NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HEALTH AND SOCIAL CARE DIRECTORATE

QUALITY STANDARD CONSULTATION

SUMMARY REPORT

1 Quality standard title

Care of dying adults in the last days of life.

Date of quality standards advisory committee post-consultation meeting:
30 November 2016

2 Introduction

The draft quality standard for Care of dying adults in the last days of life was made available on the NICE website for a 4-week public consultation period between 29 September and 27 October 2016. Registered stakeholders were notified by email and invited to submit consultation comments on the draft quality standard. General feedback on the quality standard and comments on individual quality statements were accepted.

Comments were received from 48 organisations which included service providers, national organisations, professional bodies and others.

This report provides the quality standards advisory committee with a high-level summary of the consultation comments, prepared by the NICE quality standards team. It provides a basis for discussion as part of the final meeting where the committee will consider consultation comments. Where appropriate the quality standard will be refined with input from the committee.

Consultation comments that may result in changes to the quality standard have been highlighted within this report. Comments suggesting changes that are outside of the process have not been included in this summary. The types of comments typically not included are those relating to source guidance recommendations and suggestions for non-accredited source guidance, requests to broaden statements out of scope, requests to include thresholds, targets, large volumes of supporting information, general comments on the role and purpose of quality standards and requests to change NICE templates. However, the committee should read this summary alongside the full set of consultation comments, which are provided in a table in appendix 1. Each comment in the table has been assigned an 'ID number' so it can be referenced. Comments are grouped by statement and ordered by the ID number.

3 Questions for consultation

Stakeholders were invited to respond to the following general questions:

1. Does this draft quality standard accurately reflect the key areas for quality improvement?

2. Are local systems and structures in place to collect data for the proposed quality measures? If not, how feasible would it be to be for these to be put in place?

3. Do you have an example from practice of implementing the NICE guideline(s) that underpins this quality standard? If so, please submit your example to the NICE local practice collection on the NICE website. Examples of using NICE quality standards can also be submitted.

4. Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed to deliver them? Please describe any resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment.

Stakeholders were also invited to respond to the following statement specific questions:

5. For draft quality statement 2: Draft statement 2 covers the capture of a person’s preferences in the last days of life, and the provision of care that accords with their preferences. Does this statement adequately address individualised care planning in the last days and hours of life?

6. For draft quality statement 3: Does this statement adequately represent an individualised approach to prescribing anticipatory medicines for adults in the last days of life?

7. For draft quality statement 4: Does this statement address the most important area for quality improvement in relation to hydration for people in the last days of life?

4 General comments

The following is a summary of general (non-statement specific) comments on the quality standard. Responses to consultation questions 1 to 4 are also summarised in this section of the report. Responses to questions 5 to 7 are summarised under the heading for the relevant statement in section 5 of this report.

The quality standard was welcomed explicitly by a number of stakeholders, and 28 expressed an interest in supporting it. More specific supportive comments included:

- The statements are clear, measurable, attainable and patient centred.
- The quality standard demonstrates adequate individualised care planning for adults in the last days of life.

Although broad support was indicated, some stakeholders made general comments that question the impact the standard may have or the approach adopted, including:

- The statements do not represent a big departure from current expectations or practice.
- The usefulness of this quality standard will be determined by other documents in production, such as the end of life care guideline, as there are critical interdependencies between end of life care and care in the last days of life.
- There is no mention of enabling delivery of compassionate care.

- Potential conflicts between evidence-based practice and individual preferences were highlighted.

Communication and cognitive impairment were specific matters raised by several stakeholders in their general comments. Comments included:

- More emphasis is needed on the sharing of needs, preferences and information between teams and settings; and on communication with patients, families and other staff.
- Issues around reduced capacity need to be included, as clinicians will be working with people with dementia more frequently.
- In contrast, one stakeholder noted that the inclusion and recognition of needs of people with communication and cognitive impairment is welcome.

Comments were also made on text in sections at the front and back of the quality standard, and also on out of scope matters. These comments are included in the appendix but are not summarised here.

Comments on consultation question 1

“Does this draft quality standard accurately reflect the key areas for quality improvement?”

Not all stakeholders answered this question directly. The responses of those that did break down as follows:

- Yes: 8 stakeholders
- Partially: 5 stakeholders
- No: 0 stakeholders

Most stakeholders made more detailed comments. These included priority areas for quality improvement that stakeholders considered were not covered by the draft quality standard, and areas they felt should be covered by additional statements:

- Communication with the patient, those important to them and professionals. Two stakeholders specifically identified communication that death may be near as the priority, and one that the priority is communicating with compassion.

- Care (professional or family care) to support the dying patient and their family, e.g. Marie Curie/hospice at home.
- Attending to the needs of families and carers.
- Review and discontinuing 'non-essential medications', and communication around this.
- Pain management.
- Ensuring adults have an individualised care plan.
- Discussion of needs and preferences and making shared decisions, including those who lack capacity to engage.

Some stakeholders suggested some areas covered by the quality standard need addressing further. These include:

- Inequalities and identification.
- Extending statement 2 to capture preferences of ‘those important to the dying person’.

One stakeholder expressed concerns about existing statements in their response to this question. Specifically, daily review is required by some statements, but this may not be necessary or appropriate and could lead to a ‘tick box’ culture. Assessment should be driven by individualised needs and not pre-prescribed requirements.

Responses to consultation question 2

“Are local systems and structures in place to collect data for the proposed quality measures? If not, how feasible would it be for these to be put in place?”

Only a minority of stakeholders answered ‘yes’ or ‘no’ to the question:

- Yes: 1 stakeholder
- No: 4 stakeholders

Most stakeholders instead provided more detailed comments describing current partial collection of data; suggesting how data for measures could be collected or identifying potential problems.

Comments from stakeholders that data for most of the measures is actually available in a specific locality, or that suggested ways in which the data could be collected included:

- Data for most of the measures would be available from audits of a regional Care of the Dying Patient Document that covers people in hospitals, hospices or the community.
- There are local systems in place within unique end of life care projects to capture the measures. Roll out would be straight forward, but have a resource implication.
- Most of the data is already collected, but there is a danger that collection for the quality standard would turn it into a ‘tick box’ exercise.
- The quality standard could be measured by extending the RCP End of Life Care audits, which rely on retrospective audit of patient notes, to other settings.
- Retrospective review of case notes and care plans is likely to provide the data for the measures but would be resource intensive.
- Healthcare providers are likely to develop and use care plan tools for the last days of life that would allow audit of the quality standard.

Potential problems identified in the comments include:

- What needs measuring, such as different signs and symptoms, will vary between patients and the type of monitoring will vary across settings.
- People may transfer between different organisations in the last days of life, but complete information is only likely to be held by the last organisation providing care.
- Robust data collection depends on data sharing or an integrated system allowing various stakeholders access in a more detailed way than Electronic Palliative Care Co-ordination Systems (EPaCCs) allow.
- Although achievable, and some local systems are in place, the majority of data would be collated by case note review. Collection would therefore be labour intensive, but resources are limited.
- Capturing information from bereaved relatives will be challenging.
- Further clarification is needed on what ‘local data collection’ actually involves and how measures can be implemented.

Responses to consultation question 3

"Do you have an example from practice of implementing the NICE guideline that underpins this quality standard? If so, please submit your example to the NICE local practice collection on the NICE website. Examples of using NICE quality standards can also be submitted."

Examples suggested by stakeholders included:

- Care of the Dying Person Document which has is used across the Northern England Strategic Clinical Network.
- EPaCCS as an example of collecting and sharing information across different providers for key end of life decisions.
- NHS Hartlepool and Stockton-on-Tees CCG strategy for End of Life Care.
- QI anticipatory prescribing for end of life (to be forwarded once complete).

Responses to consultation question 4

"Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed to deliver them? Please describe any resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment."

Only three stakeholders answered the first part of question 4 directly:

- One considered the statements achievable but added the caveat that this is subject to necessary resources.
- Two regarded the statements as not achievable without additional resources.

Most stakeholders who responded to question 4 identified potential resource requirements. The most common requirement was for additional resources to care for people in a community setting:

- Several stakeholders commented that a lack of community resources to provide 24 hour care is preventing, or may prevent, some people from dying at home.

- Community nursing was described as being stretched, with a lack of district and specialist support nurses, sometimes resulting in unnecessary hospital admissions; and requiring significant investment.
- Reviewing the hydration status of a dying person at home on a daily basis would require significant increase in resource for community nursing.
- Additional resource would be needed for general practice and primary care to support people who wish to die at home.
- Access to, and availability of, specialist palliative care was flagged as a potential constraint; and one stakeholder stated there are variations in access and availability of bereavement support.

Training, skills mix and education were also identified as areas where additional resource was needed by several stakeholders. Specific areas suggested included:

- Training to identify people in the last year of life and being alert to acute deterioration and reversible causes.
- Training and education to enable individualised holistic care planning.

Measurement was also an area that some stakeholders felt could be a barrier to implementation or would require additional resource.

Two stakeholders expressed different views about resource inputs, though, and suggested there were no direct resource requirements:

- There are few direct financial costs associated with achieving the standard, but there would be indirect costs to provide the structures, documentation, and education.
- The statements do not require investment, but nor do they represent opportunities for disinvestment or cost savings.

Potential cost savings, mainly resulting from preventing hospital admissions, were identified by some stakeholders. Comments included:

- Fewer hospital admissions, and a reduction in unnecessary treatments and costs, would arise from identifying preferences.

- There is potential for reducing acute hospital admissions, and the cost savings from this could offset additional resources in community services.
- Achieving the statements could result in fewer complaints regarding decision making at the end of life, and result in cost savings.

5 Summary of consultation feedback by draft statement

5.1 Draft statement 1

Adults who have signs and symptoms that suggest they may be in the last days of life are monitored for further changes to help determine if they are nearing death, stabilising or recovering

A number of themes emerged from the stakeholder comments and these have been used as sub-headings in section 5.1. Some of the key questions and issues arising from the comments include:

- Should the statement focus be on monitoring people for further changes or on identifying people entering the last days of life?
- Should the focus of the statement be on communicating that someone is entering the last days of life?
- Does the statement adequately take account of uncertainty in recognising someone is dying?
- Does the word 'monitored' in the statement suggest a certain type of assessment?
- Is the frequency of assessment appropriate?
- Who should assess a person for changes?

Comments on identifying people in the last days of life and monitoring

Several stakeholders commented that people can only be monitored for changes after their signs and symptoms have first been assessed to suggest they may be in the last days of life. This may implicitly question if the focus of the statement is correct. Indeed, one stakeholder suggested there should be a statement focussed on identifying people who are entering into the last days of life.

The uncertainty in recognising that someone is dying was also the subject of some comments. Specifically, as uncertainty is common and accurate prognosis is difficult, the emphasis should be on patient needs, support and symptom control according to some stakeholders.

The word ‘monitored’ within the statement was also the subject of comments:

- One stakeholder suggested replacing the word with ‘observed and monitored’ as monitoring may imply it is just about using equipment.
- Another suggested changing the wording to 'regularly monitored'.

Comments on implementation

Comments were submitted relating to how actions would be carried out, their frequency, who would do them and what the statement may achieve:

- One stakeholder queried if daily monitoring in the community was actually practical; another stated that the frequency of monitoring should be led by patient need and included in every patient’s individual care plan.
- Some stakeholders sought clarification on who is responsible for assessing and identifying if someone is entering the last days of life, and for ongoing review. In hospitals, recognition at ward level about end of life seems to be often delegated to intensive care according to one respondent.
- Others suggested all healthcare professionals need to develop skills in recognising a person who is dying.
- Relatives and carers may be first to recognise changes in condition, signs and symptoms according to some stakeholders so their input is needed.
- Specific conditions, such as dementia or Parkinson’s, can make identification that someone is likely to be in the last days of life complex and difficult.
- Assigning people to the categories in the statement can be difficult according to one stakeholder who was also unsure if the statement would lead to people getting more attention or more visits than they would do otherwise (as good, conscientious primary care teams would be doing this anyway).

Comments on communication

Some stakeholders emphasised the importance of communicating compassionately that someone is entering the last days of life to the person who is dying, and also to their family, carers or those important to them and suggested the statement be amended to reflect this.

The importance of communication between healthcare professionals, specialties, sites and organisations was also raised.

Comments on measuring the statement

General comments on the measures for statement 1 suggested that in some areas and settings, data is already being collected or is capable of being collected; but that collection in community settings would be more challenging.

Comments from stakeholders on process measures included:

- Suggestions that the denominator for some process measures should be expected deaths and not all deaths (as there will be a significant proportion where it was not possible to recognise that someone was approaching the end of their life).
- Reference to last 3 days prior to death is inconsistent with other measures that refer to ‘the last days’.

Outcome measure comments from stakeholders included:

- Outcome measure a) is phrased in a challenging way; could become a tick box measure; and could be misunderstood and miscommunicated in order to fulfil a quality standard.
- More pertinent measures than a) were suggested including a measure of appropriate care and treatment for every individual’s differing condition; and a measure of people receiving appropriate care and treatment in line with whether they are nearing death, stabilising or recovering (the purpose for which recognition and monitoring is so important).
- Outcome measure b) was described as difficult to measure as it requires individual case file review; and as not relevant to statement 1. The relevance to

the statement action was also queried by another stakeholder who stated that not all preferences for end of life care are achievable without longer term planning (which is beyond the scope of this quality standard).

5.2 Draft statement 2

Adults in the last days of life are given care that is in accordance with their stated preferences and responsive to their changing preferences.

This section begins with a list of some key issues to emerge from the comments. The detailed comments are then summarised using sub-headings as themes. Key issues include:

- Should care be determined by preferences?
- Should the statement address needs as well as preferences?
- Does the statement adequately take account of the ability to make preferences?
- Should the statement focus be on identifying or communicating preferences?
- Is the role of those important to a dying person adequately covered?

Comments on preferences

The ability to meet the preferences of those in the last days of life was the subject of a number of stakeholder comments:

- Several comments indicated that it may not be possible, or practicable, to meet all preferences. Reasons for this included preferences not being realistic, and insufficient resources particularly in the community setting.
- Some stakeholders suggested the statement wording should be altered to reflect the above, such as saying preferences should be ‘respected’ or by inserting ‘where possible’.
- One stakeholder cautioned that although the concept is reasonable, the statement could raise expectations of patients and relatives which then cannot be met (e.g. a patient on organ support who wishes to die at home).
- In some instances, it may not be possible to identify preferences and a best interest decision should be made.

Comments on needs

A range of comments submitted observed that the statement focus is on preferences, but suggested that the statement should also address needs:

- Some comments suggested that the statement should be explicit about what needs (and preferences) to assess and address.
- Other comments identified the type of needs that should be addressed, such as medical, spiritual and psychological needs; and religious, sexuality, disability, dementia needs or preferences, or that are not addressed adequately by the statement, such as spiritual and religious needs.
- By focusing exclusively on preferences, the statement could leave clinicians in an invidious position according to one stakeholder. Care has to address needs and preferences but there can sometimes be a trade-off between the two, hence the need for shared decision making.
- Two stakeholders supplied alternative statement wording, both of which referenced needs.

Comments on the ability to make preferences

Several stakeholders submitted comments relating to people not being able to make preferences in some situations, and emphasised the need to involve others and make preferences as early as possible. Comments included:

- Establishing stated preferences in patients with dementia and cognitive impairment who may lack capacity can be very difficult. Relatives and carers may be the best sources of information.
- The role of families and carers needs to be made more explicit in this statement.
- The statement should include fuller reference to the benefits of independent advocacy support.
- Discussions on preferences need to happen before a person enters the last days of life; and people should be empowered to complete advance care plans.
- The statement should recognise that a dying person may have appointed someone to make decisions on their behalf using a Lasting Power of Attorney

(LPA) for Health and Welfare as opposed to, or in addition to, having an existing care plan.

Consultation comments on discussion / communication

Healthcare professionals can be reluctant to start discussions about preferences for care in the last days of life according to some comments, and as a result of this difficulty the statement focus should be on having a discussion to identify preferences and then planning care accordingly.

Comments were also made on the communication of preferences and shared decisions, saying that the statement should be more explicit on communication of decisions to families and that a recording system for preferences is needed that is accessible across all care settings.

Comments on focus of statement including responses to consultation question 5

"Draft statement 2 covers the capture of a person's preferences in the last days of life, and the provision of care that accords with their preferences. Does this statement adequately address individualised care planning in the last days and hours of life?"

Although a specific question (above) was asked at consultation, it is not helpful to consider the responses to the question in isolation. Some stakeholders did not answer this question, and some provided comments relevant to the question elsewhere in their responses. This section therefore includes both sources of comments.

A number of stakeholders answered 'yes' to the first part of the consultation question. Positive comments were also made supporting the statement, or aspects of it, by several stakeholders including:

- Support the statement which acknowledges the importance of the person's preferences towards the end of life.
- Statement is very powerful.
- Statement is very clear.

- Statement is fundamental to ensuring that patients have an active role in determining the care they receive.
- Strongly support the principle of the statement.

However, comments were also made that raised concerns, suggested aspects of the statement needed changing, that the focus of the statement should change or that an additional statement was needed. These comments are summarised below:

- Place of death: Preferences have become synonymous with place of death so the statement would not address individualised care planning according to some stakeholders. A different stakeholder felt that the statement is not achievable as there are insufficient resources to allow all those who want to die at home to actually do so.
- Needs and preferences: One stakeholder stated that needs and preferences must be taken into account to address individualised care planning. Other comments suggested that the statement should recognise that preferences cannot always be met, and that preferences and needs have to be balanced. One stakeholder considered the specific focus of the statement should be on providing opportunities to discuss care preferences.
- Communication of preferences and decisions: This was highlighted by several stakeholders in comments suggesting that it should be a distinct area for quality improvement, the focus of this statement or given a greater emphasis.
- Those important to the dying person: The statement could be strengthened by including this group, and putting more emphasis on taking account of their views and needs.
- Anticipatory approaches to care planning: The statement should make clear that this should be undertaken as early as possible and include those closest to the patient.

Comments on measures

General comments on measures suggested that the data needed is already collected in some localities and in some settings, but also identified some challenges:

- Existing systems are in place including audits for hospital settings, EPaCCs , and the electronic urgent care record Co – ordinate my Care.
- However, systems can be separate, not coordinated and have no centralised capture of information.
- Data collection is also described as resource intensive, with local case note review undertaken by specialist palliative care clinicians.

Comments on structure and process measures suggest:

- Structure measures are, or may be, measurable.
- Process measure a) is feasible and captured by EPaCCs.
- Process measures b) and c) would be resource intensive as they require individual case review.

Some stakeholders stated that the draft outcome measure is problematic as it is based on satisfaction of the bereaved. Satisfaction will vary with expectation, and the views of the bereaved may not accord with those of the person who died. Some stakeholders suggested alternative outcome measures including:

- Deaths in preferred place of care.
- Carer involvement in decision making.
- Asking the bereaved if the person who died was pain free.
- Asking the person who is dying about their experience of care.

5.3 Draft statement 3

Adults in the last days of life who are likely to need symptom control are prescribed anticipatory medicines with individualised indications for use and dosage

Several stakeholders indicated that they fully supported or agreed with the statement, or considered the statement to be clear. The majority of comments took the form of observations and suggestions of matters the statement should take account of. The key issues arising from the comments are:

- Will a statement on anticipatory prescribing actually ensure that people have medicines administered to control symptoms as they arise?

- Should the focus be on reviewing and stopping current medicines that do not provide symptomatic benefit?
- What is an individualised approach to anticipatory prescribing?
- Does the statement represent an individualised approach?

Comments on administration, availability, awareness & storage

A common theme of the comments was a recognition that whilst anticipatory prescribing is important, it will not by itself ensure that people are able to have medicines administered to control symptoms as they arise. Factors that may influence this include:

- Awareness across all healthcare staff (including out of hours, paramedic and specialist teams) that anticipatory medicines have been prescribed for the person they are seeing, including individualised indications. This will require appropriate documentation and records.
- Awareness across all healthcare staff that anticipatory medicines are present with paperwork detailing appropriate doses individualised to the patient.
- Healthcare professionals being available, recognising the change of a person's condition and responding appropriately.
- A recognised means of authorising the administration of the medications for nurses in the person's home.
- Assessment prior to medication being administered to establish the cause of symptoms.
- Medicines being available out of hours', in rural areas and in community settings.
- Systems for the safe storage and rapid administration of medicines when needed.
- The route of administration. People in their last days of life may have difficulty taking medication because of swallowing issues, so there is a need to consider the ways in which medication can be delivered. The statement does not adequately address the route of administration and therefore does not represent an individualised approach to prescribing.

Comments on local approaches

A number of stakeholders suggested through their comments that implementation of the statement would need to reflect local circumstances. These included:

- Prescription needs to be capable of administration according to local policies for medicines administration, i.e. paperwork is acceptable to DN, and paramedic staff.
- Individualised prescription of anticipatory medicines needs to take into account those medicines that are available locally, or are under a locally commissioned arrangement.
- There will be local end of life care guidelines for anticipatory medicines to support GPs in choice and dosage of drugs that relate to local commissioning pathways.
- Healthcare providers are likely to produce clinical guidelines and care plans to be completed for each person who is deemed to be in the last days of life.

Comments on approach to prescribing anticipatory medicines

Some stakeholder comments emphasised the importance of limiting the occasions when anticipatory prescribing occurs. In contrast, other stakeholders suggested that the statement was too restrictive in limiting anticipatory prescribing to those who are likely to need symptom control. Comments included:

- Anticipatory prescribing should only be used when there is expected to be a serious and significant delay in obtaining the medication.
- Steps must be taken to ensure the prescription is only given when explicitly needed.
- The statement may result in some people having inadequate symptom control. As it is difficult to predict with certainty which patients will experience which symptoms, an adequate range of anticipatory medications may not be prescribed. As an alternative, the statement could seek to prescribe medication to cover the five common symptoms encountered at the end of life for all dying patients but ensure that the dosages prescribed are individualised for each individual patient.
- Suggest the statement should apply to most or all patients, not just those ‘likely’ to have symptoms.
- Avoiding delays is important, but there is a risk that patients have medicines prescribed almost automatically. On the other hand, most patients will need some medication. Whether it works to have more or less individualised care depends entirely on how it is put into practice.

Responses to consultation question 6

“Does this statement adequately represent an individualised approach to prescribing anticipatory medicines for adults in the last days of life?”

