into the homes with a laptop to provide support", she says. "They can offer one-to-one tuition, gauge key areas of importance for each individual and also assess general practice in the homes.

"We are measuring the impact of this training by auditing patient notes. If, for example, a patient does not have an advance care plan we can find out whether that's because they didn't want one or whether it's because staff didn't have a proper discussion with them about it."

Meanwhile, the Leeds pilot offered two different levels of training for social care staff. It used two methods, workbooks and workshops, for staff across five residential care

organisations. Feedback was very positive with many requesting more similar training.

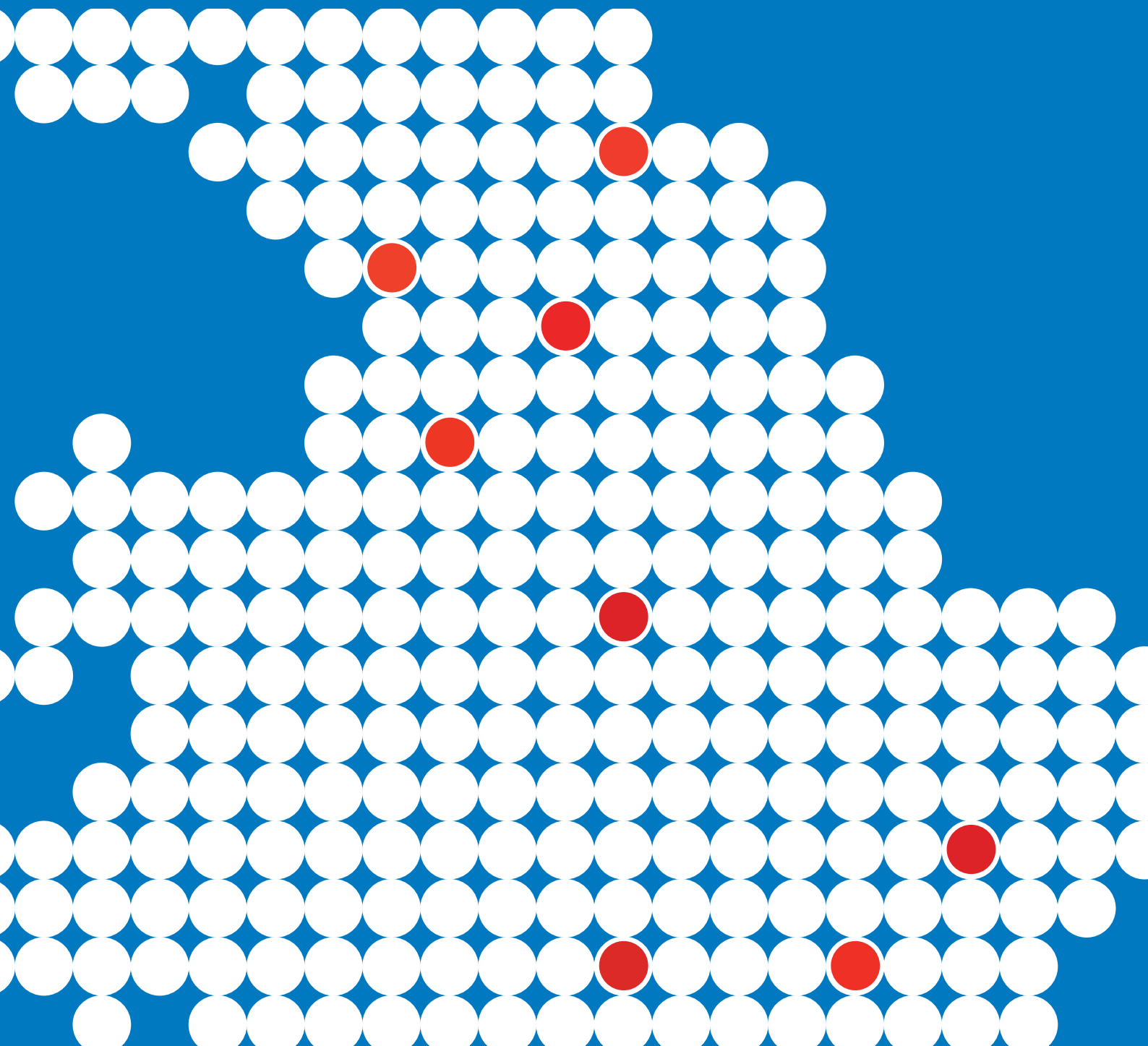
LOROS (Leicestershire and Rutland Hospice) found that 22 per cent of people taking its communication skills course were from social care. Despite some initial reticence from some - who didn't think end of life care was part of their role - all reported afterwards that it was useful and relevant. One attendee said "It was a real benefit to be with people from the health sector; we're struggling with similar issues. It was good to see that."



