NATIONAL INSTITUTE FOR HEALTH AND   
CARE EXCELLENCE

HEALTH AND SOCIAL CARE DIRECTORATE

QUALITY STANDARD CONSULTATION

SUMMARY REPORT

1. Quality standard title

End of life care for adults (update)

Date of quality standards advisory committee post-consultation meeting:   
19 January 2021

1. Introduction

The draft quality standard for end of life care for adults (update) was made available on the NICE website for a 4-week public consultation period between 11 November and 9 December 2020. 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 35 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 by the committee 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 appendix 1.

1. 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 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.

4. Do you think the end of life care service delivery (excluding care in the last days of life) has substantially changed during the COVID-19 pandemic? Can you describe any positive changes that have been introduced as a result of the COVID-19 pandemic?

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

5. For draft quality statement 4: Is there a specific aspect of coordination of care that this quality statement should focus on? If so, please provide details.

6. Do you have an example from practice of implementing the NICE guideline that underpins this quality standard? If so, please provide details on the comments form.

1. General comments

The following is a summary of general (non-statement-specific) comments on the quality standard.

* Agreement that the quality standard reflects the key areas for quality improvement.
* Support for the quality statements.
* Suggestion to change title of quality standard to ‘Palliative and end of life care’.
* An intensive care doctor committee member would have been beneficial.
* People with multiple system atrophy may wish to discuss hastened death. Staff should be able to explain it is not legal and find out the concerns they have that led them to raise this.
* Person, patient and individual are used interchangeably in the quality standard.
* The previous quality standard better reflected a personalised, holistic approach to assessing and considering how to address individual’s needs and preferences.
* Clarify that statements should be tailored to reflect local population and community needs.
* There should be better use of pharmacists in especially as 45% of those registered in the UK are of BAME origin and could be used to give advice on advance care planning to BAME communities.
* Improve management of those who have communication disorders (e.g. particular needs of end-of-life care for those with cancer of the head neck, aphasia, motor neurone disease, etc)
* Equality, diversity and inclusion need more attention throughout.

### Consultation comments on data collection

* Some stakeholders felt there are no significant challenges in collecting data to support the quality measures.
* Local systems are variable and not robustly in place to collect the data.
* Difficult for secondary care to demonstrate compliance with the quality standards.
* Some data collection methods will not always be robust, such as surveys.
* Many frail elderly patients in the last 12 months of life, will not be on the registers.
* People access services across national, regional and local administrations so standardisation of data and effective capture is needed.
* Practitioner access to effective methods of data collection needs to be improved.

### Consultation comments on resource impact

* A real and sustained change needs greater investment in community nursing, specialist palliative care, domiciliary care, social care and general practice.
* The hospice sector is under intense pressure and its finances are stretched.
* Earlier identification and speaking to people in more depth will uncover additional need leading to use of additional resource.
* Resources are required for staff training and data collection.
* The quality standard will reduce hospitalisation and transfer to hospital for significant numbers of patients and may reduce hospital length of stay.

### Consultation comments on impact of COVID-19

* Stakeholders told us the following negative impacts of COVID-19:
  + one stakeholder saw a 44% increase in home deaths which put a lot of pressure on hospice community staff and district nurses
  + carer burden has increased
  + there have been significant issues with home care provision
  + support is needed for relatives unable to see their loved ones face to face
  + care input and face to face support has reduced
  + people living with motor-neurone disease had difficulties being admitted to hospital at end of life as they need aerosol generating procedures requiring higher-level PPE and training.
* Stakeholders told us the following positive impacts of COVID-19:
  + remote consultations have been well-received by patients and clinicians, improving accessibility of palliative care services and enabling more flexible support for carers
  + remote consultations have a continuing role in routine follow-up, emotional support, and conversations on practical matters
  + suspending continuing health care fast-track funding led to some community nursing services being more involved in referral management and care package coordination
  + more flexible and responsive care packages have been provided
  + some hospices now use virtual visiting for relatives who are unable to visit.

1. Summary of consultation feedback by draft statement
   1. Draft statement 1

### Adults who are likely to be approaching the end of their life are identified using locally developed systems. [2011, updated 2021]

### Consultation comments

Statement

* Identification based on prognosis is difficult. The identification tools suggested are helpful but not used universally.
* Electronic patient records in hospitals could highlight the tools suggested on admission records to enable staff to identify at-risk patients.
* Occupational therapists already use local systems to identify these adults.
* Suggestion that the statement does not include people who are self-managing or have previously declined services but whose condition or situation has changed.
* Suggestions to reword statement: include ratified tools, use ‘recognised’ rather than ‘identified’ and remove ‘using locally developed systems’.
* Suggestion to include carers in the statement and subsequently in measures.
* Make this proactive in recognising people who may be approaching the end of their life.

Rationale

* Highlight the benefits of early identification to patient care.
* Future plans include where and how the person would like to be cared for, not just place of death.
* Remove ‘palliative’ from the care needs assessment.
* Clarify that the statement is not asking for an accurate prognosis but recognising people who may benefit from discussions, symptom control and other care.

Measures

* Local systems and structures are in place to collect this data but collection and analysis does not happen regularly and consistently across different areas.
* Proposed data sources may not accurately support the structure measure.
* The Gold Standard Framework is used to collate this data.
* Primary care services have systems set up to identify patients but there is no widely used equivalent system in hospital settings.
* The GP palliative care register needs to be used more consistently.
* Measuring the proportion of deceased adults who were identified on the palliative care register prior to death may not reflect the true population need.
* Structure and data source should include evidence of systems sharing information between clinical settings to identify the population.
* Measure should reflect that end of life planning was offered as this is a voluntary patient or relative-led discussion and can be declined.
* Replace ‘evidence of end of life planning’ in outcome measure with ‘evidence of the person being identified’.
* Include measures on timeliness of identification and the current number of people thought to be in the last year of life.

Audience descriptors

* Service providers should ensure that professionals are trained to do this.
* Include social care professionals and their role in identifying people at end of life.
* ‘Specialists and nurses’ is unclear as there are many specialists who are nurses.
* Highlight the role health professionals have in raising awareness to the public and supporting people to come forward.
* In the healthcare professionals section include frailty assessment and notifying pharmacists when the person is palliative or at end of life.

Definitions

* Include more detail in the definition of approaching end of life including support.
* Include a definition of timely (used in rationale).

Resource impact

* Training and the use of local systems and tools will have a resource impact.
* Better identification will result in increased demand for end of life care in community settings, particularly private homes.
* Use of EPaCCS and improving digital information sharing may have resource implications.
* Community end of life care reduces reliance on emergency and acute care by preventing avoidable emergency admissions and providing personalised care.

COVID-19 impact

* A stakeholder noted that in this area, COVID-19 led to increased use of:
  + assessment tools for improved collaboration between care homes, hospitals and GPs
  + pulse oximetry and oxygen saturation to determine prognosis and rapidity of referral to hospital.

Issues for consideration

* Could the statement be more proactive?
* Comments received that GPs have systems in place for this but secondary care does not. What arrangements should be in place for sharing this information between secondary and primary care?
* Update supporting information to show that this is about recognising people who may benefit from discussions, symptom control and other care.
* Updates to audience descriptors including the inclusion of social care professionals and pharmacists.
  1. Draft statement 2

### Adults approaching the end of their life have opportunities to discuss advance care planning. [new 2021]

### Consultation comments

Stakeholders made the following comments in relation to draft statement 2:

Statement

* This is a positive approach to enable people to remain in control and to ensure their views and wishes can be acted upon.
* Advance care planning should not be limited to those approaching end of life and it can be triggered at a number of transition points.
* Emphasise that advance care planning is a mechanism to document the outcome of shared decision-making and the person’s wishes for end of life.
* The advance care plan should be reviewed regularly.
* Include when advance care planning conversations should begin and who should do this.
* Having opportunities to discuss does not impose a requirement to provide advice and information on advance care planning.
* Suggestion to reword statement to include documenting the advance care plans.
* Sharing advance care plans with pharmacy teams means they can support colleagues to provide the care the person wants.

Rationale

* Make it clear that discussions apply to patients whose capacity may be or is expected to be lost or impaired at a future stage and patients where there is no such expectation.
* Note the person’s capacity to make decisions. If capacity is in doubt ensure capacity assessments are completed. If the person lacks capacity, reference best interest decisions, lasting power of attorney and plans for future care.
* Suggestions to use ‘person-led’ or ‘personalised’ instead of ‘patient-led’.
* There should be shared decision-making to support individuals to understand the different options and the risks, benefits and consequences.

Measures

* Data is difficult to collect as this is an ongoing process.
* Measure should reflect that some people decline the offer of advance care planning.
* Assessing patient satisfaction is difficult with the systems currently in place.
* Systems need to be put in place to carry out and review holistic assessments.
* Hard to measure consideration of holistic needs assessment when discussing advance care planning.
* Advance care planning considers needs and preferences so the holistic needs assessment doesn’t need to be referenced in the measure.
* The National Audit of Care at the End of Life measure misses people who are not admitted to hospital in their last months of life. Measuring a plan at the last admission does not encourage early discussions and planning.
* Bereavement surveys may be a useful data source for the satisfaction outcome.
* May be difficult to use local patient and carer experience surveys for the outcome.
* Measure the quality of advance care plans not just the number.

Audience descriptors

* Service providers section should reflect the comprehensive model for personalised care.
* Clarify how and when social work involvement should begin.
* Include occupational therapists.
* Clarify who is responsible for carrying out the advance care planning process.
* Staff should have skills, education, training, support and tools to discuss advance care planning.

Definitions

* Add the following to the advance care plan discussion definition:
  + person’s approach to life including their values and goals, and attitude towards illness, quality of life and death
  + preferred place of care and death
  + what is important to the person and wider support to meet wellbeing needs
  + emphasise to the person that this is planning in anticipation of future loss of mental capacity and that whilst they have capacity their contemporaneous views will always over-ride the advance care plan, and that they can always change their mind. This avoids people being frightened of ‘locking’ themselves into decisions about future care.

Equality and diversity considerations

* Culture and ethnicity have a profound influence on patient choices in end of life care and there is limited uptake of advance care plans by ethnic minority groups.
* Consider the needs of people with a range of protected characteristics.
* Accessibility of information needs to take levels of health literacy into consideration.
* People who do not have capacity should have the opportunity for advance care planning whether or not they are expected to have capacity in the future.
* Include accessibility in all environments such as prisons, secure hospitals and accessibility for the homeless.

Resource impact

* Staff need to be trained in communication skills and using advance care planning tools.
* All sectors need to be able to record and access the outcome measures in EPaCCs.

COVID-19 impact

* Stakeholders told us the following negative impacts of COVID-19 in this area:
  + blanket do not attempt resuscitation practice was applied in some areas
  + some care homes felt there was a lack of support.
* Stakeholders told us the following positive impacts of COVID-19 in this area:
  + advance care planning discussions were more widespread
  + staff working in care homes were rapidly upskilled in end of life care due to the high number of patients who were admitted and died during Covid-19
  + improved GP and care homes collaborations in some areas
  + the NHSE Enhanced Health in Care Homes work to increase advance care planning in care homes is excellent.

Issues for consideration

* Note that assessing capacity is addressed in the mental capacity and decision making quality standard.
* ‘Person-led’ instead of ‘patient-led’?
* Emphasise shared-decision making.
* Potential difficulties collecting the data as this is an ongoing process.
* Make it clear to the person that they can change their mind and they are not ‘locked’ into decisions about their future care.
* Culture, ethnicity and heath literacy.
  1. Draft statement 3

### Carers providing end of life care to people at home are supported to access local services that can provide assistance. [new 2021]

### Consultation comments

Stakeholders made the following comments in relation to draft statement 3:

Statement

* The role of informal carers is key to successful end of life care for people dying at home and improving carers’ support helps to reduce hospitalisation and crises.
* Make carers aware of services such as replacement or respite care, support networks, bereavement support and support when the person they care for is in hospital.
* Support should be available 24 hours a day, 7 days a week.
* Carers are not patients of the same service as the person approaching end of life so there will be no documentation of support they are offered.
* Information should be shared across and between services but there are no joined up processes to record carers of people at end of life as a specific group.

Measures

* Data not always easy to collect and the sources suggested will miss unidentified carers.
* Local systems do not collect data on the number of carers providing end of life care to people at home so this would be an estimate.
* Secondary care need a way to collect data on support for carers using existing records.
* Current systems and data coding do not distinguish between a carer supporting a person at end of life, and a carer in general.
* ‘Helped’ is ambiguous in the measures.
* Include evidence of assessment tools and pathways across services to support carers.
* Suggestion to measure whether:
  + service providers map out local services available to carers in a regularly updated directory and are aware of gaps in services
  + carers for people at the end of life receive a full carer’s assessment.

Audience descriptors

* All healthcare professionals should be aware of the directory of local services to support carers so they can signpost carers to them.
* Include continuing healthcare packages as a way care for patients can be provided in the home.
* Occupational therapists provide carers with emotional and practical support.
* Pharmacists and pharmacy teams can highlight sources of support for carers.
* Commissioners should ensure services work in an integrated and cohesive way.

Equality and diversity considerations

* Health and cultural needs of Black and minority ethnic carers need to be considered.
* Levels of health literacy, IT literacy, language and culture need to be taken into account.

Resource impact

* There are not enough services in communities to meet carers’ needs and it will take resource to develop local services.
* Workforce training in assessing of carers needs.
* Signposting directory or online resource showing available local resources and support.

COVID-19 impact

* There has been reduced access and offer of bereavement support.
* Increased demand for end of life care at home means that in some cases family members provide more care but not always with the right support in place.
* Pandemic pressures mean no face-to-face assessments are taking place and reassessments are being put on hold.
* Care Act easements brought in during the pandemic may have resulted in local variation as local authorities can reduce the depth and extent of assessments.

Issues for consideration

* Change structure measure wording from ‘helped to access support services’ to ‘can access support services’.
* Suggestion for a directory or online resource listing the support services available.
* Include making carers aware of support networks etc in audience descriptors.
* Include occupational therapists and pharmacists in audience descriptors.
* Health and cultural needs, health and IT literacy and language.
  1. Draft statement 4

### Adults approaching the end of their life receive care that is coordinated between health and social care practitioners within and across different services and organisations. [2011, updated 2021]

### Consultation comments

Statement

* The statement is achievable as a number of organisations are undertaking joint working with hospices using a GP MDT template which assists with this.
* Coordinated care relies on relationships developed between organisations, partnership agreements and good multi-agency and multi-disciplinary working.
* Coordination includes delivery of care at the right time, in the right order and setting. The contributions of different services and professionals need to be timely and well organised.
* Potential difficulties with information sharing across organisations due to IT systems not linking up. Note that GDPR and consent need to be considered when sharing information.
* Advance care plans are patient-held, updated with changes in condition or circumstance. If they are stored in the person’s electronic record the latest version may not be uploaded.

Rationale

* A lead practitioner or care co-ordinator should facilitate improved care coordination for the patient on behalf of the multi-disciplinary team.
* NHSE has committed to rolling out information sharing systems as part of the NHSE long-term plan. Highlight the need for advance care plans to be sharable on such systems.
* The role of paramedics is vital and evidence should include ways of working that include but go beyond electronic palliative care coordination systems.
* Include other benefits of information sharing.
* Multi-disciplinary team rather than multi-practitioner team is more widely used.

Measures

* Systems for measuring use of transfer of care information are not in place.
* Numerator is difficult to capture as this is not a single conversation.
* Local Care Networks have a useful focus for multi-practitioner reviews and can help measure how care coordination is working in the system.
* Process measure should be ‘shared with the practitioners across all services and organisations involved in their care’ to avoid ambiguity.
* Process measure on information being shared with the members of the multi-practitioner team may not be easy to control, measure or manage.
* Consider the experience of family members and carers to ensure groups aren’t marginalised or excluded from sharing their feedback.
* Implementing electronic information-sharing systems may be out of some service providers’ remit.
* Co-ordination and information sharing need to be across sectors and teams.
* Process measure (a) focuses on advance care plans only. Key information about current personalised care and support plans also need to be shared.
* Process measure (b) would be more meaningful as an outcome measured through patient and carer experience tools.
* Sharing any care plan could be used as evidence.
* Some additional measures were suggested including:
  + the % of late referrals to specialist palliative care services
  + use of electronic information-sharing systems (eg EPaCCs)
  + evidence of MDT discussions.

Audience descriptors

* Include ambulance trusts so that key information is easily accessible.
* Service providers ensure that systems they develop work with all health and care providers including private care providers such as care homes.
* Occupational therapists add information to people’s records and advance care plan.
* Pharmacists and the pharmacy team help coordinate care and medicines supply as they move from one care setting to another.
* Specialist palliative care pharmacist teams should be in place and known to practitioners as a source of advice on medicines issues.

Resource impact

* In some cases a full-service re-design would be needed to enable multi-practitioner working to be effective in the way this quality standard envisages.
* Switching to a new IT system to match others locally will have a resource impact.
* Investment and training in hospital discharge planning at end of life should be strengthened so that increased numbers of people can be discharged well and quickly.
* Demand for end of life care in the community is increasing so there is a resource requirement for community teams providing out-of-hours end of life care.
* Investment may be needed for surveys.

COVID-19 impact

* Difficulties organising care packages to support transfer of patients due to social care workforce shortages and NHS staff sickness.
* Single points of access and co-ordination centres have been set up successfully in some areas.
* Closer MDT working led to care being delivered sooner and patients spending less time in hospital, with fewer delayed discharges.
* Coordinated care has improved with greater cross boundary working such as virtual meetings and shared documents.

### Consultation question 5

Is there a specific aspect of coordination of care that this quality statement should focus on? If so, please provide details.