Before considering responses, it should be borne in mind that neither the draft statement nor the underpinning guideline defined what an individualised approach actually is. Therefore stakeholder comments are based on their own interpretation of what an individualised approach is. Comments made suggest there are some different interpretations.

Some stakeholders responded to the question by saying the statement does represent an individualised approach to prescribing anticipatory medication. Indeed, one stakeholder considered the statement an ‘excessively individualised’ approach requiring information not readily discernible from clinical notes.

Other stakeholders said that they agreed with or supported the statement but felt that the statement should:

- Be clearer that provision of anticipatory medications should be made on an individual basis; that a broad range of medications could be considered anticipatory; and that the provision of anticipatory medications in the community must be safe.
- Emphasise the importance of healthcare practitioners being aware of the impact of dementia on symptoms.
- Should underpin regular assessment of the patient for effect.

Several stakeholders disagreed with the target audience of the statement as, although there are common symptoms at the end of life, it is not possible to predict exactly who will get what symptoms. They suggested that statement should be amended such that:

- Anticipatory prescribing occurs for all people in the last days of life.
- Prescribing is personalised based on symptoms so far, current doses of analgesia etc.

Greater clarity is needed according to some stakeholders on:

- Ensuring drug doses are prescribed according to individual patient needs, and that their condition and should be reviewed daily.
- The term “individualised approach” as anticipatory prescribing would no longer be for the 5 main symptoms.

One stakeholder answered ‘no’ to the consultation question and said that the statement should include stopping medications and other medical interventions which do not contribute to comfort and symptom control at the end of life.

Comments on measures

One stakeholder suggested that data collection may be possible if there is consistent and agreed documentation.

Specific comments on the process measure included:

- Electronic prescribing is critical for measurement.
- The denominator is too vague: suggest ‘number of adults recognised to be in the last days of life’ – or ‘number of deceased adults’.
- The process measure does not capture subsequent use of the medicines prescribed.

Comments on outcome measures included:

- Outcome a) measures those who have their symptoms controlled, but it is not possible to control all symptoms. Suggested alternatives to this measure include symptoms controlled to a level that is acceptable to the patient; people who are comfortable at the time of death; and dying people receive treatment for their symptoms without delay and at a dosage and route that is individualised to their needs.
- Outcome b) captures the views of the bereaved. These will be difficult to collect; may be different to the views of the person who has died; and may be determined by other factors.

- There should be an additional outcome with a focus on the quality of symptom control.

5.4 *Draft statement 4*

Adults in the last days of life have their hydration status assessed daily, and a discussion about the risks and benefits of clinically assisted hydration.

Key issues arising from the comments include:

- Is it clear what hydration status means?
- What should assessment involve and how frequent should it be?
- Would daily assessment be achievable in community settings?
- Is a discussion of the risks and benefits of CAH an appropriate focus?
- If so…
    - when and how often should discussion occur?
    - can CAH be provided for people who wish to die at home?

Assessment of hydration

The focus of the first part of the draft statement is daily assessment of hydration status. Two stakeholders considered this appropriate. However, another stakeholder questioned the focus of hydration status and felt that the statement did not align with the [draft] guideline.

Neither the draft statement nor the underpinning guideline define ‘hydration status’. Consequently, some stakeholders questioned what an assessment of hydration status involves or stated what an assessment should involve. Other comments suggested that stakeholders interpreted assessment of hydration status differently:

- One stakeholder took assessment to be a check that a person is comfortable with their hydration, whilst another queried what an assessment comprises and how it would be carried out.
- Others took assessment to include observations: one stakeholders cautioned that clinical signs of hydration can be unreliable in older adults; another that oral hygiene is not always a good measure of hydration status.

- Some comments suggested assessment was, or could be, interpreted as involving blood tests.
- Another recommended that the assessment should cover aspiration.

The frequency of assessment was also commented on, with some stakeholders suggesting that daily assessment affects the achievability of the statement whereas others felt this was not frequent enough. Comments included:

- Daily assessment of hydration status may not be achievable in community settings; is not feasible in the community; would be a burden on already stretched community resources out of hours; would require significant increase in resource for community nursing.
- Daily assessment is appropriate.
- The statement wording should make clear that a daily assessment is the minimum frequency necessary, and that some people need more frequent assessment.
- Checking symptoms at least once a day is not sufficiently reassuring as a person's condition may change quickly.

Communication and discussion

The draft statement explicitly includes a discussion of the risks and benefits of CAH and a number of comments related to this part of the statement:

- Several stakeholders commented on what should be the subject of the discussion. Some suggested the statement should emphasise the communication of need for fluids at the end of life and of symptomatic benefit. Another suggested statement 4 should acknowledge the need for discussions about maintaining comfort in relation to their symptoms.
- One stakeholder commented that professionals are somewhat reluctant to discuss hydration with patients and families. Another suggested that health and social care professionals need training and advanced communication skills to have these discussions.
- The statement was taken to mean that all patients should have a discussion about the risks and benefits of CAH by one stakeholder. However, they felt that this should only happen when the situation demands it rather than with every patient.

- Two stakeholders suggested that the action should not be a discussion. One suggested that the statement should instead ‘offer’ a discussion about the risks and benefits of CAH; the other suggested the statement should say consider of the risks and benefits.

Clinically assisted hydration

The focus on CAH was questioned by some of the comments:

- Two stakeholders queried the appropriateness of a focus on CAH as they believe there is a lack of evidence about the benefits and risks of CAH. Another suggested that the focus may reflect concerns raised by the media and not clinical priorities.
- All available options need to be explored, from self-help to clinical intervention, if hydration is required.
- Instead of CAH, two stakeholders suggested the statement should have an alternative focus on:
    - Supporting patients to drink or giving good mouth care.
    - Discussions with the patient about maintaining comfort in relation to their symptoms.

The ability to provide CAH in community settings was also the subject of comment:

- Two stakeholders stated that CAH is not widespread in community settings, and is only commissioned in some areas.
- Others suggested it may not be feasible to provide CAH in a community setting, and noted that if CAH is limited to inpatient settings then this could affect preferences on place of death.

Comments on measures

Comments on process measure a):

- Cautioned that delirium may be interpreted as dehydration by generalists.
- Queried how hydration would be measured.
- Suggested using ‘number of adults recognised to be in the last days of life’ or ‘number of deceased adults’ as the denominator.

Comments on process measure b):

- Suggested the frequency of discussion should be tailored to individual needs.
- Suggested using ‘number of adults recognised to be in the last days of life’ or ‘number of deceased adults’ as the denominator.

Comments on outcome measure a):

- Suggested changing the measure to ‘Proportion of adults in the last days of life who are assessed for symptoms of dehydration and overhydration’.
- Cautioned that symptoms of over hydration & dehydration may be attributed to other causes and queried how they would be measured.

Comments on outcome measure b):

- Suggested that the measure may place a burden of understanding on dying adults and those important to them that is not welcome and technical.
- Suggested that emphasis is placed on the aims of care (which includes issues about drinks and fluids) rather than on ‘understanding hydration issues’.
- Questioned how understanding would be measured and described it as subjective.

Outcome measure c) was also described as subjective and not reflecting the aim of the statement.

One stakeholder suggested a measure with a focus on oral hygiene would be valuable.

Responses to consultation question 7

“Does this statement address the most important area for quality improvement in relation to hydration for people in the last days of life?”

As with previous questions, only a small number of respondents answered yes or no. Three stakeholders answered yes in response to the question, or said they supported the statement.

Some comments suggested that the statement focus should be on:

- Supporting the person who is dying to take oral fluids for as long as they wish.
- Documented evidence that hydration was considered and discussed.

Others implied that there may be difficulty in agreeing a focus as there is no evidence base for hydration at the end of life; and there is not a clear clinical consensus on hydration in the last few days of life.

A theme running through responses to the question is a recognition that assessment in relation to hydration is an important area. Comments included:

- It is vital that hydration for people in the last days of life is continually monitored.
- The most important areas in relation to hydration are whether the patient is symptomatic or distressed in relation to hydration.
- The most important quality area is that patients are assessed for distress around lack of fluids. The statement could simply require an on-going hydration status review and discussion.

Some stakeholders queried what assessment of hydration status involves. This will in part be the result of there being no definition, but one stakeholder noted that hydration status has a different meaning for people in the last days of life. The comments are summarised below:

- Does it comprise food / fluid charts / blood test / skin integrity / status of oral cavity / level of oedema?
- Does it include needs?
- We are concerned of how health care providers may assess hydration status.
- The normal meaning of hydration status is an assessment of fluid balance. In the care of a dying person, the assessment is of the patient’s symptoms in relation to their hydration status e.g. dry mouth, delirium, pain and discomfort from cannulae, shortness of breath from lung congestion.

One stakeholder suggested that assessment should be wider than hydration and actually cover all areas of care, and should also reference other measures put in place to maintain comfort such as regular mouthcare. Mouth care, and ensuring oral integrity, was described as paramount to comfort by another stakeholder who recommended more focus on this when considering hydration.

Comments were also made on the frequency of discussion of the risks and benefits of CAH:

- The current wording implies there is a daily discussion of the pros and cons of clinically assisted hydration. The statement wording should be reordered to “Adults in the last days of life are offered a discussion about the risks and benefits of clinically assisted hydration, and have their hydration status assessed daily”.
- It is unclear when and how often conversations on hydration take place.

Appendix 1: Quality standard consultation comments table – registered stakeholders

General comments		
ID	**Stakeholder**	**Comments**
1	Alzheimer’s Society	Dementia is increasingly becoming a cause of death – one tenth of all recorded deaths include a reference to dementia (Public Health England, 2016). Even if it is not the primary cause, it can complicate the care and management of other comorbidities at the end of life. As such, clinicians will be working with people with dementia more frequently, so it is essential that the quality standards are able to encapsulate issues around reduced capacity.
2	Association for Palliative Medicine of Great Britain and Ireland	We welcome the draft quality standard, but feel there may be a lost opportunity to make this uniform across the country. Standardisation would prevent duplication of work across the country and also allow comparison between sites.
3	Association for Palliative Medicine of Great Britain and Ireland	We would welcome clarification about the local data collection suggested throughout the document. Many large Trusts have several thousand deaths a year across hospital and community. Measuring data for all these patients would be very time consuming. Clarification on sampling a proportion of deaths would be helpful.
4	Compassion in Dying	Compassion in Dying is a national charity working to inform and empower people to exercise their rights and choices around end-of-life care. We do this by: • providing information and support through our free Information Line; • supplying free Advance Decision to Refuse Treatment (ADRT) forms and publications which inform people on how they can plan ahead for the end of their life; • running information sessions and training for professionals, community groups and volunteers on planning for the end of life or loss of capacity, including accredited Continuing Professional Development (CPD) modules; • and conducting and reviewing research into end-of-life issues to inform policy makers and promote person-centred care. We welcome this quality standard, in particular quality statement 2, though we do have comments on the specific wording of this quality standard and the responsibilities that service providers and commissioners have to ensure it is delivered.
5	Coordinate My Care	All Statements have a verb in them – determine (Statement 1), given (Statement 2), prescribed (Statement3) assessed (Statement 4). The one verb that is perhaps assumed but should be explicit if real world achievements are to be had. This is especially as it is so vital in the community context where so few deaths occur and yet the preference data suggests it as the primary preference. The missing word is ‘shared’. All the relevant data, preferences, clinical perspectives etc. need effective and systematic sharing across the

General comments		
ID	**Stakeholder**	**Comments**
		wider team to optimise the achievement of the Standard. This emphasis on robust and strategic sharing across the care landscape (hospital, community, in-hours, out-of-hours) should be placed within the What the quality statement means for service providers, healthcare practitioners and commissioner sections of the Statements.
6	Faculty of Pain Medicine of the Royal College of Anaesthetists.	The four standards themselves seem pretty straightforward and uncontroversial, and no big departure from current expectations of practice based on recent NHS guidance. We think the challenges will be in obtaining data to monitor adherence to the standards.
7	Hospice UK	Hospice UK believes that the draft standard is clear, measurable, attainable and person centred.
8	Northern Health and Social Care Trust, Northern Ireland	Feel "where possible" should be added to many of the standards and measures, especially the patient preference measures - what if patient prefers physician assisted suicide? or if patient has an advance care plan stating wants to be at home to die but now incompetent and no carers etc at home. Are we meant to phone ambulance and discharge? Autonomy is not the only factor in healthcare - we cannot always deliver patient preference nor should we.
9	Northern Health and Social Care Trust, Northern Ireland	Challenging to capture the views of bereaved relatives, from practical detail capture and with regard to timing and sensitivity.
10	RCSLT	The RCSLT are pleased to see the inclusion and recognition of needs of people with communication and cognitive impairment
11	Resuscitation Council (UK)	One of our reviewers noted that throughout this document there is a shortage of advice on how to perform many of the quality measures considered necessary. A typical example on page 18 is: ‘Structure a) Evidence of local arrangements to ensure that adults in the last days of their lives have their hydration status assessed daily. Data source: Local data collection.’ Whilst we recognise that it may not be NICE policy to specify models/methods of service delivery we feel that the absence of any practical guidance on how to achieve the quality standards represents a missed opportunity. Inclusion, for example, of some examples of best practice could address this, without being prescriptive.
12	Royal College of General Practitioners	I’ve found this quality statement very difficult to assess. The document opens with a statement that looks completely unequivocal: ‘Without an evidence-based approach to the care of dying people, there is a danger of placing tradition and familiar policies

General comments		
ID	**Stakeholder**	**Comments**
		before meeting the needs of individuals and families.' until I realised that with an evidence-based approach there is just as big a danger of putting the evidence before the needs of individuals and families. Even if the evidence clearly points in one direction, that is no reasons to put it ahead of the wishes or needs of individuals. The question that the panel should be asking is 'Are these statements likely to enhance care that is centred around the wishes and needs of patients and their families?' I have tried to adopt that approach in my response. My own conclusion is that the test is whether the health professionals want to do this important bit of clinical care or not. If they do then the statements could get in the way; if they don't the statements could make some things happen in a way doesn't especially support individualised care. (DJ) No mention of enabling delivery compassionate care – implications for both patients, professionals, population. (CMS)
13	Royal College of Nursing	This quality standard is to be welcomed in that it supports the other NICE guidelines relating to End of Life Care as well as the National Choice Offer recommendations and government commitment to these. In order that the standards are met, there needs to be recognition of variability and also access of out of hours to people who can support the administration of anticipatory medication, care and advice in a timely fashion. There is mention of the End of Life audit of people dying in hospital. This needs to be extended to the community in order that a more robust picture of the whole service is clearly identified. Education of staff is vital for continuous improvement of patient care.
14	Royal College of Physicians	The RCP is grateful for the opportunity to respond to the above consultation. In doing so we would like to endorse the response submitted by the Association for Palliative Medicine. We have also liaised with our Joint Specialty Committee for Palliative Medicine and would like to make the following comments.
15	Royal College of Physicians	List of quality statements Our experts note that three of the quality statements (1, 3 and 4 respectively) are about processes and not about outcomes, despite being nominally based on the NHS Outcomes Framework. Furthermore, our experts believe that QS2 will be challenging to measure in a meaningful way. Our experts note that it is easier to measure processes 'did we do something (or not) in providing care' and much harder to measure outcomes 'did that care make a positive difference for patient/family', and believe it is the latter that we should be looking at. There is a wealth of good evidence about what patients approaching last weeks and days are concerned about, and what their

General comments		
ID	**Stakeholder**	**Comments**
		families are concerned about. These are issues such as being pain free, having no distress from their breathing, being settled and peaceful, and having good communication between professionals and family so that the family then feel fully updated and informed. Our experts are concerned that these quality standards will have little or no impact on improving care of the dying because they do not have sufficient emphasis on meaningful patient and family outcomes. Our experts compared the quality statements to the Liverpool Care Pathway (LCP) which shifted (in inexpert hands) towards a checklist of processes and had limited positive impact in improving care for patients. Our experts note that this Pathway had (at best) a somewhat limited positive impact in improving care for patients and was (at worse) simply a 'tickbox' exercise. Given the existing quality standards and guidelines for end of life care for adults, this draft standard does not move away from existing documents in its content and usefully refers to existing guidelines in its design. How useful it ultimately proves to be will probably be dictated by other documents in development such as the 'end of life care for adults' NICE quality standard. Our lay representative made the following points: • The draft quality standard relies on the fact that End of Life Care for Adults will remain to be updated. • There are such critical interdependencies in the overall pathway that it is complex and confusing. • There is openness to interpretation by professionals working cross functionally, where everyone continues to be able to demonstrate that they have 'done their job' but in fact it remains short of the quality and need desired of patients and families during this difficult and critical time. • The fact the guideline is under development adds to the overall change dynamic which makes this yet another part of a picture which needs assurance overall. • The scope defined has fed into and influenced the way in which the particular QS on last days of life under consultation has been developed but without any assurances as to how cross the range of interdependent QS gaps will be covered in the End of Life Care for Adults. • As described the measures can probably be demonstrated to be achieved without improving the outcome and experiences for patients and families. • The NICE introduction does not provide overall assurance as to the comprehensive approach being taken cross the areas of change in relation to the critical inter-dependencies of the standards and guidelines to ensure overall cohesion and quality cross the patient pathway identifying and closing gaps whilst improving quality. Overall our lay representative acknowledges the intent and way that using NICE processes, this QS has taken input and attempted to describe at a high level the standards needed to drive change. It is unclear however that practice and behaviours will change and

General comments		
ID	**Stakeholder**	**Comments**
		care quality improved for patients without there being more context, reassurance, and adoption of measures which relate to those outcomes important to patients and families.
16	Royal College of Physicians and Surgeons of Glasgow	Additional emphasis is needed in respect of the need to communicate this with patients, families and other staff and also of the need to record this in patients file. The standards also need to tie in with NICE Guidance on Palliative Care and the need for Anticipatory Care Planning at an earlier stage of illness. If bereaved relatives are to be approached, then it would be important to specify how the views of the bereaved relatives should be sought and who should do this. We believe that further support and guidance on end of life care will be required in order to support clinical staff of all grades about the need to make the decisions in respect of these statements and undertake monitoring for the symptoms and signs of impending death.
17	Royal College of Physicians of Edinburgh	The Royal College of Physicians of Edinburgh notes the response provided by the Association for Palliative Medicine of Great Britain and Ireland to this consultation, which welcomes the draft quality standard and, however, recognises there may be a lost opportunity to make this more uniformly implemented across the country.
18	Royal College of Psychiatrists	This quality standard is appropriate and demonstrated adequate individualised care planning for adults in the last few days of life
19	St Luke's Hospice	The Quality Standards set no standard determining how patients dying in a setting where multiple different agencies are supporting them (such as community) coordinate care beyond the general statement in the introduction to ensure the other standards are met. This risks the provision of care in community will not have the appropriate drivers to ensure collaboration in the delivery of a high standard of end of life care.
20	Sue Ryder	Sue Ryder believe that NICE should consider building a human rights approach into its quality standards on end of life care. This could be a powerful tool for highlighting and articulating what is important in delivering good end of life care, and it could provide a framework to help understand and think through the issues that can arise when delivering end of life care.

General comments		
ID	**Stakeholder**	**Comments**
		Human rights that are crucial to consider when providing care at the end of life include the right to life, the right to be free from inhuman or degrading treatment and the right to private and family life. This sort of approach is set out in ‘End of Life Care and Human Rights: A Practitioner's Guide’, by the British Institute of Human Rights and Sue Ryder. (Link)

General: comments on introduction, end sections of quality standard etc.		
ID	**Stakeholder**	**Comments**
21	Healthwatch Hartlepool	Page 4 of the document: Coordinates Services 2nd Paragraph: The Health & Social Care Act sets out a clear expectation that the care system should consider NICE quality standards in the planning & delivering services as part of a general duty to secure continuous improvement in quality. Commissioners and providers of Health & Social Care should refer to the library of NICE quality standards when designing high quality services, other standards that should be considered – dying adults, are listed in Related Quality Standards. This is concerning as it is assumed providers will know or need informing of how to deliver appropriate care.
22	Healthwatch Hartlepool	Also in the Bibliography there is reference to the Dept. of Health (2013) More Care, Less Pathway – A review of the Liverpool Pathway. It is our view that this needs to be of great consideration as too many clinicians were putting their own interpretation on how they should behave rather than how they must behave or provide care towards patients in their last days. It is worrying clinicians need to be advised on how to treat a person in the last few days of life. Overwhelming should be consideration of dignity and respect.
23	Older People’s Advocacy Alliance	In relation to comments on involving family and carers, independent advocacy support can offer carers support to be involved in shared decision making and as such should be referenced as another means to ensure they are receiving support whilst supporting their loved one in their final days.
24	Royal College of Physicians	“Although many people receive high-quality care at the end of their lives, independent reviews (such as the review of the Liverpool Care Pathway and review of choice in end of life care published by the Department of Health) , audits (the Royal College of Royal College of Physicians’ End of life care audit) and surveys (the Office for National Statistics’ National survey of bereaved people) have identified variation in the care provided to people approaching the end of their lives.”