Sharon De Caestecker, head of education at LOROS

flexible approaches

raised awareness



Starting the conversation

The Leeds pilot used professional actors to role-play end of life conversation scenarios, which were recorded and used to help participants learn from their own experiences.

The two-day advanced communications course was designed for non-cancer staff and was attended by GPs, senior nurses and care home managers.

One GP commented "Recently, a woman passed away. It was sudden and the family were

distressed. As a result of the training I could deal with this situation much better, as I could identify the cues and cope with the anxiety. I felt better with the family and with the end result."

Another GP who attended said "The course was very useful. It gave me a chance to practice scenarios that come up in regular practice. In real life I am under pressure not to make mistakes. The course provided an opportunity to make mistakes and learn from them."

A third added "At the time of the course I had a patient who has since died. However, prior to this the course helped me feel more confident discussing end of life care issues with her. Before the course I could not have done this. It helped me feel more confident in asking the patient if they realise they are not going to recover from their illness."

feel more confident

6

Project resources

- **Benchmarking tool**

This sets out some key quality standards to support education commissioners, service providers, managers and staff to select the right training.

- **TNA questionnaires**

The pilots' work has been used to develop new questionnaires, one for employers, one for employees and one for trainers. They can be used as they are or adapted to meet local needs.

- **Commissioning guidance**

The Manchester pilot is developing guidelines for service commissioners to help them embed the right communication competences in the workforce.

These resources will be available at <http://www.endoflifecareforadults.nhs.uk/education-and-training/communication-skills>

*the right communication
competences*

OWNERSHIP OF INITIATIVE End of life care is everybody's business: get commitment from all stakeholders and show impact of training on service quality, user experience, safety and cost benefits

EFFECTIVE RELATIONSHIPS Structures for partnership working and staff development across health and social care including training providers, commissioners, Skills for Health, Skills for Care, voluntary sector, educators, service users

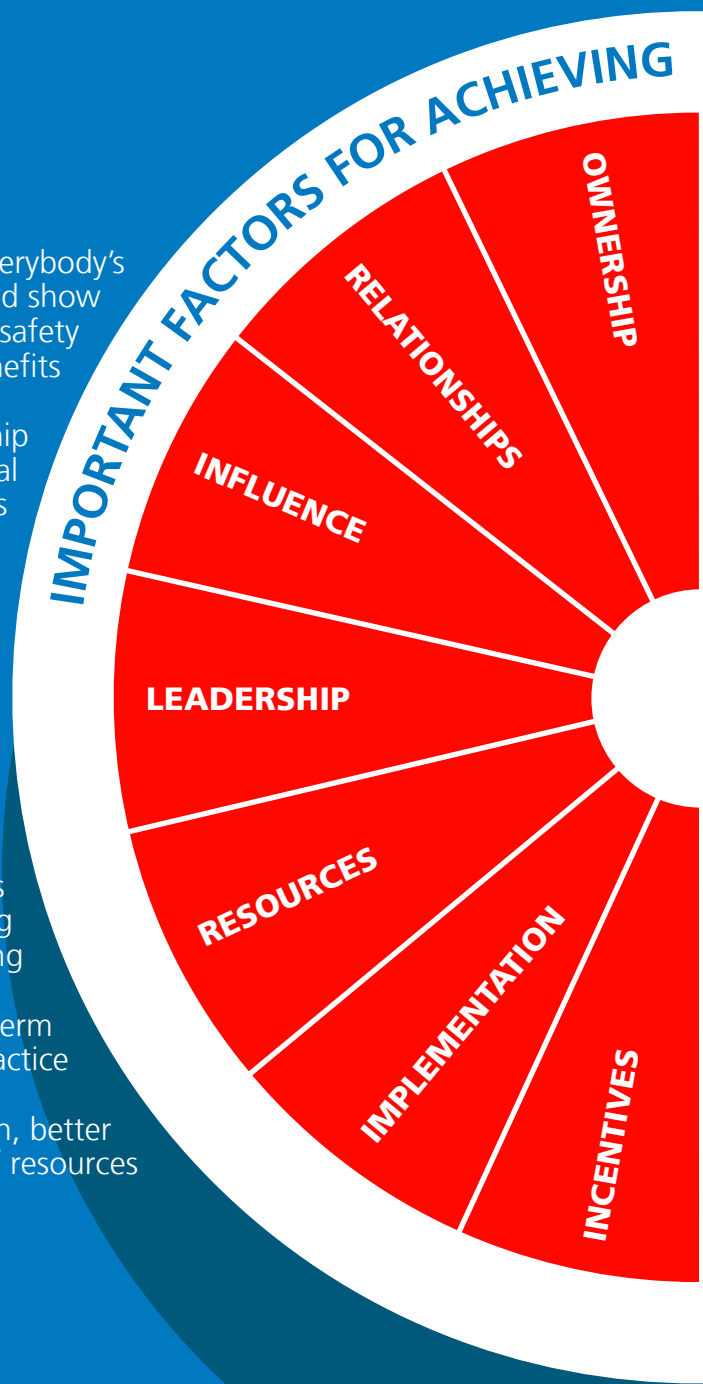
PEOPLE WHO INFLUENCE Raise profile of end of life care and engage with public, find clinical and social care champions, develop a more supportive culture