Stakeholders made the following comments in relation to consultation question 5:

* Focus on:
  + recording and sharing wishes and preferences in relation to a patient’s care
  + transfer of information around identification of patients approaching the end of life and advance care planning conversations between care settings
  + a single point of access for information sharing across clinical and community areas.
* All providers and services need to be able to access the information easily.
* Using “Team around the Family” can help to address co-ordination and communication.
* Individualised plans of care need to be immediately accessible.
* An identified health or social care practitioner should coordinate end of life care.

Issues for consideration

* Measures need to focus on more than just advance care plans being shared.
* Include paramedics, occupational therapists and pharmacists in audience descriptors.
* Comment that Local Care Networks have a useful focus for multi-practitioner reviews and can help measure how care coordination is working in the system. How would this work? We may be able to use this to help measure coordination?
* Can we focus on a specific aspect of coordination? The guideline does not contain recommendations on areas suggested by stakeholders such as a lead practitioner or care co-ordinator or ‘team around the family’.
  1. Draft statement 5

### Adults approaching the end of their life have access to support 24 hours a day, 7 days a week. [2011, updated 2021]

### Consultation comments

Stakeholders made the following comments in relation to draft statement 5:

Statement

* This statement is achievable. In some services all end of life patients and families are given a phone number for 24hr support and a 24hr advice line for a hospice if appropriate.
* Having access to a co-ordinated patient record is key.
* Specialist providers should be identified and the professionals involved need to know who they are, how to engage them in the person's care and when.
* 24-hour helpline is a good idea but it is unclear how this would be commissioned.
* 24/7 telephone end of life care advice should be made available for professionals.
* 24/7 specialist palliative care is not universally available.
* This is aspirational outside the acute care setting. In most areas out-of-hours services may be available but not necessarily reflective of an individual dying patient’s needs.
* Support is not available during holiday periods. After hours services often advise people to go to A&E or wait until clinic opens the next day.

Rationale

* This is more than reassuring for carers. It is a reflection of services being ‘wrapped-around’ the person and accessible in a way that meets their needs.

Measures

* Some outcomes do not relate to the standard being assessed.
* Measure local arrangements for healthcare professionals to access specialist palliative care advice on a 24/7 basis.
* Process measure b) may be better as an outcome measure on whether people know they have access to an advice line and how to do so.
* Suggestion to add some measures for people approaching the end of their life:
  + numbers of emergency ambulance calls out of hours
  + numbers of crisis admissions to hospital or number of A&E presentations
  + anticipatory medication prescribed
  + information given on what to do in a crisis
* Suggestion to change process measure c) to prescribing anticipatory medication.

Audience descriptors

* Healthcare professionals should include the ambulance service.
* Clearly state that commissioners must commission specialist palliative care advice that is accessible 24/7 and that service providers must make this available.
* Emphasise that patients and their carers are clearly told how to access the services.
* Prescribers issuing emergency prescriptions for end-of-life care should be responsible for ensuring the pharmacy they refer a person to has stock of the prescribed medicines
* Pharmacists in the community ensure that local GP practices know about services they provide to aid medicines provision for palliative and end of life patients.

Definitions

* Include detail about the out of hours advice line to differentiate from other types of support.
* Support definition should state whether face-to-face assessment and intervention by a member of the multi-practitioner team is included where needed.
* There is no definition of what the term ‘access’ means. This is critical if data collection is to be reliable and valid as all the measures of this standard use this term.

Equality and diversity considerations

* Accessibility of information needs to take into consideration levels of health literacy.

Resource Impact

* 24/7 arrangements can be achieved dependent on the quality of commissioning arrangements in the local area.
* Resource requirement for community teams providing out of hours end of life care.

COVID-19 impact

* Stakeholders told us the following positive impacts of COVID-19 in this area:
  + hospice and end of life care services rapidly adapted to comply with the latest regulations
  + moving services online ensured that patients and carers continued to have access to support
  + an ambulance service has upskilled their employees in end of life care
  + nursing services have been extended to support care homes and local hospices, merging to provide 24 hour access to specialist palliative care.

Issues for consideration

* Amend the rationale to better reflect that this is more than reassuring for carers.
* Include measure on arrangements for healthcare professionals being able to access specialist palliative care advice 24-hours a day.
* Update audience descriptors to highlight actions to be taken by prescribers and pharmacists.

1. Suggestions for additional statements

The following is a summary of stakeholder suggestions for additional statements.

* Availability of medication, effective management of poly-pharmacy, and reducing inappropriate medications in end of life care.
* Include a separate statement on holistic needs assessment and include provision for separate holistic carer assessment.
* Education and training on end of life care delivery for carers and practitioners.

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# Appendix 1: Quality standard consultation comments table – registered stakeholders