General: comments on introduction, end sections of quality standard etc.		
ID	**Stakeholder**	**Comments**
		Our experts note that ‘approaching end of their lives' is ambiguous, given that earlier, the distinction between 'last days' and 'end of life' is made. Our experts suggest changing to 'approaching last days of life'.
25	Sue Ryder	As comment 5 [ID 200]

Responses to consultation question 1: Key areas for quality improvement		
ID	**Stakeholder**	**Comments**
26	Alzheimer’s Society	Alzheimer’s Society supports the four areas NICE has selected for quality improvement. Everyone who is diagnosed with dementia will have dementia at the end of their life, either as the cause of death or as a condition that complicates the care and management of another condition. Dementia causes a slow, gradual decline in frailty – this makes judging prognosis difficult and can make it harder to identify when a person is in the last few days of life. Healthcare practitioners must be able to identify particular symptoms and behaviours which suggest a person is in the last few days of life so that they receive the right care and symptom management. The majority of people with dementia die in care homes with high levels of social care need. For people with dementia living in care homes, the link between social care and palliative care is even more important – social care staff are not always adequately trained to support people with dementia and identify health needs such as pain, which can cause delays in getting adequate care and lead to undignified treatment at the end of life. Care in the last few days of life for people with dementia needs to be coordinated between services and across settings to make sure they receive the right support. Further, many people with advanced dementia will lack mental capacity to communicate or be involved in decisions about their care towards the end of their lives. Despite this, the person should still be involved in decisions as far as possible – previously expressed wishes and views of people such as family members and carers should also play a significant role.
27	Association for Palliative Medicine of Great Britain and Ireland	We welcome this draft quality standard. It addresses the main areas of concern identified by the Neuberger report (recognition of dying, appropriate and measured prescribing for symptom control and issues/communication re hydration). However, we believe that there are additional areas that should be included within it: • There is no mention of honest, sensitive communication with the patient (if possible), those close to them and professionals that death may be near • There is no mention of availability of trained staff to assess and manage symptoms appropriately • There is no mention of coordination of care which is one of the most difficult areas for dying patients and their families • There is no mention of confident, able care (professional or family care) to support the dying patient and their family e.g. Marie Curie/hospice at home

Responses to consultation question 1: Key areas for quality improvement		
ID	**Stakeholder**	**Comments**
		• Need to include appropriate review of discontinuing 'non-essential medications' and communication around this
28	Belfast Health and Social Care Trust	This draft quality standard accurately reflects the key areas for quality improvement.
29	Bradford, Airedale, Wharfedale & Craven Palliative Care Managed Clinical Network	Good and effective communication underpins all care provision for patients and those important to them in the last days of life. Why is there not a quality statement which will measure this? As an organisation we feel this should be included in the quality statements.
30	EPA UK/EU	This quality standard clearly meets the clinical needs of adults in their last days of dying and we welcome a commonly agreed approach on how to respond when a person is close to dying. The central question we pose is whether clinical care should ever be considered separately from care of the person. We observe that in NG31 Communication is included, yet excluded here. NG31 Section 1.2 offers health care professionals sound guidance on how to communicate with patients and those important to them and is aligned to one of 5 priority areas cited in The Royal College of Physicians (RCP) report ''National Care of Dying Audit of Hospitals' and Leadership Alliance for the Care of Dying People (LACAP)report 'One Chance to Get it Right': • **sensitive communication** takes place between staff and the dying person, and those identified as important to them LACAP's statement of the duties and responsibilities of health and care staff includes that: 'Health and care staff must make time to talk with dying people, their families and those identified as important to them, including carers. They must listen, respond sensitively to their issues and concerns, provide information in a way that meets their communication needs and check that explanations and information are understood. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf We learn from clinical patient case notes in the RCP report that : ' In total '93% of patients whose death was predictable had documentation that they would probably die. However, in ' total, only 25% of people who were recognised as being likely to die had documented evidence of a discussion with a healthcare professional about their likely imminent death'. **We suggest that simple adhering to clinical procedure without connecting to the human being is not true care and could seriously affect quality of experience for the person dying.** https://www.rcplondon.ac.uk/projects/outputs/end-life-care-audit-dying-hospital-national-report-england-2016
31	EPA UK/EU	The Independent Review of the Liverpool Care Pathway 2015 is called More Care and Less Pathway. This is the important message to all involved in the end stage of life, that the quality of care is driven by compassion, true consistent simple care and communication. We ask that this Quality Standard includes a statement on communicating with compassion. 'Common qualities

Responses to consultation question 1: Key areas for quality improvement		
ID	**Stakeholder**	**Comments**
		that are associated with 'compassion` 'are that the individuals feel truly listened to, they feel heard and met, truly seen for who they are and not just another condition in a bed, another operation on a table. They are recognised as an individual with their own set of concerns or worries and they are treated with respect and dignity and feel cared for' http://www.thesoulfuldoctor.co.uk/blog/compassionate-care Compassion and Care of Dying - what patients and those important to them want.' A recent social media campaign ' Hello my name is…' initiated by Dr Katy Grainger highlighted negative impact on patients of doctors and healthcare workers failing to connect to the patient by introducing themselves and finding out who the person is beyond the illness. In her own words ' I made the stark observation that many staff looking after me did not introduce themselves before delivering my care' ' Introductions are about making a human connection between one human being who is suffering (or dying) and another human being who wishes to help. They begin a therapeutic relationships that can instantly build trust in difficult situations' http://hellomynameis.org.uk Two Canadian reports 'What matters most in end-of-life care: Perceptions of Patients and Family Members' and 'Defining Priorities for Improving end-of-life care in Canada' confirm the importance of compassionate care by patients and their families who have consistently ranked features of compassion among their greatest healthcare need. http://www.cmaj.ca/content/174/5/627 http://www.cmaj.ca/content/182/16/E747
32	EPA UK/EU	Specialist training on supporting a dying person is a requirement and needs inclusion in the NICE guidelines. The dying person may have had many years notice of their impending terminal illness or may be in their state from an acute medical episode. As the journey of the dying person can be so variable from their level of conscious awareness and their medical illness, to their mental, emotional and physical condition, their state must be constantly monitored and assessed by a multi-disciplinary team at every intervention. Everyone involved in the care of the dying requires specific training in their area of work to be able to should be aware of the possible frequent changes of symptoms at every intervention. Training with discussion and exploration of our own specific journey and understanding of death can help us individually to be a support to others on their journeys.
33	Great Western Hospitals NHS foundation Trust	Outside the inpatient setting, daily review as required by several of the standards, may not be necessary or appropriate and is thus not a good marker of quality or key area for improvement If care is to be fully patient centred, assessment should be driven by individualised need not pre-prescribed requirements. If clinicians are focused on reviewing these pre-prescribed areas, opportunity for patient and carer focused meaningful conversations could be missed and a shift towards a tick box culture encouraged.
34	Healthwatch Hartlepool	One of the concerns raised by our executive overall is the lack of clarity of the qualifications expected of those delivering palliative

Responses to consultation question 1: Key areas for quality improvement		
ID	**Stakeholder**	**Comments**
		care, who has to be trained and to what standard that should be appropriate for this type of care. Also within the document there is reference to all marginalised groups under the single heading of 'Mental Health'. We would hope that regard could be given to specific cohorts of patients in respect of Learning Disability, Sensory Loss, BAME, Refugee/Asylum Seekers with bespoke packages tailored to their needs.
35	Hospice UK	The need for care coordination is rightly identified as critical, especially in the last days of life. It is disappointing that there is no quality statement specifically on this issue.
36	Hospice UK	The views of bereaved relatives are identified in both quality statement 3 and 4 as a data source to evidence that the person's care needs are being met. Attending to the care needs of families and carers before death is, however, not mentioned during this period of care. The role of families and carers is mentioned on page 5, but only in the context of involving families and carers in decision making where appropriate. In our view, it is an omission not to refer to the needs of families and carers in their own right in the final days of life.
37	Leeds Palliative and End of Life Care Managed Clinical Network	It does not capture pain management however it is noted p26 this is for a future quality standard
38	Leeds Teaching Hospitals	Yes
39	Marie Curie	We believe this draft quality standard does accurately reflect the key areas for quality improvement. There are several key resources needed to ensure this is successfully implemented: the resource to collect and collate outcomes in a standardised and continuous format; and a comprehensive training programme particularly on involving family and carers in end of life.
40	NHS Hartlepool and Stockton-on-Tees CCG	Statements 1,2 and 3 all reflect key areas of good end of life care. We have some reservations about clinically assisted hydration in statement 4. Hydration is very important in the last days of life and that people should be able to drink as and when they wish and be given whatever support they need to be able to take oral fluids for as long as they wish it. However unless a person is already on clinically assisted hydration then it is rare for it to be beneficial in the last days of life. While communication about any treatment is always advisable, placing the recommendation within NICE guidance about this may affect people's expectations of how their loved one's hydration should be managed.
41	Northern Health and Social Care Trust, Northern Ireland	Yes we think these are the key areas for improvement.
42	Resuscitation Council (UK)	We recommend this as an additional key improvement need that arises from the clinical guideline: **'Adults in the last days of life have an individualised care plan that describes clearly their needs and preferences and the**

Responses to consultation question 1: Key areas for quality improvement		
ID	**Stakeholder**	**Comments**
		actions required to address these.'
43	Resuscitation Council (UK)	We recommend this as an additional key improvement need that arises from the clinical guideline: **'Adults in the last days of life are given documented, repeated opportunity to discuss their needs and preferences, to make shared decisions about their care and treatment, and to include those important to them in discussions and decision-making if they wish.'**
44	Resuscitation Council (UK)	We recommend this as an additional key improvement need that arises from the clinical guideline: **'For adults in the last days of life who lack capacity to engage in discussions and decisions about their care and treatment, discussions are held and decisions made in accordance with capacity legislation, for example adherence to a valid and applicable Advance Decision to Refuse Treatment, discussion with a legal proxy with powers to consent to or refuse treatment, discussion with others important to the patient.'**
45	Royal College of General Practitioners	I don't think they fully address inequalities or identification (CMS) I think that the draft quality standard addresses some of the key areas for quality improvement. However I do think that it would be better if it addressed communication with relatives in more detail. In addition it makes no mention of communication regarding DNAR decisions - with the patient, relatives and other teams.(LS)
46	Royal College of Nursing	The whole quality standard needs to be tightened to reflect the variation across the country and the lack of community services available for people who wish to remain at home which includes the care home in which they live.
47	Royal College of Physicians	Our experts believe that overall the standard does reflect the key areas in need for further improvement, and is in keeping with the 'one change to get it right' guidance that addresses the biggest concerns from the public as well as professionals. However, our experts note that there is no mention of: • honest, sensitive communication with the patient (if possible), those close to them and professionals that death may be near • availability of trained staff to assess and manage symptoms appropriately • coordination of care which is one of the most difficult areas for dying patients and their families • confident, able care (professional or family care) to support the dying patient and their family eg Marie Curie/hospice at home Given these omissions, our experts were unsure whether the standards reflected the holistic nature of a palliative care and multidisciplinary approach, and suggest an explicit statement about communication with family or close persons would be helpful. This is often limited or lacking, and is an additional area which needs quality improvement.

Responses to consultation question 1: Key areas for quality improvement		
ID	**Stakeholder**	**Comments**
48	Royal College of Physicians and Surgeons of Glasgow	All four areas are important and should be part of good practice in care provision. This is a useful document that does refocus on the needs of individuals in the last days of life. The recommendations are "top line" rather than overly prescriptive. In addition to the management of an individual being an overriding message, there is an additional clear statement that once an individual is felt to be dying, there are several key decisions that will need to made, and possibly reviewed, such that there are active elements to management. This seems a positive step and should support better daily review of these patients in respect of these key elements.
49	The British Geriatrics Society	Overall this quality standard reflects the key areas for improvement. Statement 2 could be strengthened to include 'those important to the dying person' One of the 5 priorities of care identified by the Leadership Alliance for the care of dying people is 'The people important to the dying person are listened to and their needs are respected'.
50	Western Health and Social Care Trust	**Comment: Yes** The quality statements reflect some fundamental key areas for quality improvement, however in Northern Ireland (NI) there are additional key quality statements / standards / priorities that relate to patients within the last year of life (however not specifically just the last few days). Some of the above would support the key priority areas for NI which includes: • Identification for patients who may be in the last year of life. Wider than statement 1. • Keyworker – identification and allocation - not included in above statements. • Advanced Care Planning – relating to statement 3 above • Specialist palliative care service provision Mindful that this draft is alluding to all patients identified as in the last few days of life so will span across all care settings and a variety of health care providers including those providing care informally (family, friends, neighbours, others)

Consultation question 2: Local systems and structures in place to collect data?		
ID	**Stakeholder**	**Comments**
51	Association for Palliative Medicine of Great Britain and Ireland	It will be difficult to collect data for the proposed quality measures because: • Not all patients in the last few days of life show the same signs and symptoms, nor have the same needs • Some measures are vague and will be difficult to measure • Monitoring signs and symptoms of dying will depend on the condition and the environment in which the patient is being cared

Consultation question 2: Local systems and structures in place to collect data?		
ID	**Stakeholder**	**Comments**
		for - this could be very different between, for example, home and critical care. If this just means daily review with observation for recovery then it would be feasible for these to be put in place. However, if this means monitoring of breathing, colour changes, level of consciousness this is very detailed and will be a challenge to measure. There is a danger of medicalising death with too many measures. • There are different documents etc. across the country that are used to support the care of dying patients, making meaningful national data collection difficult
52	Bradford, Airedale, Wharfedale & Craven Palliative Care Managed Clinical Network	It is achievable to gather data and we have local systems in place to support this. However although some data can be collated by analysts from our electronic systems the majority of data is collated by case note review. Completing annual audit is very labour intensive and within our organisations this is undertaken by specialist palliative care clinicians. Resources are limited and there is ongoing concern that an increasing workload is stretching services too thinly. End of life educators / facilitators are patchy across the organisation and posts are often fixed term which makes recruitment and retention difficult. A biennial national audit is undertaken monitoring caring for patients in hospital. Are there plans to audit care for patients in the community (own home)?
53	Great Western Hospitals NHS foundation Trust	Local systems do not routinely collect data at the level of detail required. This could be put in place, but not without encouraging a tick box culture – see above.
54	Leeds Palliative and End of Life Care Managed Clinical Network	Though Leeds has Electronic Palliative Care Coordination System (EPaCCS) this would capture part of this information only. There would need to be developments on electronic records to create templates and build reports to allow full capture of this information. It SystmOne or other large ER provider could lead/ be commissioned on this this would assist a number of small providers i.e. Hospices and prevent duplication of effort
55	Leeds Teaching Hospitals	It is possible to collect data to support these quality measures, but will be extremely time consuming to do so - this could form part of the RCP EOLCA. We feel it would be unlikely that clinicians would be able to undertake more than the biannual RCP EOLCA, as retrieving medical notes and auditing of them is extremely time consuming and would take staff away from direct patient care for considerable periods of time.
56	Marie Curie	The denominator of the number of adults in the last days of life may be difficult to use. There are systems in place to identify patients who died within an organisation, however a patient may be in the last days of life and then transferred to a different organisation and die very quickly. In this situation, the original organisation may not capture this on their databases and this patient data would be lost. Therefore it would be better to use a denominator of patients who have died, although the same number would be lost it would be easy for the organisations to identify the patient group.
57	Marie Curie	It may be difficult to record accurate data for the following quality measures: Proportion of bereaved people who feel satisfied with the care provided in the last days of the person's life and; Proportion of bereaved people who feel satisfied that the person who

Consultation question 2: Local systems and structures in place to collect data?		
ID	**Stakeholder**	**Comments**
		has died was supported to drink or receive fluids if they wished. As each patient may have a number of people who are bereaved, an organisation would not be able to capture and identify feedback from all of these people? If we don't know the total population of bereaved people we are measuring, we cannot identify the proportion of those who are satisfied.
58	National Council for Palliative Care	Generally, we are doubtful that systems and structures are currently in place to collect much of the data for the proposed quality measures. We note that there appears not to be a willingness or ability to invest in data collection in England.
59	NHS Hartlepool and Stockton-on-Tees CCG	At present in HAST we are using the regional Care of the Dying Patient Document which is used whenever people are identified as being in the last days of life, whether in hospital, hospice or the community. These documents are audited and so data for much of the quality measures will be available. We also use RAIDR to assess how many of each practice's patients have advanced care plans and have recorded wishes on their preferred place of death.
60	Northern Health and Social Care Trust, Northern Ireland	There are local systems in place within unique end of life care projects to measure these. This would be straight forward to roll out, however there is a resource implication for this.
61	Royal College of General Practitioners	No. Resource and governance implications? Similar to LCP. (CMS) Locally, most of the data required is already collected, and it would not be difficult to collect most of it. However, I worry that collection of this information in this way will turn it into a tick box exercise - especially when considering the standard regarding assessing hydration status. I also think it would be necessary to get more collaboration between teams in terms of entering data - for example between GP practices and district nurses.(LS)
62	Royal College of Nursing	The ability to collect robust data is predicated on the IT systems having a solution to data sharing or an integrated system allowing various stakeholders access in a more detailed way than Electronic Palliative Care Co-ordination Systems (EPaCCs). There is no mention of social care providers, non-NHS or ambulance services being part of this.
63	Royal College of Physicians	Our experts note that the structure and process outcomes are rather vague and refer to 'local arrangements'. This may be due to the huge diversity of services across the country, and at present there is no universally agreed means of measuring many of these. Our experts believe that at present the best way we can do this is with the RCP Care of the dying audits which relies on retrospective audit of patient notes. It may be that these draft quality standards help direct future data capture and audit. Our experts question whether NICE will develop audit tools for quality standards, or for guidelines only. Our experts note that choice of home as place of death may not be possible if care is unavailable to support a person. This may need to be 24hr care which is not available everywhere. A mapping exercise is needed to know how much this would cost and

Consultation question 2: Local systems and structures in place to collect data?		
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		whether it would be feasible. Reviewing the hydration status daily of a patient dying at home is not practicable unless the community nursing service is to be massively increased in resource.
64	Royal College of Physicians and Surgeons of Glasgow	Local systems and structures are not currently in place to monitor them – at least not on a routine basis. However, in those areas with electronic patient records there could be a reasonable expectation of more accurate data collection Nevertheless, it would be very difficult to track and review notes of patients for whom someone thought they were dying but they survived; asking staff to record such instances would not be useful since extrapolation of a message from that information would be very difficult unless the recording was 100% accurate. Review of notes and care plans of patients who had died would show whether imminent death had been recognised pre death; in hospital settings death may of course be sudden and unexpected, or occur despite the best efforts of the clinical team – this guideline relates to expected deaths. Hospital services could be asked to show evidence that care plans included questions about advanced care plans on admission to hospital, and that if death was imminent, that there was discussion about updating these if appropriate; this could be audited by care record sampling. Care home and hospice residents should have anticipatory care plans in place and evidence of this could be requested.
65	St Joseph's Hospice	Our initial thoughts are that some of the data would be quite hard to collect because organisations don't have a "tick box" end of life care plan. It might be possible to retrospectively audit sets of notes (in the same way that the National Care of the Dying Audit of Hospitals do) which is very time consuming. Given the amount of time that it takes to review notes it might be better to go for fewer quality measures.
66	The British Geriatrics Society	Healthcare providers are likely to develop and use care plan tools for the last days of life to ensure that care and communication is documented in order to facilitate audit and attainment of the quality standard. It will be important to show that the outcome of the care plan is an individualised assessment of the dying person's preferences and needs. Not all healthcare organisations have systems and resources in place to gain feedback from bereaved relatives in a systematic way, this is an essential enabler to improve end of life care.
67	Western Health and Social Care Trust	Statement 1. Adults who have signs and symptoms that suggest they may be in the last days of life are monitored for further changes to help determine if they are nearing death, stabilising or recovering. **Comment: Yes would be possible, but only with adequate resources** • End of life Care Audits – across all care settings and involving patients receiving generalist or specialist palliative care. • Quality Improvement model Prognostic indicators available to determine and diagnose someone who is dying which may assist in data collection • Palliative Performance Scale (PPSv2) – Victoria Hospice Society 2001 - currently utilised by the Specialist Palliative Care

Consultation question 2: Local systems and structures in place to collect data?		
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		Teams in WHSCT **Requires:** • Adoption and standardisation of recognised prognostic end of life signs and symptoms (indicators) nationally/locally (Care of dying adults in the last days of life – NICE Guidance NG31 – recommendation 1.1.2) • Resource for above activities – education / development / raising awareness and roll out across all care settings • Adequate skilled workforce with knowledge to monitor and assess changes • Specialist services available for advice and support if required.

Consultation question 3: Examples from practice?		
ID	**Stakeholder**	**Comments**
68	Association for Palliative Medicine of Great Britain and Ireland	An example from practice of implementing the NICE guideline that underpins this quality standard would be the Care of the Dying Person Document which has been developed & is used across the Northern England Strategic Clinical Network across most primary, secondary and tertiary care centres. In several centres this is used alongside e-prescribing and electronic alerts to monitor care.
69	Leeds Palliative and End of Life Care Managed Clinical Network	EPaCCS is a good example of how information can be collected across different providers to provide a shared record for key end of life decisions this would need expansion to capture all the measures.
70	NHS Hartlepool and Stockton-on-Tees CCG	HAST CCG has a strategy for End of Life Care.
71	Royal College of Physicians	Our experts explain that any individualised care plan for the last days of life that follows the ‘one chance to get it right’ principles should effectively meet all four of the quality standards. Given that all localities have devised their own version of this, there should be many examples of how this has already been embedded into current practice. As with the LCP, success or failure will be dictated as much by the way it is implemented and educated, rather than the document itself. Our lay representative notes that reassurance is needed that care will be ‘pain free and comfortable’ and so although the

Consultation question 3: Examples from practice?		
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		language is clinical in principle it can be interpreted as an expectation that whatever may be needed will have been thought about and readily available not subject to delay with issues of administrative process or authorisation. The need for access to timely professional support will be key.
72	Western Health and Social Care Trust	QI anticipatory prescribing for end of life to be forwarded once complete.

