

National Institute for Health and Clinical Excellence

NICE Quality Standards Consultation – End of Life Care

Closing date: 5pm – 22 July 2011

Organisation	Compassion in Dying - a national charity that supports people at the end of life to have what they consider to be a good death by providing advice and information around their rights and choices.
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Are you happy to be named as a consultee to the Quality Standard on the NICE website? <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No	

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Please provide comments on the draft quality standard on the form below. When feeding back, please note the draft quality statement number and indicate whether you are referring to the statement, measure or audience descriptor.

In order to guide your comments, please refer to the general points for consideration on the NICE website as well as the specific questions detailed within the quality standard.

Please add rows as necessary.

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	<p>Compassion in Dying welcomes the NICE quality standards on end-of-life care and we are broadly supportive of the overall draft statements. We have commented only on those standards which are of most relevance to our work, or where we have specific comments to make.</p> <p>Compassion in Dying's expertise is in current patient rights at the end of life, with a focus on medical treatment preference tools for when an individual has lost capacity. Advance Decisions (which we supply free of charge) and Lasting Powers of Attorney (LPA) are the two tools which allow a patient, who has lost mental capacity, to refuse particular medical treatments (or set the level at which they are to be applied) which may unnecessarily prolong life. The Advance Decision or LPA must be completed or appointed when the individual has capacity. Importantly, these two tools are binding under the Mental Capacity Act 2005.</p>
QS 1.	<p>People approaching the end of life are identified in a timely way.</p> <p>Structure: The emphasis in the documentation for QS1 is about identifying the dying individual in order to offer additional care and support, but misses the important point that unless an individual is identified as 'dying' it is more likely they will receive inappropriate medical treatments and their wishes for end-of-life-care will not (or cannot) be followed.</p>

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	<p>This is especially true in secondary care where such treatments are more likely to be available. It is also an issue in care homes where the staff on duty, when an incident occurs with a dying person, may not feel they have the authority NOT to call an ambulance, so often they do and the individual is transferred to secondary care where they die. This can often occur in a patient's home, when a responding ambulance team feel they must take an individual to hospital because there is no identification of the individual as dying/not wanting invasive medical procedure or for their life to be prolonged. A system for registering such treatment wishes would be of benefit to service users and those at the coal-face of service delivery.</p> <p>The identification of (and evidencing of the effectiveness of) 'local active processes' needs to ensure that those people who fall outside of the traditional systems for identifying and processing patients (such as Advance Care Planning and the Gold Standards Framework) are captured. Whilst we recognise that 'a proportion of deaths will be unexpected and therefore unlikely to be identified in time to be included on a register or equivalent system', it is possible that a large portion of these deaths are non-cancer deaths (MND, cardio-vascular conditions etc.) which might warrant specific intervention and mention in the Quality Standards.</p>
QS 3.	<p>People approaching the end of life are offered comprehensive and regular assessments, which include the opportunity to discuss and document their current physical, psychological, social and spiritual needs and preferences.</p> <p>Structure: The issue of when is the best time to discuss treatment preference options fits into QS 3.</p> <p>Patients should feel able to ask healthcare professionals about their treatment options at any stage, and healthcare professionals should have the appropriate training to feel comfortable with this. Appropriate timing to discuss patients' rights around treatment options, (including in the event that they lose capacity,) is at the professional's discretion – taking cues from the patient and gently introducing the topic when necessary, as well as answering patient's questions clearly</p>