| ID | Organisation name | Statement No | Comments |
| --- | --- | --- | --- |
| General Comments / responses to question 1 | | | |
| 1 | Association for Palliative Medicine | General | Yes this reflects the key areas for improvement |
| 2 | Association of British Neurologists | General | All the quality standards are appropriate and things that if achieved will improve the lives of individuals with neurological illness approaching end of life, and their carers. |
| 3 | Association of British Neurologists | General | General comment: Patients with advanced neurodegenerative movement disorders such as Parkinson’s disease, atypical parkinsonism or Huntington’s disease are often discharged from Neurology specialist services when they are no longer well enough to attend out-patient appointments. Thus, the patients, their families and carers, but also the GPs, community-based nurses etc are often left without any expert neurological support from either consultant neurologists or hospital-based specialist nurses when they maybe most need it. This is unacceptable. Future commissioning needs to ensure that hospital-based services are better integrated with typically community-based end of life care. |
| 4 | BAME Health Collaborative | General | Availability of medication / Appropriate/effective management of poly-pharmacy, and reducing inappropriate medications in end of life care. I don’t see how we will achieve this aim if we do not have their input from pharmacy /Pharmacist. There must be better use of pharmacists in this endeavour, especially as 45% of those registered in the UK are of BAME origin and could also be used to give advice on ACP to BAME communities. |
| 5 | British Geriatrics Society | General | We think the 6 Quality standards are a helpful and concise summary of some the key areas necessary to provide quality end of life care. Given most deaths are in old age we commend to you the Comprehensive Geriatric Assessment.  We think the importance of training and supporting the workforce is an important area which is currently missing. This is vital for individualised clinical care and to ensure a palliative care approach across the health and social care workforce. Training should include an understanding of frailty in older adults, identification and assessment of frailty, the uncertain trajectories of illness and the particular needs of older people with frailty and their family and at end of life. [**https://www.bgs.org.uk/resources/resource-series/end-of-life-care-in-frailty**](https://www.bgs.org.uk/resources/resource-series/end-of-life-care-in-frailty) |
| 6 | Faculty of Intensive Care Medicine | General | There is no intensive care doctor on this Committee which could have been beneficial. |
| 7 | Marie Curie | General | The draft quality standard broadly reflects the key issues in end-of-life care – identifying people who are approaching the end of life, providing opportunities for people to discuss advance care planning, supporting carers, ensuring coordination between health and social care services and ensuring adequate support at all times for people at the end of life.  Marie Curie is broadly supportive of the quality statements outlined in this standard. However, we are concerned that carers are not adequately served by the draft Statement 3 in its current form. |
| 8 | Multiple System Atrophy Trust | General | The MSA Trust feels that the draft quality standards do reflect the key areas |
| 9 | Multiple System Atrophy Trust | General | With a terminal progressive condition such as MSA it is naïve to think that some people will not think or talk about hastening death. Obviously assisted dying is not legal in the UK, although a significant proportion of people with MSA were in favour of a law change in our national needs survey <https://www.msatrust.org.uk/wp-content/uploads/2020/02/MSA-TRUST-PEOPLE-LIVING-WITH-MSA-FULL-TECHNICAL-REPORT-FINAL.pdf>  People with MSA and/or their families may ask about hastened death. This should be discussed openly with them whilst explaining this is not legally possible. It is important to assess and discuss this fully as there may have been particular concerns that have led people to these discussions, such as fear about symptoms and other interventions may be helpful in allaying these concerns.  We are not sure what training professionals may have had, or do have, around explaining the current legislation and their role in discussions to ensure these are conducted effectively? |
| 10 | NHS England and NHS Improvement | General | Given the definition shared at the beginning of the standard refers to progressive life-limiting conditions that can last “years”, we suggest the term ‘palliative’ should be included within the title and descriptions of the standard i.e. ‘palliative and end of life care’. (PC) |
| 11 | NHS England and NHS Improvement | General | Terms patient, person and individual are used interchangeably throughout the Quality Standard. Suggest just one is used. (PC) |
| 12 | NHS England and NHS Improvement | General | Id also suggest there is room here for ensuring the standards highlight the need to reflect local population and community needs and tailoring the approach and building upon the standards to meet these are otherwise this again may be seen as a ‘one size fits all’ approach to care and not a response to local need. (N&M) |
| 13 | Royal College Of Nursing | General | “Does this draft quality standard accurately reflect the key areas for quality improvement?”  Clarity is the issue here as there is no one place to obtain the data to support. General Practices; health services and social care all use different solutions for their clinical records; most not communicating with each other. Definitely these areas are crucial in excellent end of life care, but they are open to localised interpretation i.e. twenty-four hour services, these are likely to be out of hours services who do not know the population and have a limited understanding of palliative care. |
| 14 | Royal College of Occupational Therapists | General | The draft quality standard does reflect the key areas for quality improvement. |
| 15 | RCP | General | 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 British Geriatrics Society (BGS). We would also like to comment as follows. |
| 16 | RCP | General | Does this draft quality standard accurately reflect the key areas for quality improvement?  Yes. However a greater emphasis on;  -the skills of practitioners to have advance care planning conversations and document these  -Consistent and reliable use of local systems of documentation and transfer of information between care settings |
| 17 | Royal College of Physicians and Surgeons of Glasgow | General | The Royal College of Physicians and Surgeons of Glasgow although based in Glasgow has a membership of 15,000 and represents Fellows and Members throughout the United Kingdom. While NICE has a remit for England, many of the recommendations are applicable to all devolved nations including Scotland. They should be considered by the relevant Ministers of the devolved governments.  The College welcomes this Quality Standard and endorse its principles. The aims and objectives of all statements are valid, worthy and represent the best possible end of life care.  However, the standards have been written for professionals involved in end-of-life care and not for the person at the end of life or their family and friends. The College would suggest a simple document explaining what each standard means. |
| 18 | Royal College of Physicians and Surgeons of Glasgow | General | One of our lay reviewers said “I found the draft quality standard and its background paper impenetrable. I suspect that its form and conte]nt were designed by a quality assurance committee, rather than someone writing for the reader.” |
| 19 | Royal College of Physicians and Surgeons of Glasgow | General | Another of our lay reviewers said “I think it is a laudable set of principles that I would expect to be followed by any of the carer professions irrespective of their existence as a formal standard.  My only concern is around the measures that are proposed to determine the “quality” of the compliance with the various standards. Specifically, where ratios are being used. While I believe that it is reasonably feasible to determine an accurate measure for the numerators, in most cases the same cannot be said for the denominators (with the possible exception of “the number of deceased adults”). It seems to me that the denominators for the other measures will often tend to be similar to the numerators as those statistics will potentially be gathered at the same time (i.e. when a care plan is being drawn up). There will always be some who slip through the cracks and are never counted. Thus, the ratios will most likely tend towards unity and be somewhat meaningless.” |
| 20 | Royal college of speech and language therapists (RCSLT) | General | Whilst there is mention of the increasing numbers of people with dementia requiring end of life care - and the need for advance care planning - there is no suggestion of the special support required to ensure that the individual could express their needs and wants if they had difficulty with communication. We believe the expertise of the speech and language therapist is required here, while assistance from communication aids should also be considered. |
| 21 | Royal college of speech and language therapists (RCSLT) | General | We were disappointed to not find any reference to improving management of those who have communication disorders (e.g. particular needs of end-of-life care for those with cancer of the head neck, aphasia, motor neurone disease, etc) |
| 22 | Royal college of speech and language therapists (RCSLT) | General | We note that the issue with mental capacity was considered as an important area of quality improvement though this suggestion has not been progressed. Decision making and mental capacity is covered by separate quality standard (NICE quality standard Decision making and mental capacity (QS194)) and we think it would be better if that reference was within the document and flagged up at appropriate places to those following these standards rather than being a note at the end. |
| 23 | Society for Acute Medicine | General | Yes, this draft quality standard accurately reflect the key areas for quality improvement. |
| 24 | South West End of Life Network | General | Nationally, regionally and within localities, there is a move towards developing shared strategy across all ages. Would it be helpful for the NICE quality standards to reflect this i.e. shared quality standards for children as well as adults? |
| 25 | South West End of Life Network | General | The phrase “approaching the end of their life” may be interpreted in various ways. To some it may mean last weeks or days, to others the last year or years of life. We think it would be helpful to clarify this. Network members suggested this could be either through time frames (last years, months or weeks of life) or possibly referring to advancing and incurable illness. |
| 26 | South West End of Life Network | General | Sharing in case it is helpful: we have identified the following statements as necessary and sufficient to enabling good end of life – key points of leverage which, if achieved, meet the needs of a wide range of stakeholders: We recognise when the last months, days and hours of someone’s life are approaching.We help them to be as comfortable and as cared for (physically and emotionally) as they want to be throughout.We help them (and those around them) to understand and anticipate what may happen during the time they have left.We understand what really matters to them about this; how they want to live, what they want to achieve and how they want to die.We support them to live well in their own way, as part of their community, focusing on what matters to them together.We share what matters to them as appropriate, so that they are supported through times of illness in a way that feels right to them, including in the last days of their life.We help those close to them to feel supported throughout, including after their death. Further information is available here: <https://www.nextstageradicals.net/blog/improving-end-of-life-care-what-does-good-look-like/> |
| 27 | The GSF Centre in End of Life Care | General | **General Comments**  Overall a brilliant development and reduction into 5 Quality Standards, which we would greatly support , endorse, and wish to help to implement in practice . The key in future would be the accuracy and feasibility of the measures and the investment in teams including workforce training and digital enablement , to ensure this happens .  This is strongly in-line with the GSF 1357 Summary as part of GSF Quality Improvement Programmes , with several hundreds of accredited teams demonstrating progress in this area, as examplars in inspiring others- the GSF Frontrunning teams . All such team have attained all/most of the measures that you indicate, plus others eg the GSF Key Outcomes Ratios we use for Primary Care GSF accreditation (attached ) . Therefore, we can validate that these standards are reasonable and can be achieved , leading to improved integrated coordinated care .  For information - we at GSF directly teach teams across all sectors the 5 Quality Standards cited here , with a few modifications and 2 additional key tasks being compassionate care and systematic care . See 1357 video on GSF Homepage <https://www.goldstandardsframework.org.uk/>)  **The summarised key comments and suggestions** for areas omitted below include :-   * Tightening and **refining the measures** of numerator and denominator for   + QS 1- to include current data not just those that died , to enable speedier QI process in line with research evidence ,   + QS2 – to increase accuracy of measure not just related to satisfaction Including   + QS 3 adding carers’ needs assessment as key measure to enable broader support eg signposting, supporting * QS 1 to include **frailty and the Electronic Frailty Index** as important took, notably as this frailty correlates with likelihood of being in last stages of life * QS 2 to include **Lasting power of attorney or proxy or nominated spokesperson** as key important data to note * QS 2 – suggestion of 3 key pieces of information needed to transmit in an emergency (GSF Level 2 of ACP) ie **resuscitation DNAR, LPOA/ proxy spokesperson , and preferred place of care/ death** * Q2 greater public awareness (non-medial) of ACP discussions, rather than professional initiation * QS 3 – to cross reference **bereavement i**n carers support * And **carers needs assessment tools** as key intervention * QS4- Suggestions for QS 4 coordination on more **accurate measures of process and outcome** * QS 5 to add **Anticipatory Prescribing or Just in case boxes** as simple measures rather than access to pharmacists * Important addition of **workforce training** across all areas as potential resource implication (across all health and social care sectors plus in ICS integrated care areas) * Important addition of resources to support effective **digital record sharing or EPaCCS** |
| 28 | The GSF Centre in End of Life Care | General | Just to add before the deadline, since sending this I have received / seen a few things I think are relevant, and could send more if wanted   * The COVID bereavement study [www.covidbereavement.com](http://www.covidbereavement.com) which describes the incredible traumatic bereavement of so many people in time of excess deaths , with estimated 2.6 m people affected by 670,000 + deaths , so the vital importance of bereavement care at this COVID time . So including bereavement is so vital at this time. * The importance of spiritual care especially at this time of COVID and in bereavement , and he vital role of chaplains and hospices’ outreach to support spiritual distress * An update Carers Assessment Tool from Edge Hill Uni , and there rea others * An update from Nottinghamshire EOLC group on the high proportions attained , measure by EpaCCs audits – could send but very encouraging |
| 29 | University of Bedfordshire | General | **My comments relate to all of the Statements 1-5 that underpin the draft quality standard** Research investigating access to care for ethnic minority groups with life limiting conditions and ethnic patient groups have found that patients who have cancer and/or non-cancer conditions and experience cultural and language barriers in communication with care providers are particularly at risk of inadequate end of life care (1,2).  This programme of research has highlighted that the time required to discuss end of life care issues with patients is greater for South Asian patients where there are cultural or language barriers to direct communication with the patient. In addition, the assumption that all patients expect or wish to take an active part in decision-making about their end of life care during the end of life phase may not be a valid or a culturally competent one (3,4).  The timing of discussions about end of life care in the cancer and non-cancer setting appears to be influenced by a number of factors: treatment modality and setting; consultant’s approach; care provider role and confidence; and patient preference. Without open discussion early on to provide information and discover patient preferences, then following up over time to revisit these, it may not possible for service providers to be confident that the care is being delivered in culturally sensitive and, therefore, patient-centred way (5,6).  There is limited communication between multi-disciplinary staff and patients about end of life because of lack of staff time, issues of privacy, staff confidence and cultural barriers for both patients and care providers. Good communication between patients and providers is the key process enabling access to quality end of life care that meets both the emotional and physical needs of patients under the care of kidney services. The ideal picture of good practice is one of the gradual conversations and rapport built up over time to enable a comprehensive and timely understanding of patient needs and wishes. Other researchers have described some of the challenges of disclosing end of life prognosis and a need for an individualized approach to discussing end of life care that is culturally competent. In-service training together with reflective practice and a team approach were suggested as ways to achieve this (5, 6).  The global impact on ageing societies living and dying with the increasing burden of non-communicable diseases like cancer and non-cancerous conditions, such as Type 2 Diabetes Mellitus (T2DM) and complications is predicted to great in the future. Although South Asian populations (those originating from the Indian subcontinent – India, Pakistan, Bangladesh and Sri Lanka) in the UK are relatively young compared to the White European population they are ageing and - with higher prevalence of T2DM -related end stage kidney failure (ESRF), relative risk of acceptance rate to renal replacement therapy (RRT) of 5.8 compared to the White European population, and longer waiting times for donor organs - there is a demand for end of life care which meets this group’s needs (7). As well as shifts in the age structure of populations, many countries are becoming increasingly diverse as populations grow and migration patterns respond to economic and political change around the world. By the 2050s, ethnic minorities are predicted to make up 30–40% of the UK population so there is a growing need for health services to be commissioned for a diverse population. This is the case elsewhere in the world too and inequalities associated with migration and socioeconomic status can contribute to inequalities in access to healthcare through generations (7). |
| 30 | Weldmar Hospicecare | General | In response to your question whether the standards reflect key areas for improvement we would agree. |
| Responses to question 2 | | | |
| 31 | Association for Palliative Medicine | Question 2 | Local systems are very variable and not robustly in place to collect the data. Would it not be wise to aim to have a national system to collect relevant data and be able to monitor inequalities etc |
| 32 | Association of British Neurologists | Question 2 | Concern as to how secondary care will be able to demonstrate compliance with the quality standards. The data sources and processes proposed for each standard are difficult if not unrealistic. Often the data source is local audit - I assume of notes but it is unlikely “local notes” will contain these data. Often the outcome suggested does not relate to the standard being assessed.. Without  realistically achievable processes, services will not engage with the standards which will be a shame given the important areas they cover. |
| 33 | Marie Curie | Question 2 | We do not anticipate any significant challenges in collecting data to support the quality measures in the draft Quality Statement or the proposed addition outlined above. |
| 34 | Motor Neurone Disease Association | Question 2 | We have some concerns that some data collection methods identified in parts of the Quality Standard will not always be robust and/or routine, such as a reliance on surveys. The data may also not be representative given there are inconsistencies in identifying people at end of life, and there is also work still to be done in ensuring there is Advanced Care Planning taking place, as indicated in the NACEL round 2 audit. |
| 35 | Multiple System Atrophy Trust | Question 2 | At present we feel that data collection is generally poor. Any systems that are set up should be clearly based on improving patient care rather than as tick box exercises that allow CCG’s/Trust to upload details purely for audit.  At present information sharing capacity and protocols are not robust. This may be because IT infrastructure is not in place or because the various agencies do not co-ordinate effectively.  In terms of collection of data some of these sets seem fairly blunt. For example, the number of Advance Care Plans in place can be counted but are they up to date. Preferred place of death may change as people’s situation and support available changes so these could skew out come measures in this question and question5.  There is an issue with people completing surveys when people are dealing with the reality of impending death or its aftermath and the completion or non- completion of these surveys may skew findings. We are not sure if any research has been done in this area? |
| 36 | Royal College Of Nursing | 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?”  See above comment in Question 1, there is no one robust system in use to record everything. |
| 37 | Royal College of Occupational Therapists | Question 2 | More work is needed to improve practitioner access to effective methods of data collection. |
| 38 | RCP | 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?   * 1. In general these systems for measurement can be in place, and should be based in primary care registers, however many of these patients will not be on palliative care registers particularly frail elderly patients in the last 12 months of life. This may make current registers unmanageable.   2. Systems for measuring use of transfer of care information and consistent use are not in place, but are important |
| 39 | Society for Acute Medicine | Question 2 | This varies on geographical location. In some areas, there are local systems in place (such as Coordinate My Care) but not in others. |
| 40 | University of Bedfordshire | Question 2 | Inequalities in outcomes and access to services have been documented as common experiences for minority ethnic groups in the UK (8). Research investigating access to care for ethnic minority groups with life limiting conditions and ethnic patient groups have found that patients who have cancer and/or non-cancer conditions and experience cultural and language barriers in communication with care providers are particularly at risk of inadequate end of life care (9, 10).  As end of life care aims to address the total care of a person with advanced and incurable disease to help them live as well as possible until they die (4), investigating how this gets delivered by non-palliative care teams and to patients with a range of cultural backgrounds is important to understanding equity of access. The chronic nature of some conditions that are highly prevalent in minority ethnic communities – for example, kidney disease and availability of renal replacement technology in the UK make kidney care a complex area for predicting and delivering end of life care. However, as the numbers of people with End Stage Kidney Failure and those from ethnic minority groups are set to increase in the future, a better understanding of how to deliver quality end of life care in this context will be valuable for commissioners, providers of services, patients and their families (4). |
| Responses to question 3 | | | |
| 41 | Greenwich & Bexley Community Hospice | Question 3 | The level of resource allocated to enable a real change in place of death, moving activity from hospital to community does not appear to be realistic. If we are to see a real and sustained change, greater investment is required in community nursing, specialist palliative care, domiciliary care and general practice. In addition investment in training for generalists to enable them to develop their skills and in clinical supervision to support their resilience and mental wellbeing when caring for an increased number of dying people will be key. |