Consultation question 4: Are statements achievable by local services given net resources required to deliver them?		
ID	**Stakeholder**	**Comments**
73	Association for Palliative Medicine of Great Britain and Ireland	• Statement 1 – Recognising when a person may be nearing death At the moment this data is collected bi-annually as part of the National Care of the Dying Audit. There would not be the capacity to collect this data routinely without extra resource as it involves time consuming retrieval and analysis of medical case-notes, which inevitably takes clinicians away from patient care. Signs and symptoms that suggest a person may be in the last few days of life can be different in differing settings. For example, signs and symptoms in the last few days of life may be very different at home compared to in the critical care setting. The statement should be amended to include MDT discussion and senior clinician input into recognition/monitoring process. • Statement 2 – Shared decision making and advance care planning There needs to be clarity about what is meant by *preferences* – does this mean preferred place of death? Some preferences will be easier to record, deliver and monitor than others, impacting on their ability to be used as a quality measure. There needs to be an acknowledgement that preferences of any kind can change over time, and often change as death approaches. Unless properly acknowledged, this could provide skewed information if used as a quality measure. The choice of home as the place of death may not be possible if care is unavailable to support a person – this may need to be 24 hour care which is not available everywhere. There would need to be a mapping exercise to know how much this would cost and whether it would be affordable. • Statement 3 – Anticipatory Prescribing It should be achievable for patients approaching the last few days of life to have medication prescribed in anticipation of symptoms. The quality measure mentions individualised indications for use and dosage, but there is some contradiction in

Consultation question 4: Are statements achievable by local services given net resources required to deliver them?		
ID	**Stakeholder**	**Comments**
		having a system that ensures anticipatory prescribing available to all (Care of Dying Order Set) vs. individualised prescribing. It is possible to have an e prescribing system that offers a safe balance, with prescribers needing to tick chosen medications and sign them off. • Statement 4 – Maintaining hydration Reviewing the hydration status daily of a patient dying at home is not practicable unless the community nursing service is to be massively increased in resource, which would be unaffordable. Daily review is more easily done in hospital and documents used to support the care of dying patients, such as the previously mentioned Northern England Strategic Clinical Network Care of the Dying Person Document has a daily prompt to consider this. It should be possible to measure the proportion of adults with a documented discussion about hydration, but this does not check the patient or carer's understanding of the discussion.
74	Compassion in Dying	In regards to resources and cost, evidence suggests that interventions to ensure treatment preferences are expressed and recorded lead to fewer hospital admissions and a reduction in unnecessary treatments, which will both in turn lead to cost savings. We commissioned the International Longevity Centre (ILC) to conduct a literature review of existing evidence on the economic and social impact of Advance Care Planning. Evidence indicates that Advance Care Planning can lead to cost savings for care providers, fewer unplanned or inappropriate hospital admissions and more people dying in their preferred place of care. One study the (ILC) identified showed that the chance of dying in hospital is nearly 70% lower for those who have an Advance Care Plan in place, with deaths outside hospital associated with cost savings of £3,659.[1] Another study measuring the impact of a care planning intervention found that a reduction in unplanned hospital admissions in the last year of life is associated with cost savings of £2,024 per person.[2] Compassion in Dying's My Life, My Decision programme also demonstrates how third sector and voluntary organisations have a valuable contribution to make around supporting individuals with advance Care Planning.[3] [1] Abel, J., Pring, A., Rich, A., Malik, T., & Verne, J. (2013) "The impact of advance care planning of place of death, a hospice retrospective cohort study." BMJ Supportive & Palliative Care, 3: 168-173. [2] Baker, A., Leak, P., Ritchie, L., Lee, A., & Fielding, S. (2012) "Anticipatory care planning and integration: a primary care pilot

Consultation question 4: Are statements achievable by local services given net resources required to deliver them?		
ID	**Stakeholder**	**Comments**
		study aimed at reducing unplanned hospitalisation." British Journal of General Practice, 62(595): e113-120. [3] Compassion in Dying, My Life, My Decision: Planning for the end of life, October 2016 http://compassionindying.org.uk/library/my-life-my-decision-planning-end-life/
75	Leeds Palliative and End of Life Care Managed Clinical Network	Currently no, I think we risk a lot of organisation trying to set up systems to measure the QM with limited IT capacity. If a key ER providers were commissioner to develop templates and reporting to allow this data capture a lot of time and money could be saved by individual organisations. Electronic prescribing is not fully implemented across all providers making data capture of anticipatory medication and checking doses have been adjusted an area of significant development.
76	Leeds Teaching Hospitals	Education, audit and guidance for staff about how to develop an individualised plan of care for patients
77	NHS Hartlepool and Stockton-on-Tees CCG	We are already trying to achieve these quality statements locally. There does need to be more support in the community but steps are already being taken to improve community services and reduce acute admissions to hospital. Some of this is around ensuring patients are not admitted to hospital just before they die and that plans are being put in place, so that they are dying in the location they have chosen. It is hoped that by reducing acute admissions there will be a cost saving that can then be used to support community services.
78	Northern Health and Social Care Trust, Northern Ireland	Yes given the resources necessary - for statement 1, 3 & 4, this would largely be training for all levels of staff to recognise and manage patients in the last days of life appropriately. For statement 4 Resources would involve ensuring ready availability of good quality, rapid access nursing support in all community areas where patients who wish to die at home.
79	Royal College of General Practitioners	Statement 1: Significant training and skills mix implications to enable professionals to identify people in the last year of life. Then training for being alert to acute deterioration and distinguishing by assessment reversible causes and expected deaths. There is an opportunity to include preventing 'avoidable deaths' (CMS) Statement 2: Significant training and skills mix implications to enable effective personalised holistic care planning and inequalities training. Communication skills requirement. Time and funding resource for general practice to deliver. (CMS) Statements 3 & 4: Community nursing and general practice resources and training implications Access to Specialist Palliative Care All become more important with increasing ageing population and deaths in the community (CMS) I think in primary care it would be important for teams to work together - for example with Standard 1 it might be that district nurses are visiting daily and that the GP visits when a change in the patient's condition is noticed - but it may be the GP who has

Consultation question 4: Are statements achievable by local services given net resources required to deliver them?		
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		conversations with the patient and relatives and prescribes any anticipatory medications. Improving the care in the community for patients in their last days of life is likely to reduce spend in secondary care. Locally, however, the nursing teams (intermediate care teams) which try to manage patients in the community and prevent admission are stretched, and at times they refuse to take additional patients on, meaning that patients are sometimes admitted to hospital unnecessarily. I think that significant investment is needed in these teams in order to reduce admissions, but that with investment and reduction in admissions there is opportunity for overall cost savings. (LS)
80	Royal College of Nursing	There is a need for far more robust community and primary care services in a number of areas. This must include social care and out of hours support. The lack of district nurses and specialist support nurses in the community as well as social care affects the experiences of people wishing to remain in their home, including care homes. There are also huge variations in the availably and access to bereavement support.
81	Royal College of Physicians	Our experts note: • There are few direct financial costs associated with delivering these standards but indirect or supporting costs are needed to provide the structures, documentation, and education. Ideally, implementing these would result in fewer complaints regarding decision making at the end of life, resulting in cost savings. • All quality measures are gathered by local data collection. This would need resources in terms of time, staffing and money. • Collecting data for the National Care of the Dying Audit takes up a significant amount of time. Following discussion with other London Palliative Care hospital teams who were struggling with data collection, a decision was made to stop at 40 case notes, instead of the target of 80. • Choice of home as place of death may not be possible if care is unavailable to support a person – this may need to be 24 hr care which is not available everywhere. A mapping exercise would be needed to know how much this would cost and whether it would be affordable. • Reviewing the hydration status daily of a patient dying at home is not practicable unless the community nursing service is to be massively increased in resource.
82	Royal College of Physicians and Surgeons of Glasgow	All could be achievable and they do not represent opportunities for disinvestment or cost savings, but nor do they require investment. However, in order to measure statement 1, documentation from team members would need to state the likelihood that the patient is possibly in their last hours or days of life. Since the withdrawal of the LCP, there are no standard documents in place that record these decisions and clinical impressions. This could make the statement difficult to measure.
83	The British Geriatrics Society	Barriers to achievement of clinical standards: Availability of specialist palliative care services to provide end of life care education and support to clinical teams, Shortage of

Consultation question 4: Are statements achievable by local services given net resources required to deliver them?		
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		single rooms on acute wards, Lack of community services to enable people to die in their own home if this is their wish.
84	Western Health and Social Care Trust	**Comment - No** There needs to be investment in resources required locally to be able to comprehensively deliver. Education, development and raising awareness are paramount - clear frameworks and models for this will need careful consideration. The delivery of rolling education programmes, development and raising awareness and consideration of the delivery (who? how? where? when?) essential. System's processes and models would need developed and agreed. The monitoring and measuring of these standards would need to be ongoing across all care settings. Suggestion of dedicated full time permanent 'ends of life care facilitators' within the WHSCT (standardised regionally) would need to be considered to ensure that the standards statement translate into safe, effective and quality end of life care and become embedded over time. Networks need to be developed to ensure standardisation, quality and support locally, regionally and nationally. Dedicated administration support would also be paramount to support these standards. Staff release and time for education and development paramount. Consideration to the wider public - raising awareness, support and education - a public health approach and potential for public health campaign. Involvement of all providers including statutory and voluntary sectors. Adequate work force delivering on the ground to meet these standards including access to specialist advice and support.

Comments on statement 1		
ID	**Organisation name**	**Comments**

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85	Association for Palliative Medicine of Great Britain and Ireland	We believe the denominator should be "adults in the last days of life" as in the other quality statements. As it is, it reads as though all deaths may need to be recorded.
86	Association of Hospice and Palliative Care chaplains	This statement may be hard to measure because…AHPCC is responding from a general perspective of ensuring that at each stage spiritual care is assessed and needs responded to with skilled and informed support. Local chaplains should be informed of end of life care patients so that a full assessment can be undertaken, hopefully building on assessment already carried out by clinical team.
87	Association of Supportive and Palliative Care Pharmacy (Formerly PCPN)	Is this practical - daily monitoring in community setting – may be chicken and egg – i.e. dying needs to be diagnosed or recognised as possibility to trigger daily review.
88	Belfast Health and Social Care Trust	BHSCT process document: Identifying patients who may be approaching the end of life and are suitable for inclusion in the palliative and end of life care register (GP) and coordination system (BHSCT) (not exclusive to last days). BHSCT palliative and end of life care coordination system. BHSCT prompts document that guides clinicians when assessing a patient who might be entering the last days of life. Various education sessions on aspects of identification, supporting and recording.
89	Belfast Health and Social Care Trust	The BSHCT has an identification process that can be used across all settings and enables flexibility for clinical preference in choice to identification tool (eg GSF, SPICT, regional clinical prognostic indicators). Currently the data collation requires referral to community to enable early planning at home. While tools and processes are available, effort is required to encourage use of these and embed identification of last days of life into practice. Without both embedding into practice from undergraduate onwards and effective communication to patients, families and cares and between settings, data analysis will be limited.
90	Belfast Health and Social Care Trust	Trust and GP systems are in place to monitor and support people who may be nearing the end of life (five phases including long term palliative; potential last year of life; and) as per the Northern Ireland End of Life Care Operational System to encourage support and early planning in community. Both GP and Trust information systems enable collection of data for the quality standard for those people who have been identified and this identification communicated to relevant community teams. Although access is available, most hospital teams do not currently use the community information system and further work would need to be undertaken to enable cross setting recording of patients for data analysis. The benefit of this would need to be considered against the extra workload to be trained in and access a further information system. It is hoped that the development of the Palliative and

Comments on statement 1		
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		End of Life Key Information System (KIS) of the Electronic Care Record (ECR) in NI will provide a conduit of information to and from the existing BHSCT community information system and, in doing so, enable data collection across settings. The BHSCT Palliative and End of Life Coordination System enables recording of five phases at the end of life, with phase four being potential last days or hours which would be in line with the last days of life as specified by this quality standard. Data collection systems are not in place for those patients who are identified and solely supported in hospital settings only at the last 2-3 days of life.
91	Belfast Health and Social Care Trust	Formal recommendation of an appropriate ICD-10 code may support consistent local, regional and national data collection on identification and subsequent care in the last days of life and may be the most universal method of data collection. ICD-10 code Z51.8 was often used to identify people supported by the Liverpool Care Pathway although this was never formally recommended in the NHS coding guidelines.
92	Belfast Health and Social Care Trust	This statement would be difficult to measure as it requires individual case file review for every adult death, however, these figures on adult deaths in hospital may be collated via the regular Mortality and Morbidity meetings. The resources needed to review and measure this on an on-going basis may not be feasible for the number of adult deaths within the Trust each year.
93	Belfast Health and Social Care Trust	This statement would be difficult to measure as it requires individual case file review for every adult death, however, it could be measured via the local BHSCT Palliative and End of Life Care Coordination System (part of the community information system) for those individuals whose identification of last days of life was communicated to community; and via the Mortality and Morbidity meetings for deaths in hospital.
94	Belfast Health and Social Care Trust	This statement would be difficult to measure as it requires individual case file review for every adult death, however, these figures on adult deaths in hospital only may be collated via the regular Mortality and Morbidity meetings. The resources needed to review and measure this on an on-going basis may not be feasible for the number of adult deaths within the Trust each year.
95	Belfast Health and Social Care Trust	Data collection of patients who are aware of their palliative/non-curative prognosis is recorded on local systems (where it is communicated to community, however, this may be at any phase of ELCOS and is not restricted to awareness of last days of life
96	Belfast Health and Social Care Trust	This would be extremely difficult to measure and would require individual case file review. It is, however, possible to measure locally how many people who were identified and recorded on the BHSCT Palliative and End of Life Coordination System were able to die in their last preferred place of care.
97	Bradford, Airedale, Wharfedale & Craven Palliative Care Managed Clinical Network	Statement adequately reflects the monitoring of patients that may be in their last days of life. It is suggested that *assessment occurs at least every 24 hours.* Will there be recommendations on what level or role this should be?
98	Bradford, Airedale,	The document is mainly consistent in using 'the last days' but then changes to the last *3 days prior to death*. This is too specific as

Comments on statement 1		
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	Wharfedale & Craven Palliative Care Managed Clinical Network	many patients deteriorate and die within 1-2 days yet we will be asked to gather data on the last 3 days. Wording needs to remain consistent throughout the document.
99	Bradford, Airedale, Wharfedale & Craven Palliative Care Managed Clinical Network	Gathering data is achievable and local systems and structures are in place to support gathering of electronic data. However this is undertaken by specialist palliative care clinicians and is time intensive. Acute hospitals and hospices undertake annual audit and therefore data collection is possible for all required elements. Are there plans to support a national audit of caring for patients in the community (own home and care homes)?
100	British Liver Trust	Is there potential to ensure, when the patient wants it, their next of kin / loved ones are unambiguously communicated with and it is clearly explained that this is the end of life and that death is imminent? It is our experience that many people feel that they were not informed and poorly prepared for their loved ones death
101	Catholic Medical Association (UK)	One of our main concerns is that the guideline focuses upon the belief that the diagnosis of dying can be accurately and safely made. Prognosis is particularly difficult in non-malignant conditions such as heart and respiratory failure and dementia. Palliative care should be based on the patient's needs rather than the perceived prognosis which is at best a subjective judgment. In the Royal College of Physicians" End of Life Care Audit – Dying in Hospital: National Report for England (2016)" the clinical notes of 9,302 patients who died were studied. Of these only 83% were recognised as dying in the last few days of life, the remaining 17% were unexpected deaths. Furthermore, early deaths within 4 hours of admissions were excluded from the analysis. There appears to be a significant false negative rate i.e. a failure to identify those who are in fact dying. There is no evidence as to the false positive rate i.e. those who did not in fact die and were therefore excluded from the audit but who may have been treated as being in the final days of life. There have been reported incidents where patients have been wrongly judged to have been dying. Finally, there is no actual data regarding the true negative rate i.e. those who were correctly identified as likely to survive. Without this data it is not possible to either have a prognostic tool or to know how accurate such a tool would be to identify those who are dying. NICE recognises that the diagnosis of dying is difficult, but has not quantified the accuracy of prognostic tools using prospective studies. The use of monitoring is important but was conspicuously absent with the Liverpool Care Pathway proforma both with regards to vital signs and the need for hydration and nutrition.
102	East & North Herts NHS Trust	This statement may be hard to measure -Data source b denominator-number of adult deaths. Not all deaths within the acute trust environment are expected/recognisable and therefore, if counted, would make the result appear lower. Generally we believe about 80% of deaths can be expected so it may be worth including this within the denominator and minus 20% off deaths.
103	EPA UK/EU	All health professionals need to develop skills in recognizing a person who is dying. This involves clinical/observational skills as well as intuitive skills. To develop intuitive skills people need to develop trust in what they are observing/feeling/seeing. From there it is important to communicate what it being observed to patients, families and fellow health care professionals. This allows the

Comments on statement 1		
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		person who is nearing death to be prepared as well as family/friends. Assessment of changes in the person, including their medical signs and symptoms, with relevant specialist advice sought when there is a high level of uncertainty because of conflicting results or changing symptoms. Communication between medical specialties, hospital sites, and departments needs to be clear, focused and timely to avoid unnecessary interventions. Very simple non-medical exchanges from the multi-disciplinary team can easily be overlooked as not important but are crucial for dying patient. Constant interaction, verbal reassurance and quality of gentle touch and tender care build trust and confidence for the dying person that they are cared for in a consistent way. Having an allocated carer to the dying person in a hospital setting in the last 3 days of life could provide this important link between professional, non professionals and the person. **Validation of the German Version of the Quality of Dying and Death Questionnaire for Health Professionals** *AM J HOSP PALLIATIVE CARE* September 2016 33: 760-769, first published on September 23, 2015 **The significance of touch in palliative care** **Sally Sims** Macmillan Lecturer, Department of Nursing, King's College, London *Palliat Med* January 1988 2: 58-61
104	EPA UK/EU	Many adults close to dying are cared for by close family or carers. Live-in or domiciliary carers are often left to monitor and make decisions based on complex range of symptoms that may present in the client. They rely mainly on own powers of observation, intuition but also telephone consultations with medical and nursing specialists. It is rare for carers to be referred to a specialist palliative team. Carers often make on the spot decisions related to client care without any formal training. Although we are aware of the existence of the Gold Standards Framework, it is not universally applied. http://www.goldstandardsframework.org.uk/training-programmes There are examples of elder care training and support where no mention is made of care of dying and death. This is one example of level of support given to carers. *A carer assigned a client in advanced stage of breast cancer two weeks before she died, is not briefed on matters related to dying, symptom recognition, or medication. The carer is left to respond to delicate and emotionally charged domestic situation in which the husband wants life to continue as normal (meals on time at dining room table) even when the patient's body is shutting down :weakness, immobility, inability to eat solids and incontinence. The client on attending a routine breast cancer check appointment was admitted to hospital, and died within 24 hours of admission.* Elder care agencies have a responsibility to ensure carers in their employment are fully informed and supported to care for patients in the last days of their lives. Families are often traumatised or in need of post bereavement support because the journey with their loved one has been difficult. **This quality standard if used by care agencies as an essential guide for carers would offer them invaluable support**.

Comments on statement 1		
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		We offer this: that sections headed ‘**What the quality statement means for service providers, healthcare practitioners and commissioners’** be expanded to include an expectation that this group ensures all healthcare workers, carers and those in contact with dying patients receive training or briefed on death and care of dying patients in last days of life.
105	Faculty of Intensive Care Medicine	The FICM and ICS noted that it is often the family recognise the patient is in their final illness before the base team. Recognition at ward level about end of life seems to be often delegated to intensive care and, in some of these situations, admission to an ICU is not appropriate. The decision to escalate to intensive care cannot be made by a referring team without discussion with the intensive care consultant and it is never a decision made by the relatives. Palliative admission to ICU is sometimes appropriate but again this needs very careful discussion. The FICM and ICS believe this could be better reflected in the document.
106	Faculty of Intensive Care Medicine	We are aware of a few centres establishing formal critical care-palliative care links with very positive early results in terms of effective communications with patients and better symptom control
107	Faculty of Intensive Care Medicine	Recommendations 1.2.2, 1.2.3, 1.4.9 and 1.5.12/13 are all auditable standards which demonstrate engagement with EOLC planning.
108	Imperial College Healthcare NHS Trust	It is good to be clear about recognition and continual reassessment of change in condition that is a complex entity. It may be prudent to consider mentioning that changes do not necessarily necessitate a u turn in the clinical management plan which non specialists can on occasion be prone to do. This lends to conflicting messages and challenging communication thereafter.
109	Leeds Palliative and End of Life Care Managed Clinical Network	Use of phase of illness could assist here in addition to Barthel or Karnosky. Data capture is biggest difficulty, need to be robust electronic capture to allow reporting.
110	Leeds Teaching Hospitals	This statement would benefit from including the importance of discussing this with the patients and / or their family
111	Marie Curie	The current drafting of this statement implies that the signs and symptoms have been recognised but they can only be monitored if they have been recognised. It is important that staff need to develop the skills to recognise the symptoms in the first place – the second step is then to monitor them.
112	Marie Curie	It is also worth highlighting that a not insignificant number of patients have an acute event at the end of life, such as a bleed. It is worth considering where patients like these would fit into this statement as they would not necessarily have signs or symptoms to suggest they are in the last days of life and yet are not excluded from the denominator.

Comments on statement 1		
ID	**Organisation name**	**Comments**
113	National Council for Palliative Care	Statement 1 does not clarify how frequently patients entering their last days need to be monitored. Whilst this will fluctuate on a case by case basis, this statement needs to reflect that frequency of monitoring should be led by patient need and included in every patient's individual care plan.
114	National Council for Palliative Care	Whilst we welcome Statement 1's acknowledgement of the need for additional monitoring, this statement also needs to reflect the need for health professionals to communicate the underlying condition with the individual and the people important to them. If a person is dying, it is vitally important that this is communicated compassionately, sensitively and in a timely manner – Statement 1 needs to reflect this.
115	National Council for Palliative Care	Outcome A presently states that the primary outcome of Statement 1 will be: *'Proportion of adults in the last days of life that are told that they may be close to death (unless they do not wish to be informed)'.* Whilst this outcome is valid, a more pertinent outcome of Statement 1 stems from what will be achieved through greater monitoring – namely, appropriate care and treatment for every individual's differing condition. This outcome could read: 'Proportion of adults whose signs and symptoms suggest they may be in the last days of life receive appropriate care and treatment in line with whether they are nearing death, stabilising or recovering'.
116	National Council for Palliative Care	Outcome B is not relevant to Quality Statement 1. It is more appropriate for Quality Statement 2.
117	NHS England	The thrust of this statement should be on the purpose for which recognition and monitoring is so important, i.e. for the resulting actions to be appropriate to whether the patient is likely to recover, stabilise or die soon – in other words, monitoring needs to be purposeful. The desired outcome should be 'Proportion of adults whose signs and symptoms suggest they may be in the last days of life receive appropriate care and treatment in line with whether they are nearing death, stabilising or recovering'.
118	NHS England	This outcome (proportion of adults cared for in accordance with their preferences in the last days of life) is not relevant to this quality statement.
119	NHS Hartlepool and Stockton-on-Tees CCG	Would also add re quality statement 1: uncertainty is common. Even the most experienced of clinicians do not always accurately predict prognosis. When providing care for someone who is likely to die in the next few days, the emphasis needs to be on appropriate support and symptom control. Regular review to assess for change is important, as in some conditions people do recover. There also needs to be more acceptance that uncertainty exists, and 'just in case' plans being put in place. In our local Trust the 'Amber Care Bundle' is being piloted to identify and support patients admitted who may not survive that admission.
120	Northern Health and Social Care Trust, Northern Ireland	The statement is clear. Obtaining evidence to demonstrate that the specific details surrounding this quality statement have occurred is dependent on professionals documenting carefully in medical notes (this will be the case for all of the quality statements). For example – does the adult/patient recognise that he/she may be dying, has the professional asked their preferences and have they been carried out?