LEADERSHIP Build leadership capacity in workforce, work with peers to build credibility

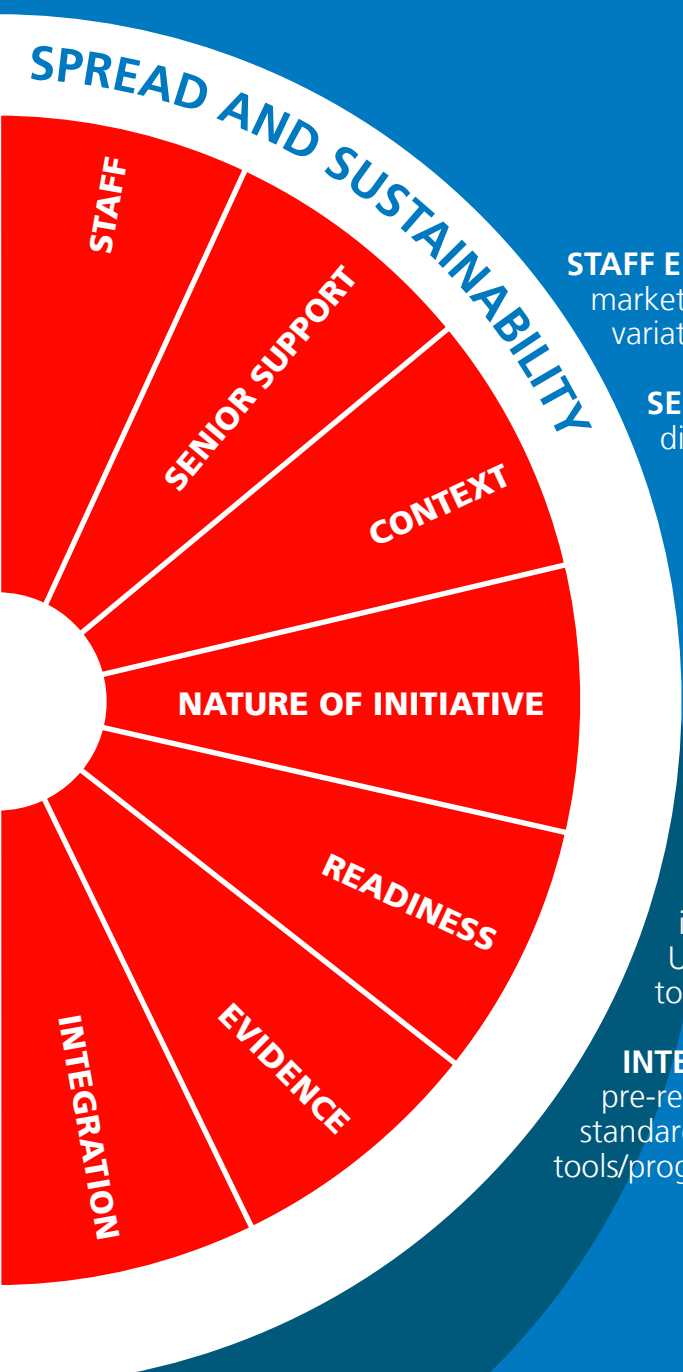
DEDICATED RESOURCES Consider the resources available (eg, free e-learning modules), existing capacity and capability for training