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	<p>and sensitively. Ideally, this would be around diagnosis or when the individual reaches a particular stage in their illness, so that a care plan can be developed and revisited. Healthcare professionals should feel confident enough to discuss options with the patient at all points during the patient's care, recognising that making decisions about treatment is a key legal end-of-life right.</p> <p>There is confusion amongst the general public around what our end-of-life rights are. A 2011 poll conducted by YouGov¹ for Compassion in Dying found that 60% of people would only want 'comfort care' and that 14% would want 'to be kept alive at all costs' at the end of life, however only 3% had an Advance Decision (we recognise that this was asked to a general population and didn't target those specifically in end-of-life care). The poll also revealed that over half of respondents wrongly believed that they had the legal right to make medical treatment decisions on behalf of an adult loved one or next of kin if they lost the ability to communicate.</p> <p>Evidence tells us that healthcare professionals can lack the necessary skills in end-of-life care communication.² Additional training, such as that initiated by the Dying Matters coalition,³ is needed to ensure that appropriate and effective conversations happen. Alongside this, protocols for recording patient preferences and encouraging (if appropriate) the filling in of an Advance Decision or appointing an LPA, or a care plan such as Preferred Priorities for Care is needed.</p> <p>1. http://www.compassionindying.org.uk/files/YouGov%20EOL%20poll%202011.pdf 2. http://www.nursingtimes.net/nursing-practice-clinical-research/clinical-subjects/palliative-care/end-of-life-care-communication-skills-lacking-among-nurses/5019692.article 3. http://www.dyingmatters.org/news/end-life-training-boosts-gps-confidence</p>
QS.5	<p>People approaching the end of life and their carers and families have timely access to information in an accessible format, appropriate to their individual needs and preferences.</p> <p>Structure:</p>

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	<p>Informing patients (and their loved ones and carers etc.) of their rights at key times is vital to ensure that they can make their own decisions.</p> <p>Information which is accurate, clear and consistent is needed to inform every decision made by patients, carers and healthcare professionals. Information should be available which spans the end-of-life journey, from appropriate and realistic discussions around prognosis (predicted time until death), to what community and out-of-hours services are available, to what patients can and can't refuse at the end of life in advance should they lose capacity, and at any point when they have capacity.</p> <p>End-of-life care can be daunting for anyone to think about (from patients in palliative care, to those with life-limiting conditions who want to plan their end-of-life care, to the general public who want to document their treatment preferences but have no current health issues). Consequently, the range of information that people need is extensive. Having consistent, accurate, up-to-date and clearly set out information available from a variety of sources and in a variety of formats and media would help to lessen stress and anxiety. Written information, whether delivered in printed paper form or electronically using new media is important as it provides people with a means of retaining the information. It is also important to provide people with a means of discussing their concerns and provide information that is customised to meet their specific circumstances.</p> <p>The End of Life Care Strategy states that: <i>For those approaching the end of life and for their carers, friends and families, it is important to access reliable sources of information as quickly as possible. Gaining access to information that is understandable and appropriate to the individual situation can reduce anxiety and enable and empower people to cope more effectively. Often, it is when people do not understand and have little information that they feel the most powerless and vulnerable.</i> (pg 74)¹</p> <p>Unless patients are told what their rights and choices are (for example, by health and social care professionals or an end-of-life rights expert) it is very difficult for them to find out what they can and can't do. Compassion in Dying have launched</p>

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	<p>an End-of-Life Rights Information line (0800 999 2434) which informs people of their choices and rights.</p> <p>Whilst we recognise the value of ‘local arrangements’, national guidance which allows for local subtleties to impact on practice, is key to ensuring that everyone is treated fairly.</p> <p>1. Department of Health (2008) End of Life Care Strategy</p>
QS 6.	<p>People approaching the end of life are offered the opportunity to help develop and regularly review a personal care plan that sets out their needs, preferences and decisions in relation to all aspects of current and future care and treatment.</p> <p>Structure:</p> <p>Ensuring that legally binding decisions documented in an Advance Decisions and with an LPAs, as well as other patient preferences, are recorded in patients records, and in a care plan, is essential. Currently there is no unified system for recording and storing these preferences across England and Wales, although there are examples of good practice.¹ New initiatives are to be applauded, however the majority of these appear to focus on resuscitation orders, and wider treatment orders (such as the refusal of artificial nutrition and hydration) are not being addressed in the same context.² Compassion in Dying is part of an Advance Decision Coalition which campaigns for the central registration (or similar system) for Advance Decisions and LPAs. This would ensure that patient wishes could be stored and accessed effectively, thereby making it much more likely that healthcare professionals will be aware of, and can act upon, patient treatment wishes.</p> <p>We support the promotion and documentation of personal care plans and draw particular attention to the ‘future care and treatment’ aspect. It is important that the option of completing/appointing an Advance Decision or LPA is widely promoted as part of end-of-life care and that the preferences set out by individuals in them impact on the development and implementation of a care plan. Health professionals must be made fully aware of their responsibilities under the Mental</p>