| 42 | Motor Neurone Disease Association | Question 3 | We think it is important to note that local services are under stress. Although we do not have readily available data for MND deaths, data shows there have been increased deaths at home generally. The hospice sector, although not solely responsible for end of life and palliative care in the community, is under intense pressure and its finances are stretched. As a sector it is under considerable threat. |
| 43 | Multiple System Atrophy Trust | Question 3 | People will likely be accessing services across national, regional and local administrations so standardisation of data and effective capture is needed.  If professionals are speaking to people in more detail and at an earlier stage, they are likely to uncover addition need which will require action and this will entail additional resource. |
| 44 | Royal College of Occupational Therapists | Question 3 | The statements in the quality standard are achievable as they should already be included in interventions provided by health and social care professionals. |
| 45 | RCP | Question 3 | 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.   * Consistent implementation of these standards would reduce hospitalisation and conveyance to hospital for significant numbers of patients, it may also reduce hospital length of stay. However more resource in primary, community and social care would be required. * Resources are required for skill development of staff in advance care planning, and in public campaigns to support culture change. |
| 46 | Society for Acute Medicine | Question 3 | Yes. I cannot comment on cost saving initiatives. |
| 47 | The Royal Marsden NHS Foundation Trust | Question 3 | **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.**  Resources required for additional training and data collection if not already using that data for local service improvement. |
| 48 | University of Bedfordshire | Question 3 | A range of studies from the UK and overseas, suggest that patients wish to plan for the end of their lives and look to their clinicians to initiate discussions at the appropriate time (4). Most of the patient experience research, however, has excluded participants from different ethnic and faith communities, as well as excluding non-English speakers, and we know little of whether the same is true for people with different cultural backgrounds or about the delivery of their care. Our studies among cancer and non-cancer patients, with a focus on care provided to South Asian kidney patients at end of life, therefore, goes some way to filling that gap (1-10). This lack of knowledge hampers commissioners and providers to develop evidence-based person-centred hospice and palliative care services.  With population predictions and increasing rates of cancer diagnoses, and non-cancerous conditions, such as type 2 diabetes, it is likely that the number of South Asian patients with ESKF will grow in the future and will benefit from greater understanding of end of life kidney care. Kidney care providers require time to engage with South Asian patients and their families to understand and meet their emotional as well as physical needs as they approach and progress through the end of life care pathway. More research is required to investigate South Asian patients’ experiences later on and as they progress through the kidney end of life care pathway. This could be achieved through further research with informal carers and care providers, and comparisons across different patient groups. In-service training and a team approach are ways to improve understanding of the issues and increase the confidence of all providers who need to engage with patients about end of life care. It is also important examine equity in access and uptake of hospice and palliative care services. This is likely to be influenced by the diversity of the workforce, and the availability of culturally competent services. Health Equity Audits (HEAs) conducted at national, regional, and local level would be a useful starting point to informing the current inequities within hospice and palliative services. The findings from the HEAs could inform the development of targeted interventions to improve access to services, with ongoing evaluation (7).  References:   1. Randhawa G, Owens A, Fitches R, and Khan Z. (2003) The role of communication In developing culturally competent palliative care services In the UK: a Luton case study. International Journal of Palliative Nursing. **9**, 24-31. 2. WilkinsonE, RandhawaG, Brown E, Da Silva GaneM, Stoves G, WarwickG, Atkhar T, Magee R, Sharman S, Farrington, K. (2014) Communication as care at end of life: an emerging issue from an exploratory action research study of renal end of life care for ethnic minorities in the UK. Journal of Renal Care, 40, S1, 23-29. 3. Owens A. & Randhawa G (2004) “It’s different from my culture; they’re very different”: providing community based ‘culturally competent’ palliative care for South Asian people in the UK. Journal of Health and Social Care in the Community. **12**, 414-421 4. Wilkinson, E., Randhawa, G., Brown, E., Da Silva Gane, M., Stoves, J., Warwick, G., Akhtar, T., Magee, R., Sharman, S, & Farrington, K. (2017) Time, Timing, Talking and Training: Findings from an exploratory study to improve quality of end of life care for minority ethnic renal patients. Clinical Kidney Journal. DOI:10.1093/ckj/sfw151 5. Randhawa G. & Owens A. (2004) The meanings of cancer and perceptions of cancer services among South Asians in Luton, UK British Journal of Cancer. **91**, 62-68. 6. WilkinsonE, RandhawaG, Brown E, Da Silva GaneM, Stoves G, WarwickG, Akhtar T, Magee R, Sharman S, Farrington, K. (2016) Exploring access to end of life care for South Asian people with end stage renal disease through recruitment in action research. BMC Palliative Care. **DOI:** 10.1186/s12904-016-0128-1 7. Wilkinson, E., Waqar, M., Randhawa, G., Tomlin, A. & Sinclair, A. (2016) Diabetes, Older people and Ethnicity: a realist review of the literature. Journal of Diabetes Research, <http://dx.doi.org/10.1155/2016/8030627> 8. Randhawa G (2007) Tackling health inequalities for minority ethnic groups: challenges and opportunities. Better Health Briefing 6, Race Equality Foundation & Department for Communities and Local Government. 9. Owens A. & Randhawa G. (2004) South Asian patients: progress and challenges in palliative care. Cancer Nursing Practice. **3**, 8-10. 10. Randhawa G. & Owens A. (2004) Palliative care for minority ethnic groups. European Journal of Palliative Care. **11**, 19-22. |
| 49 | Weldmar Hospicecare | Question 3 | In response to your question 3 regarding any potential disinvestment, we have not identified any but would see further investment would be needed in the fulfilment of Statement 3, 4 & 5 in particular |
| Responses to question 4 | | | |
| 50 | Association for Palliative Medicine | Question 4 | Yes care has changed substantially due to the pandemic. More remote interactions with patients and families e.g. telephone clinics. Needing to support relatives unable to see their loved ones face to face. |
| 51 | Marie Curie | Question 4 | Marie Curie has innovated significantly with respect to its services due to the Covid-19 pandemic. In particular we have introduced a number of digital health innovations due to visiting restrictions in our hospices and local/national lockdowns. We are facilitating virtual visiting for relatives who are unable to visit patients in hospices and remote consultations for patients.  During the pandemic, remote consultations in particular became essential for delivering palliative care, with all hospice clinicians having to adapt to providing care remotely. These have been well-received by both patients and clinicians – remote consultation has improved the accessibility of palliative care services for some patients, increased patient choice regarding how they wish to access services and enabled more flexible support to carers. While face-to-face consultations may still be optimal for establishing relationships between patients and healthcare workers, remote consultations may have a continuing role in routine follow-up, emotional support, and conversations on practical matters.  Our Liverpool Hospice’s IMPaCT (Integrated Mersey Palliative Care Team) service delivers a virtual integrated palliative care team. This includes a daily (Mon-Fri) city-wide triaging call with community palliative care teams to discuss the needs of new and existing patients. This service is now also linked in with community geriatricians and the frailty team, who can also access the advice line. Scaling up these services across a wider region to include more healthcare partners has enabled better understanding of and responsiveness to challenges within the local health system, such as identifying and problem-solving equipment and medication shortages and staffing issues. There has been an overwhelmingly positive response to this from community and frailty teams who now feel better supported, and this has enabled more patients to remain safely at home and receive appropriate care. It’s also supported appropriate admission to hospice services and safe discharge home.  The suspension of CHC fast-track funding has seen many of our community nursing services across England become more involved in the management of referrals and coordination of care packages. Benefits seen include:  • More flexible and responsive care packages delivered at the right time.  • Closer multidisciplinary team working  • Much faster funding decisions, meaning that care can be delivered sooner, and patients spend less time in hospital, with fewer delayed discharges.  We have also seen expansion of our rapid response services, and in addition to providing hands-on care to people at end of life in care homes, in several areas these teams are now supporting the verification of expect deaths in care homes.  Several of our hospices, including Bradford, Newcastle, West Midlands, and Birmingham expanded their bereavement offers during COVID-19; for some this was through local commissioning partnerships and others through grant funding. All are working in close partnership with other palliative care and bereavement service providers in their localities to ensure a coordinated, system-wide responses, and these changes have meant that these hospices are now providing bereavement support for people within their catchment areas who may have missed out on support previously. Technology has supported the breaking down of geographical barriers, with one example being a hospice providing virtual support to a bereaved relative living in Switzerland. |
| 52 | Motor Neurone Disease Association | Question 4 | It is worth acknowledging that carer burden has increased during the Covid-19 pandemic. There have also been significant issues with home care provision. Testing of home care workers and PPE supply has been inconsistent, so people living with MND have been put at risk when reliant on home-based care.  There has also been unpreparedness for admission of people living with MND at end of life during the pandemic due to aerosol generating procedures required such as Non-Invasive Ventilation and cough augmentation, which requires higher-level PPE and training. We are aware of instances where people living with MND have not been able to die in the location of their choice or have been unable to access hospice care as a result.  We were particularly concerned by the confusion early in the pandemic surrounding DNACPR decisions, especially where there was evidence of blanket policies being applied. |
| 53 | Multiple System Atrophy Trust | Question 4 | Care input and face to face support has reduced during the Covid-19 pandemic. Also, many hospice services have been reduced and these often provide leverage to accessing better GP and community- based support. |
| 54 | Weldmar Hospicecare | Question 4 | In response to your question 4 regarding any change in services due to the pandemic: during lockdown periods our face to face visits have reduced however, our telephone contacts increased and face to face visits were continued throughout if required. Our local CCG called together an emergency palliative care group who have continued to meet and have morphed into a countywide steering group. Held virtually, the right stakeholders are represented who have the power to make decisions and attendance is good. This has been a good outcome and fits well with Quality statement 4. |
| Responses to question 6 | | | |
| 55 | Greenwich & Bexley Community Hospice | Question 6 | There are some excellent examples of how volunteers and non-clinicians have been used to support the ACP process and to widen perspectives about death and dying in the community. Greenwich & Bexley Community Hospice has evaluated ACP volunteer roles (published) and we are now looking at how we can use compassionate neighbours to promote and support this project. Ref: Advance care planning in a UK hospice: the experiences of trained volunteers; Jones P, Heaps K, Rattigan C, Marks-Maran D (2015) EUROPEAN JOURNAL OF PALLIATIVE CARE, 22(3) |
| 56 | Macmillan Cancer Support | Question 6 | Local practice case studies summarised in our policy report: Macmillan Cancer Support (2019) At the Crossroads: How can the NHS Long Term Plan improve end of life care in England?  * **Multidisciplinary and Integrated working to provide care in the community:** The North Manchester Macmillan Palliative Care Support Service (NMPCSS), **p32** * **Reducing avoidable hospital admissions through improving systems and services to improve patient triage and response, and workforce training:** South West Ambulance Service NHS Foundation Trust and Macmillan Cancer Support, **p36** * **Increasing the number of people identified at end of life and offered an advance care plan**: Milton Keynes, **p41** * **Information and sharing system, allowing patients to record and share with healthcare providers, in real time, their medical details, advance care plans and wishes.** Co-ordinate My Care.**p29** |
| 57 | NHS England and NHS Improvement | Question 6 | I’ve received a late response from our AHP team, but not direct comments on the QS. They have some information pertaining to question 5.  5.Do you have an example from practice of implementing the NICE guideline that underpins this quality standard? If so, please provide details.  Devon Carers in Devon are working to the NICE guidance in relation to Quality statement 3: Support for carers. An Occupational Therapist working with Devon Carers to deliver carers services and support on behalf of Devon County council would be willing to be contacted to discuss and share how they are meeting this NICE guidance in relation to support for carers. (Details were provided) |
| 58 | Greenwich & Bexley Community Hospice | Question 6 | In COVID we have a seen an increase of 44% in home deaths, however this has taken its toll on hospice community staff as well as District nurses. This is not sustainable without a growth in workforce. |
| 59 | University of Cambridge | Question 6 | Example from practice that underpins the quality statements of Holistic needs assessment and Support for carers: the Carer Support Needs Assessment Tool Intervention (CSNAT-I) is a practice intervention specifically designed to assess and support adult carers of patients at end of life. CSNAT-I has two components: 1) an evidence based comprehensive assessment tool that is delivered within 2) a five-stage person-centred process of assessment and support that is facilitated by practitioners, but carer-led to ensure support is tailored towards carers’ needs and priorities.  Trials have shown that the intervention can significantly reduce carer strain and distress during caregiving1,2, improve carers’ experiences of interactions with practitioners such as quality of information and communication2, and reduce early grief and improve mental and physical health post bereavement3. Added benefits of the intervention from carers’ and practitioners’ perspective, included enabling visibility and legitimacy of carers’ needs, reassurance and empowerment.4,5  Eighty-five end of life care organisation in the UK hold licences to use the intervention in practice (with another 83 organisations outside the UK in 14 different countries). The CSNAT intervention is recommended for end of life care primary care as part of the RCGP/ Marie Curie Daffodil Standards (Standard 3 Carer Support)6 and was identified as a practical approach that GPs and their primary care teams could adopt and implement when NHS England and NHS Improvement identified end of life care as a quality improvement topic for primary care in 2019. As a result, the CSNAT intervention has been included in NHS England Quality and Outcomes Framework (QOF)7.  1 Aoun SM, Grande G, Howting D, Deas K, Toye C, Troeung L, et al. (2015) The Impact of the Carer Support Needs Assessment Tool (CSNAT) in Community Palliative Care Using a Stepped Wedge Cluster Trial. PLoS ONE 10(4): e0123012. doi:10.1371/journal.pone.0123012  2 Lund L, Ross L, Petersen MA, Blach A, Rosted E, Bollig G, Juhl GI, Fahrholt H, Winther H, Laursen L, Hasse M, Weensgaard S, Guldin M-B, Ewing G, Grande G, Groenvold M. The effect of the Carer Support Needs Assessment Tool (CSNAT) intervention in the Danish specialized palliative care setting: a stepped wedge randomized, controlled trial. BMJ Support Palliat Care 2020 Epub ahead of print: doi:10.1136/ bmjspcare-2020-002467  3 Grande GE, Austin L, Ewing G, O'Leary N, Roberts C. Assessing the impact of a Carer Support Needs Assessment Tool (CSNAT) intervention in palliative home care: a stepped wedge cluster trial. BMJ Supportive & Palliative Care 2017: 7 (3): 326-334. doi: 10.1136/bmjspcare-2014-000829. Epub 2015 Dec 30.  4 Aoun S, Deas K, Toye C, Ewing E, Grande G, Stajduhar K (2015). Supporting family caregivers to identify their own needs in end-of-life care: qualitative findings from a stepped wedge cluster trial. Palliative Medicine; 29(6): 508-517. doi: 10.1177/0269216314566061  5 Aoun S, Toye C, Deas K, Howting D, Ewing G, Grande G, Stajduhar K (2015). Enabling a family caregiver-led assessment of support needs in home-based palliative care: potential translation into practice. Palliative Medicine; 29(10): 929-938. DOI: 10.1177/0269216315583436  6 RCGP Standard 3: Carer Support. <https://www.rcgp.org.uk/clinical-and-research/resources/a-to-z-clinical-resources/daffodil-standards/the-daffodil-standards/standard-3-carer-support-before-and-after-death.aspx>  7 NHS England/RCGP QOF. <https://www.rcgp.org.uk/clinical-and-research/about/clinical-news/2019/may/new-daffodil-standards-and-qof-supporting-quality-improvements-in-palliative-and-end-of-life-care.aspx> |
| 60 | RCP | Question 6 | Do you have an example from practice of implementing the NICE guideline that underpins this quality standard? If so, please provide details.   * There are many local examples of initiatives to promote identification and early end of life planning discussions. The use of EPACCS for sharing information occurs in a number of localities. |
| Statement 1 | | | |
| 61 | British Geriatrics Society | Statement 1 | Identification through prognostication is difficult and the tools suggested to identify people likely to be in their last year of life whilst helpful are not used universally. One method advocated by NHSE in the Frailty General Medical Services (GMS) contract for Frailty in 2017-2019 was to use a two-step approach, using the Electronic Frailty Index (eFI with scores 0.24 or more) to identify a population group that may be at risk of adverse health outcomes (such as mortality), then apply clinical judgement using tools, such as the Clinical Frailty Scale to individual patients within this group to diagnose frailty. Patients with a score of 7 or more have severe frailty and may be in their last year of life. This tool should not be used in people with learning disabilities who may have high dependency needs but are robust. We suggest these are tied into identification. The inherent uncertainty of identification needs to be emphasised- clinicians are concerned about getting it wrong/find it too hard and therefore there is a risk that this statement may be hard to engage with. |
| 62 | Compassion in Dying | Statement 1 Pg 6 – Audience (Adults who are likely to be approaching the end of their life) | The last sentence should include the documentation of preferences as discussions alone are insufficient to ensure that preferences are respected “…support needs assessed and start to discuss and document the care and treatment they might want in the future.” |
| 63 | Faculty of Intensive Care Medicine | Statement 1 | The recommended use of tools such as the Gold Standards Framework (GSF) and SPICT would definitely help in patient selection. With the advent of electronic patient records hospitals (if they haven’t already) should be able to add prompts re GSF or SPICT to admission records in order to enable staff to identify at-risk patients |
| 64 | Greenwich & Bexley Community Hospice | Statement 1 | The role of primary care in identifying adults who are likely to be approaching the end of life is vital. However once identified, it is important that they link with other service providers and there is a need to have systems in place to cross check these lists, for example, in a recent audit of patients known to Greenwich & Bexley Community Hospice the number of patients know to the Hospice was, in some cases, greater than those on an individual GP practice EoLC register. A joined up system is vital to enable this record sharing, and unfortunately Coordinate My Care, our EPaCCS system still required the consent of the patient to create a record and so will never be comprehensive. |
| 65 | Greenwich & Bexley Community Hospice | Statement 1 | It is insufficient to simply identify adults if nothing is done about their needs – so we support the other statements in this regard, but there needs to be a strong link – especially if there is to be any incentivisation to support identification |
| 66 | Greenwich & Bexley Community Hospice | Statement 1 | Thought should be given to how this standard in particular will be communicated to the public, and what the benefits of early identification will be to patient care |
| 67 | Hospice UK | Statement 1 | We feel this draft quality standard does broadly reflect the key areas for quality improvement in this area. |
| 68 | Hospice UK | Statement 1 Measures | While local systems and structures are in place to enable the collection of this data this collection and analysis does not always happen regularly and consistently across different areas. |
| 69 | Hospice UK | Quality Statement 1 Measures | If a key measure is ‘evidence of local systems to systematically identify adults who are likely to be approaching the end of their life’, the proposed data sources may not accurately support this.  Using the number/proportion of deceased adults who were identified on the palliative care register prior to death as a measure may not reflect the true population need as:   * Records of deaths can be delayed, therefore any data taken from these figures could be out of date quickly and not reflective of new changes and improvements to identification processes. * There are barriers to being identified as approaching end of life, particularly for those with general frailty and coexisting conditions. Clinicians do not always feel comfortable determining and discussing when someone is approaching the end of life.   Suggest that this measure of how many adults are on the palliative care register is further benchmarked or compared against projections/estimates of how many adults are likely to have palliative care needs within different settings to give a more current picture of the effectiveness of identification processes.  Suggest that attention is paid to, in particular, the diagnosis, age and ethnicity of those who were successfully identified as being at the end of life, and the diagnosis, age, ethnicity of those who died without being identified on the palliative care register. This level of analysis is crucial to understanding which, if any, population groups or conditions are missing out on care and support towards the end of life. |
| 70 | Hospice UK | Quality Statement 1  Question 3- resourcing | Ensuring the timely and effective identification of adults who are likely to be approaching the end of their life is dependent on healthcare professionals across multiple different settings feeling confident in doing so. There is likely a resourcing consequence to this Quality Statement in the implementation of workforce training which covers identification and the use of local systems and tools. |