IMPLEMENTATION PROCESS Consider long-term objectives, use phased approach, build on good practice

INCENTIVES FOR CHANGE Job satisfaction, better relationships, best practice, better use of resources



This wheel shows key factors (identified by the pilots) that support spread and sustainability of communication skills training. It is based on the New Improvement Wheel, developed by the Modernisation Agency in 2005, which illustrates that spread and sustainability are inextricably linked and that the relative importance of each factor varies depending on local context.



STAFF ENGAGEMENT Raise the profile of training via targeted marketing, ensure training is relevant to all staff, consider variation in language between health and social care

SENIOR SUPPORT Present TNA to trust boards and directors, seek support from influential managers

LOCAL CONTEXT Align with local policies, assess local needs via targeted approach (including TNAs)

NATURE OF INITIATIVE Link training to organisational strategies/objectives, use person centred approaches

READINESS FOR IMPROVEMENT
Capitalise on the available support tools and guidance including common core competences, e-ELCA modules, relevant data and information

EVIDENCE OF IMPROVEMENT Consider return on investment, patient reported outcomes, complaints. Understand the baseline and use improvement measures to track progress

INTEGRATION IN PRACTICE Embed end of life care in pre-registration curricula, commissioning processes, quality standards, job descriptions and other workplace development tools/programmes



Looking to the future

“As information and technology is introduced to facilitate co-ordinated care and to support communication, it is essential



that training is provided to ensure staff have the access and the computer skills they need.” Stafford Scholes, communication skills pilot project service user group

Meeting the real need

The ultimate aim of improving the provision and quality of communication skills training for staff is to ensure that we meet the needs of people approaching the end of their

lives and their families. To ensure this happens we need to prioritise the importance of early conversations - staff responding to triggers and cues - and their ability to address the person’s needs and preferences through those conversations. By ensuring that the health and social care workforce has the right competences to do this, we may ensure cost savings further down the line and support the government’s aim of providing greater choice for service users.

cost savings

quality standards

What does good training look like?

- Learning outcomes are aligned with the common core competences and principles for end of life care
- It builds on existing competences and supports incremental learning
- It is selected to match identified need and service users' priorities
- The use of evidence-based methodologies including experiential learning (ideally including a blend of didactic, demonstration and role play with individual feedback on performance) has proved effective
- It is flexible and relevant to all sectors and roles
- It is delivered by trainers who have appropriate knowledge and experience, who are qualified to deliver communication skills training and apply recognised best educational practice
- Outcomes are monitored and evaluated, including workforce confidence and competence, service quality, value for money and impact on the user experience
- The benefits of multidisciplinary, cross-sector and team-based training are recognised
- It is embedded into all organisations (from all sectors) and supported by HR, job descriptions, personal development plans and the KSF
- Uptake and participant satisfaction are monitored
- It is subject to quality standards against which it can be benchmarked.

Financial incentives

- Linking communication to complaints has indicated that better trained staff could lead to fewer complaints about end of life care - resulting in savings (further work is needed to fully understand the cost implications of complaints)
- A needs-based approach, supported by a TNA, avoids costs of unnecessary training and supports commissioners (such as GPs) to purchase training that can really make a difference
- There are cost benefits associated with improved staff confidence, competence and job satisfaction, which lead to better retention, productivity and improved outcomes for service users
- Incorporating processes to demonstrate return on investment will make training more cost effective
- Innovative training options, such as interactive discussions, video and e-learning, may provide cost savings as well as positive outcomes.

Embedding communication skills



Jill Banks Howe, principal lecturer in end of life care and Linda Nelson, principal lecturer in adult nursing, Teesside University

Teesside University plans to introduce the National Occupational Standards (NOS) for communication in end of life care into curriculums across all its health and social care courses.

Students across all programmes already have competences related to communication skills, which are assessed in practice, but the addition of specific competences related to end of life care will make this more explicit.