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	<p>Capacity Act 2005 - in particular, they must understand the legally binding nature of Advance Decisions (if valid and applicable) and LPAs, and their broader responsibility under the Act to consider the person's past and present wishes and feelings, including any relevant written statement made by a patient when they had capacity.</p> <p>Whilst we recognise the importance of 'local arrangements', as each locality has its own set of issues that impact on the delivery of care, we feel that there is a tension between setting national objectives and ways of working, and the onus being on individual PCTs (or Clinical Commission Groups) and Trusts etc, to learn from practice and implement their own ways of working. Money which flowed out of the End of Life Care Strategy was not ring-fenced for particular tasks. A Help The Hospices national survey, conducted in 2009, found that most PCTs were unable to identify additional funding for end-of-life care in their budgets.³</p> <p>Money must be available to develop appropriate systems and fund staff training in order to ensure that care plans can incorporate medical treatment preferences alongside implementing the standards set out by NICE. However, in 2011/12 there will be no extra money linked with the End of Life Care Strategy and simultaneously there will be increased pressure on commissioners and providers to reduce costs.</p> <p>The Preferred Priorities for Care (PPC) tool (or 'approach'), which has been in use since 2007, is designed to capture information about where patients would like to be cared for at the end-of-life. It records patient care wishes, what services are available and any reasons for change in the care trajectory. Local audit has shown it to be effective at ensuring patients are cared for (and usually die) in their preferred place.^{4 5} However, its purpose is not to capture information on medical treatment options and it is not legally binding. PPC is reliant on good coordination between healthcare professionals and knowledge of what services can be provided. Concerns about the levels of care (and access to knowledge about levels of care) available to support patient wishes, especially in the community setting, have been expressed by healthcare professionals.⁶ There are important lessons to be applied to managing the outcomes of Advance Decisions or LPA decisions, e.g. if a patient is at home and does not want artificial nutrition and hydration they will need dedicated comfort care which needs effective organisation.</p>

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	<p>Process:</p> <p>We welcome the ‘process’ standards which would document how many people have a documented care plan or advance care plan (ACP) that sets out their preferences. ACPs should contain, where possible, an Advance Decision or details of an LPA as best practice. To the best of our knowledge no UK research or audit has examined the numbers of Advance Decisions i) in general use in the UK ii) in use in end-of-life care programmes. However, a recent YouGov poll reported 3% of respondents as having one⁷ and a Freedom of Information request revealed that for the period 01/10/2007 to 5/05/2011 there are 55,998 active Health & Welfare LPAs, however this figure does not include cases where a LPA has been revoked or where the individual has died and the LPA has been cancelled so this figure is probably slightly inflated.</p> <p>Unsurprisingly, no UK data is available on whether the medical preferences detailed in an Advance Decision/LPA (whether or not they are incorporated into an ACP) are respected. Compassion in Dying recently conducted a systematic review which examined <i>To what extent are the medical treatment wishes laid out in preference tools respected?</i>⁸ The systematic review demonstrated that Advance Decision tools work effectively in end-of-life care and that patients’ medical treatment preferences <i>are</i> being respected. One particularly successful tool being widely used across the US is called POLST (Physicians Orders for Life Sustaining Treatment),¹⁰ which is targeted specifically at those patients at the end of life or in a frail state. The idea is simple – it translates patient end-of-life medical preferences into physician orders which can be easily followed by the healthcare professionals (including transfer staff) involved in the individual’s care. Importantly, there is a system in place to store the information both electronically and with medical records. There are valuable lessons to be learnt from the principles of this tool which could be developed and applied across England and Wales, e.g. the translation of a traditional Advance Decisions to POLST (which is done alongside the patient), ensures that all health professionals understand the detail and the form is kept electronically with the patient’s notes. The Washington State Department of Health POLST form can be access here: http://www.ohsu.edu/polst/programs/documents/WADec2008.pdf</p>