| 71 | Kidney Cancer Support Network | Statement 1 | **Adults who are likely to be approaching the end of their life are identified using locally developed systems**  We never experienced any such attempt on the part of either the primary care GP, the specialist oncology department or the acute medical and oncology units to which X was briefly admitted in the last few months.  The GP, to whom we had gone for a repeat prescription, on reading the reports, made random comments such as “things aren’t looking too good, but I suppose you know that” when no one had discussed a prognosis at that stage formally and then when X broke down and I too was failing to hold back tears – but was then was very keen to write the prescription and send us off. No enquiries into home/work situations, level of physical care needed/assistance required and no attempt to reach out beyond the standard 10-minute consultation and the usual “let me know if you need anything”. This from a GP who on the practice staff description lists palliative care as one of his interests.  Admissions to the local AMU, and at a later stage the oncology and then acute stroke wards at a tertiary hospital all resulted in discharges with no follow-up plans or appointments and no advice beyond speak to your GP and attend your oncology clinic appointment when next scheduled.  The most dire situation was being discharged from the acute stroke ward late at night on the 20 December and being told that they would be unable to source a wheelchair to transfer X to the car and that the best bet would be for me to go and look for one – “check near the entrances and the cafe love, you’re bound to find one somewhere.” No assistance to transfer a very frail man with new onset balance problems and gait disturbance. Essentially, their problem and limited interest stopped as soon as they handed over the discharge report and X got up off the bed. |
| 72 | King’s College Hospital NHS Foundation Trust | Quality statement 1 (structure) | **A Shared Electronic Record.**  Structure and data sourcefor this needs to also include evidence of systems that share information identifying adults who are likely to be approaching the end of their life between clinical settings, for example, a securely connected electronic health record that is accessible between settings (e.g., Local Care Records system in London) or an Electronic Palliative Care Coordination System (EPaCCS – e.g., Coordinate My Care system in London). This is because patients may be identified as approaching end of their life in one setting and transfer to another and it is necessary that this information is shared efficiently and accurately. |
| 73 | King’s College Hospital NHS Foundation Trust | Quality statement 1 (outcome) | Numerator: palliative care registers Measuring the numerator may prove challenging in hospital settings. Primary care services have systems set up to identify patients e.g., palliative care registers (usually Gold Standards Framework or Supportive and Palliative Care Tool Indicators). There are no equivalent registry systems that are widely used in hospital settings. It would require a significant investment to implement these systems in hospitals.  One method of identifying patients approaching the EOL in hospitals could be to look at a validated frailty score and number of admissions in the last 6-12months.  AMBER is not an equivalent registry system. It was developed specifically to identify patients who are clinically unstable and whose recovery is uncertain. It is applied on each episode of admission to hospital to enable discussions about ceilings of treatment and patient wishes for this particular episode. AMBER also acknowledges that a particular patient may survive this admission. It is not designed to record the longer term prognosis following the successful treatment and discharge of the patient. AMBER is variably implemented in Trusts as well- this maybe due to organisational culture as well.  AMBER is also just a hospital document and is not shared with primary care at present. What would be preferable is using the Advance Care Planning process and systems such as an Electronic Palliative Care Coordination System (EPaCCS), for example the Coordinate My Care system in the London area.  There needs to be further consideration as to how this standard would be implemented in hospitals. The challenges to implementation of this would be practicalities, confidence in use of tools and culture. |
| 74 | King’s College Hospital NHS Foundation Trust | Quality statement 1 (outcome) | Numerator: “evidence of end-of-life planning” This should instead read “evidence that end-of-life planning has been offered”. Advanced care planning is not mandated and only offered clinically. It is voluntary and a patient or relative-led discussion- and there are incidents where these groups decline the conversation. Therefore, recording that it has been offered and declined by the patient/relative is also a valid numerator. |
| 75 | Macmillan Cancer Support | Statement 1  (Identification) | Q1. Does this draft quality standard accurately reflect the key areas for quality improvement?   * Statement should specify that service providers need to make sure that staff have training (not just tools) to support early identification. Some professionals lack the confidence and communication skills to support early identification. Macmillan Cancer Support (2019) At the Crossroads: How can the NHS Long Term Plan improve end of life care in England? * Statement should specify that once a person is identified as being at end of life, this should be recorded in electronic information-sharing systems.   Q2. 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?   * There needs to be more consistent use of the GP Palliative Care Register. In the Evidence Review “What are the best service models to support the identification of people who may be entering the last year of life?”, the National Primary Care Snapshot Audit 2010/11 showed that over a 2 month period only 27% of people who died were on the Palliative Care Register. It is estimated (by the GP practices) that a further 15% of deaths were predictable but not put on the register. The Audit showed that those included were more likely to receive well-coordinated care, with the opportunity to have ACP conversations. [Evidence submitted in NICE briefing paper].   Q3. 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.   * It is important that resource allocation takes account of the demand for increased end of life care in community settings – particularly private homes – see answer to question 4 in this statement. Macmillan Cancer Support (2020) Demand for end of life care in the home: an urgent need for action, “Think. Improve. Change” Medium blogspace. * Community end of life care is one of the few interventions shown to be effective in reducing reliance on emergency and acute care, largely through preventing avoidable emergency admissions and providing personalised care. Macmillan Cancer Support (2019) At the Crossroads: How can the NHS Long Term Plan improve end of life care in England? * **These points apply to all Quality Statements within this standard.**   Q4. Do you think the end of life care service delivery (excluding care in the last days of life) has substantially changed during the COVID-19 pandemic? Can you describe any positive changes that have been introduced as a result of the COVID-19 pandemic? [outlined within consultation questions written on draft QS]   * Yes – service delivery has had to respond quickly to increased demand for end of life care in community settings – particularly the home. **This point applies to all Quality Statements within this standard.**   Excess deaths in private homes have been consistently higher during Covid-19 than before. Data indicate that this trend is likely to continue: when there were fewer cases of Covid-19 in the late summer, excess deaths in the home remained above average, whilst deaths in other settings fell.  At the same time professionals have told us that that there is a lack of resource and capacity in community care, making it hard to meet demand for good quality end of life care at home. We may well see a similar pattern following the second wave of Covid-19. Macmillan Cancer Support (2020) Demand for end of life care in the home: an urgent need for action, “Think. Improve. Change” Medium blogspace.   * Early identification often requires a proactive approach on the part of professionals. However, during the pandemic professionals told us of disruption of services, with ways of working becoming reactive rather than proactive. Professionals noted that the holistic needs of those at the end of life were less likely to be considered. These changes were attributed to capacity constraints and the redeployment of professionals providing end of life care to NHS settings.   Pockets of good practice did exist – for instance staff being trained to have discussion with patients at an early stage in a patient pathway. |
| 76 | Motor Neurone Disease Association | Statement 1 (audiences) | Whilst there seems to be a focus on healthcare professionals, we wondered if there should also be a mention of social care professionals and their role in being aware of the systems in place that help with identifying people at end of life. |
| 77 | Multiple System Atrophy Trust | Statement 1 Question 3 | Identification of people at the end of life is dependent upon the availability and implementation of tools to do this. The denominator of “All adult deaths” and the numerator identifying those on some sort of register will take a lot of resource. How will it be possible to work out from all adult deaths who should have been on a register for EOL and those whose deaths could not have been foreseen and who therefore won’t have Advance Care Plans and holistic care plans in place. |
| 78 | NHS England and NHS Improvement | Quality Statement 1 | Would this benefit from a more explicit definition of “approaching end of life” (PC) |
| 79 | NHS England and NHS Improvement | Quality Statement 1 (Rationale) | Rationale – emphasis on “plans for future” needs to be broader than just preferred place of death. This is not just about where someone would like to be cared for, but how. (PC) |
| 80 | NHS England and NHS Improvement | Statement 1 Service Providers | To promote integration, should reference not be made here to social care providers? Arguably, it is reasonable for a care home worker to identify someone as deteriorating and approaching end of life. (PC) |
| 81 | NHS England and NHS Improvement | Statement 1 Adults who are likely to be approaching the end of their life | Is “treatment” the right word here? Should the term “support” be used as well? (PC) |
| 82 | NHS England and NHS Improvement | Quality statement 1 | This statement is achievable as it is already identified on the caseload information of our Community Nursing Services; EoL care plan which is reportable. It would be pertinent to have a parameter on the definition of ‘timely’ however. (N&M) |
| 83 | NHS England and NHS Improvement | Quality statement 1  Quality measures outcome | This is a key area for improvement. Whilst the measures address evidence of identification, they do not address timeliness of the process. As the ambition that this occurs early in a patient’s trajectory suggest data collection should also address this. Given primacy of use registers in the standard, which are a tool in primary care, there is a risk the type of evidence to be used to demonstrate the standard has been met in secondary care would not be consistent - the term used is ‘evidence of end of life planning’. It Is it possible to be more specific? (N&M) |
| 84 | NHS England and NHS Improvement | Quality statement 1 | To note the terminology “Healthcare professionals (such as GPs, specialists and nurses)” maybe unhelpful as there are many specialists who are nurses especially in this field and vice versa so suggest reconsideration. Also this standard does not support those not already under services as may be self-managing or previously declined services but condition/situation changed and I wonder whether reframing this to highlight the role health professionals have in raising awareness to the public and supporting people more widely to come forwards and be empowered to begin discussions? (N&M) |
| 85 | Royal College Of Nursing | Statement 1  (definitions) | Suggest adding the highlighted: Adults who are approaching the end of their life may be identified using a ratified tool that is based on best practice and evidence i.e. Gold Standard Framework, prognostic indicators, Amber Care Bundle and Support Palliative and Palliative Care Indicators Tool (SPICT). |
| 86 | Royal College of Occupational Therapists | Statement 1 | Adults who are likely to be approaching the end of their life are identified using locally developed systems by the healthcare professionals caring for them. This means that they can have their care and support needs assessed and start to have discussions about the care and treatment they might want in the future.  Occupational therapists are already using local systems to identify adults who are likely to be approaching the end of their life. They use their clinical judgement and tools to support this. |
| 87 | Royal Pharmaceutical Society | Statement 1 | We are supportive of this standard and the rationale behind it. It is absolutely the case that a systematic approach that enables healthcare professionals to identify those who are likely to be approaching the end of their life should be in place in all localities.  It should never be the case that responsibility of informing health professionals of an end of life diagnosis falls on the person or his/her family. However, at present, too often in relation to pharmacists and pharmacy teams, information about diagnosis is not systematically or routinely shared. A 2018 RPS survey of pharmacists in Wales found that only 11 per cent of pharmacists were ‘always’ made aware of that a person they care for is on a palliative care register. Worryingly, 63 per cent of respondents noted that they were ‘never’ made aware, whilst 25 per cent noted that they are ‘sometimes’ informed. Anecdotal evidence suggests that a similar situation also exists in England.  Without the information being communicated to them, pharmacists depend on person actively sharing their health status or will have to see a significant change in the person’s medicines regimen to become aware that the person is at a palliative or end of life stage. When information is shared with pharmacists, they can then be ready to proactively support the person and their loved ones and will be able to explore issues or worries related to both prescribed medicines and wider issues related to their diagnosis.  It is essential that as part of the implementation of this quality statement and measures that pharmacists are notified that the person is palliative and when they are end of life. |
| 88 | South West End of Life Network | Statement 1 | “Identified” sounds depersonalising. Would "recognised" be more human than "identified"? |
| 89 | South West End of Life Network | Statement 1 | Perhaps we need to be explicit that we aren't asking teams for accurate prognostication (as we know how difficult this is and can put clinicians off), but as a way to recognise people who may benefit from discussions/ symptom control/ planning/ coordinated care across settings etc. |
| 90 | South West End of Life Network | Statement 1 | Is "using locally developed systems" necessary in the wording of the statement? We also recognise that there is significant variation in the methods used. |
| 91 | South West End of Life Network | Statements 1, 2 | Could the statements reflect the need to be proactive in recognising and finding out preferences, rather than something ad hoc, that may or may not happen? |
| 92 | The GSF Centre in End of Life Care | Quality Statement 1  Page 5-6 | * **We strongly support the fact that early identification for more proactive care is recommended and mentioned first here –** this will be invaluable in mainstreaming proactive care in line with NHS Long Term Plan Sect 1.42 recommending care that is proactive person-centred and coordinated . * **I**n our GSF experience it can be achieved across all sectors if the positive gains from early identification are recognised . In addition, if the Needs based coding and Needs Support Plans are effectively implemented for more systematic care – as we teach as part of the GSF QI training programmes . * **In addition trying to tighten up these measures** more exactly as otherwise appears too loose and STP/CCGs/teams can tick box these whilst not really being as effective as they may be . In our experience working with several hundreds of teams in this area, teaching early identification of patients/ people, it is possible to do (with workforce training ) and we use QI Run Charts or Trackers to watch progress as teams develop this and eventually at accreditation ensure hight levels if identification – see examples on GSF website or Frontrunners |
| 93 | The GSF Centre in End of Life Care | Statement 1  Question 2 (data collection feasibility) | * **Suggest including 2 Outcome Measures for early identification** **for accuracy and QI enabling** * This stated outcome measure a) ie **those identified/ those died**, although useful , is in our experience too retrospective , so would not readily support the planned rapid QI process ( i.e. the numbers died may take time to confirm , especially hospital patients who died elsewhere , and might be over a year old before fully estimated, so might lead to delayed benchmarking and fewer improvements in practice in our experience ). * So suggest to use BOTH - * A) retrospective assessment related to number of people who died were identified as you suggest but also * b) a more current assessment of proportions of people in final year of life to ensure rapid QI. As a more more current ‘live’ measure using evidenced data of average that coud be identified * as a working estimate for QI action and improvement , based on **identification estimates for each setting ie those identified (numerator) / average predicted number of deaths (denominator) .** This latter figure, of estimated proportion who die each year in each setting is * **0.9-1%** in primary care/ general population (ONS) , (though might be higher during COVID with excess deaths ) * **30%** in hospital patients (cf Clarke Imminence of Death 2014 Pall Care Journal ) * **Estimated 80%** care homes residents ,(but we include **100%** residents in practice , as all residents can be considered to be approaching end of life, living with life limiting conditions eg dementia . multi-morbidities , and benefit from additional supportive care ). Slightly harder to estimate in domiciliary care, prisons and retirement villages but we have some averages from GSF experience here .   We at GSF Centre regularly assess both – see attached Key Outcome Ratio used in GSF Accreditation. As in the attached anonymised example  Note this first outcome measure is easier for primary care QOF/GSF pall care registers/ Electronic Palliative Care Coordinating System ( EPaCCs), but harder for hospitals who do not have a current register of identified patients (GSF accredited hospital wards have developed such a ‘ register’ which ideally can link with EPaCCS from community ). So this measure should eventually mean that population-based EPaCCS includes data from all sources including social care (eg care homes) .  .  (Page 6, Line 1 R PC00-1 QOF relates to Primary care Register – need also to **include hospital** register or actively other linked up to EPaCCS (currently inconsistent in uptake from secondary care) This might be clarified by the National Audit of Care at End of Life (NACEL) but this only applies in the final days , not final year of life, so needs to be more extensive )  Inclusion in identification rates of hospital patients in the last year of life in hospital Mortality and Morbidity (M and M) meetings , in line with the Clarke 30% figures, would be recommended as part of professional learning and to inform Boards of progress – not just that related to actual patient deaths <https://qualitysafety.bmj.com/content/21/7/576>  NB. Until recently , for several years this was used by PHE NHS EOLC Intelligence Network Fingertips in comparing data of each GP practice’s identification rates as submitted for QOF eg whether they were identifying about 1% of the population of their practices , more or less as comparative charts – previous weblink GP Practices’ Finger tips QOF palliative Care eg <https://fingertips.phe.org.uk/profile/general-practice/data#page/10/gid/2000004/pat/166/par/E38000004/ati/7/are/F82034/iid/294/age/1/sex/4/cid/4/tbm/1/page-options/ovw-do-0_cin-ci-4> |
| 94 | The GSF Centre in End of Life Care | Statement 1 Questions 1 and 2 | **Service providers , healthcare professionals and others integrate frailty indicators eg EFI and add to tools page 7**   * **Needs to include reference to Frailty indices eg Electronic Frailty Index (EFI)** - all GPs have access to the EFI for suggested patients and are seeking EFI plus clinical assessment eg Rockwood score to assess degree of frailty – mild, moderate. Severe , so goo to cross reference this , as this is becoming the main cause of death ahead for most elderly people (cross reference British Geriatric Society assessments Fit For Frailty and EFI <https://www.bgs.org.uk/resources/resource-series/fit-for-frailty> etc ) * Q 3 collection of data therefore is easier when digital system works across sectors eg (EPaCCS) * Suggest integrating and EFI frailty into the register in GP practice , hospital and care homes   **Wider population Commissioners monitor and oversee** an acceptable level of whole population early identification of people/ patients from all sectors (notably via primary care EPaCCs ) but to include those also from hospitals , care homes and others –  Cross reference the findings from the GSF EOLC metrics pilot 2017 attached to demonstrate that this can be possible (see later point under QS 4 Coordination ) |
| 95 | The GSF Centre in End of Life Care | Statement 1 Pages 5/6/7  Question 1  GSF reference | **Thank you for including the GSF reference but please can we ask that you amend this specific identification GSF reference to GSF PIG. Suggest some terminology consistent, acceptable + accurate ,**   * **P6/7 GSF Reference** Line 7 and 11 and page 7 line 10 here and elsewhere - great to include GSF but to be accurate , please do refer to the ‘**Gold Standards Framework’ as this is a fully comprehensive QI programme ,** in which we include the identification tool we developed **‘the GSF Proactive Identification Guidance or PIG’** <https://www.goldstandardsframework.org.uk/PIG>. The reference to the Gold Standards Framework could refer to the QI programmes for each sector used to implement these and other NICE standards <https://www.goldstandardsframework.org.uk/> * **As might be seen from attached and website we at GSF do much more than just provide this one tool, we show people hope to use it , use Needs based coding , needs support care plans , monitor their progress , accredit and recognise their attainments as part of the GSF QI programmes in 9 sectors and the GSF Quality Awards in End of Life care – But commonly misquoted – thank you.**   Please see (as said in email )   * GSF website <https://www.goldstandardsframework.org.uk/> * How GSF helps early identification – <https://www.goldstandardsframework.org.uk/cd-content/uploads/files/1%20%20vs%204%20%20Evidence%20that%20use%20of%20GSF%20Improves%20identification.pdf> * -GSF 2020 Anniversary vimeo celebration July 2020 <https://vimeo.com/showcase/7310462/video/434789767> |
| 96 | The GSF Centre in End of Life Care | Statement 1 Question 3 | **Workforce training required with resource implications**  To improve earlier identification of people across all settings **requires intensive workforce training** , **appropriate and optimal use of tools and improved recording in health records** including EPaCCs to ensure best implementation of this standard in practice .  **The GSF QI Training Programmes in EOLC** for all settings (primary care , hospitals , care homes , domiciliary care, retirement villages , prisons , hospices etc ) ensure that early identification is the building block for future progress , with evidence of good progress in GSF trained and successfully accredited teams – see how GSF has helped early identification <https://www.goldstandardsframework.org.uk/cd-content/uploads/files/1%20%20vs%204%20%20Evidence%20that%20use%20of%20GSF%20Improves%20identification.pdf>  This is an area that we at GSF have focussed on (as well as QS 2 and 4) , -  We at GSF Centre have trained several thousand teams with hundreds accredited and accredited , demonstrating that this can be achieved by all sectors (GSF Frontrunners examples of good practice  See attached Frontrunners examplars and below <https://www.goldstandardsframework.org.uk/evidence> Front Runners in Primary Care Hospitals and Care Homes  **Use of EPaCCS** and improvement of digital information sharing especially across sectors , might have resource implication |
| 97 | The GSF Centre in End of Life Care | Statement 1 Question 3 | In addition, it is important to note that once people are identified and included on the register the next step is the most important ie there are further recommended steps of turning early identification into effective proactive care (in line with Sect 1.42 of the NHSE Long term Plan, ie of **needs-based coding** (red, amber, green ,blue) related to deterioration and potential decline of the patient , and then developing a localised Needs-Support Plan or GSF Core Care Plan as in Guidance on use of GSF PIG- <https://www.goldstandardsframework.org.uk/How-to-use-the-GSF-PIG-in-your-practice>  Needs-based coding and the use of Proactive Needs Support Plans have been used extensively across all settings- more information and the success of their use can be discussed as wanted . |