The relevant NOS cover the ability to:

- communicate effectively with a range of people in an appropriate way
- develop and maintain communication with people about difficult issues
- present information in a variety of formats, as appropriate to circumstances
- listen to individuals and their families and provide information and support
- work with people in a sensitive and flexible way, recognising that their priorities and ability to communicate may vary over time.

Initially the communication competences will be introduced into the nursing curriculum. "End of life care is firmly embedded in the pre-registration nursing curriculum", explains Linda Nelson, principal lecturer in adult nursing.

"Students are introduced to various learning and teaching strategies across the three years. These include case scenarios, user and carer experiences and key lectures to introduce frameworks and policy drivers. The addition of the NOS competences will ensure that they are assessed specifically on communicating with patients and families at the end of life.

"The provision at Teesside University covers a wide range of health care professions including paramedics, radiographers, physiotherapists, social work and midwifery as examples. The ultimate aim is to introduce the competences into all our undergraduate curriculums."

Actions

The NEoLCP wants to share what it has learned from this project with its partners and to work with them to achieve sustainable change. This includes:

- Supporting GP consortia and service providers to commission end of life care training
- Working with Dying Matters to address wider attitudes to death and dying
- Working with clinical pathways groups and social care to redesign pathways that identify early triggers and cues for staff to initiate conversations
- Working with the cancer networks and disease specific networks to embed and align within existing guidance and protocols
- Linking with our other projects, such as routes to success, bereavement and commissioning
- Most care professionals will be involved in caring for people nearing the end of life at some point and they have a professional responsibility to ensure they can communicate well with them. The professions should be encouraged to debate whether this training should be a requirement for accreditation
- Looking for opportunities to embed training, for example, in pre-registration curricula and mandatory qualifications
- Looking for opportunities to embed competences in regulation, for example with the Care Quality Commission
- Linking with other relevant training and working more closely with the voluntary sector to align approaches.

sustainable change

Appendix 1: communication skills pilot project evaluation

A brief summary of The Institute of Healthcare Management's evaluation of the project. The full report can be found at <http://www.endoflifecareforadults.nhs.uk/publications/talking-about-eolc>

User view:

Ann Macfarlane OBE
User consultant and advisor
(Member of the project steering group)

"This project has focused heavily on the inclusion of people who will be greatly affected by any ground level improvements that it creates."

"All of us have only one opportunity to experience a good death. This work has highlighted the fact that health and social care professionals involved with the 12 pilots are committed to improving the skills training that is vital for communicating with those nearing the end of life. Most pilots struggled to build an inclusive approach to service users in a range of settings. The importance of engagement is recognised by these teams. At a national level, the programme has worked to involve people who have experienced significant bereavement and those with life-limiting conditions."

"The challenge now is for planners, commissioners, providers and those who evaluate communication skills training to meet the expectations of people whose quality of life depends upon it."

Report summary

The Institute of Healthcare Management was commissioned to evaluate the pilot scheme launched by the NEOFCP.

Overall, the evaluation suggests that the pilot programme successfully engaged 12 sites in completing and acting upon a local training needs analysis (TNA) and actively engaging stakeholders in sharing learning.

The key findings relate to the significance of:

- Undertaking a locally-sensitive TNA
- Engaging a broad spectrum of stakeholders at all stages
- Appreciating the varying needs of stakeholders
- Recognising that end of life care involves a range of staff beyond cancer services.

Key challenges identified:

- Early recognition and discussion to empower the individual and involve them in care planning
- Responding to the new financial and structural environment of the NHS and social care
- Integrated working with social care and councils
- Recognition of the need to discuss end of life care, in training and care planning - and in wider society.

Outcomes include:

- A strong network established that actively shared learning
- TNA completed that engaged range of partners
- Funding used well
- Raised awareness of the benefits of such training
- Examples of personal behaviour change to illustrate good practice
- Valuable questions for setting the future direction for this work
- Early implementation of training improvements.

The evaluation report provides the project context and an overview of the findings; the appendices contain the detailed information from each stage of the project and add depth and detail.

The project team proposes the following recommendations:

- Explore the added value of linking training to GP revalidation
- Explore the training of multidisciplinary teams and integrate this over the virtual care pathway
- Explore the development of quality standards to benchmark communication skills training
- Use *Equity and excellence: liberating the NHS* (2010), as a strategic lever ("No decision about me without me"). Connect the choice agenda to this work
- Explore innovative ways to support other training methods and analyse the cost-effectiveness of coaching and mentoring, etc.