Comments on statement 1		
ID	**Organisation name**	**Comments**
		The statement talks about the adult/patient being assessed to determine if he/she is dying. Need clarity on who is responsible for making that assessment. Is it the patient's consultant/medical team? Is it a MDT decision?
121	Northern Health and Social Care Trust, Northern Ireland	The statement is quite vague as there is considerable cross over in signs / symptoms of an acutely deteriorating patient due to reversible cause and those of a dying patient. Perhaps" adults who are clinically assessment as being in the last days of life".
122	Northern Health and Social Care Trust, Northern Ireland	Feel there should be a standard measure with focus on communication with family as the patient in last hours of days have usually very limited communication and the communication needs of the family frequently increase.
123	Northern Health and Social Care Trust, Northern Ireland	Outcome for quality standard 1 - proportion of adults in the last days that are told that they are close to death - concerned this becomes box to tick in frail, delirious, frightened patient and to what end? More important honest conversations had in last weeks when the patient is able to engage in the conversations. It could be appropriate for a few patients but in general wards could be as damaging as the hydration issues were in past. Communication with family re: closeness to death in last hours more appropriate.
124	Parkinson's UK	We welcome the emphasis on identifying whether a person is at the end of life, and the acknowledgement of the complexity in recognising this. However, it is not always appropriate to only *'seek advice from those experienced in providing end of life care, such as specialist palliative care team'*. Given the complexity of Parkinson's, which includes over 40 motor and non-motor symptoms, there are a number of clinical features that herald the onset of end-of-life care in long-term neurological conditions, such as: • Swallowing problems • Recurrent infections • Marked decline in physical function • First aspiration pneumonia • Cognitive difficulties • Weight loss • Significant complex symptoms

Comments on statement 1		
ID	**Organisation name**	**Comments**
		We therefore recommend that the rationale is broadened to recognise the role of a Parkinson's specialist in identifying when a person with Parkinson's is in their last days of life. **Recommendation:** The quality statement acknowledges the role of specialists in identifying whether a person is in their last days of life
125	Resuscitation Council (UK)	Agreed. Perhaps 'observed and monitored' would avoid the assumption that 'monitoring' requires only the use of equipment.
126	Resuscitation Council (UK)	Our reviewers thought that this attempt to use 'plain English' gave the wrong impression by using the word 'checked', implying perhaps that this might be a brief, cursory event. We suggest: 'Adults who are thought to be dying are **assessed** at least once a day for symptoms and changes that might show that they are nearing death, that their condition is stable **or that it is** improving.'
127	Royal College of General Practitioners	On one level this statement simply supports the idea of good clinical care. 'Continue to assess this patient'. In reality when patients are very sick or nearing death it can be quite difficult to put them into one of these three categories. Does the panel think that including this statement means that patients will get more attention, or more visits than they would do otherwise? It is possible, but good conscientious primary care teams would be doing this anyway. For patients in hospital I am not well informed, but I can see that it may help to include a standard to make explicit that patients who are dying need as much attention as those who are not. (DJ)
128	Royal College of General Practitioners	'a) Proportion of adults in the last days of life that are told that they may be close to death (unless they do not wish to be informed).'- This has the potential to be misunderstood and miscommunicated in order to fulfill a quality standard. I agree there is something around preparedness of the patient and family/carers, including pre-bereavement and bereavement needs. (CMS)
129	Royal College of Physicians	Statement 1. Adults who have signs and symptoms that suggest they may be in the last days of life are monitored for further changes to help determine if they are nearing death, stabilising or recovering. Our experts suggest changing 'monitored' to 'regularly monitored'
130	Royal College of Physicians	The quality measures for QS 1 are as follows: • Evidence of local arrangements and systems to ensure that it is recognised when an adult may be entering the last days of their life. • Evidence of local arrangements and systems to monitor signs and symptoms of adults thought to be in the last days of life; and to review changes in condition of adults to help determine if they are nearing death, stabilising or recovering

Comments on statement 1		
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		- Proportion of adult deaths with documented evidence that their signs and symptoms were monitored in the last days of life. - Proportion of adult deaths with documented evidence that it was recognised that the person was likely to die in the coming hours or days. - Proportion of adults who have the recognition that they are thought to be dying reviewed. - Proportion of adults in the last days of life that are told that they may be close to death (unless they do not wish to be informed). Our experts note that most of these quality measures are already routinely collected. There are good prognostication tools to aid this including the Supportive & Palliative Care Indicators Tool (SPICT). The National Audit of Care of the Dying Person covers many of these measures. In response to point three, our experts note that it crucial that signs and symptoms are not only monitored but that they are addressed. Our experts emphasise the importance of focussing on the outcome rather than the process. Not whether pain was measured but whether pain was controlled, for instance. **Numerator – the number in the denominator in which the care records show evidence of monitoring of signs and symptoms in the 3 days prior to the actual death.** **Denominator – the number of adult deaths** Our experts note that the 'denominator' should be expected deaths. If death is recognised in the next quality standard, then this gives the expected deaths.
131	Royal College of Physicians of Edinburgh	Quality statement 1: It is important that adults who may deteriorate and enter into their last days of life are monitored to identify when this might happen. Statement one starts presuming that in fact this stage has been already identified. Thus a statement that adults who may soon need last days of life care should be monitored to timely identify when this state has been reached is important. A simple screening question *eg Q1 Could this patient be in the last days of life?* would be beneficial. This transition into last days of life care should be quickly identified. Otherwise, if it is not identified, patients will die without adequate care in the last days of life. It should not be presumed that they are identified routinely. There are guidelines for identifying this phase such as *Recognising and managing key transitions in end of life care* Kirsty Boyd,1 Scott A Murray2 BMJ 2010 http://www.bmj.com/content/341/bmj.c4863.long
132	St Luke's Hospice	The outcome identifying the proportion of adults in the last days of life that are told that they may be close to death (unless they do not wish to be informed). This appears to be phrased in a challenging way. We wonder if rephrasing this to something like the proportion of patients given the opportunity to be told that they are close to death should they wish it, creates less risk of approaching this in a way that mandates a discussion that patients don't want to be forced to conduct.

Comments on statement 1		
ID	**Organisation name**	**Comments**
133	St Raphael's Hospice	The statement does accurately reflect the key area for improvement around recognising a patient is dying. The measure is easier to monitor in an inpatient setting e.g. hospital or hospice, where the patients can be reviewed multiple times a day. However, in the community where a number of different professionals maybe involved in the care and may not be visiting daily – who will be responsible for making this assessment and reviewing it daily?
134	St Raphael's Hospice	The process to be measured are clear and logical, however, this information will be easy to collect within an inpatient setting but once again will be much harder within the community setting, unless the responsibility for collecting and analysing data is assigned to a particular professional body e.g. the CCG, who has an overview of all deaths within their area and other organisations e.g. hospices can feed into it.
135	Sue Ryder	Sue Ryder are keen that this quality standard is not seen as proposing the routine weighing of people at the end of life. For providers who do not have the sort of specialist beds that are able to weigh people easily, weighing someone can be a disruptive process for the individual concerned. We would support weighing people only where appropriate.
136	Tees Esk and Wear Valleys NHS Foundation Trust	This can be harder to detect in patients with dementia who may have difficulty in communication and in whom presentation may be affected by their dementia. Staff caring for these patients need an increased awareness of this and need to be trained in communication and recognising symptoms in these patients. This may be particularly the case where the patient is at home or in a care home rather than hospital. Relatives or carers may notice changes in the patient which are not recognised by professionals thus it is important to actively seek relatives' and carers' views.
137	The British Geriatrics Society	Possible sources of evidence: use of national early warning score (NEWS) to monitor patient's condition and trigger timely clinical review, use of treatment escalation plans e.g. AMBER to guide clinicians' response to medical deterioration. Evidence of senior medical review from an appropriately trained professional, (not necessarily from specialist palliative care, physicians particularly geriatricians are experienced in recognising and managing end of life care).
138	The British Geriatrics Society	It is important that people are told (unless they do not wish to be informed) that they may be close to death, and that healthcare professionals seek their preferences for end of life care and strive to achieve them, however not all preferences for end of life care are achievable without longer term planning which is beyond the scope of this quality standard e.g. a person may wish to die at home but facilities and personnel are may not be in place for this to occur.
139	Western Health and Social Care Trust	**Comment: Yes would be possible, but only with adequate resources** • End of life Care Audits – across all care settings and involving patients receiving generalist or specialist palliative care. • Quality Improvement model.

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		• Prognostic indicators available to determine and diagnose someone who is dying which may assist in data collection. • Palliative Performance Scale (PPSv2) – Victoria Hospice Society 2001 - currently utilised by the Specialist Palliative Care Teams in WHSCT. **Requires:** • Adoption and standardisation of recognised prognostic end of life signs and symptoms (indicators) nationally/locally (Care of dying adults in the last days of life – NICE Guidance NG31 – recommendation 1.1.2). • Resource for above activities – education / development / raising awareness and roll out across all care settings. • Adequate skilled workforce with knowledge to monitor and assess changes. • Specialist services available for advice and support if required.

Comments on statement 2		
ID	**Stakeholder**	**Comments**
140	Association of Supportive and Palliative Care Pharmacy (Formerly PCPN)	Do we need also to acknowledge that all preferences whilst considered may not be possible/practible eg wish to die at home if care is not available; wish to stay in hospital when dying is not imminent and no acute symptoms; scarcity of hospice beds delaying transfer.
141	Belfast Health and Social Care Trust	This can be currently measured as the existence of existing advance care plans is recorded in the BHSCT Palliative and End of Life Coordination System.
142	Belfast Health and Social Care Trust	This statement may be able to be measured in part as preferences for care are recorded at a basic level on the Coordination System and in more detail in the patient held advance care plan (for those patients who have decided to document one).
143	Belfast Health and Social Care Trust	It is, however, possible to measure locally how many people who were identified and recorded on the BHSCT Palliative and End of Life Coordination System were able to die in their last preferred place of care, which may be considered as an alternative outcome measure.
144	Belfast Health and Social Care Trust	Part a is feasible. Parts b and c require individual case review. The resources needed to review and measure this on an on-going basis would not be feasible for the number of adult deaths within the Trust each year.

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145	Belfast Health and Social Care Trust	Your Life Your Choices information booklet A Record of My Wishes Advance Decision for Refusal of Treatment.
146	Bradford, Airedale, Wharfedale & Craven Palliative Care Managed Clinical Network	Acute hospital setting – adequate data will be gathered in a local audit and biennial national audit but certain elements e.g. *evidence of local arrangements to identify existing advance care plans or advance decisions for adults recognised to be in their last days of life* will not be gathered in the national hospitals audit. This data can be obtained from EPaCCS but this is not captured in the current case note review as our patient case notes systems are separate. Therefore this increases the complexity of the audit and therefore increases the time spent on non-clinical activity. Hospice and community – information will be accessible via EPaCCS although analysis is time intensive for clinicians.
147	Bradford, Airedale, Wharfedale & Craven Palliative Care Managed Clinical Network	Data collection is time consuming as both local case note review and bereaved carer surveys are undertaken by specialist palliative care clinicians. Resources are limited as there has been no increase in palliative care team establishments. National guidance on team establishments would be beneficial to support teams with business cases to increase specialist palliative care teams.
148	Catholic Medical Association (UK)	"I would add that we should not "give up" on any patient, terminal or not terminal. It is the one who is beyond medical help who needs as much if not more care than the one who can look forward to another discharge." Dr Elizabeth Kubler-Ross. Patient management should be holistic and should address the medical, psychological and spiritual needs of the patient. Consent to treatment is especially important in palliative care as in other fields of medicine and should always be sought in a timely fashion where the patient has capacity. As in any other field of medicine, consent should be sought from patients for the diagnosis and treatment of their condition throughout the patient journey and not confined to the last few days of life. This is particularly true of palliative care where the needs and wishes of patients should be actively determined before the patient loses capacity as a result of the underlying condition or treatment. Decisions about palliative care must be made or supervised by senior clinicians who should be available for further help and advice as the patient's condition changes. It must be clear to the medical team and relative who is the named responsible consultant. The Neuberger Review recommended that "A named consultant or GP, respectively, should take overall responsibility for the care of patients who are dying in hospital or the community"[3]. Neuberger also recommended "the name of a registered nurse responsible for leading the nursing care of the dying patient should be allocated at the beginning of each shift. This nurse

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[3] Neuberger Review "More Care Less Pathway, 2013) Recommendation 26

Comments on statement 2		
ID	**Stakeholder**	**Comments**
		will be responsible also for communicating effectively with the family, checking their understanding, and ensuring that any emerging concerns are addressed".[4] There should be regular audit of the care of the dying which takes into account medical treatment, nursing care, spiritual support and the concerns of relatives and carers. We also agree with the Neuberger Review that "The National Institute for Health Research fund should fund research into the experience of dying. Research priorities must extend also to systematic, qualitative and mixed methods research into communication in the patient and relative or carer experience".[5]
149	Children's Hospice Association Scotland	Shared decision making with young adults in transition should take into account the needs of parents and siblings, as well as an active recognition of "adults with incapacity" regulations, which are more usually applied in patients with an older age group. . Any communication with families of a young adult requires particular expertise in supporting every member of the family through decision making, keeping the young person and their best interests at the heat of this.
150	Compassion in Dying	While draft quality statement 2 does go some way to address care planning in the last days of life, it does not give the appropriate impetus on health and care professionals to provide opportunities to discuss care preferences. Therefore, we believe the statement should be reworded as: 'Adults in the last days of life are given the opportunity to express and formally record their care preferences, and care is provided in accordance with these preferences' The use of *opportunity* in this rewording makes the statement more consistent with the language used in other NICE quality statements that refer to care planning and care preferences (such as statement 3 of the End of life care for adults Quality Standard and statement 5 of the Motor Neurone Disease Quality Standard). With appropriate training (see points below) health and care professionals will have an understanding that preferences must be reviewed, so while 'responsive to their changing preferences' is important, we do not feel it is a priority to include in this statement, as this should happen naturally if health and care professionals are providing opportunities for preferences to be discussed.
151	Compassion in Dying	We believe the opening statement of this section ('People who are dying may want to be involved in decisions about the care they receive') does not reflect the importance of shared-decision making and the rationale behind including this in the Quality Standard. Continuing on from the points raised in comment 3 [ID 150] we suggest changing the wording to 'People who are dying must be given the opportunity to be involved in decisions about the care they receive'.

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[4] Neuberger Review "More Care Less Pathway, 2013) Recommendation 27.
[5] Neuberger Review "More Care Less Pathway, 2013) Recommendation 5.

Comments on statement 2		
ID	**Stakeholder**	**Comments**
		This section also needs to make reference to the fact that a dying person may have appointed someone to make decisions on their behalf using a Lasting Power of Attorney (LPA) for Health and Welfare as opposed to or in addition to having an existing care plan. It is critical for health and care professionals to be aware of the existence of an LPA for Health and Welfare in cases where the dying person does not have capacity to make a decision about their own care in the last days of life. This addition would ensure the Rationale better reflects section 1.3.2 of the Shared decision-making section in the full guideline for care of dying adults in the last days of life.
152	Compassion in Dying	In addition to being asked about preferences for care, dying people should also be informed about the different ways in which these preferences can be recorded. This will become increasingly important following the full implementation of the Resuscitation Council's ReSPECT tool. There will then be numerous ways to formally record care preferences and dying people must be given the right information in order to determine which tool is right for them. For example, if a person has strong feelings about refusing certain treatments, it should be made clear to them that only an Advance Decision to Refuse Treatment will make this preference legally binding. Therefore, we believe quality measure b) should read: b) Evidence of local arrangements to ensure that adults in the last days of life, and those important to them, are asked about preferences for their care and informed about the different ways these preferences can be recorded.
153	Compassion in Dying	The Care Quality Commission's report 'A different ending' highlighted healthcare professionals' lack of understanding of the Mental Capacity Act and said this can act as a barrier to good care. In 2014 a House of Lords Select Committee report on the Mental Capacity Act, and the Government's response to this report, highlighted the poor understanding of the Mental Capacity Act amongst professionals, particularly GPs. In 2015 the Government Health Committee reported that care staff often feel that they lack the confidence, skills and training needed to raise end of life issues with patients. Without appropriate training on the Mental Capacity Act and care planning, professionals will not have the knowledge or skills to be able to effectively discuss care preferences with dying people. Training on the principles of the Mental Capacity Act is also vital for ensuring healthcare professionals understand their responsibilities in relation to supporting patients to make decisions, and best interest decision-making when a person does not have capacity. Therefore training of professionals in this area must be a priority for service providers and we believe explicit reference to that should be made in this section.
154	Compassion in Dying	Similarly to the point above [ID 153], commissioners have a responsibility to ensure they are doing everything possible to

Comments on statement 2		
ID	**Stakeholder**	**Comments**
		commission services which will be able to deliver on this quality standard. This means that they must commission services that have trained professionals able to have conversations with dying people about their preferences for care and who are able to understand and apply the principles of the Mental Capacity Act in relation to patients who do and do not have capacity to make decisions.
155	Coordinate My Care	This Statement is very powerful and worthy of this important Standard. However, great challenges present themselves so that this Statement and this Standard move struggle beyond the aspirational or the occasional success. **Communication of the patient preferences across the clinical services landscape** is paramount and very challenging. This needs including in the QS2: Shared decision-making. Often the preferences are captured on native digital systems at the clinician's workplace. But this fails to communicate these preferences (along with important clinical perspectives) across services (in-hours and out-of-hours) across buildings and across time. Faxed summaries of the preferences (with the rest of the urgent care plan) are often not processed quickly at the Urgent Care Service's (Ambulance / OOH GP / NHS111) end and are staff/process intensive. Therefore such faxes often fail to deliver their intended usefulness in the real scenario. There are storage and destruction responsibilities and there are complications about how such a fax can be updated so as to ensure the one version of the plan is seen by the clinicians responding in end of life – dying – scenarios. In fact the one version of the plan (the latest version) needs to be accessible to all who might care for the patient – the in-hours and the out-of-hours care services. Therefore there needs to be something in the Standard and relating to this statement specifically **about the responsibility to effectively share the preferences to all clinical stakeholders around the patient**. This 'shareability' of preferences and plan needs to be optimised going forward through use of digital solutions – electronically held care plans that are shared across services, time and buildings – in-hours and out-of-hours – fully updateable and live. Otherwise we may continue the scenario whereby the courageous work of the patient and the good work of the clinician sit on a native system within the community nursing department or the hospice team office. This serves only as a record that good collaborative work has occurred and will assist in-hours staff from the same team because they can access the information on the native system. But important information such as this needs safe and secure deployment – it needs to be put to work so that the preferences of the patient and the overall plan (from the patient and the clinical team) can be delivered in real time, time and time again. Digital platforms like Coordinate My Care (CMC) can do this deployment and ensure that technology does the heavy lifting in terms of safely holding and effectively sharing the patient's preferences within a care plan. In-hours or out of hours – in terms of services or which part of the day – an accessible care plan across buildings and services is a powerful tool for **ensuring delivery of this important Statement.**

Comments on statement 2		
ID	**Stakeholder**	**Comments**
156	Coordinate My Care	In this Draft Quality Standard on page 11 – relating to the rationale for Quality Statement 2 “*A person’s wishes or needs may change in the last days of life, and so their preferences should be reviewed and* ***updated throughout this period****.’* In the community setting this is very challenging. In community there are services that know and don’t know the patient, know and don’t know the plan. Getting the plan into the hands of those who don’t know the patient is key as they are the services responding in the out-of-hours component of the day/week. They are most likely to be in the position to transfer the dying patient to a new place of care (often inappropriately) and the least likely to be resourced with the personalised plan for the patient. The ‘updateability’ component of care plans is problematic when we consider the range of services that often end up in the patient’s home (face to face or by phone) in the last days. Again the digital solution is key. One version of the truth – the plan – available to all. The key is not just capturing the preferences but sharing the preferences and sharing them in a way that facilitates updating in a clean and clear way. Sharing the preferences across the team enhances the chances of the patient getting their preferences met. Sharing the preferences and the plan effectively brings the team together around the patient. Teams don’t arrive ‘cold’ and start again. They arrive ‘warm’ with key information and continue to deliver the preferred plan of the patient and those caring for them day to day. A robust digital solution can also assist easily and speedily in the local data collection for evidence gathering. As a digital solution we can tell right now that the living patients (7000) in London have preferences as follows: PPC 93%; PPD 83%. This is a capture of an actual place expressed or patient not able or wishing to state a preference. A digital solution can provide data on preference achievement more easily in terms of resource and speed – 69.3% died in their preferred place. All these comments also speak to the **Coordinated Services section on Page 4** of the Draft and the role of commissioning. The role of quality, digital cannot be underestimated going forward.
157	East & North Herts NHS Trust	This statement may be hard to measure from an acute hospital perspective with respect to PPD/ Data source c. Whilst we would endeavour to discharge to PPD it may not be that we are made aware if the actual PPD did meet the patient’s preference. This would have workforce issues if we were to follow such patients up following discharge.
158	EPA UK/EU	It is necessary to empower people to complete advance care plans so that everyone involved in the last days of care are aware of what the client wants. Empower people to ask for what they want while at the same time being realistic in what can be achieved. If people choose to die at home they need to be aware that it can only work if they have a full time carer/carers at home to support them as well as the ability to access various services such as community nurses. Adults with the dementia (stage two and three) and close to dying, it is too late to consult them about their preferences for care, many no longer have mental capacity to make that decision. Anticipation of cognitive decline in dementia patients means these conversations must be had before loss of cognitive capacity. Social and health care practitioners must be made aware of the progressive nature of the illness and advise client and those important to them accordingly. A person diagnosed with dementia can

Comments on statement 2		
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		be supported, at the earliest, to put in place Advance Care Plans, write wills and appoint trusted persons as powers of attorney. At the point of, or close to death health care practitioners are confirming earlier stated preferences with people important to them rather than seeking this information from the patient.
159	Faculty of Intensive Care Medicine	This is a reasonable concept; often for patients on organ support the options can be limited (i.e. trying to get patents home to die – if that is their wish). This sometimes has the potential to raising expectations of both the patient and relative which can be difficult to meet.
160	Greater Manchester Chaplaincy Collaborative	Whilst we recognise that this document attempts to provide an over-arching perspective, we are disappointed that nowhere in it is Spiritual and Religious Care referred to. An option would be to include it in the Rationale for Statement 2 “Shared Decision Making” along with examples of other preferences. Unless Spiritual and Religious Care is explicitly mentioned it is very easily overlooked by those for whom it is not important or grouped together as one and the same thing by non-specialists. It is important that the person approaching the end of life (as well as earlier in the process) and the people close to them have the opportunity of a spiritual assessment done by a specialist spiritual care provider eg chaplain and this is available to everyone regardless of their place of care. It is also important that having made the assessment resources are available to be able to provide for or facilitate the needs identified.
161	Leeds Palliative and End of Life Care Managed Clinical Network	This information can be collected through EPaCCS
162	Leeds Palliative and End of Life Care Managed Clinical Network	Proportion of adults cared for in accordance with their preferences could be at conflict to the outcome proportion of bereaved people who feel satisfied with care in last days of life. Patients and families can have different what the patient wants is not always what the family wants.
163	Leeds Teaching Hospitals	As opposed to ‘given care’ should we be aspiring to planning and delivering individualised care
164	Marie Curie	The role of families and carers needs to be made more explicit in this statement, particularly on how shared decision making is reached at and then subsequently communicated to families and carers. At present, the outcome measures focus on the number of bereaved people who are satisfied with the decisions made, but there is no provision to include family and carers in the decision making process or to communicate the decisions to them. While professionals may be working with the patients to meet their wishes and gain an understanding of what they want, if the family and carers are not informed, they may not be satisfied with the outcomes.
165	Marie Curie	This is a better measure than focusing solely on preferred place of death, which often changes. Although the emphasis here is on the last few days of life (identified as 3 days in this document) the patient is far less able to engage with conversations. Although