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	<p>Outcome: Alongside ensuring that the care planning delivered is in line with patients' needs, preferences and decisions there should be documentation of whether they received the level of medical treatment care they requested at the very end of life – essentially whether their medical preferences were respected or not.</p> <ol style="list-style-type: none"> 1. Social Research Institute (2011) End of Life Locality Registers evaluation <i>Ipsos Mori</i> 2. Oblensky L, Clark T, Mercer M (2010) A patient and relative centred evaluation of treatment escalation plans: a replacement for the do-not-resuscitate process <i>Journal of Medical Ethics</i> 36: 518-520 3. http://www.helpthehospices.org.uk/media-centre/press-releases/extra-investment-must-get-through/?locale=en 4. Johnson S, Sherwen E (2010) Preferred Priorities for care: West Essex Evaluation West Essex NHS 5. Fisher S, Duke S (2010) Preferred place of care at the end of life for people in hospitals <i>End of Life Care</i> 4(2): 35-41 6. Munday D, Dale J, Murray S (2007) Choice and place of death: Individual preferences, uncertainty and the availability of care <i>Journal of the Royal Society of Medicine</i> 100 (5): 211-5 7. http://www.compassionindying.org.uk/files/YouGov%20EOL%20poll%202011.pdf 8. http://www.compassionindying.org.uk/research.html 9. http://www.ohsu.edu/polst/
QS 10.	<p>People approaching the end of life receive consistent care at all times of day and night, that is coordinated effectively across all relevant health and social care organisations, and which is delivered by practitioners who are aware of the persons current medical condition, care plan and preferences.</p> <p>Introduction: Coordinating end-of-life care is vital. Out-of-hours care poses particular challenges and highlights the need for a system which records patient's medical treatment preferences which can be accessed by all relevant healthcare staff (including transfer staff, discharge staff, consultants etc) and thus acted upon 24/7.</p> <p>Draft quality measure</p>

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	<p>Structure:</p> <p>C. Appropriate systems are needed urgently to ensure that those delivering care can access documented patient preferences (see QS 6). Unless all healthcare staff can access relevant information they will not be able to act, or take into consideration, the patient's preferences.</p> <p>D. Formal structures need to be in place to enable health and social care professionals to document patient preferences. There also needs to be clarity amongst key professionals about the difference between legally binding preferences and those which are more 'simply' statements of wishes.</p> <p>E. 'Locality-wide registers' have been on the agenda since the 2008 End of Life Care Strategy. They have been piloted in eight sites across England, with the evaluation of their success focussing on technical issues and uptake, rather than whether patients' were receiving the level of medical care they requested.¹ The report details key lessons at each stage of development and implementation that other NHS organisations considering developing their own register should consider.</p> <p>We welcome the implementation of the findings of this report, which states that: <i>Following the pilot it is intended to put this to the Information Standards Board for approval as a national data set, which will provide a basis for the development of other registers. Once the basics are agreed, more targeted discussions can be had about any additional information it may be useful to collect. These additional items may contain information for particular groups of patients or within particular localities.</i></p> <p>A key outcome of the pilot evaluation is that locality registers appear to have commonly agreed core minimum dataset which includes resuscitation orders and preferred place of death (alongside carer/hospice details and diagnosis). Whilst these are important, wider treatment orders (such as the refusal of artificial nutrition and hydration or antibiotics) should also be considered and are frequently detailed in Advance Decisions and LPAs (see QS. 6).</p> <p>Another point of interest to emerge from this pilot report concerned the identification of wider end-of-life training needs</p>