| 98 | The GSF Centre in End of Life Care | Statement 1 Question 4 | COVID has made a difference in this area of identification in the following ways   * Increased use of improved assessment tools eg RESTORE 2 and NEWS for improved collaboration between care homes, hospitals and GPs * Increased use of pulse oximetry and oxygen saturation to determine prognosis , (GSF coding ) and rapidity of referral to hospital (recent guidance from RCGP and others ) * Acknowledge very rapid decline of some patients/ residents with COVID , meaning that the usual trajectory of illness od sped up, and urgent action required earlier * The ‘ silent hypoxia’ of some is recognised , so clinical decompensation can be rapid- hence the value of pulse oximetry   However, the mainstreamed use of tools to improve early identification and the building up of teams abilities in earlier proactive care (needs based coding of all residents in GSF homes for example) ensured that GSF helped support many care homes respond appropriately and fare better during the peak of the COVID crisis in Spring- |
| 99 | The GSF Centre in End of Life Care | Statement 1 Question 6 | See other attachments supporting this QS on identification   * BMJ article ion achievements of GSF accredited practices * Confidential in press- Article on GSF in Hospitals IJPN accepted Nov 2020 * Frontrunners in 3 areas * Description of the GSF 1,3,5,7 Summary on Homepage GSF website |
| 100 | The GSF Centre in End of Life Care | Statement 1 Additional notes | **Terminology**   * P 5 Line 8- do not refer to **palliative** care needs assessment , as not always related to palliative care service or provision , especially in social care and will be misunderstood often and possibly just referred to Specialist palliative care teams . Suggest just say ‘**people can have care needs assessed’** etc * P 5 Line 23- too vague to say ‘ had evidence of EOL planning’ as could be too woolly and inclusive, and better to say ‘**or had evidence of the person** **being identified’** ie on GPs’ / hospital register. Use of GSF Needs-based Coding confirms this |
| 101 | University of Cambridge | Statement 1 Rationale | We recommend that Statement 1 should include carers as well, as follows “Adults who are likely to be approaching the end of their life and their carers are identified using locally developed systems”. We welcome development of a systematic approach to identify people who are likely to be approaching the end of their life. However, the rationale implies that once identified, not only are people with palliative care needs able to be supported but also their carers. This is unlikely to be the case, as there is no consistent, systematic approach in place at present to identify carers of people with palliative care needs, in hospital, community settings and even in many hospices, Such identification is a prerequisite for carer support. This is evidenced in the report from Hospice UK in 20181: “Carers have to be consistently identified in the first place to be supported, without this there is no starting point for support.”  1 Ewing G and Grande GE. Providing comprehensive, person-centred assessment and support for family carers towards the end of life: 10 recommendations for achieving organisational change. London: Hospice UK, 2018.  <https://www.hospiceuk.org/docs/default-source/What-We-Offer/Care-Support-Programmes/Research/carers-report---10-recommendations-for-achieving-organisational-change_final.pdf?sfvrsn=0> |
| 102 | University of Cambridge | Statement 1 Quality Measures | In addition to the need to include carers in the quality statement on identification as a prerequisite for providing support at end of life, the quality measures do not take account of the significant problems that exist in recording information about carers across care settings. The reasons include a lack of separate record systems for carers in acute hospital settings 1,2, in primary care carers are not necessarily registered at the same practice as the patient1 and will only have a record at their own practice, and many hospices will have no fully functioning record systems for carers 3 despite an ethos of supporting carers as well as patients.  We turned to other related NICE documents for further clarity on carer identification and record systems. NICE Guideline on Supporting Adult Carers recommends at 1.2.2.  “Use every opportunity to identify carers, including GP appointments, flu jab appointments, home visits, outpatient appointments, social care and other needs assessments, including admission and discharge assessments and planning meetings. Record details about carers you have identified (with the carer's consent)”. This is additionally important in end of life care provision where people approaching end of life care themselves are often identified late, if at all, and time is often short for putting in place support for the person who is ill and their carer.  However, this may again founder on significant problems with carer record systems. Without these in place, the efforts made in identifying carers may not lead to appropriate provision of support.  1 Ewing G and Grande GE. Providing comprehensive, person-centred assessment and support for family carers towards the end of life: 10 recommendations for achieving organisational change. London: Hospice UK, 2018.  <https://www.hospiceuk.org/docs/default-source/What-We-Offer/Care-Support-Programmes/Research/carers-report---10-recommendations-for-achieving-organisational-change_final.pdf?sfvrsn=0>  2 Hall A, Ewing G, Rowland C, Grande E (2020). A drive for structure: A longitudinal qualitative study of the implementation of the Carer Support Needs Assessment Tool (CSNAT) intervention during hospital discharge at end of life. Palliat Med First published online 3 June 2020. [https://doi.org/10.1177/0269216320930935](https://doi.org/10.1177%2F0269216320930935)  3 Higgerson J, Ewing G, Rowland C, Grande G. The Current State of Caring for Family Carers in UK Hospices: Findings from the Hospice UK Organisational Survey of Carer Assessment and Support. London: Hospice UK, 2019. <https://www.hospiceuk.org/docs/default-source/What-We-Offer/Care-Support-Programmes/current-state-of-caring-for-family-carers_web> |
| 103 | Weldmar Hospicecare | Statement 1 | Your second question was whether local systems are in place to collect the data? GSF is used across most of our areas so helps with this |
| Statement 2 | | | |
| 104 | Association for Palliative Medicine | Page 8  Quality statement 2 | Advance care planning should not be limited to those approaching end of life and advance planning can be triggered at a number of transition points. |
| 105 | Association for Palliative Medicine | Page 9  Quality statement 2 | ACP data very difficult to collect as is rarely a single conversation/entity but rather a process happening over a number of interactions |
| 106 | Association for Palliative Medicine | Page 11 Quality statement 2 | Discussion might also include an individual’s approach to life and attitude towards illness/QoL/Death |
| 107 | Association for Palliative Medicine | Page 11 Quality statement 2 | Holistic needs assessment not necessarily appropriate for every palliative care interaction/assessment. Should be judged by the assessor. |
| 108 | BAME Health Collaborative | Statement 2 | Stardard 2 Advance care planning’ (ACP) We need to look out how this is communicated to BAME communities as Racial and ethnic minorities may be disadvantaged in the quality of care they receive if they have a serious illness and are unable to make decisions for themselves because most have not talked to anyone about their goals, values, or preferences for care.  Culture and ethnic have a profound influence on patient choices in end of life care and we know there is the limited uptake of advance care plans and advance directives by ethnic minority groups in health care. What attention has been given to the cross- cultural consideration in ACP for patients, nurses, policy makers and others involved in planning and providing EOL care to people of diverse cultures |
| 109 | British Association of Social Workers | Statement 2 | BASW England members said that it is imperative that adults approaching the end of their life have opportunities to discuss advance care planning, therefore it is positive that this has been considered within the standard. Members felt this was a positive approach to enabling people to remain in control, and to ensure their expressed views and wishes can be acted upon and involve those who they wish to assist them with decision making and carrying out specific actions.  Members felt that in relation to health and social care practitioners, there should be clarity about how and when social work involvement should begin, as the relationship needs to have been established to support effective advanced care planning and a rights based approach. It is important that service users have access to a social worker who can provide a social model perspective, as well as information about positive risk taking.  It would be valuable if the standard could also include information relating to decision making roles, e.g. Lasting Power of Attorney for health &welfare, and finance and property and advance statements relating to medical treatment.  Equality and Diversity considerations need to go beyond accessible information to thinking about cultural sensitivity in a broader sense about the concepts of advance planning and the needs of people with a range of protected characteristics |
| 110 | British Geriatrics Society | Statement 2 | Conversation over time and deliberate revisiting and reviewing advance plans is vital as people’s views change and mental capacity may alter- in our view this  statement needs to include a focus on real time assessment and re-assessment and the competence/support to the wider workforce in assessing mental capacity  Currently it is not clear on which/when an individual should start ACP conversations with the patient is.   Often older people are not given a terminal diagnosis rather older people specialists are constantly parallel planning treatment-on a continuum between disease modifying and palliation . A frailty score of 6 and above should trigger ACP conversations. |
| 111 | Compassion in Dying | Statement 2  Quality statement | The quality statement should read:  “Adults approaching the end of their life have opportunities to discuss **and document** advance care plans”  The reasons for this are:   * Limiting advance care planning to “discussions” risks negating this vital aspect of end-of-life care. If we create or endorse a narrative which says talking about what you want at the end of life is enough to achieve a good death we are doing dying people a disservice. The people Compassion in Dying supports often tell us that having the conversation was not enough for them or a loved on to have their wishes for care and treatment wishes respected: <https://medium.com/death-dying-and-digital/we-need-to-do-more-than-talk-about-death-56893516a36>.   Please see below some examples of what we hear on our national information line:   * “How do I make surepp I am not given artificial nutrition when I have dementia?” * “How can I make sure that the paramedics know I don’t want to be resuscitated?” * “Dad was 81 and was taken into hospital with sepsis due to a failed knee replacement. Dad had previously refused an amputation and so I knew he wouldn’t want this. I told them and said I didn’t give permission but was told I had no say in it and they wheeled him to theatre. I feel as though all our wishes were ignored. I wasn’t prepared for the lack of control I had over decisions, I wish he’d have made a Living Will or a Lasting Power of Attorney, because the things he said to me verbally that he wanted were not adhered to.” * The recent Court of Protection case of An NHS Trust v AF & Anor [2020] EWCOP 55 (09 November 2020) also demonstrated (analysed in detail here - <https://openjusticecourtofprotection.org/2020/11/09/should-life-sustaining-treatment-be-continued/>) that the discussion of future treatment preferences is irrelevant and meaningless if they are not documented using the tools provided for by the Mental Capacity Act 2005. If clinicians do not have a documented evidence of an individual’s care preferences, they will not able to respect those preferences. If there is to be a genuine commitment to person-centred care, then there must necessarily be a concerted effort to not just discuss but also document treatment preferences. * The legal mechanisms available for documenting treatment and care preferences must be specified so that people are not denied the ability to make decisions about their care in a meaningful way. Therefore, a list of how treatment and care preferences can be documented - an Advance Statement, Advance Decision to Refuse Treatment, a Lasting Power of Attorney for Health and Welfare, a DNAR form and/or TEP/RESPECT form – is an essential component of any end-of-life care document * Finally, coordinated care (priority 4) cannot be achieved without documented advance care plans. As the denominator on pg 18 is “number of adults who have an advance care plan”, not including documentation within this statement results in a gap between discussing preferences and coordinating care. |
| 112 | Compassion in Dying | Statement 2 Rationale –line 2 (pg 8) | “…allow them to make **and document** specific decisions and plans for their future care…” |
| 113 | Compassion in Dying | Statement 2 Structure (a) (pg 8) | Evidence of local arrangements to ensure that adults approaching the end of their life have opportunities to discuss **and document** advance care plans. |
| 114 | Compassion in Dying | Statement 2 Process (pg 8) | Add a new calculation to capture documentation and to demonstrate a genuine commitment to meaningful advance care planning. This data is easy to collect as the relevant codes already exist within SNOWMED.  Numerator – the number in the denominator who have documented their advance care plans using any of the following tools (an Advance Statement, Advance Decision to Refuse Treatment, a Lasting Power of Attorney for Health and Welfare, a DNAR form and/or TEP/RESPECT form)  Denominator – the number of adults approaching the end of their life. |
| 115 | Compassion in Dying | Statement 2 Audience - health and social care practitioners (line 2) | “…give adults approaching the end of their life opportunities to discuss **and document an** advance care plan that takes into account their holistic needs assessment. |
| 116 | Compassion in Dying | Statement 2 Definitions – Advance care planning (pg 11) | Advance care planning is a voluntary process of discussion **and documentation** about future care between an individual and their care providers, irrespective of discipline.  Add a bullet point to topics covered:  Treatments they may wish to refuse in the future |
| 117 | Compassion in Dying | Statement 2 | In support of our recommendation on documenting advance care plans,  **Note**: If a decision is made not to include documentation within advance care planning, we would be grateful for an explanation of this decision. |
| 118 | Faculty of Intensive Care Medicine | Statement 2 | I would support this. Evidence suggests that good ACP improves qualitative outcomes with respect to care, whether life-saving treatments are pursued or not. Individual organisations may be capable of initiating such discussions (see above) however to influence change at national level this will require significant effort, given that YouGov & Compassion in Dying have recently highlighted significant [lack of awareness within the general population](https://www.politicshome.com/members/article/half-of-people-do-not-understand-dnrs-new-polling-from-compassion-in-dying-finds) re such matters. This is despite a [High Court Ruling accepted by the Secretary of State for Health & Social Care](https://compassionindying.org.uk/health-secretary-national-dnar-guidance/) in July 2020. |
| 119 | GMC | Statement 2 Rationale | Statement 2 states that ‘Adults approaching the end of their life have opportunities to discuss advance care planning.’  The rationale for this statement could make it clearer that discussions about advance care planning apply both to patients whose capacity may be or is expected to be lost or impaired at a future stage (when decisions will need to be made about ongoing care and treatment), as well as to patients where there is no such expectation. (See also 1.6.7 of ‘End of life care for adults: service delivery – NICE guideline [NG 142] Publication date 16 October 2019: https://www.nice.org.uk/guidance/ng142/chapter/Recommendations#advance-care-planning which stated that: ‘The committee also felt that advance care planning should not be restricted to planning for possible future loss of mental capacity.’)  Paragraph 53 of our Treatment and care towards the end of life guidance states that for patients whose capacity may be or is expected to be lost or impaired, doctors should ‘encourage’ them to think about what they might want should this happen. The statement, or the rationale for the statement might therefore consider strengthening the language from providing ‘opportunities’ for discussion to ‘encouraging’ discussion for these types of cases. |
| 120 | Greenwich & Bexley Community Hospice | Statement 2 | There is a need to assess the quality of ay ACPs as well as the number. This includes observation of updates to records, and that as the patient’s needs changes this is recorded. In terms of data recording if we only focus on the number of records (in my view) we are in danger of ending up in another LCP scenario, particularly as GPs locally are incentivised to create a record, but the quality and completeness is not measured or part of this incentive. |
| 121 | Greenwich & Bexley Community Hospice | Statement 2 | It will be difficult to assess patient satisfaction around the support they receive to plan their future care with current systems in place. This will need investment and infrastructure/ staffing to make this robust. We will also need to be clear who (roles and organisations) is responsible for carrying out the ACP process, so where it is not satisfactory we can address this and we can be specific with our questioning to service users. |
| 122 | Hospice UK | Quality Statement 2  General | We are pleased to see advance care planning included in this way as a new Quality Statement. |
| 123 | Hospice UK | Quality Statement 2  Measures | The focus on ‘satisfaction of adults approaching the end of their life’, sourced through ‘local patient and carer experience surveys’ could prove difficult. It is of course of the utmost importance that all those with end of life care needs receive care that is appropriate to their needs and wishes, and that every effort is made to determine patient and carer satisfaction. Surveys of carers or of patients at the end of life can however raise ethical considerations around who issues the survey and in which setting it is conducted. Currently there are not consistent local or national systems to measure patient satisfaction at the end of life, and introducing these in an extensive and statistically significant way would have cost implications in addition to procedural considerations. |
| 124 | Hospice UK | Quality Statement 2  Measures | The draft Quality Statement suggests using the National Audit of Care at the End of Life measure for the number of people with an advance care plan on arrival at their final admission to hospital as an indicator for the success of advance care planning locally. While this is a partial measure, over-reliance on this would miss those who are not admitted to hospital in their last months of life, and particularly those with non-specialist palliative and end of life care needs. Additionally as early advance care planning discussions have been highlighted as beneficial to patients and carers, relying on a measure which only establishes that a plan is in place at the very last admission, perhaps only hours or days before death, would not encourage the early discussions and planning we know to be most effective. |
| 125 | Hospice UK | Quality Statement 2  Question 3 | It is important that health and social care practitioners across all settings are comfortable discussing advance care planning, so that individuals are able to discuss their wishes, along with their family and/or carers, at the earliest opportunity, and also so that a person’s plan can be continually updated as their wishes, circumstances, and care settings change.  With this in mind specialist training on communication skills and the use of advance care planning will be necessary across but not limited to GPs, specialists, community nursing, care workers in care homes, and social workers to ensure that these discussions are effective, patient-led, and can occur in whichever setting is most appropriate to the individual. |
| 126 | Hospice UK | Quality Statement 2  Question 4 | The COVID-19 pandemic has demonstrated the importance of advance care planning and encouraging public discussions around death and dying, these issues were acutely in focus within care home settings in particular.  As the draft Quality Standard notes in its definitions, ‘advance care planning is a voluntary process of discussion’, without increased public awareness of advance care planning, and other issues surrounding death and dying, the opportunities to discuss advance care planning created by the recommendations of this Quality Standard may not be taken up by the public. It is therefore important for commissioners and service providers to consider what activities, resources and public engagement they could participate in to encourage public conversations around death and dying. There are a wealth of resources on public awareness of death and dying at Dying Matters (<https://www.dyingmatters.org/overview/resources> ). |
| 127 | Kidney Cancer Support Network | Statement 2 | **Adults approaching the end of their life have opportunities to discuss advance care planning. [new 2021]**  Good communication and discussion around this aspect only kicked in when Hospice at Home became involved but there was nothing prior to that. Advance care planning discussions were mainly confined to DNAR and disconnection of his ICD until X was finally admitted to the hospice.  Until then, no one had asked X how he felt emotionally and what questions did he have that did not relate to a physical symptom or issue.  What could have been done better: the oncologist would not at any stage give any estimate of anticipated prognosis when, clearly, he was in the end stages. This impacted on him negatively thinking incorrectly that he had longer to live and could delay certain decisions e.g., contacting other family and financial decisions, which increased his anxiety and worry later on.  We also experienced a lack of knowledge at different levels with different units giving conflicting advice.  Everyone from the GP to the ward nursing manager should not fail to ignore the patient as a human being. It does not take a specialist psychiatrist or psychologist or trained counsellor to broach these subjects, but someone with a heart, empathy and a desire that every person should be treated as someone from their own family. Life limiting diagnoses and the prospect of death should not be regarded as awkward conversations but as an essential element of any treatment pathway and indeed, one of the most important. |
| 128 | King’s College Hospital NHS Foundation Trust | Quality statement 2 (process) | Numerator: “proportion of adults approaching the end of their life who have discussions about advance care planning”. This should read “proportion of adults with expected deaths who are at end-of-life, have been offered discussions”.  Advanced care planning is not mandated and only offered clinically. It is voluntary and a patient or relative-led discussion- and there are incidents where these groups decline the conversation. Therefore, recording that it has been offered and declined by the patient/relative is also a valid numerator. |
| 129 | King’s College Hospital NHS Foundation Trust | Quality statement 2 (process) | **Denominator: “the number of adults approaching the end of their life”.**  The number of adults approaching the end of their life (the last year) is not an easily quantifiable statistic and shall vary according to speciality. Clinicians may offer a prognosis but often this is not entirely accurate, especially in chronic and long-term conditions resulting in an inaccurate denominator value.  Cheon et al. The accuracy of clinician’s predictions of survival in advanced cancer: a review. Annals of Palliative Medicine. 2015;5(1):22**-9-9.**<https://doi.org/10.3978/j.issn.2224-5820.2015.08.04>    White et al. Systematic review of predictions of survival in palliative care: how accurate are clinicians and who are the experts? PLOS ONE. 2016;11(8):e0161407. <https://doi.org/10.1371/journal.pone.0161407>    Glare et al. A systematic review of physicians’ survival predictions in terminally ill cancer patients. BMJ. 2003;327(7408):195–8. <https://doi.org/10.1136/bmj.327.7408.195>  We would suggest the use of the GSF question within primary care but also speciality medicine (those looking after LTC/chronic diseases) to attempt to identify patients not getting better and nearing the EOL. |
| 130 | King’s College Hospital NHS Foundation Trust | Quality statement 2 (process) | **Holistic needs assessment**  Even though there are validated tools available to assess holistic needs there is no robust system in place for ensuring that this is done in every clinical setting, nor in every specialty. Where it is done in some specialties there is no further system in place to ensure that needs identified using these tools are being addressed and met. Therefore, setting up systems for these would need to be the first step before it is used as a factor in measuring quality. Systems need to be place to review these holistic assessments as these are processes as well.  It would be advisable to offer holistic assessments to those patients with LTCs/chronic conditions within each Trust- e.g. The Comprehensive Geriatric Audit (CGA) would be a good example of this. |