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(Note: The North East and South East London Cancer Networks worked jointly on this project, as did NHS West Essex and the East of England cancer networks. The Leeds pilot project was carried out by the Leeds Partnership (consisting of NHS Leeds Community Healthcare, Leeds Teaching Hospitals NHS Trust, Sue Ryder Care Wheatfields Hospice, St Gemma's Hospice and Leeds City Council.)

The communication skills pilot project steering group:

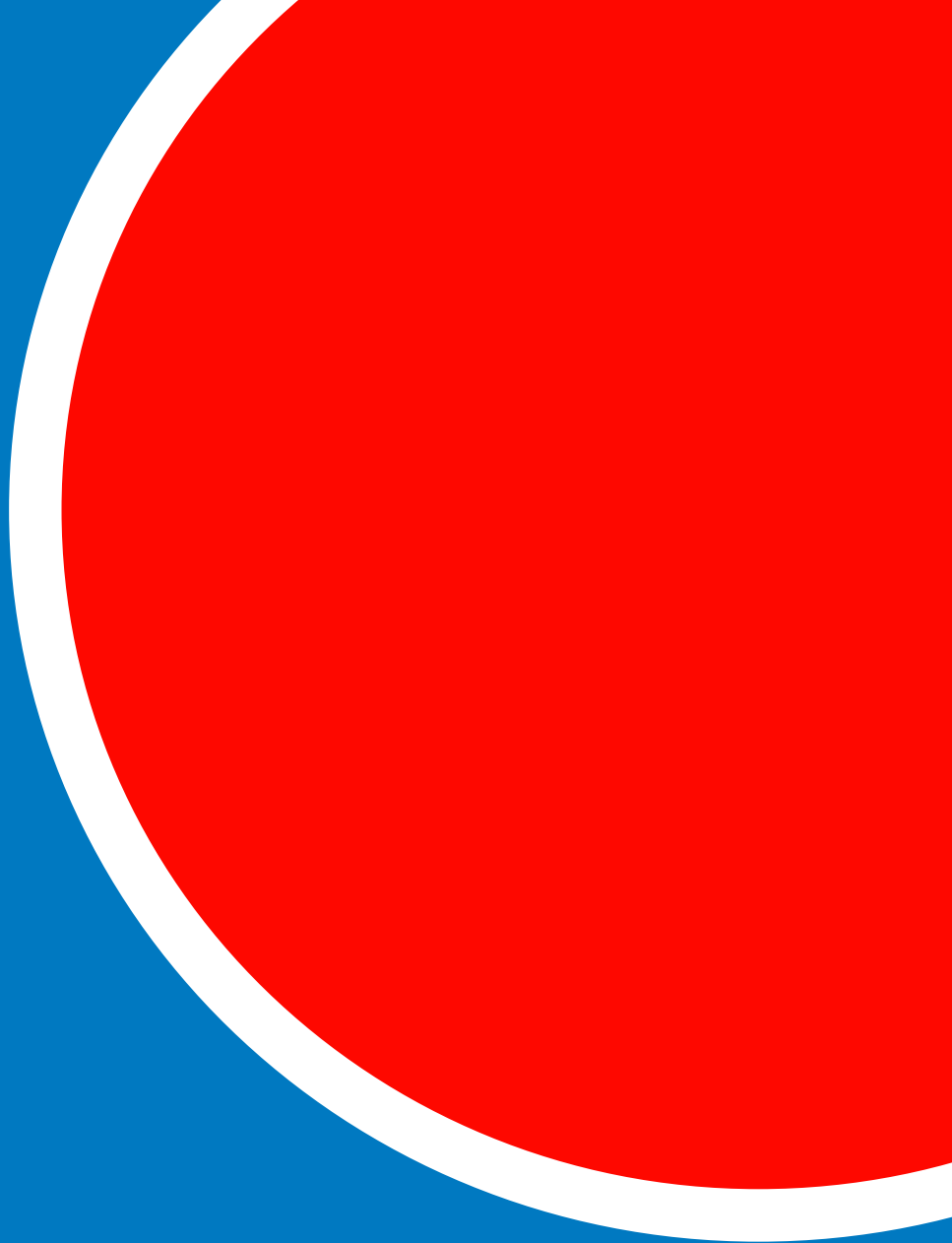
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