Comments on statement 2		
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		that is not to say they can't and attempts should always be made, it would be better to be focus on having these conversations much earlier before the patient gets to the last few days of life.
166	National Council for Palliative Care	Similarly to Statement 1, Statement 2 needs to place a greater emphasis on communication – for any decision reached by the patient and the clinician, it is important that this is communicated clearly and compassionately with those close to the individual and their multi-disciplinary team.
167	National Council for Palliative Care	Whilst the National Council for Palliative Care (NCPC) welcome Statement 2's emphasis on patient choice, this statement needs to demonstrate a greater balance between patient choice and a patient's need for care and treatment – only then would this statement adequately address individualised care planning and shared decision making. This is apparent for two reasons: firstly, it is quite common for people in the last days of life to be semi-conscious or unconscious and lack capacity, it would therefore not be possible for an individual to express their preferences and clinical input would be required. Secondly, complete emphasis on patient choice can leave clinicians in an invidious position and works against the principal of shared decision making.
168	NHS England	This statement is currently focused on 'preferences' alone – adults in the last days of life need to have care that meets their needs, not only preferences. Both are important and there may have to be trade-offs between the two (this is part of shared decision making discussions), but focusing exclusively on preferences can leave clinicians in an invidious position. I suggest this is amended to 'Adults in the last days of life are given care that is in accordance with their individualised care plan, which is in line with their current and changing needs and preferences.' This needs to be reflected in the rationale, the measures and what the QS means…..The focus on individualised care planning (as a dynamic process) may make this more measurable.
169	Northern Health and Social Care Trust, Northern Ireland	This statement is very clear. Not sure if it is necessary to be specific about how often the professionals need to check if preferences are the same or has the adult/patient changed their mind on anything.
170	Northern Health and Social Care Trust, Northern Ireland	Adults in the last days of life are given care that is in accordance with their stated preferences and responsive to their changing preferences where this is possible. On occasion stated preferences are not realistic / achievable.
171	Northern Health and Social Care Trust, Northern Ireland	Consider re-wording to include carer involvement in decision making.
172	Older People's Advocacy Alliance	The consultation question asks if this statement is adequate. It is encouraging that the statement makes reference to health professionals asking if the person would like someone important to them to be present when discussing preferences about their care. For those who don't have family and/or friends, and even those who do, having the support of an independent advocate can support shared decision making.

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		To this end, OPAAL considers that the reference to advocacy is inadequate; the statement would be strengthened by a fuller reference to the benefits of independent advocacy support. Being proactive about the promotion of independent advocacy support around end of life care can ensure that people are able to make informed choices, express their wishes and communicate their needs to appropriate health and care professionals. Many older people tell us that they are not aware of their rights around end of life care. Our stakeholders tell us that care will only be quality when we are comfortable with talking about end of life wishes, starting conversations about death, end of life, making plans and informed choices, these are all areas where advocacy support can improve outcomes. It's vital that this statement presents a full explanation of the benefits of independent advocacy. Evidence from OPAAL's Cancer, Older People and Advocacy programme indicates that the person offering the initial information about a peer support service needs to understand what the benefits are to allow them to explain those potential benefits to the patient. Leaflets in themselves simply add to the pile of information that older people in particular find overwhelming. There is an obvious need to provide staff training on what independent peer advocacy is and what it can do to support the patient. Simply referencing advocacy in the standard, as in this current reading, is not sufficient.
173	Parkinson's UK	Parkinson's UK strongly supports the principle of quality statement two. Shared decision-making and in particular, an anticipatory approach to care planning is of critical importance in supporting people with Parkinson's who are at the end of life. We are also pleased to see that there is an acknowledgement in Statement two that there is a stipulation for professionals to be responsive to changing needs and preferences. However, we are concerned that the second quality statement presupposes that a person in their last days of life has full mental capacity and is able to articulate their care preferences. For this reason, we are concerned that it does not adequately address individualised care planning in the last days and hours of life. With this in mind, it is also essential that those closest to the patient (friends or family) are involved in these discussions as they may be aware what the patient would be most comfortable with. Loss of capacity to communicate end of life wishes is a high risk for people with Parkinson's, as up to eight out of 10 people who have Parkinson's for more than 10 years develop dementia. (Perez et al, Risk of dementia in an elderly population of Parkinson's disease patients: A 15-year population-based study, 2012). Research also shows that half of Parkinson's patients are unable to make or communicate decisions in the last month of life - 68% had difficulty communicating and 47% were confused. (Fleming, A., Cook, K. F., Nelson, N. D., & Lai, E. C. (2005). Proxy reports in Parkinson's disease: Caregiver and patient self-reports of quality of life and physical activity. Movement Disorders, 2011), 1462–

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		1468 cited in Walker, BGS, 2013) There is also growing evidence that people with Parkinson's are not asked about end-of-life issues when they are able to communicate. For example, the findings of the 2015 Parkinson's audit found that only 28% of those with markers of advanced Parkinson's had any recorded discussion of end of life care issues. Furthermore, a 2008-2011 UK study also showed that 90 per cent of patients with Parkinson's had not discussed their wishes with a health or legal professional or written them down. (Walker RW, End Stage Disease in Parkinson's, Presentation to Autumn 2013 British Geriatrics Society meeting). **Recommendation:** Parkinson's UK recommends that the principle of shared decision-making makes clear that anticipatory approaches to care planning should be undertaken as early as possible. It is also important to state that family or friends of the patient are involved if the patient lacks capacity or is unable to communicate.
174	Resuscitation Council (UK)	We suggest a change of wording to ensure that people's needs are met, as well as their preferences being respected: 'Adults in the last days of life are given care that is in accordance with their **needs and** stated preferences and responsive to their changing preferences **and changing needs**.' This will require a change of wording of the text relating to statement 2 to ensure that there is inclusion of needs as well as preferences. An alternative would be to have an additional, separate quality statement 'Adults in the last days of life are given care that is in accordance with their **needs** and responsive to their changing **needs**.' It is crucial that emphasis on a patient's preferences does not distract from the importance of assessing, recognising and addressing a patient's needs.
175	Royal College of General Practitioners	'Adults in the last days of life are given **holistic** care that is in accordance with their stated **needs and** preferences and responsive to their changing preferences.'- Try and be more inclusive and explicit of the need to assess religious/sexuality/disability / dementia needs or preferences (preference implies some capacity and the ability to change if desired) etc (CMS) I support this, though I am a little surprised that it does not specifically include having a discussion to define their wishes and then planning care accordingly. The statement is included in the detail on p13, but not in the headline statement. My prejudice is that the discussion is the difficult bit to initiate, after that everything becomes easy. (DJ)
176	Royal College of Physicians	The quality measures for QS 2 are as follows: • Evidence of local arrangements to identify existing advance care plans or advance decisions for adults recognised to be in the last days of life. • Evidence of local arrangements to ensure that adults in the last days of life, and those important to them, are asked about

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		preferences for their care. - Evidence of local arrangements to ensure that adults in the last days of life are cared for in accordance with their stated preferences. - Proportion of adults in the last days of life who have documented preferences for their care in the last days of life. - Proportion of adults who have their preferences for care reviewed in the last days of life. - Proportion of adults cared for in accordance with their preferences in the last days of life. - Proportion of bereaved people who feel satisfied with the care provided in the last days of the person's life. Our experts note that there are existing systems in place such as CMC or the GSF register but that these are not coordinated. Individual hospital systems have their own method of recording preferences but a national system of recording this type of information is needed. Further to this our experts note that satisfaction is very problematic as an outcome. This is because it varies according to expectations. Accordingly, it mitigates against those with lower expectations (often those with poorer socioeconomic status). Our experts suggest asking bereaved whether their relative was pain free, as this more objective and a much more meaningful outcome.
177	Royal College of Physicians of Edinburgh	Quality statement 2: There is no mention of the carer of the patient. The carer will have an opinion as to what the patient would prefer and it would be helpful for the carer to be referred to in this statement. Patient and carer information leaflets with easy to understand explanations of a lot of the information around hydration and symptomatic relief medications would also be hugely valuable in assisting conversations with patients, relatives and carers.
178	St Joseph's Hospice	The discussions around preferences of care would be difficult to collect for many establishments although many are in the process of doing so, which I think would be important to include under the question of how feasible it is to put a process in place to collect data
179	St Raphael's Hospice	This statement is fundamental to ensuring that patients have an active role in determining the care they receive. Potentially the capture of data maybe easy depending on local provision e.g. in London the electronic urgent care record Co – ordinate my Care (CmC) already captures this data. If there is not a centralised record capture of this data will be more problematic as different versions may be held by the various professional involved with the patient.
180	St Raphael's Hospice	There is potential of this not reflecting what we want reflected i.e. the bereaved person has high satisfaction because the persons wishes were followed; when the reality may be that the bereaved person is dissatisfied because the patient had a distressing death as a result of following their expressed wishes e.g. to die at home. Issues pertaining to responsiveness of community services and treatment of symptoms.

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		The statement outlines why it is important that a person is given the opportunity to state wishes/preferences and that these are captured and documented. However what is not covered in the statement is the training and support required by healthcare professionals to enable them to undertake these sensitive communications. There remains a reluctance to enter into these discussions by many healthcare professionals (HCP). There is also an associated difficulty in healthcare professionals being able to access the outcome of discussions in order that the person is not asked the same questions on a continual basis.
181	Sue Ryder	Sue Ryder believe that in cases where it is appropriate to do so, the best person to ask about an individual’s experience of care is that individual themselves. This is because they are uniquely well placed to know about their own preferences and experiences, and also because it respects the role that individuals should have in making decisions about their own care. Capturing the thoughts, preferences and experiences of individuals can be done through sensitive use of real-time data capture systems (such as electronic surveys). This can be more timely and immediate than relying on backwards-looking measures involving bereaved relatives. Sue Ryder recently rolled out this sort of system in its hospices.
182	Sue Ryder	Sue Ryder have some concerns about how this data collection might work for bereaved people whose relative accessed multiple different services/settings at the end of life (e.g. if they changed care setting). These relatives could potentially receive requests for feedback from a number of different providers and it is important that they are not overburdened in such cases.
183	Tees Esk and Wear Valleys NHS Foundation Trust	It can be very difficult to establish stated preferences in patients with dementia and cognitive impairment who may lack capacity. Best interests decisions may have to be made; again relatives and carers will often be the best source of information. The patient may have made advance decisions or statements and it is important to actively seek these and ensure they are communicated to all involved in the patient’s care.
184	The British Geriatrics Society	To ensure these standards are met and can be evidenced healthcare providers are likely to produce clinical guidelines and care plans to be completed for each person who is deemed to be in the last days of life. The key will be to ensure an individualised assessment occurs when the care plans are completed.
185	The British Geriatrics Society	Healthcare providers will need to devise robust systems to gather feedback from bereaved relatives.
186	Tissue Viability Society	I think there needs to be some clearer guidance on the range of preferences that need discussing as part of a persons end of life care if evidence is to be captured that demonstrates care providers are complying with NICE recommendations. A framework to support care planning may help with this, particularly when auditing. From a skin integrity point of view, there should be discussions about repositioning, pressure relieving equipment etc and the consequences of preferring not to concord with the advice given, and standards should be supported by consensus documents such as SCALE (Skin Changes at Lifes End). *Sibbald, RG, Krasner. D.L, Lutz. J,B, et al. The SCALE Expert Panel: Skin Changes*

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		At Lifes End. Final Consensus Document. Oct 1, 2009.
187	Western Health and Social Care Trust	**Comment : Yes** • Evidence of advanced care planning discussions / advanced care planning • Research and Audit • Quality improvement Model **Requires:** • A recording system in place that is accessible across all care settings where these stated preferences can be kept. Regional advanced care planning documentation will assist with this. Linking up to the electronic care record will be necessary.

Responses to consultation question 5: Does statement 2 adequately address individualised care planning in the last days and hours of life?		
ID	**Stakeholder**	**Comments**
188	Alzheimer's Society	Alzheimer's Society supports the inclusion of a quality statement which acknowledges the importance of the person's preferences towards the end of life. As stated in the equality and diversity considerations, a person with dementia may be unable to communicate their preferences for care. It is likely that a person with advanced dementia will lack mental capacity or have very limited mental capacity when they are approaching the end of life. But, it should not be assumed that just because a person has advanced dementia they lack capacity to make decisions about their care or are unable to express any preferences about care at the end of life. Capacity is decision-specific and should be continually reassessed so that the person is able to be involved in discussions and decisions about their care as much as possible. They may need additional support to do so and may benefit from a person such as a family member or carer being present to help with this. It is very important that any wishes the person has previously expressed (including an advance decision to refuse treatment) are considered and followed if appropriate – a valid and applicable advance decision must be followed if the person lacks capacity. The person may also have made a Lasting Power of Attorney for Health and Welfare. Any other preferences such as around place of care and religious or spiritual beliefs should be facilitated as much as possible. Preferences should be recorded and be easily transferable between healthcare practitioners and care settings. Even if the person has recorded preferences in advance, they may still be able to express preferences in the last few days of life. Healthcare professionals should therefore remain responsive to the needs and wishes of the person as they approach the end of life.

Responses to consultation question 5: Does statement 2 adequately address individualised care planning in the last days and hours of life?		
ID	**Stakeholder**	**Comments**
189	Association for Palliative Medicine of Great Britain and Ireland	We are pleased that this statement acknowledges that a person's wishes or needs may change in the last days of life, and so their preferences should be reviewed and updated throughout this period. We are not sure that this statement adequately addresses individualised care planning because preferences have become synonymous with preferred place of death and because an individualised plan of care also requires a trained individualised assessment which is not mentioned in any of the quality standards. It may feel disingenuous to discuss a person's preferences in the knowledge that the choice of home as the place of death may not be possible if care is unavailable to support that person.
190	Bradford, Airedale, Wharfedale & Craven Palliative Care Managed Clinical Network	This statement adequately addresses individualised care planning in the last hours and days of life. .
191	Great Western Hospitals NHS foundation Trust	Yes
192	Leeds Palliative and End of Life Care Managed Clinical Network	Where a person lack capacity and has not made their preferences known a best interest decision should be being made. Noted that cognition is referred to on p21 but only with reference to accessible information not best interest decisions.
193	Leeds Teaching Hospitals	This standard should include ensuring patients are involved as much as they would like in decisions about their care
194	NHS England	No, the statement does not adequately address individualised care planning – this cannot be based solely on preferences; current and changing needs must also be taken into account, and in some cases, the dying person would not be in a position to express any change in preferences if they are semi-conscious or unconscious.
195	NHS Hartlepool and Stockton-on-Tees CCG	Yes it is important firstly to discuss a person's preferences about their care at the end of life in a timely way so plans can be put in place. Hence the recommendation that we identify patients who are likely to be in the last year of life so that there is time to have such discussions. Also it is important to be able to adapt to changing situations and a person's preferences stated on an Advanced Care Plan may be different to what they actually want when the time comes and so flexibility is needed. Education of clinicians, supportive staff and carers is important so that they feel able to adapt care plans according to the changing needs and wishes of the person who is dying.
196	Northern Health and	This statement does adequately address individual care plans in the last days of life, but wishes may not always be achievable

Responses to consultation question 5: Does statement 2 adequately address individualised care planning in the last days and hours of life?		
ID	**Stakeholder**	**Comments**
	Social Care Trust, Northern Ireland	depending on available community resources for those patients who wish to die at home.
197	Royal College of General Practitioners	As above (CMS) [ID175] I think that some of the statements in this section are broad, particularly the question about whether bereaved relatives are satisfied with a patients care - and I wonder how appropriate it really is to ask them just after they've been bereaved for the sake of ticking a box? (LS)
198	Royal College of Physicians	Our experts believe that 'choice' in healthcare needs to be tempered by resources, and the mantra that 'preferences are not promises' needs to be used. Designing care around choices is important, but these cannot always be met when it conflicts with other limiting factors. Our experts suggest changing 'are given care in accordance with stated preferences' to a more dilute 'preferences are used to provide care'. Furthermore, our experts note that preferences have become synonymous with preferred place of death. An individualised plan of care also requires a trained individualised assessment which is not mentioned in any of the quality standards. The addition of the word 'individualised' would help emphasise the statement further.
199	Royal College of Physicians and Surgeons of Glasgow	For statements 1 and 2 the most important aspect of caring for a patient in last days of life is the recognition that he/she has reached this stage. This decision should be reached by the team *and* the most senior clinician caring for the patient. Then the team can monitor for changes as outlined in the quality statement. The statements should recognise the need for a multidisciplinary decision to be taken regarding whether the patient be entering last days of life and the team contribution to monitoring to determine if they are nearing death, stabilising or recovering. It also needs to be recognised that even with some form of anticipatory plan, that patients frequently have different priorities as they get closer to death and so these plans need particularly to be reviewed at these times. The other concern is that patients can be too unwell to communicate their wishes and preferences. The comments about daily reviews are difficult to judge; in a hospital, hospice or care home reviews of a patient near to death would be expected to be more frequent than that.
200	Sue Ryder	NICE should consider giving communication challenges greater prominence in this quality standard. In the current draft, communication concerns are mentioned, but primarily in the context of equality and diversity considerations. Equality and diversity concerns are important, but there are wider communication issues that should be mentioned as well in their own right.

Responses to consultation question 5: Does statement 2 adequately address individualised care planning in the last days and hours of life?		
ID	**Stakeholder**	**Comments**
		Having challenging conversations effectively and sensitively is vital for good end of life care across the range of areas covered by the quality statements. Good communication is essential for shared decision-making, for instance. There are inherent challenges regarding communicating about end of life care in general. For instance, some professionals feeling uncomfortable instigating conversations about people's end of life care preferences, and the skill involved in conducting these conversations sensitively. NICE should consider treating communication as a distinct area for quality improvement, or at a minimum, giving it greater prominence across the document. Communication should be recognised as an equality and diversity consideration, but wider communication issues should not be forgotten either.
201	The British Geriatrics Society	No, it needs more emphasis on taking account of the views and needs of those important to the dying person.
202	Western Health and Social Care Trust	This statement is not achievable with current resources, particularly with the focus on preferred place of death, as evidenced by the continued high percentage of patients dying in acute hospital settings rather than at their residence. Community resources in terms of accessibility to out of hours GPs, rapid response nursing teams, carers and access to medication out of hours are lacking to support this statement. Investment in the services that will keep people in their preferred place of care will ultimately save money on hospital admissions and will provide a higher quality of end of life service in the trust. One potential and easy solution - Giving rapid response nursing teams access to IV antibiotics out of hours, rather than having them dispensed from hospital pharmacies (not all patients will have families who can drive the distances to other hospitals to pick up drugs and therefore patients end up in hospital when it could have been avoided) will allow patients to be treated in their place of residence rather than have a hospital admission towards the end of life.

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203	Association of Supportive and Palliative Care Pharmacy (Formerly PCPN)	Need to ensure that all HCP aware of anticipatory medicines present in the home and that prescription is such that these can be administered according to local policies for medicines administration. ie paperwork is acceptable to DN, and paramedic staff. Local out of hours GP service aware that drugs are there, that paperwork details appropriate doses individualised to the patient.
204	Association of	Need for individualised prescription of anticipatory medicines needs to take into account those medicines that are available locally,

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	Supportive and Palliative Care Pharmacy (Formerly PCPN)	or are under a locally commissioned arrangement e.g. from community pharmacies. Local palliative care anticipatory medicines, core drugs, just in case boxes.
205	Association of Supportive and Palliative Care Pharmacy (Formerly PCPN)	Local EOLC guidelines for anticipatory medicines to support GPs in choice and dosage of drugs will relate to local commissioning pathways. E.g. individualised drug and dosing for patients with low eGFR and pain may be oxycodone, alfentanil or fentanyl injection
206	Association of Supportive and Palliative Care Pharmacy (Formerly PCPN)	Anticipatory medicines may be prescribed however the limiting factor maybe administration in more rural locations due to availability of services.
207	Belfast Health and Social Care Trust	The importance of communication is not mentioned and this ought to be a separate quality standard.
208	Belfast Health and Social Care Trust	Since the withdrawal of the Liverpool Care Pathway, there is no reliable/consistent method of identifying and recording symptom burden and management/effectiveness of symptom control.
209	Belfast Health and Social Care Trust	Data collection may be possible if consistent documentation is agreed and used correctly.
210	Belfast Health and Social Care Trust	BHSCT clinical prompts at end of life document advises assessment of symptoms and provision of anticipatory medications. The Northern Ireland Regional Palliative Medicine Group has developed a regionally-adopted symptom guidance document. BHSCT pilot using a symptom monitoring /treatment escalation chart.
211	Catholic Medical Association (UK)	We are very concerned that there are risks in anticipatory prescribing as was noted in the Draft Guidance (Long Draft, p 223, l 32ff) where the danger is of “injudicious administration and prescription of medication by inexperienced staff, possibly unfamiliar with the person.” Anticipatory prescribing must not be allowed to substitute for proper ongoing assessment and care for the patient. Anticipatory prescribing should only be used when there is expected to be a serious and significant delay in obtaining the medication (for example in general practice over a weekend when chemists may be shut).
212	Children's Hospice Association Scotland	Adults at the younger range of 18-25 years with palliative care needs may have underlying conditions which are better known about by paediatricians and by clinicians working in “children’s palliative care”. Encouragement should be made to facilitate discussions about symptoms and their management, including doses of what may be “unusual” medications by “adult” clinicians

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		with children’s teams as these symptoms and options may vary from those seem in adult populations,
213	Children's Hospice Association Scotland	The doses of medications as well as their pharmacokinetics may differ for those individuals in young adulthood from older populations, as well as their diversity of multiple morbidities – this may impact on the rationalisation of medications in the days towards and at end of life.
214	Coordinate My Care	A quality plan of care captures and shares more than the patients’ preferences. Key care plan items are the clinical ceiling of treatment and the symptom control management plan CMC as a pan London service gets a unique perspective on care delivery – overlap and gaps. A key message from London Ambulance service is that there is through the Coordinate My Care Personalised care plan a preference statement on a care plan is good to know but often fails to help them deliver on the preference. The Ceiling of treatment is similar. It is aspirational but without an actual Symptom Management Plan (anticipated symptoms **and** the management plan) the preference and the ceiling of treatment can re aspirational but not deliverable. **Statement 3 is a good statement but the communication of it reliably across the Urgent Care Landscape is pivotal.** Digital platforms like CMC where the plan is accessible, is stored safely, accessed from all clinical buildings, and through mobile devices (smartphones) is vital going forward. Otherwise the best of intentions to share information (up to date and updateable) with Urgent Care Services will be thwarted through paper use, faxes, processes for receiving and sharing such communications internally within Urgent Care Service teams, so that the front line responder may not be in possession of the plan. There seems to be an assumption that the clinician responding to the patient with symptoms and delivering medication (anticipatory medication) knows the patient or the plan. It is likely that they won’t know the patient or the plan. The plan needs explicit sharing – an anticipatory plan so to speak. Often an ambulance crew never get to know there are medications already in the house. A simple communication such as this can be a positive change maker for the patient. Something about sharing needs to go in the Rationale section or the *What the quality statement means for service providers, healthcare practitioners and commissioner* section.
215	EPA UK/EU	There needs to be thorough assessment prior to medication being administered. Post assessment medication notes need to be written as symptoms can arise at any time and need to be pre-empted. It is important to ask why someone is having the symptom they are having. The more the cause can be ascertained the great the opportunity to relieve the symptom. for example, agitation can be causes by urinary retention or constipation and when these symptoms are relieved so is the agitation. There is a responsibility on the part of the person who is nearing the end of their life to readjust certain things such as their food as certain foods can cause nausea and vomiting at this stage of life. It is also the responsibility of the person who is nearing the end of their life to have conversations with their family/friends.