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	<p>associated with the use of the locality register: <i>The key training element identified is to support clinicians in the development of communication and care planning skills. Allowing healthcare professionals to feel comfortable having these conversations is vital in order to get them to engage with the project and in order to get a critical mass of patients consented to the register. (see QS 3.)</i></p> <p>We welcome the continued gathering of information on transfers in and out of community hospitals, hospital discharges and the use of locality registers.</p> <p>Process:</p> <p>B. There needs to be an appropriate system in place to ensure that practitioners are aware of care plans and patients' preferences. This would allow the formalised system (which could be tailored to local needs) to be audited and lessons learnt from different regions.</p> <p>C. DH QM 9.3/9.4. 'Audit of whether data provided by PCTs or other services for patients approaching the end of life has been uploaded onto ambulance systems' 'Audit of whether, for calls where information was uploaded and available, the crew took appropriate action'. We recognise that following 'acquired information' by ambulance services is not an easy task and that Ambulance Trusts' policies on DNAR differ across England and Wales. There is a danger that these policies may not interact appropriately with hospital/community care policies on Advance Decisions and ACPs.</p> <p>Outcome:</p> <p>A. Aligning care to preferences is vital to ensure patient choice can be realised. We welcome the continued recording of Preferred Priorities for Care-type statistics and recommend that a similar audit of whether medical treatment preferences were respected (as detailed in Advance Decisions and LPAs) form part of the quality standard.</p> <p>Audience:</p> <p>Ensuring that systems such as information sharing protocols are in place is vital. Without a solid system, healthcare</p>

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	<p>professionals and commissioners will not be aware of current end-of-life rights and therefore will not be able to act on them appropriately. Importantly, patients may not be given the opportunity to have their preferences documented without such protocols.</p> <p>1. Social Research Institute (2011) End of Life Locality Registers Evaluation – final report <i>Ipsos Mori</i></p>
QS 12.	<p>People approaching the end of life being cared for in hospital, receive timely, safe and effective end of life care appropriate to their needs and preferences at all times of day and night.</p> <p>Structure:</p> <p>We agree with the principles of this quality standard. One of the significant recommendations of the Palliative Care Funding Review¹ is that the funding system for palliative care needs to change. This is in recognition of the drive for cost-effective healthcare, the work of third sector service-provider organisations such as Macmillan and Marie Curie Cancer Care in providing excellent quality care, the importance of patient choice and the need for one system to be implemented across England. The report suggests a per-patient funding system (or ‘tariff’), whereby individual patients can decide where they receive care. Patient choice and a shift in the provision of care, so that more home or hospice care can be delivered, appear to be central to the funding review.</p> <p>In theory, personal budgets allow people more choice about their own provision and could go some way to help those who do not access current palliative care provision because community services do not meet their needs (a result of which can be that people die in hospital rather than in the community). Evidence on the success of personal budgets, in terms of whether they are a useful tool at ensuring people’s choices can be respected, is needed.</p> <p>Whilst we support initiatives that allow more people to die at home, or in the community setting, this can’t always happen. It is essential that the provision of end-of-life care across all settings is standardised and that patients who are hospitalised (through choice or unavoidable clinical need) can have a good death in hospital. Place of care is important, but quality of</p>

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	<p>care is crucial.</p> <p>1.Hughes-Hallet T, Craft A, Davies C (2011) Palliative Care Funding Review http://palliativecarefunding.org.uk/</p>
QS 15.	<p>People approaching the end of life who need to be moved, are transferred in a timely, safe and effective way to enable them to receive care in the place most appropriate to their needs and preferences.</p> <p>Structure: Transferring patients between, or within, settings can prove challenging when trying to respect patient’s preferences, especially if they have lost capacity. This is usually due to a lack of communication of documented preferences and potential inter-professional confusion over what is in the patient’s best interest. If a patient has documented that they do not want to receive artificial nutrition or hydration should they lose capacity, this will have an obvious impact on where they are cared for during the end-of-life phase.</p> <p>Documents should be transported appropriately with patients, and transportation policy should be strong enough to ensure that patients’ preferences are respected. Details recorded on a POLST form in the US (see QS 6.) are stored electronically and a paper copy is kept with the patient at all times. Protocol dictates that the POLST is kept at the front of a patient’s notes, and stored electronically, and the simplicity and directness of the form means that healthcare professionals are able to trust the content and act on the preferences, even when a patient is being moved between settings.</p>

Closing date: 22 July 5pm

PLEASE NOTE: The Institute reserves the right to summarise and edit comments received during consultations, or not to publish them at all, where in the reasonable opinion of the Institute, the comments are voluminous, publication would be unlawful or publication would be otherwise inappropriate.