| 131 | King’s College Hospital NHS Foundation Trust | Quality statement 2 (outcome) | It will be a challenge to measure this outcome because the number of adults approaching the end of their life is not easily quantifiable (denominator).  Clinicians may offer a prognosis but often this is not entirely accurate, especially in chronic and long-term conditions resulting in an inaccurate denominator value.  We would suggest the use of the GSF question within primary care but also speciality medicine (those looking after LTC/chronic diseases) to attempt to identify patients not getting better and nearing the EOL |
| 132 | King’s College Hospital NHS Foundation Trust | Quality statement 2 (outcome) | To measure the satisfaction of adults at the EOL:  Bereavement surveys may also be a useful data source for this outcome in addition to patient and carer satisfaction surveys. The medical examiner role may also have some valuable input here. How this has been implemented in Trusts can be variable. Post pandemic- Grief and bereavement processes have adjusted during this time. Covid has affected these processes regardless of cause of death. |
| 133 | King’s College Hospital NHS Foundation Trust | Quality statement 2 (outcome) | A numerator/denominator score is not going to measure the quality of advance care planning that is occurring simply that an ACP document has been filled in. Without statements that assure for quality advance care planning runs the risk of becoming a form-filling exercise. Quality over quantity imperative here.  What does ‘good’ advance care planning look like? It is voluntary, it is patient-led, it is holistic, it should be shared effectively with care providers across settings. The content of any advance care planning document should reflect all of these domains. Where a patient does not wish to proceed with advance care planning, they could consent to this document stating their wish to decline further discussion at this particular time. The offer should always be open-ended.  Patient education leaflets and a variety of resource and communication tools may increase yield/uptake of ACPs.  ACP should NOT exclude any form of access to care and treatment management that a patient maybe clinically or psychologically be deemed benefit from.  It might be very challenging to say what a ‘model’ ACP should look like- this is a process and whatever the document looks like- it needs to be flexible enough to adjust with the patient’s clinical course and the various MDT involved. |
| 134 | Macmillan Cancer Support | Statement 2  (Advance Care Planning) | Q1. Does this draft quality standard accurately reflect the key areas for quality improvement?   * In the main yes. However, the statement should make clear that Advance Care Planning (ACP) is a mechanism to document the outcome of shared decision-making on the end of life wishes of the person at end of life, with these decisions made through discussion between the person, their loved ones and professionals. * Statement should make clear and explicit that Advance Care Plans should be reviewed regularly. Professionals have told us that patients’ end of life care preferences can change over time. Macmillan Cancer Support (2019) At the Crossroads: How can the NHS Long Term Plan improve end of life care in England? * Whilst having an Advance Care Planning conversation with someone who is in their last year of life is the responsibility of all health and care professionals, service providers should ensure that, within a service, professionals with expertise in this area are known to other staff. Professionals have told us that in some places Health and Care Professionals do not have this information. Macmillan Cancer Support (2019) At the Crossroads: How can the NHS Long Term Plan improve end of life care in England? * Preferred place of care and death should be added to the list of what an Advance Care Plan discussion might include.   Q2. 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?   * We note that the Quality Standard makes multiple references to satisfaction measures. To ensure effective measurement of these measures the intended data source: “local patient and carer experience surveys” could be strengthened by a national level survey – such as the “National Survey of Bereaved People” (VOICES) resuming. The survey, which used to be published annually but has not had a new release since 2016, is a valuable document that tracks reported quality of end of life care in the last three months of life from the perspective of relatives and carers. * Data collection for proposed quality measures should also be supported through incentive frameworks and contractual leavers – for instance through the Quality Outcomes Framework (QOF), and the Cancer Outcomes and Services Dataset (COSD). This would encourage reporting on the quality improvement measure(s) within this standard. A QOF indicator focused on advance care planning would be useful, and feasible to code. * Local systems/structures could also be strengthened through a prioritisation of EOLC and through reporting regularly on related activity at a Sustainability and Transformation Partnership (STP) and Integrated Care System (ICS) level. In 2017, the End of Life Care Coalition analysed the plans for STPs in England and found that **41%** of them made no mention of, or provided little detail about, how end of life care would be improved in their populations.2019 analysis likewise found that the majority of provisional STP plans did not mention end of life care. Macmillan Cancer Support (2019) At the Crossroads: How can the NHS Long Term Plan improve end of life care in England? * **These points apply to all Quality Statements within the standard.**   Q4. Do you think the end of life care service delivery (excluding care in the last days of life) has substantially changed during the COVID-19 pandemic? Can you describe any positive changes that have been introduced as a result of the COVID-19 pandemic?   * Related to Advance Care Planning specifically, professionals told us during the first peak of Covid-19, that positive changes included staff being trained to have Advance Care Planning discussions. We also heard that, during the pandemic, Advance Care Planning discussions became more widespread, and focused on more by professionals * We heard how staff working in care homes have had to be rapidly upskilled in end of life care due to the high volume of patients who have been admitted and have died during Covid-19 – many (but not all) of these deaths have been of patients in the last days of life. This has meant that staff have had to have more Advance Care Planning conversations with residents, and difficult conversations with families and friends who have not been able to visit. Greater experience of such difficulty has led to an increase in the skill level of staff.   However, during the pandemic we also became aware of rare instances of Do Not Attempt Resuscitation (DNR) orders being poorly handled, not made on an individual basis and not made on a basis of patient consultation. NHSE has sent a letter to GPs, community providers and trusts reiterating this message, which Macmillan welcomes. Patient-facing information and resources would do much to support these efforts. Examples of poor DNR practice in England: Booth.R (2020) UK healthcare regulator brands resuscitation strategy unacceptable, The Guardian, 1st April. |
| 135 | NHS England and NHS Improvement | Quality Statement 2 - statement | The wording used in the 2011 quality standard better reflected a personalised, holistic approach to assessing and considering how to address individual’s needs and preferences through personalised care and support planning. It feels a lot has been lost by condensing the number of quality statements. Including only advance care planning in the quality statements loses some of the wider, personalised conversations that would be included in the holistic needs assessment. (PC) |
| 136 | NHS England and NHS Improvement | Quality Statement 2 - rationale | Rather than “patient-led” these discussions should be “personalised” and focused on what matters to the person. There should also be shared decision-making to support individuals to understand the different options for care and treatment, and the risks, benefits and consequences of these, enabling the person to make an informed choice. (PC) |
| 137 | NHS England and NHS Improvement | Quality Statement 2 - Service Providers | This section could better reflect the comprehensive model for personalised care e.g.  “The staff carrying this out are trained to have these personalised, patient-led discussions, to facilitate shared decision making, and to help the person to develop an advance care plan, taking into account areas important to them identified in the holistic needs assessment.” (PC) |
| 138 | NHS England and NHS Improvement | Quality Statement 2 - Health and social care practitioners | It feels a little passive to say “give adults approaching the end of their life opportunities to discuss advance care planning”. Practitioners should be more actively ensuring that these conversations take place. (PC) |
| 139 | NHS England and NHS Improvement | Quality Statement 2 - Adults who are likely to be approaching the end of their life | It feels a little passive to say “are given opportunities to talk to health or social care staff about the things that are important to them and use this to help plan for the care and treatment they want in the future.” This could be phrased more actively e.g. people are supported to have these discussions. (PC)  Additionally, the conversation should include what “support” they want in the future, to reflect their wider wellbeing needs. (PC) |
| 140 | NHS England and NHS Improvement | Definition of Advance care planning | The discussion should include consideration of what is important to the person and include not just future care needs, but also wider support to meet wellbeing needs. Suggest final sentence on personalised care and support planning in relation to ACP is moved and put at the beginning of this Quality Statement. The bullets are very focused on care needs, but this should be broader e.g. the person’s values and goals might not relate just to their care, but to their life. And their wishes about their care and treatment should also extend to wider support. (PC) |
| 141 | NHS England and NHS Improvement | Statement 2 Definition of Holistic Needs Assessment | Not just about the negative of thoughts/concerns, but also about ensuring what works well for the person is understood and continues to happen. (PC) |
| 142 | NHS England and NHS Improvement | Statement 2 Equality and Diversity Considerations | Accessibility of information also needs to take into consideration levels of health literacy. (PC) |
| 143 | NHS England and NHS Improvement | Statement 2 Equality and Diversity Considerations | Does there need to be reference to ACP for people who lack capacity here? (PC) |
| 144 | NHS England and NHS Improvement | Statement 2 | This statement is achievable. In organisations they are progressing ACP discussions as part of EoL template wider organisational work around how this is recorded by all services and training to support clinicians with approaching ACP conversations. (N&M) |
| 145 | NHS England and NHS Improvement | Statement 2 Quality measure Structure  Process | This is a key area for improvement. Should the item not also include the need to record, as if the discussion is not recorded it cannot be communicated to all members of the care team  The numerator – there is an issue with this as undertaking advance care planning is voluntary, not mandated. So, whilst the measure will give some indication – should it not be the number who have been offered opportunity? (N&M) |
| 146 | NHS England and NHS Improvement | Statement 2 | Suggest this is more ‘person-led’ than ‘patient-led’ as they may be a variety of settings and consideration needs to be given to when the person is not “still fully able to communicate” their wishes to ensure care continues given the changing situations the person and their family/may find themselves in. “ensures” is also a strong word here and suggest maybe that advanced care planning is only (as it eludes) the planning stages so this ‘supports’ not ensures delivery of as this relies upon a number of other factors. (N&M) |
| 147 | NHS England and NHS Improvement | Statement 2 | Suggest this is more than simply training people to assess but providing staff with the correct skills, education, training, support and tools to carry out the role effectively and to empower the person and their family/carers to plan to meet their needs and not the needs of the system. (N&M) |
| 148 | NHS England and NHS Improvement | Statement 2 Process data source numerator | Need to consider how it will it be judged the advance care plans takes into account a holistic needs assessment? This will be difficult to articulate and measure and not critical to this standard. (N&M) |
| 149 | NHS England and NHS Improvement | Statement 2 Definition of Advance care planning | There is the potential for confusion here. There are a range of devices that people, and professionals can equate with ACP. Would for example completion of a ReSPECT - a form of emergency care and treatment plan or a Treatment Escalation Plan as oppose to an ACP - count as ACP (N&M) |
| 150 | NHS England and NHS Improvement | Statement 2 (definition) | In the definition of advance care planning, it is important to emphasise that this is planning in anticipation of future loss of mental capacity. The person must be assured that whilst they have mental capacity, their contemporaneous views will always over-ride any previous views they have expressed in an advance care plan, and that they can always change their mind. This avoids people being frightened of ‘locking’ themselves into statements or decisions about future care. **(BW)** |
| 151 | NHS England and NHS Improvement | Statement 2 (measure) | Strongly agree with this statement: Adults approaching the end of their life have opportunities to discuss advance care planning. If the number having these conversations is to be measured, correct and consistent coding needs to be used. (10 Care) |
| 152 | NHS England and NHS Improvement | Statement 2 (measure) | Again, strongly agree with this statement: Proportion of adults approaching the end of their life whose advance care plan takes into account their holistic needs assessment. Collection of this data may be hard to measure as this type of information is not usually coded. It may therefore require manual audit of notes (which has capacity implications). (10 Care) |
| 153 | North West Boroughs Health | Statement 2 Pg.8  1stparagraph | There should be a reference to a person’s capacity to make decisions and if capacity is in doubt to ensure capacity assessments are completed. If the person lacks capacity, reference Best Interest decisions, LPA and plans for future care. |
| 154 | North West Boroughs Health | Statement 2  Pg.9 last paragraph | “Staff carrying out ACP should be trained”. Could the term “Skilled” be used instead of “trained”? |
| 155 | North West Boroughs Health | Statement 2  pg. 12 | ACP information in different languages. Can this be developed nationally, the principles of Advance Care Planning is the same and is not dependent on the language you speak. This would avoid the need for significant financial investment. Can links to resources be included within this guidance? |
| 156 | Rowcroft Hospice, Devon | Statement 2 | It would be great to see a measure that captures peoples view on whether they have had a quality discussion/s about their future care with a relevant health/social care professional. |
| 157 | Royal College Of Nursing | Statement 2  (rationale) | Suggest adding the highlighted: Advanced Care Planning (ACP) gives people the opportunity to have meaningful patient-led discussions around “What Matters to Me”, supporting them to make specific decisions… |
| 158 | Royal College Of Nursing | Statement 2  (equality and diversity considerations) | Should have some reference to accessibility across all environments i.e. prisons, secure hospitals, accessibility for the homeless. |
| 159 | Royal College of Occupational Therapists | Statement 2 | Adults approaching the end of their life have opportunities to discuss advance care planning.  Health and social care practitioners (including occupational therapists) must give adults approaching the end of their life opportunities to discuss advance care planning that take into account their holistic needs assessment. They ensure that advance care planning is an ongoing process, and that advance care plans are reviewed as the person’s condition, circumstances or wishes change.  Adults approaching the end of their life are given opportunities to talk to health or social care staff about the things that are important to them and use this to help plan for the care and treatment they want in the future. Occupational therapists have a key role in identifying priorities and helping the person to set occupational goals i.e. those activities that they want or need to do. |
| 160 | RCP | Statement 2 | Developing the skills, systems and culture for advance care planning conversations and documentation will be central to achieving these standards. This will require considerable skill development by many clinical professionals, and a more proactive approach identification of people approaching the end of life in all care settings to start or continue advance care planning conversations. It will also require public campaigns to increase the expectation and understanding in patients and families of the place of advance care planning. Consistent local systems for documentation and transfers of information across care settings, specifically related to advance care planning conversations are required. Easy access to those systems in all care settings is also essential |
| 161 | Royal Pharmaceutical Society | Statement 2 | An opportunity to develop and advance care plans on the future nature of their care should always be available to those approaching the end of their life. We are therefore wholly supportive of the addition of this new quality statement.  When an advance care plan is in place, sharing this with the pharmacy team would help to ensure that persons and their families have increased access to support from the pharmacy team and that decisions about their medicines can be discussed. The pharmacist would also be in a more informed position to assist colleagues such as nurses paramedics who may require more information to enable them to treat the person in their own home.  Similarly, to the practice of sharing information on diagnosis discussed above, our survey of pharmacists in Wales indicated that details of advance care plans are seldom communicated to pharmacists. When asked if they had ever seen any advance care plans for their patients, 81 per cent of respondents stated that they had not.  To maximise the benefits of advance care planning, plans should be shared with all relevant health and social care professionals, including pharmacists. |
| 162 | South West End of Life Network | Statements 1, 2 | Could the statements reflect the need to be proactive in recognising and finding out preferences, rather than something ad hoc, that may or may not happen? |
| 163 | South West End of Life Network | Statement 2 | Advance care planning is important. Could we also mention the importance of finding out what matters "now"? This may well have a more significant impact on the quality of life in the last days, weeks, months and years of life, than the presence or absence of an advance care plan. And it’s never too early to find out what matters “now”. |
| 164 | South West End of Life Network | Statement 2 | “Advance care planning” isn't always fully understood. Perhaps consider rephrasing to consider plans and preferences, and how these will be listened, and adhered to, where possible. |
| 165 | South West End of Life Network | Statement 2 | Do we need to say that people have a written plan (often people do not have one), or rather we can evidence that a quality conversation has taken place? |
| 166 | The GSF Centre in End of Life Care | Statement 2 Question 1 | **Overall we strongly support and are pleased to see that ACP (Advance Care Planning ) is a top priority but suggest also needs a broader concept of non-medicalised ACP public discussion.**   * From Page 8- **Greater public awareness** **and ‘de-medicalise’/ normalise ACP discussions** Although excellent to include and mainstream ACP here, also need to raise greater public awareness of the importance of such discussions for families and carers to have such a discussion , before that of care providers , and ‘de-medicalise’ the topic so that it becomes normalised as part of general public behaviours, social care staff and healthcare providers . (as in GSF ACP 5 Steps below and video , guidance , leaflets below) . Our experience for example in mainstreaming ACP in Retirement Villages does not mean HNA precedes this discussion .It is suggested that ACP follows holistic needs assessment (HNA) – though often useful in a medical context , this should not just be restricted to this conversation , but ACP discussions should occur as part of greater public awareness , often before discussions with health/social care providers begin ?   **At GSF we developed 3 levels of ACP uptake , and seek all hospital wards to attain at least up to Level 2 (which over 90% do) ie successfully implemented across all areas ie**   1. **Level 1** ACP- offered ACP discussion to identified patient / person + given information leaflet (Planning your Future Care or GSF 5 Steps to ACP) 2. **Level 2 ACP** - to have recorded the 3 key things for urgent emergency care (eg if ambulance comes ) and these 3 things to be included on EPaCCs ie    * **DNAR- resuscitation discussion or Respect form**    * **LPOA- Lasting Power of attorney/ nominated spokesperson**    * **PPC- Preferred Place of care** 3. **Level 3 ACP** - to have a full ACP discussion completed and recorded either virtually or in paper but to be included on EPaCCs data  * **ACP after HNA?** Should the HNA always precede the ACP discussion – maybe’ could’ not should in line 8 * **Page 11- Definition of ACP needs to include LPOA/ spokesperson ‘ who will speak for you if you can no longer speak for yourself –** need to add nominated proxy spokesperson or Lasting power of attorney (LPOA ) or ‘substitute decision maker’ . NB many international examples quoted in the OUP book suggest that this element is the most important in a crisis and should ALWAYS be included in ACP discussions (not always next of kin) eg in ACP Australia * Advocacy of key spokesperson of relative is included in the Mental Capacity Act Section 4.1 , and this is also something recommended as best practice through Dying Matters   (page 11) ACP definition – ‘Advance care planning is a voluntary process of discussion about future care between an individual and their care providers, irrespective of discipline. This does not include the fact that ACP discussions could be **within families before involving healthcare** so should be extended to include this area, especially since COVID has demonstrated that decline can be rapid and not easily predicted in the usual way. |
| 167 | The GSF Centre in End of Life Care | Statement 2 Question 2 data and measures | **Measures -some confusing ,maybe not feasible** **and suggestions**   * I think measure b) is confusing (page 9) – ie ACP taking into account HNA/nos ACP undertaken - am not certain what this means as the definition of ACP should include preferences and needs ? * Outcome Measure (page 9 )numbers satisfied/numbers identified is not really feasible as difficult to ensure satisfaction is accurate and consistently measured. * There are some new developments in the concept of ‘ **goal concordant care ‘** which imply care provided/ outcomes in line with people’s preferences eg <https://www.liebertpub.com/doi/pdfplus/10.1089/jpm.2017.0459>   So care or dying in preferred place of care is one measure but there are others more generally in line with goal concordant care |
| 168 | The GSF Centre in End of Life Care | Statement 2 Question 3  Resources | **Resources**  – workforce training needed in communication skills , confidence , ability to use ACP tools   * And recording of outcomes measures in EPaCCs – needs to ensure these are functional in each area with good inter-operability , and that include hospitals , primary care , social care etc * Hospices may need suppotri8ng as they can support improved integration in their area(in our experience working with many hospices – we have 17 hospices functioning with us as GSF Regional Training Centres across the country , leading on delivering GSF raining along with other educational initiatives as centres of excellence in their areas . See eg NE Essex, Jersey etc ) <https://goldstandardsframework.org.uk/regional-training-centres> * NHSE Enhanced Health in Care Homes (EHCH ) and recommendation to include ACP for all care homes residents needs greater support and workforce training in ACP provided by care homes |