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216	Faculty of Intensive Care Medicine	We are aware of a few centres establishing formal critical care-palliative care links with very positive early results in terms of effective communications with patients and better symptom control
217	Leeds Palliative and End of Life Care Managed Clinical Network	To allow audit of all patients electronic prescribing would be critical – with a reporting function, audit could take considerable time if based on paper drug charts.
218	Leeds Palliative and End of Life Care Managed Clinical Network	Same issues as comment 9, e.g. patients may refuse pain relief and families are wanting it or vice versa in that patient given pain relief to ease symptoms and families feel that patient is being assisted to die. Though good communication can alleviate concerns it doesn't for a minority of families and does need consideration
219	Leeds Teaching Hospitals	Should 'who are likely to need symptom control' be changed to who are likely to experience symptoms which required treatment
220	Marie Curie	Following an anticipatory prescription, it is often the case that the professional who decides to use it is a nurse, rather than the doctor who wrote the prescription. Steps must be taken to ensure the prescription is only given when explicitly needed. Professor Jane Seymour's 2014 paper proposes 4 key conditions which nurses felt must be met before they felt comfortable giving an anticipatory prescription: 1) Symptoms are irreversible and the patient is approaching the end of life; 2) Patient is unable to take oral medication; 3) The patient has given consent where possible: 4) The decision is independent of influence from a patient's relatives. The full paper is available online at the following link: http://pmj.sagepub.com/content/early/2014/07/28/0269216314543042.full.pdf?ijkey=zs4WEEg2XFcCKVd&keytype=ref
221	Marie Curie	We have concerns about the proposed outcome of "Proportion of adults in the last days of life that have problematic symptoms controlled as they arise". This could potentially have implications for patients with very complex and difficult symptoms, as for some patients we get symptoms to a level that is acceptable to the patient but they may not be 'controlled'. Also if services are going to be measured on this then they may be less willing to take on very complex patients where symptom control is not achievable, despite anticipatory prescribing
222	National Council for Palliative Care	Access to anticipatory drugs is a critical part of ensuring good symptom management and NCPC therefore welcomes this statement. In addition, Statement 3 needs to acknowledge the importance of anticipatory drugs not only being available, but also health practitioners being on hand to administer them quickly and effectively in line with the needs of the patient.
223	NHS England	Full support for this statement.
224	NHS England	Denominator is too vague – I suggest 'number of adults recognised to be in the last days of life' – or 'number of deceased adults' – recognising that if the latter is chosen, there will be a proportion of deaths that are unexpected or sudden, so one would never expect the proportion to be 100%.

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225	NHS England	The difficulty with the way this outcome measure is phrased is that it assumes all ‘problematic symptoms’ can be controlled. I think the thrust of this QS is that dying people receive treatment for their symptoms without delay and at a dosage and route that is individualised to their needs.
226	NHS England	Service providers should not only ensure that systems are in place for the assessment, prescription and access to medicines – they must also have systems in place for the safe storage and rapid administration of medicines when needed. Ditto for commissioners.
227	Northern Health and Social Care Trust, Northern Ireland	This statement is clear. Having medicines prescribed does not always mean they are available. Usually easy to access drugs from hospital pharmacy (in hours and out of hours pharmacy service available) but this can be more challenging in community. Probably once anticipatory medicines prescribed for a community patient they should be obtained and available in patient’s home. Patients discharging from hospital should have their anticipatory drugs sent home with them even if they have not been requiring them whilst in hospital.
228	Northern Health and Social Care Trust, Northern Ireland	This quality measure would suggest what we are no longer prescribing for the 5 main symptoms “prescribed anticipatory medicines using an individualised approach”. We feel that further clarification is required around the use of the term “individualised approach” as this may be limited by the prescribers’ knowledge.
229	Northern Health and Social Care Trust, Northern Ireland	Proportion of bereaved people who feel satisfied with the level of symptom management…. It may be difficult to get bereaved relatives’ view for people who die in community / nursing home. This also raises the issue of “when” families are asked this question and the sensitivity of the timing of this question.
230	Northern Health and Social Care Trust, Northern Ireland	Feel there should be a standard with focus on quality of symptom control - key concern for patients and families in last days.
231	Older People’s Advocacy Alliance	This statement similarly references advocacy in relation to communication needs, the comments made on statement 2 extend to this statement too, both need to be more expansive on the role of independent advocacy.
232	Palliative & End of Life Care Team, Bolton NHS Foundation Trust	In the community setting it has taken a long time for GPs to prescribe 4 drugs in anticipation of symptoms. Concerns raised about the cost, the wastage of drugs and also how far in advance to ensure drugs are in the patients’ homes. There is also a drive to produce drug prescription charts with current EOLC recommended drugs pre-printed with space to specify doses e.g. morphine, levomepromazine, hyoscine hydrobromide and midazolam. It’s the difficult balance of ensuring patients are managed safely at the end of life but also ensuring the generalists have enough knowledge and understanding to individualise prescribing in anticipation and acknowledging when to seek advice. Obviously we have an on-going education program in hospital and community settings but the subtleties of individualising patient care can be

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ID	**Stakeholder**	**Comments**
		hard to teach in a limited time frame.
233	Parkinson's UK	Parkinson's UK does not agree that this statement adequately represents an individualised approach to prescribing anticipatory medicines for adults in the last days of life. Although we welcome the principle of the quality statement, the guideline should recognise that many people in their last days of life may have difficulty taking medication, because of swallowing issues as noted above. This is of particular importance for people with Parkinson's, for whom the priority when someone with Parkinson's is dying, is to find ways to safely administer a safe dose of dopaminergic medication when swallowing ability is lost or poor. There are serious risks, and the consequences of suffering are high for the individual if dopaminergic medication is stopped - reactions could include; neuroleptic malignancy syndrome, severe rigidity/contractures, dopamine withdrawal syndrome. **Recommendation:** We recommend that the statement to be expanded to include a consideration of the ways in which medication is delivered by a patient in their last days of life.
234	Resuscitation Council (UK)	Agreed.
235	Royal College of General Practitioners	I support this in principle, but wonder how easy it will be to measure. It's correct that avoiding delays is important (p 17). The risk is that in order to comply with the standard, patients have medicines prescribed almost automatically; this might happen before sensible end-of-life discussions happen with patients and families; families infer that this palliative care before they have been told, etc. On the other hand. Most patients will need some medication; even if they don't in the end all need it, no harm has been done by prescribing in and having the supplies available 'just in case'. Whether in reality it works to have more or less individualised care depends entirely on how it is put into practice, and there is no guarantee either way. (DJ)
236	Royal College of General Practitioners	Anticipatory prescribing does not then assume use. This too should be monitored alongside review of clinical need and impact. (CMS)
237	Royal College of General Practitioners	b) Proportion of bereaved people who feel satisfied with the care provided in the last days of the person's life.' - This is a much wider outcome statement than linked to anticipatory prescribing? (CMS)
238	Royal College of Physicians	Our experts note that it would be the exception to find someone unlikely to need symptom control. Although this is a process measure it arguably will improve care if enhanced to include most or all patients, not just those 'likely' to have symptoms, since lack of availability of injectable meds at the right time is a major contributor to poor symptom control. Our experts suggest changing the statement to 'Adults in the last days of life are prescribed anticipatory medicines with individualised indications for use and dosage, unless there is clear indication these will not be needed'.

Comments on statement 3		
ID	**Stakeholder**	**Comments**
239	Royal College of Physicians	The quality measures for QS 3 are as follows: • Proportion of adults in the last days of life prescribed anticipatory medicines using an individualised approach. • Proportion of adults in the last days of life that have problematic symptoms controlled as they arise. • Proportion of bereaved people who feel satisfied with the care provided in the last days of the person's life. Our experts note an example of a local hospice who audited anticipatory prescribing and reported collecting data was practically difficult. Our experts believe that control of problematic symptoms may be difficult to analyse. Death rattle, for example, at the end of life is not always possible to control and our experts question whether this could that be seen as failing to control problematic symptoms. An alternative may be the proportion of patients who were comfortable at the time of death.
240	St Joseph's Hospice	Might be pertinent to add 'and availability of medication out of hours' as this is a common problem
241	St Luke's Hospice	Need to ensure anticipatory medicines in home can be administered by different staff caring or visiting patient e.g. in hours/out of hours/community/paramedic and specialist teams. Appropriate documentation and records that can be shared across teams – whether paper or electronic documentation. OOH care providers need to be aware that these are in place.
242	St Luke's Hospice	Individualised prescription must take into account local preferences e,g in Sheffield use of oxycodone for patients with low eGFR on last days of life algorthims. Use of diamorphine in community setting and morphine in acute setting. This will differ in other areas but will relate to local drug availability and commissioning pathways.
243	St Raphael's Hospice	This statement is key to ensure that patients identified as being in the dying phase have appropriate anticipatory medications prescribed to ensure symptoms that may occur as their condition deteriorates can be treated appropriately. It relies on healthcare professionals recognising the deterioration of the patient's condition and responding appropriately, as well as the knowledge and confidence to prescribe appropriate doses of medications for specific symptoms. This can be problematic in both getting a timely prescription for end of life care medications and also having a recognised means of authorising the administration of the medications for nurses in the persons home.
244	St Raphael's Hospice	This statement is measuring two things – the number of patients who have appropriate anticipatory medication prescribed in the last phase of life in order to that symptoms if they occur can be treated. Secondly the potential for bereaved relatives to report satisfaction with the care of a relative in the last phase of life. There is a risk that this outcome does not reflect what is aimed for because of the potential for delayed response by community services to attend a patient if they are at home and the consequent bereaved person's perception of the responsive care that was delivered – despite the anticipatory medications being prescribed and in the home.

Comments on statement 3		
ID	**Stakeholder**	**Comments**
245	Sue Ryder	In our experience as a specialist palliative provider, this statement is currently too broadly worded. NICE may want to consider rewording it. The notion of having “problematic symptoms controlled as they arise” might mean very different things in different settings. For example, an individual who is being looked after in the community might have anticipatorily prescribed medicines, but if they need a nurse to give them those medicines, and that nurse takes some time to reach them, then this will introduce a delay in receiving those medicines. It is unclear how “as they arise” should best be understood in this context.
246	Sue Ryder	Sue Ryder believes that this statement may have unintended consequences. It suggests that healthcare practitioners should “ensure that they assess what symptoms are *likely* to occur for an individual in the last days of life; discuss what medicines might be needed with the dying person, those important to them, and other members of the team caring for them; and prescribe anticipatory medicines…” While professionals know which symptoms are relatively common in patients that are dying (e.g. SOB, pain, nausea, agitation, rattly breathing) it is difficult to predict with certainty which patients will experience which symptoms. We are concerned that statement this may lead to some health professionals not prescribing an adequate range of anticipatory medications for individual patients and for those patients to receive inadequate symptom control (for instance a doctor on the ward may decide that he thinks because a patient has not had much pain up until now that he has a low risk of getting pain in the last days of life and therefore does not prescribe any anticipatory pain relief. This patient might well rather have the pain relief prescribed in case they needed it.) This would be especially problematic for patients in community settings when there would be a potential delay in getting new prescriptions. One alternative approach that might be worth considering would be to prescribe medication to cover the five common symptoms encountered at the end of life for all dying patients but make sure that the dosages prescribed are individualised for each individual patient.
247	Tees Esk and Wear Valleys NHS Foundation Trust	Symptom control can be more challenging in patients with dementia who have communication difficulties and whose symptoms may present in unexpected ways. It is important to adopt a multidisciplinary approach for these patients using information from mental health specialists as well as palliative care staff and carers.
248	The British Geriatrics Society	To ensure these standards are met and can be evidenced healthcare providers are likely to produce clinical guidelines and care plans to be completed for each person who is deemed to be in the last days of life. The key will be to ensure an individualised assessment occurs when the care plans are completed.
249	The British Geriatrics	Healthcare providers will need to devise robust systems to gather feedback from bereaved relatives.

Comments on statement 3		
ID	**Stakeholder**	**Comments**
	Society	
250	Western Health and Social Care Trust	**Comment: Yes** • Currently quality improvement initiative being carried out within WHSCT to measure anticipatory medication prescribing in the hospital setting for patients who are end of life – education provided to junior doctors and reviewing anticipatory prescribing post education delivery in progress. **Requires:** • Consideration of resource / people to carry out similar QI initiatives/ provision of education and learning across all sectors of the WHSCT and to wider workforce involved.

Responses to consultation question 6: Does statement 3 adequately represent an individualised approach to prescribing anticipatory medicines?		
ID	**Stakeholder**	**Comments**
251	Alzheimer’s Society	Alzheimer’s Society supports this draft statement but would emphasise the importance of healthcare practitioners being aware of the impact of dementia on symptoms towards the end of life. A person with advanced dementia may have difficulty communicating what symptoms they have including pain, thirst or discomfort (for example from an infection). Although dementia causes increasing frailty as it progresses, the person may also have another comorbidity which would affect the symptoms they experience and the medication they require. It is important therefore that staff are able to notice and respond to the different symptoms a person with dementia may experience so that any appropriate medication can be prescribed.
252	Association for Palliative Medicine of Great Britain and Ireland	It is not always possible to predict which patients will get which symptoms, and therefore who will require these drugs and who will not. To ensure that patients are not disadvantaged, especially at home when obtaining medication rapidly may be more difficult than e.g. in a hospital or hospice, all patients in the last few days of life should be prescribed anticipatory medications. As far as possible, this prescribing should be personalised (e.g. based on symptoms so far; current doses of analgesia).
253	Bradford, Airedale, Wharfedale & Craven Palliative Care Managed	Represents an individualised approach to prescribing anticipatory medication. Data can be gathered by local and national audit.

Responses to consultation question 6: Does statement 3 adequately represent an individualised approach to prescribing anticipatory medicines?		
ID	**Stakeholder**	**Comments**
	Clinical Network	
254	Great Western Hospitals NHS foundation Trust	The statement requires an excessively individualised approach and information which is not readily discernible from clinical notes.
255	Leeds Teaching Hospitals	This standard need to be more clear about the need to ensure drug doses are prescribed according to individual patients needs and their condition and should be reviewed daily
256	NHS Hartlepool and Stockton-on-Tees CCG	Yes it is important that medication for symptom control is prescribed in a timely manner, so that they can be administered when they are required and so avoid pain and distress for the person who is dying.
257	Northern Health and Social Care Trust, Northern Ireland	Perhaps an alternative could be “Adults in the last days of life who are likely to need symptom control are prescribed anticipatory medicines tailored to their individual needs”.
258	Royal College of General Practitioners	Yes – but assumes full complement of staff to deliver and does not address carer/family concern or empowerment which are a major reason for people diverting from their care plan (if they have one) (CMS) I think it needs to be clearer that decisions regarding the provision of anticipatory medications should be made on an individual basis - and a broad range of medications could be considered anticipatory. Also it should be recognised that the provision of anticipatory medications in the community must be safe - we have had to avoid / limit prescribing in a small number of patients whose relatives / carers were themselves drug addicts. (LS)
259	Royal College of Physicians	Our experts note that the statement ‘likely to need symptom control’ suggests that we know who will get symptoms and require these drugs and who will not, which is inaccurate. Individuals should all be prescribed these drugs or they will be disadvantaged. In the majority of cases anticipatory prescribing is currently a standard set of four medications for pain, agitation, nausea and secretions.
260	Royal College of Physicians and Surgeons of Glasgow	This is an important area and data collection should be straightforward from care records. However, it can be relatively easy to see that anticipatory medications have been prescribed but it will not ensure that these medications have been given with the desired effect. The statement should underpin regular assessment of the patient for effect. Care plans can make it easier to measure this statement.
261	The British Geriatrics Society	No, it should also include a statement about stopping medications and other medical interventions which do not contribute to comfort and symptom control at the end of life.
262	Western Health and Social Care Trust	**Comment: Yes** All patients at the end of life should have anticipatory prescribing, as we know there are common symptoms for the majority of

Responses to consultation question 6: Does statement 3 adequately represent an individualised approach to prescribing anticipatory medicines?		
ID	**Stakeholder**	**Comments**
		patients who are dying and it would be reasonable to expect that all patients should have access to the medications they will need at the end of life regardless of where they are. This will require a review of community accessibility to common palliative drugs for end of life symptom management, particularly during out of hours.

Comments on statement 4		
ID	**Stakeholder**	**Comments**
263	Association of Supportive and Palliative Care Pharmacy (Formerly PCPN)	Need to emphasise the importance of communication of need for fluids at end of life. Importance of symptomatic benefit e.g. only if patient expressing thirst in context of good mouthcare and supported intake of fluids
264	Association of Supportive and Palliative Care Pharmacy (Formerly PCPN)	Availability of fluids in community is not widespread practice and is only commissioned in some areas. There are practical issues about obtaining fluids and equipment, competency in administering especially in nursing homes, and ongoing monitoring of the patient. The administration and review of parenteral fluids needs to be carefully co-ordinated between GP/specialist palliative care and nursing home/District nursing services as well as OOH services.
265	Association of Supportive and Palliative Care Pharmacy (Formerly PCPN)	Need for guidance on risks and benefits of CAH, no evidence that it delays death, lack of evidence for CAH in dementia patients
266	Belfast Health and Social Care Trust	This is an area of concern for health and social care professionals and the public. However, this could be a complex discussion and requires education and training for health and social care professionals in end of life care issues, including advanced communication skills.
267	Belfast Health and Social Care Trust	Some BHSCT wards have examples of ceilings of care documents that address some end of life interventions. Hydration may not routinely be included.
268	Belfast Health and Social Care Trust	It is good practice to document ceilings of care, and significant conversations around end of life care, however there is variable recording of clinical conversations and decisions within medical notes. It is not consistent or standard practice to document "an individual care-plan for dying patients" in the notes, and professionals are somewhat reluctant to discuss hydration with patients and families.

Comments on statement 4		
ID	**Stakeholder**	**Comments**
269	Bradford, Airedale, Wharfedale & Craven Palliative Care Managed Clinical Network	Appropriate to assess hydration status daily. However there is concern about focusing on clinically assisted hydration (CAH). Why was this considered to be 1 of only 4 quality statements? It appears that we are being led by concerns raised by the media and not our own clinical priorities. Discussion about supporting patients to drink and CAH is vital but the statement appears to specifically focus on CAH. The concern is that the focus will be on commencing CAH but this has added complications in the community setting. There is the potential that if we continue to focus on CAH we medicalise death (especially in home and hospice settings) and then potentially risk inappropriate admissions to hospital.
270	Bradford, Airedale, Wharfedale & Craven Palliative Care Managed Clinical Network	It will be difficult to measure: • *The proportion of adults in the last days of life with symptoms of dehydration and overhydration.* There is concern that delirium will be interpreted by generalists as dehydration and CAH commenced or patients will be inappropriately admitted to hospital. • *The proportion of adults in the last days of life, and those important to them, who understand hydration issues and the aims of care.* Greater emphasis needs to be given to support patients to drink or give good mouth care rather than focusing on CAH. • *Proportion of bereaved people who feel satisfied that the person who has died was supported to drink or receive fluids if they wish.* This is very subjective and therefore meaningful data will be difficult to gather in a bereaved carer survey.
271	Catholic Medical Association (UK)	Monitoring of the hydration status of those who are thought to be dying is important. However, this also ought to be done for those who have swallowing difficulties (true dysphagia) or who are unable to take oral hydration and nutrition for other reasons such as sedation. Monitoring may required the use of simple blood tests as well as clinical observations. In addition to those with swallowing difficulties, the provision of hydration is particularly important for those who have difficulty in accessing water, including those who have significant cognitive ability. The need to assess hydration is not confined to those deemed to be dying as many patients in hospital have difficulties when it comes to feeding and obtaining adequate hydration in hospital. The symptoms of thirst are not simply relieved by oral care as shown in animal models.
272	Children's Hospice Association Scotland	When considering younger adults who have moved into adult services from a paediatric setting, there may be more evidence of alternative routes of access for nutrition and hydration (and medication) such as long established gastrostomy or jejunostomy tubes. Consideration of managing this and potentially withdrawal of this is an area which could usefully be added to the standard. Also, there may be a greater diversity of ranges of routes of administration, eg a “non-needle” approach, so consideration of medications being given by intranasal and buccal route should be included within the standard.
273	East & North Herts NHS Trust	Outcome a- this needs to clarify what are considered to be outcomes of over hydration & dehydration as some symptoms could be attributed to other causes. It is debatable if this is useful to capture at end of life.

Comments on statement 4		
ID	**Stakeholder**	**Comments**
274	EPA UK/EU	End of life care needs to be compassionate and dignified and all conversations have to be frank, honest and respectful. People need to be given both the pros and cons of having clinically assisted hydration.
275	Healthwatch Hartlepool	Again this repeating what should be standard care. Commissioners such as CCG's use contractual and service specification arrangements to ensure providers they commission services from, assess the hydrations needs of adults in their last days discussing the risks and benefits of clinical assisted hydrations with the dying person and those important to them. Again this should be a standard expectation for a good death. If hydration is required all available options need to be explored from self-help to clinical intervention.
276	Hospice UK	If possible, we would suggest that it may be better to change the title of quality statement 4 to 'Hydration' or 'Assessing Hydration'. There is some concern that the title 'Maintaining Hydration' could imply that if a patient is no longer able to take adequate fluids their hydration should be maintained with a drip.
277	Hospice UK	In this statement, we would suggest that the sentence on page 21 that begins "Adults who are in the last days of life are checked daily to make sure they are drinking enough to stay hydrated" should be amended to say "Adults who are in the last days of life are checked every day to assess their ability and desire to drink, and whether they have symptoms which may be caused by under or over hydration. If the person is not able to drink and this may be causing them problems, their doctor might suggest giving them fluids through a drip or tube to see if this helps". In addition, we would also suggest that consideration should be given to adding in "or according to the person's wishes".
278	Hospice UK	It may also be helpful to include, within the rationale section, a statement to remind practitioners that "as death approaches, the desire to take in fluid can diminish".
279	Imperial College Healthcare NHS Trust	Little guidance on exactly what a hydration assessment involves. Could be taken to mean invasive blood tests by some, oral hygiene is not always a good measure of hydration status, leaves too much open to interpretation here.
280	Imperial College Healthcare NHS Trust	Daily hydration status – concerns expressed by those in community settings as to how this would be achieved on a daily basis.
281	Imperial College Healthcare NHS Trust	Statement b implies that every person, either themselves or their relatives, should have a discussion re the potential risks and benefits of clinically assisted hydration, we are all in agreement that this is not normal practice. The risks and benefits are discussed openly when the situation demands it rather than with every patient. This sounds like discussing treatments that are potentially not on offer.
282	Leeds Palliative and End of Life Care Managed Clinical Network	Need to be clear what is the metric to be used for measuring hydration. Frequency of conversation – should be tailored to individual needs

Comments on statement 4		
ID	**Stakeholder**	**Comments**
283	Leeds Palliative and End of Life Care Managed Clinical Network	Again will need to be clear how dehydration overhydration is measured, where patients are admitted to the provider with dehydration overhydration and die within 24 hours of admission will this be considered?
284	Leeds Palliative and End of Life Care Managed Clinical Network	Need local information as response rate to voices across city is low
285	Leeds Teaching Hospitals	This could be phrased differently to ''Adults in the last days of life are offered a discussion about the risks and benefits of clinically assisted hydration, and have their hydration status assessed daily''
286	Marie Curie	The process for this statement focusses on the assessment and not the appropriateness of intervention. Whilst the patient may be assessed as overhydrated, what would be more useful to know is was this then rectified. In terms of the outcome "Proportion of adults in the last days of life with symptoms of dehydration and overhydration", it is unclear how this could be measured and further detail is needed. We don't take blood from dying patients, as it would be inappropriate. In terms of assessing overhydration – the patient may sound 'bubbly' but there could be causes other than overhydration.
287	National Council for Palliative Care	Whilst clinically assisted hydration (CAH) has been proven to work for some, there is still a lack of evidence about the benefits and risks of this clinical practice. With this in mind, we recommend further research is completed in this area before it is included as an integral part of this Quality Standard. We suggest that Statement 4 should instead acknowledge the need for discussions with the patient about maintaining comfort in relation to their symptoms.
288	National Council for Palliative Care	We hold two concerns about the use of the word 'understanding' in Outcome B. Firstly, it has the potential to place a burden of understanding on dying adults and those important to them (even if this is unwelcome by them) about an area that is quite technical and difficult to understand. Secondly, not all health professionals working in end of life care are sufficiently trained to engage effectively in conversations about CAH – this could quite easily result in misinformation being provided and misunderstanding for the patient. Conversations about 'maintaining comfort' are both more easily explained and more easily understood.
289	NHS England	The same concerns apply re. the measurability of the denominator as stated in row 6 above [ID 224].
290	NHS England	The way this outcome is phrased potentially places a burden of 'understanding' on dying adults and those important to them even if this is unwelcome by them. I would suggest that the emphasis is placed on the aims of care (which includes issues about drinks and fluids) rather than on the 'understanding hydration issues' component.
291	Northern Health and Social Care Trust, Northern Ireland	The statement is clear and would likely address the quality issues around hydration.

Comments on statement 4		
ID	**Stakeholder**	**Comments**
292	Northern Health and Social Care Trust, Northern Ireland	Burden on already stretched community resources out of hours, especially at weekend to be assessing hydration status and whether patient is improving - needs continuity of care and resources. Such resources which could be better spent elsewhere if the patient was otherwise comfortable and keen die at home. This monitoring also relates to the inference of standard 1.
293	Northern Health and Social Care Trust, Northern Ireland	Resources would be needed if we are going to be routinely giving iv/sc fluids for last days of life for all patients in the community. Checking bloods to monitor the treatment - leaves staff very vulnerable. When is the decision to stop taking bloods made? Again daily hydration check - if district nurse in but if no syringe driver and comfortable is this best use of limited resources?
294	Northern Health and Social Care Trust, Northern Ireland	How do you assess if adults in last days understand hydration issues and aims of care? Again this statement could benefit from including "where possible" discussion about the risks.
295	Northern Health and Social Care Trust, Northern Ireland	The practicalities in a community environment would need to be considered.
296	Northern Health and Social Care Trust, Northern Ireland	Nursing and residential homes have not been stated in the list of service providers or health care practitioners. This exclusion may permit an opt out from the meeting of the standard. From practical experience many admissions to acute care from care homes can be due to dehydration.
297	Northern Health and Social Care Trust, Northern Ireland	A measure to consider a focus on oral hygiene, which has not been mentioned, would have been valuable.
298	Palliative & End of Life Care Team, Bolton NHS Foundation Trust	At present this is often only addressed if raised by the patient or family. Developing local arrangements to audit this would improve patient care. However, we'd need to look into the feasibility of provision of artificial hydration and nutrition in the community setting. If only available in an in-patient setting it would have implications on patients decision making re PPC.
299	RCSLT	The RCSLT suggest the inclusion of 'and signs of aspiration' after; 'they ensure that staff are aware of the potential risks and benefits of clinically assisted hydration…. **and signs of aspiration"**
300	RCSLT	We would like to suggest the inclusion of assessment of aspiration and discussion around acceptance of risk, if aspiration is identified.
301	Resuscitation Council (UK)	We suggest a slight addition to the wording to make clear that a daily assessment is the minimum frequency necessary and that some people need more frequent assessment: 'Adults in the last days of life have their hydration status assessed **at least** daily,

Comments on statement 4		
ID	**Stakeholder**	**Comments**
		and a discussion about the risks and benefits of clinically assisted hydration.' Similar wording ('at least once daily') should be used consistently in the text relating to this statement.
302	Royal College of General Practitioners	Hydration status. I don't understand why this is here. The guideline that I commented on some months ago was very clear that hydration is never indicated for dying patients (it was perhaps the most useful piece of guidance); this quality statement looks as if it is ignoring NICE's own guidance. It needs something more subtle, such as if the question is raised by patients or family for the professionals to explain carefully why it is not advised. (DJ)
303	Royal College of Physicians	The quality measures for QS 4 are as follows: • Evidence of local arrangements to ensure that adults in the last days of their lives have their hydration status assessed daily. • Evidence of local arrangements to ensure that adults in the last days of their lives, and those important to them, have discussions on the potential risks and benefits of clinically assisted hydration. • Proportion of adults in the last days of life who have their hydration status assessed daily. • Proportion of adults in the last days of life who have a discussion about the risks and benefits of clinically assisted hydration. • Proportion of adults in the last days of life with symptoms of dehydration and overhydration. • Proportion of bereaved people who feel satisfied that the person who has died was supported to drink or receive fluids if they wished. Our experts were concerned about these quality measures and questioned the assessment of hydration status, asking who would carry this out and how. Our experts note that education is needed around this and it is currently not possible in a national health or in many local communities. Our experts explain that as written there is a disconnect between the statement and what follows to support and describe what is intended and what 'monitoring' may mean. Our lay representative notes that checking symptoms 'at least once per day' doesn't seem sufficiently reassuring given the fact that individuals may quickly change status. As an individual, family member, or carer this leaves one feeling worried and exposed potentially for long periods
304	Royal College of Physicians	Our experts note that it does not specify who the discussion should be with and suggest 'consideration of the risks and benefits' would be better.
305	St Luke's Hospice	Subcutaneous fluids for CAH not available in all areas. Need to support commissioning of this service to enable patients to access treatment
306	St Luke's Hospice	Ensure communication around fluids at end of life and need for assessment and monitoring maybe difficult in community setting.

Comments on statement 4		
ID	**Stakeholder**	**Comments**
307	St Raphael's Hospice	This statement to have discussions about the risk/benefits of clinically assisted hydration and daily assessment of hydration status may be attainable in an inpatient setting but is not a realistic expectation in a community setting. Community Healthcare Professionals (HCP) will discuss issues with patients and families as appropriate and try and answer any questions raised.
308	St Raphael's Hospice	The qualification that hydration is assessed daily is not feasible in the community – nor is there clarity about who should undertake the daily assessment. In an inpatient setting both medical and nursing teams can undertake the observation and review. In the community setting there is the question of which healthcare professional is visiting everyday (GPs/DNs/Hospice services do not necessarily see a patient everyday) and whether they have the prerequisite skills to assess for hydration/dehydration or the clinical/communication skills to discuss this with the person or their family/carer. Nor may there be the facility to commission services to safely administer clinically assisted hydration in a person's home. This statement would appear to be setting HCPs up to fail.
309	St Raphael's Hospice	A) This data is not routinely recorded. How to access? B) Subjective data – where and by whom recorded – how to access to share with all involved HCP?? C) There is a risk that this outcome will not reflect what is aimed for – subjective
310	Sue Ryder	As comment 5 above [ID 200]
311	Sue Ryder	Sue Ryder agree that people should be checked every day to check they are comfortable with their hydration. It is important to recognise that in some settings, a practitioner other than the doctor will be called on to perform this check or to explain about hydration. For example, it might be the CNS that does so. The quality statement should state that these checking and explaining functions should be performed *by the lead practitioner*, and not mandate that this be a doctor, as a doctor may not be present day to day in all settings.
312	Sue Ryder	Sue Ryder have some concerns about how this outcome measure will be interpreted and measured 'on the ground'. NICE may wish to consider rewording this outcome measure to make it less broad and open to varying interpretation. The proportion of adults who "understand hydration issues and the aims of care" could be interpreted in very different ways depending on how stringent a definition of "understand" is adopted. To best measure an individual's understanding of hydration requires a judgment to be made by a professional who is engaged in effective communication with that particular individual. This is important both to ensure that the individual is given appropriate information in a way that they can process it, and also to ensure that the practitioner is able to adequately assess the individual's own thoughts and understanding of the issue. Ideally, practitioners should be recording their conversations relating to hydration in a detailed way that might allow this measure to

Comments on statement 4		
ID	**Stakeholder**	**Comments**
		be assessed by a third party, but in some settings such records may be less forensic due to time limitations In settings (e.g. a care home) where someone is dying without regular clinical intervention, they might most regularly be in contact with care assistants who might not be trained to have these conversations or record them adequately. To upskill this sort of professional – whilst desirable from the perspective of the communication skills required - would represent a significant resource demand on a system that is already under considerable pressure.
313	Tees Esk and Wear Valleys NHS Foundation Trust	Clinical signs of hydration can be unreliable in older adults and it may be inappropriate to repeatedly take blood samples from distressed or agitated patients with dementia. It is thus important to discuss with carers the appropriateness of blood tests and administration of clinically assisted hydration and refer to any advance statements. It may be appropriate to give small amounts of oral fluid to patients even if they have swallowing difficulties and risk of aspiration if they are unable to tolerate parenteral fluids but this needs to be a best interests decision if the patient lacks capacity.
314	The British Geriatrics Society	Suggest change wording to: '*proportion of adults in the last days of life who are assessed for symptoms of dehydration and overhydration'.*
315	The British Geriatrics Society	This outcome will be difficult to measure/audit.
316	Western Health and Social Care Trust	**Comment: YES** • Research and Audit • Quality improvement Model **Requires:** • Consideration of resource / people to carry out QI/ research and audit - provision of education and learning across all sectors of the WHSCT and to wider workforce involved.

Responses to consultation question 7: Does statement 4 address the most important area for quality improvement in relation to hydration?		
ID	**Stakeholder**	**Comments**

Responses to consultation question 7: Does statement 4 address the most important area for quality improvement in relation to hydration?		
ID	**Stakeholder**	**Comments**
317	Alzheimer’s Society	Alzheimer’s Society supports this statement as it is vital that hydration for people in the last days of life is continually monitored. Difficulties with swallowing are common for people with advanced dementia. Although early discussions around what should happen once a person with dementia reaches the stage where they are unable to swallow is preferable, there should be further discussion with the person with dementia if they are able or the people close to them including carers about whether artificial hydration is in the person’s best interests. In cases of advanced dementia, where it is solely the dementia which is causing the swallowing difficulties (and not another reversible cause), artificial hydration may be an invasive procedure that neither contributes to comfort nor quality of life. It is vital that the person with dementia (if they are able) can contribute to the discussion about artificial hydration. If they lack capacity, the benefits and risks of clinically assisted hydration must be clearly explained to the people close to them (including family members and carers) as it can be an emotive and distressing experience. This includes withdrawal if the person is already receiving clinically assisted hydration.
318	Association for Palliative Medicine of Great Britain and Ireland	We believe the most important areas in relation to hydration are whether the patient is symptomatic or distressed in relation to hydration. An individualised identified need for assisted hydration should be balanced against the individual’s preference to be cared for at home which may preclude clinically assisted hydration. The quality statement would read better if phrased as “Adults in the last days of life are offered a discussion about the risks and benefits of clinically assisted hydration, and have their hydration status assessed daily”. This would prevent ambiguity and the perception that there needs to be a daily discussion of the pros and cons of clinically assisted hydration.
319	Great Western Hospitals NHS foundation Trust	Yes
320	Leeds Palliative and End of Life Care Managed Clinical Network	Unclear how hydration will be assessed – is this purely food/fluid charts/ blood test/ skin integrity/ status of oral cavity/ level of oedema unclear what will be required here. High risk of varied interpretation. Unclear how often it is expected conversations on hydration take place this should be tailored to the individual and family a minimum of once but for some this may be a repeated conversation
321	Leeds Teaching Hospitals	All areas of care should be re assessed daily, not just hydration needs. Could there be reference to other measures being in place to maintain comfort e.g. regular mouthcare.
322	NHS Hartlepool and Stockton-on-Tees CCG	As stated above, it is very important for a person who is dying to be able to take oral fluids for as long as they wish and that they be supported in whatever way needed in order to achieve this. Education is required so that people are not denied oral fluids on the basis of concern about impaired swallowing. Some patients may already be receiving clinically assisted hydration and so this would continue and they would have their condition monitored to ensure they do not become overloaded with fluid. Outside of this situation, it is rare for clinically assisted

Responses to consultation question 7: Does statement 4 address the most important area for quality improvement in relation to hydration?		
ID	**Stakeholder**	**Comments**
		hydration to be beneficial in the last days of life.
323	Northern Health and Social Care Trust, Northern Ireland	Yes we believe this is representative.
324	Royal College of General Practitioners	'hydration status' – may need defining. I don't think this covers 'needs'? 'a discussion about the risks and benefits of clinically assisted hydration' - Unclear when, with whom, how often etc. (CMS) I think there needs to be acknowledgement of the difference between providing hydration in a hospital setting and within the community. Clearly hydration status should be assessed in the community, but it is not practical to provide intravenous fluids or gastrostomy. It should be an individual decision as to whether subcutaneous fluids are started, but consideration needs to be made of the increased nursing care required to help support patients with submit fluids. Certainly it would be a shame if the standards resulted in an increased number of admissions purely to allow clinical assisted hydration. (LS)
325	Royal College of Physicians	Our experts note that given the lack of evidence base in this area, it is reasonable to simply require an on-going hydration status review and discussion. The measures will be methodologically challenging, particularly outcome b) 'Proportion of adults who understand hydration issues and aims of care'. The assessment aspect is extremely important, but a conversation about clinically assisted hydration should not be mandatory for every case. Our experts note that the issue of hydration amongst these QS is controversial and that thus far, there is no evidence base for hydration at the end of life: • Dev et al 2012. Little evidence that clinically assisted hydration of dying patients, through iv or sc infusions reduces symptoms of thirst. • Bruera et al 2013. RCT – no difference to four symptoms of dehydration; fatigue, myoclonus, sedation and hallucinations. • Lanuke et al 2012. Can increase risk of ascites and pulmonary oedema. • Morita et al 205. Not shown to reduce confusion at the end of life. • Good et al. 2008. Cochrane Review Our experts suggest that the most important quality area is that patients are assessed for distress around lack of fluids. An individualised identified need for assisted hydration should be balanced against the individual's preference to be cared for at home which may preclude clinically assisted hydration.
326	Royal College of Physicians and	We are not aware of a clear clinical consensus on hydration in the last few days of life which makes audit of performance challenging. Nor is there standard documentation for recording hydration status and so consideration will need to be given locally

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	Surgeons of Glasgow	to including this in patients care plans so that these can be measured as evidence for the statement. It could be better simply to say that there should be documented evidence that hydration was considered and discussed, and that if bereaved relatives are being interviewed that they would be asked if they felt it had been appropriately addressed.
327	The British Geriatrics Society	The wording of this statement is problematic as is 1.4.4 of the clinical guideline. The normal meaning of hydration status in clinical care is an assessment of fluid balance in order to calculate the requirement for fluid resuscitation or diuresis. In the care of the dying person the assessment is of the patient's symptoms in relation to their hydration status e.g. dry mouth, delirium, pain and discomfort from cannulae, shortness of breath from lung congestion. The dying person may be dehydrated or oedematous but not troubled by symptoms of either, in which the case the care plan may not change.
328	Western Health and Social Care Trust	**Comment:** Mouth care and ensuring oral integrity is paramount to comfort and we would like to see more focus on this when considering the hydration aspect of end of life care. We are concerned of how health care providers may assess hydration status and we wouldn't want to encourage interventions such as blood taking at end of life as a form of assessment. Adults who are in the last few days of life generally do not drink as much (natural, normal process) but as long as this is not causing discomfort and that regular mouth care is being maintained we would like to suggest this is appropriate good care, although appreciate for some a trial of artificial fluids may be appropriate . We would like to see more focus on health care providers being able to communicate sensitively about the issue of hydration at end of life and being given access to communication skills training to help address this.

Stakeholders that responded to the consultation but had no comments to make		
ID	**Stakeholder**	**Comments**
329	Department of Health	Thank you for the opportunity to comment on the draft for the above quality standard. I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation.
330	Macmillan Cancer Support	Thank you for giving Macmillan Cancer Support the opportunity to comment on the Nice Quality Standards for Care of the Dying Adult. We do not have any comments to add to this standard.

Registered stakeholders who submitted comments at consultation

Abbreviation used in report	**Name of stakeholder**
AHPCC	Association of hospice and palliative care chaplains
APM	Association for Palliative Medicine of Great Britain and Ireland
AS	Alzheimer’s Society
ASPCP	Association of Supportive and Palliative Care Pharmacy (Formerly PCPN)
BAWCPCN	Bradford, Airedale, Wharfedale & Craven Palliative Care Managed Clinical Network. This includes Bradford Teaching Hospitals Foundation NHS Trust; Bradford District Care Foundation Trust; Marie Curie Care, Bradford Hospice; Airedale NHS Foundation Trust (includes Hospital & Community Services); Sue Ryder Care, Manorlands Hospice
BGS	The British Geriatrics Society
BHSCT	Belfast Health and Social Care Trust
BLT	British Liver Trust
CHAS	Children's Hospice Association Scotland
CiD	Compassion in Dying
CMA	Catholic Medical Association (UK)
CMC	Coordinate My Care
DoH	Department of Health
ENH	East & North Herts NHS Trust
EPA	EPA UK/EU
FICM	Faculty of Intensive Care Medicine
FPM	Faculty of Pain Medicine of the Royal College of Anaesthetists
GMCC	Greater Manchester Chaplaincy Collaborative
GWHT	Great Western Hospitals NHS foundation Trust

HASTCCG	NHS Hartlepool and Stockton-on-Tees Clinical Commissioning Group
HH	Healthwatch Hartlepool
HUK	Hospice UK
ICHT	Imperial College Healthcare NHS Trust
LPELCN	Leeds Palliative and End of Life Care Managed Clinical Network
LTH	Leeds Teaching Hospitals
MC	Marie Curie
MCS	Macmillan Cancer Support
NCPC	National Council for Palliative Care. Includes a contribution from the Motor Neurone Disease Association.
NHSCT	Northern Health and Social Care Trust, Northern Ireland
NHSE	NHS England
OPAA	Older People’s Advocacy Alliance
PELCBol	Palliative & End of Life Care Team, Bolton NHS Foundation Trust
PUK	Parkinson’s UK
RC	Resuscitation Council (UK)
RCGP	Royal College of General Practitioners
RCN	Royal College of Nursing
RCP	Royal College of Physicians
RCPE	Royal College of Physicians of Edinburgh
RCPSG	Royal College of Physicians and Surgeons of Glasgow
RCPsy	Royal College of Psychiatrists
RCSLT	Royal College of Speech and Language Therapists
SJH	St Joseph’s Hospice

SLH	St Luke’s Hospice
SR	Sue Ryder
SRH	St Raphael’s Hospice
TEWVT	Tees Esk and Wear Valleys NHS Foundation Trust
TVS	Tissue Viability Society
WHSCT	Western Health and Social Care Trust