| 169 | The GSF Centre in End of Life Care | Statement 2 Question 4  COVID | **Covid** has helped to   * Improve GP and care homes collaborations in many cases , though other care homes have felt abandoned and alone in the pandemic * **emphasise the importance of advance care planning** discussions – the need to have undertaken these for all residents in care homes , at home etc , * the negative impact and issue of some blanket DNAR practice across areas , highlighted and rejected by RCGP , CQC , * the NHSE Enhanced Health in Care Homes work to increase advance care planning in care homes is excellent and even more relevant now with COVID * and the need for **the general public awareness of undertaking ACP** ie to be involved earlier (as COVID has a rapid acceleration) etc * so the time seems right to mainstream ACP both in public arena (eg Dying Matters and other campaigns ) an as a measure of good practice   see also example of this in care homes with SURVEY FEEDBACK - how GSF trained care homes found GSF helped them undertake ACP with all residents ,which greatly helped during the COVID crisis - see attached |
| 170 | The GSF Centre in End of Life Care | Statement 2 Question 6 | **Additional resources and examples**   * **GSF ACP 5 Steps video ,** guidance , leaflets etc (taught within GSF programmes but also freely available ) <https://www.goldstandardsframework.org.uk/advance-care-planning> and you tube <https://www.youtube.com/watch?v=mPtu-FpY1Kw> * ‘Advance Care Planning in End of Life care’ OUP Book 2018 Ed Keri Thomas , Lobo, Deterring , Chapter 1 Overview of ACP * ACP Australia <https://www.advancecareplanning.org.au/> or substitute decision maker <https://www.advancecareplanning.org.au/about-us/news-case-studies-and-blog/case-study-community-discussions> * See COVID GSF Care Homes Feedback Survey attached to email |
| 171 | The GSF Centre in End of Life Care | Statement 2 Additional note | Page 8 Line 6 suggest to use ‘person-led’ not patient -led as includes people who are not ‘ patients ‘ eg living at home receiving domiciliary care / Retirement village etc  Page 9 last line again ‘person-led’ not patient led |
| 172 | The Law Society | Statement 2 | Comments on the draft Quality Statement 2: Adults approaching the end of their life have opportunities to discuss advance care planning. [new 2021]  This response focuses on Statement 2 of the National Institute for Health and Care Excellence draft quality standard relating to end of life care for adults.  In principle, we agree that this quality statement accurately reflects the key areas for quality improvement with regard to advance care planning.  Nevertheless, our support is conditional on the below points:  Specificity of Advance Care Planning  Any reference to advance care planning should be specific, as in practice it is often assumed that no one has a Health and Welfare Lasting Power of Attorney, or advance decisions in place. It often seems to be focused on “Do Not Attempt Cardiopulmonary Resuscitation” decisions, and depending on the location of decision, completion of a ReSpect form.  It is also assumed that that Advance Care Planning is only relevant to those who currently have capacity to participate in decision-making, when it can be just as important for those whose who do not now (or indeed perhaps ever) had such capacity.  There should therefore be clear guidance so as to ensure that there is identification of  a. Whether the person has previously undertaken any advance care planning;  b. Whether they have appointed a Health and Welfare Lasting Power of Attorney and (if so, what the powers of that attorney might be, because not all will have the power to make decisions about life-sustaining treatment)  c. If the person does not have capacity to participate, whether there is an Attorney or Deputy to consult and/or others interested in their welfare.  Any discussion of advance care planning must always be on the adult’s own terms, so that such planning is always done with, and not to the person. This applies equally for those lacking capacity to participate, who should always be encouraged to participate insofar as possible. If they cannot, then their wishes, feelings, beliefs and values will need to brought into the making of recommendations through (if relevant) an attorney or deputy and those interested in their welfare.  Additional Comments  We suggest that ‘having opportunities to discuss’ may not go far enough, as it does not necessarily impose a requirement to provide advice and information on advance care planning. In our view, it would be preferable to have a requirement to discuss and for it to be advisable to ensure this is as clear and effective as possible. |
| Statement 3 | | | |
| 173 | Association for Palliative Medicine | Page 12 Quality statement 3 | Data not always easy to collect. Voluntary organisations may be able to provide some of this information. |
| 174 | Association of British Neurologists | Statement 3 | There is an specific problem with statement 3  - support for carers. This is an important QS however the carer is not the patient of the same service as the person approaching end of life. Therefore there will be no documentation of support they are offered. |
| 175 | British Association of Social Workers | Statement 3 | Members raised the following points:  Support for carers should be considered within the standard. It would be helpful to have clarity around carer’s rights. Furthermore, carers need to be asked if they are both willing and able to continue within their caring roles, and consideration should be made to risk and impact.  Service users must be recognised within their context and what matters to them  Questions must be asked with regards to what the best way is to carry out the assessment with the care based on the way they want it to happen, with a non-judgemental approach.  Finally, equality and diversity considerations must be taken account of. It is imperative that the health and cultural needs of Black and Minoritised carers are considered – a stronger statement in relation to this crucial area is needed. |
| 176 | British Geriatrics Society | Statement 3 | Vital and requires evidence of the assessment tools and pathways across services to support carers including the role of the third sector - |
| 177 | Faculty of Intensive Care Medicine | Statement 3 | At a superficial level this may be interpreted as being of limited concern to Intensive Care Medicine, however “transfer home from ICU for EoLC” is not an alien concept and as a consequence of the COVID-19 Pandemic where mutual aid and transfer services have escalated; one potential role of any (future funded) intensive care transfer service could include an increased incidence of transfer home for EoLC |
| 178 | Greenwich & Bexley Community Hospice | Statement 3 | At present there are not joined up processes to record carers of people at end of life as a specific and discreet group, systems between local authorities, primary care, hospices and community services as well as the wider voluntary sector will need to be established to enable this monitoring. |
| 179 | Greenwich & Bexley Community Hospice | Statement 3 | At Greenwich & Bexley Community Hospice we are currently involved in a pilot project with management of ASC pathways having been commissioned to a voluntary sector consortium. This includes information, advice and guidance through a single point of access as well as a significant number of statutory carers assessments (LB Bexley). This could be an opportunity to test out systems to measure impact. |
| 180 | Hospice UK | Quality Statement 3  General | We are pleased to see the specific inclusion of a quality statement on support for carers. The role of informal carers is key to successful end of life care for people dying at home, and this has been additionally emphasised throughout the pandemic. |
| 181 | Hospice UK | Quality Statement 3  Measures | The quality measures assume a level of data that unfortunately is not currently in place. In both Numerator/Denominator examples the denominator is ‘the number of carers providing end of life care to people at home’ – as it stands the number of carers providing end of life care is an estimate at best, local systems do not necessarily collect this data routinely and effectively. A particular consideration is that people with caring responsibilities for someone approaching the end of life may not self-identify as being a ‘carer’, and therefore are likely to be unknown to the health and care system. |
| 182 | Hospice UK | Quality Statement 3  Measures | Suggest that to bring this draft quality standard in line with NICE guideline NG150 supporting adult carers (specifically recommendation 1.3.1.) and the Care Act 2014, a separate measure is included to ensure that carers for people at the end of life receive a full carer’s assessment. Without the comprehensive holistic needs assessments outlined in the 2011 quality standard and NG150, carers will miss out on accessing support which is appropriate to their needs, detrimentally affecting their own wellbeing in addition to the experience of the person they are caring for. |
| 183 | Kidney Cancer Support Network | Statement 3 | **Carers providing end of life care to people at home are supported to access local services that can provide assistance. [new 2021]**  All I can say is thank heavens for Google. No information given initially by GP, oncology unit, AMU, or even by the stroke unit. We visited the local Macmillan centre and were given a handful of leaflets and financial advice, which was not needed nor requested. I registered for Carers Support but was only contacted three weeks later.  He was discharged from an acute stroke unit 4 days prior to Christmas and despite acknowledging that a Fast Track Care package was required after a physio and OT assessment, we were then advised that “Christmas was not a good time” and that we would need to manage by ourselves until the New Year (this turned out to be over two weeks later).  There was confusion also as the hospital was in a different county (Hampshire) to our GP and home (West Sussex), and no referrals could be made across counties and only to the GP, apparently.  The GP finally came out on Christmas eve and with no warning produced an “end of life medication package” of midazolam and morphine for “just in case the community nurses need it over Christmas”. He then gave us details of ECHO to contact as no one from the GP practice would be available over the festive period.  I set up Careline for fall alarms, panic button, a carer’s card and key safe – amazing service.  I purchased a walker, commode, shower stool, urinal, incontinence pads, remote cameras, etc. via Amazon.  Once our local hospice became involved on 2 January, support was more accessible. At this stage we were informed about basics like a Blue Badge, Carers Support and a hospital bed and pressure mattress were ordered.  We were contacted by the West Sussex Physio and OTs on 8 January, who came out, saw that everything had already been done, had no further suggestions and left. |
| 184 | King’s College Hospital NHS Foundation Trust | Quality statement 3 (structure) | Supporting Carers: From a systems point of view- there needs to be mapping of what is available locally for each Trust and community providers.We would like to suggest that the initial evidence that needs to be provided for this quality standard is whether service providers have mapped out the local services available to support carers as a first step.Are they also aware of the gaps in services to support carers in their area?The next piece of evidence for quality is whether they have a system of regularly updating a ‘directory’ of these services. The next level of evidence could be that all healthcare professionals are aware of this directory of these local services to support carers in order to signpost carers to them. |
| 185 | King’s College Hospital NHS Foundation Trust | Quality statement 3 (outcome) | Some level of role out of awareness of carers needs/ relative experience.Examples of a validated tool to formally assess carers need is the Carers Support Needs Assessment Tool (CSNAT), Adult carers quality of life questionnaire (AC-QOL) and Zarit Carer Burden Inventory. https://www.england.nhs.uk/publication/the-carer-support-needs-assessment-tool-csnat-for-use-in-palliative-and-end-of-life-care-at-home-a-validation-study/ |
| 186 | Macmillan Cancer Support | Statement 3  (Support for Carers) | Q1. Does this draft quality standard accurately reflect the key areas for quality improvement?   * When highlighting what the statement means for different audiences, the statement would benefit from explicitly referencing Continuing Healthcare Packages as one of the ways in which care for patients can be provided in the home, and thus be of assistance to carers.   Q2. 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?  Current systems and data coding do not allow for a distinction between a carer supporting a person at end of life, and a carer in general. This distinction is not currently made in primary care for example. Data collection would be enhanced if services were supported to make this distinction in their data reporting activity.  Q4. Do you think the end of life care service delivery (excluding care in the last days of life) has substantially changed during the COVID-19 pandemic? Can you describe any positive changes that have been introduced as a result of the COVID-19 pandemic?  Professionals have explained to us how the increased demand for end of life care in the home has meant that in some cases family members take on the responsibility of providing more care, but not always with the right support in place.   * Carers’ Assessments can help with advice and support for carers; but pandemic pressures have resulted in no face-to-face assessments taking place and reassessments being put on hold. Care Act Easements brought in during the pandemic may have resulted in local variation, with local authorities now able to reduce the depth and extent of assessments. Carers UK (2020) Help and Advice, Getting an Assessment; DHSC (2020) Care Act easements: guidance for local authorities, Updated 1 September. |
| 187 | Marie Curie | Statement 3 Question 1 Does this draft quality standard accurately reflect the key areas for quality improvement? | The draft quality standard broadly reflects the key issues in end-of-life care – identifying people who are approaching the end of life, providing opportunities for people to discuss advance care planning, supporting carers, ensuring coordination between health and social care services and ensuring adequate support at all times for people at the end of life.  Marie Curie is broadly supportive of the quality statements outlined in this standard. However, we are concerned that carers are not adequately served by the draft Statement 3 in its current form. On the whole, this represents a worsening of the position for carers than the 2011 version of the Quality Standard where carers were reflected across several of the standards; in this draft only one Quality Statement covers the needs of carers and it is incomplete.  Ensuring carers of people at the end of life are appropriately supported is vital to the experience of the dying person. Statement 3 as it is currently drafted refers only to supporting carers to access local services – there are no quality measures in the draft Statement 3 on the need to identify carers and assess their needs. We know that carers’ needs are often not assessed, and even in specialist palliative care, caregivers often feel overlooked or lacking information. In order to effectively support carers, they must be identified, and a carers’ needs assessment undertaken.  In addition to the identified quality measures under Statement 3 an additional quality measure should be included – the number of carers identified and carer assessments carried out. This should support an objective in Statement 3 in line with the position in the 2011 version of the Quality Standard - stating that carers should be offered comprehensive holistic assessments and holistic support appropriate to their needs and preferences.  There is a clear body of literature demonstrating the benefits of carer assessment, showing that carers whose needs are assessed – for example via the CSNAT intervention . A recent study found, for example, that carers’ assessments using CSNAT had a positive effect on carers’ well-being, reduction of distress, interaction with healthcare professionals and their involvement in healthcare decisions . Similar findings have been reported in the UK and Australia. |
| 188 | Marie Curie | Statement 3 Question 3 | To meet the proposed additional quality measure for Statement 3 – a measure of carers’ assessments conducted and carers identified – resource would be required to ensure such assessments are completed. Rollout of tools such as the Carer Support Needs Assessment Tool (CSNAT) would support local providers in achieving this measure.  There are also not enough services in communities catering for the needs of carers, so even if assessed, it will take resource to develop local services to meet the quality standard in Statement 3. |
| 189 | Motor Neurone Disease Association | Statement 3 Question 1 | We agree that a focus on carers would be appropriate. The National Audit for Care at End of Life (NACEL) showed that 58% of families and others felt their needs were asked about, and 66% of families and others felt that they had enough emotional and practical support. These figures still leave a significant percentage of others feeling otherwise. We hope Statement 3 will assist in improving the situation for carers.  The Quality Standard should also go further to ensure that information can be shared across and between services. |
| 190 | Motor Neurone Disease Association | Statement 3 (audiences) | Although it might not fall within the scope of this Quality Standard, we wondered if there should be a greater focus on making carers aware of other services such as replacement/respite care and also making them aware of bereavement support. |
| 191 | Motor Neurone Disease Association | Statement 3 (audiences) | There seems to be a focus on providing emotional and practical support with the primary aim of enabling the carer to provide care. However, we think there is a need to provide support to meet other needs that carers have in their own right, such as their own wellbeing or financial security, that will also impact on being able to provide care at end of life. |
| 192 | National Bereavement Alliance | Statement 3 – support for carers | While we welcome the inclusion of the statement on support for carers, we are disappointed that this is not extended into bereavement support. We believe that this represents a very problematic de-prioritisation of bereavement care, given that the QS will be replacing the existing QS13 on End of Life Care for Adults, which includes a specific statement on bereavement care. This is likely to have an adverse impact on the priority which commissioners are able to give to bereavement care, which is already an underfunded and patchy area of provision.  Bereavement is associated with risks to health and wellbeing, increasing the risk of mortality, physical health problems, physical disability, use of medication and hospitalisation ([[1]](#endnote-1)). Widow(er)s ([[2]](#endnote-2)) and children bereaved of a parent ([[3]](#endnote-3)) are more likely to visit their GP.  In Scotland in 2011, the annual cost of hospital stays associated with the death of a spouse was estimated at £20 million ([[4]](#endnote-4)) – we estimate that across England in 2019-2020 (before the pandemic) this would equate to annual costs somewhere between £180m and £260m. The figure would be much higher if it included the impact of the death of a child, parent or someone else close, and the costs of increased use of other health and social care services and days off work or away from school.  While many people are resilient and regain their equilibrium, many experience impacts on their physical and mental health and functioning. This can include high levels of distress for a period of time, including disturbing memories of the events leading up to the death or the death itself, blaming others for the death or feelings of remorse for their own past behaviour. Those bereaved in ways that are unexpected and shocking may also face often acute health and safety needs in the immediate aftermath of the death.    A minority of people experience high levels of distress and chronic grief symptoms that persist in impacting on their lives for a substantial period ([[5]](#endnote-5)) . Around 10% of the general population of bereaved adults are likely to suffer ‘complicated’ or ‘prolonged’ grief following a death ([[6]](#endnote-6)) (these collections of difficulties are distinct from, but often found alongside, other mental health disorders such as depression, anxiety and PTSD): rates are likely to be higher among those bereaved of a child, or following a traumatic death ([[7]](#endnote-7)).  Before the pandemic, between 20 and 30% of bereaved adults were not getting the support that they would like from organised services - beyond their family and friends ([[8]](#endnote-8) [[9]](#endnote-9)). There is evidence that those in greatest need may be more reluctant to seek help ([[10]](#endnote-10)). National monitoring data on access to bereavement services for particular groups is lacking, but evidence from similar health and social care services (palliative care and mental health services) suggest that there are particular barriers to accessing support for those from ethnic minorities ([[11]](#endnote-11) [[12]](#endnote-12) [[13]](#endnote-13)).  The pandemic has highlighted and exacerbated these pre-existing pressures. Interim findings from recent survey of 532 people bereaved during the pandemic (through any cause of death) has found that 45% of bereaved people were not contacted by the hospital or care provider after the death and 51% were not provided with any information about bereavement support.  This demonstrates that even the minimum standard of care outlined in QS13 is not currently being met for around half of respondents.  If no statement on bereavement care is included in this quality standard, we risk the standard of bereavement care slipping even further down the agenda, and a greater proportion of bereaved relatives being left without preparation for the death (where possible), practical support in the immediate aftermath, information about grief, and signposting and provision of emotional support services for those that need them. This will de-prioritise the preventative support that bereavement care can provide, increasing the burden on bereaved families, on schools and employers, and on mental health services for those whose needs escalate. Including a statement on bereavement care in the quality standard could help to reduce the risk of anxiety, depression, PTSD and Prolonged Grief Disorder among bereaved families.  We would welcome the opportunity to work with the committee to develop a suitable statement to ensure that bereavement retains a crucial focus within end of life care. |
| 193 | NHS England and NHS Improvement | Quality Statement 3 | Do we need to clarify this as “unpaid” carers? Is this just intended to provide support to people with their caring responsibilities? This could be broader, to include carers and important people that are providing support to the patient at home. (PC) |
| 194 | NHS England and NHS Improvement | Quality Statement 3 Section (whole section) | Lacks reference to pre- and post-bereavement support (PC) |
| 195 | NHS England and NHS Improvement | Statement 3 What the quality statement means for different audiences | The examples of possible support focus on the practicalities of caring for someone at home. What about the wider practical impact e.g. access to benefits? Or examples of emotional support e.g. peer support networks, counselling, pre-bereavement support etc. (PC) |
| 196 | NHS England and NHS Improvement | Statement 3 Definitions of Carers | Would this benefit from insertion of the term “unpaid” to help distinguish between formal and informal carers (PC) |
| 197 | NHS England and NHS Improvement | Statement 3 Equality and Diversity Considerations | Accessibility of information also needs to take into consideration levels of health literacy. (PC) |
| 198 | NHS England and NHS Improvement | Quality statement 3 | Should this not also consider that needs have been asked about not just supported – to ensure the element of personalisation and assessment is included? (N&M) |
| 199 | NHS England and NHS Improvement | Statement 3 Data source b) carers quality of life | This is the first place in this statement that the term quality of life is used. In rationale section the term well-being is used. These are different conceptually. It would be useful to clarify what is the outcome of interest that aligns with the statement best. This outcome is not routinely collected at present in the majority of services and it is not an easy outcome to collect. It requires unless a process and survey tool for surveying carers before the patient’s end of life unless a retrospective measurement after death is judged adequate. As most data collection is focussed on an after death to capture experience and satisfaction with service provision, as oppose to a carer’s quality of life. The data source description with emphasis on adult social care assume the patient will be in receipt of social care. – they may not, but the carer still require support. (N&M) |
| 200 | NHS England and NHS Improvement | Statement 3 | “process of discussion” infers a linear and possibly single discussion which may lead to individuals missing the point of these discussions, further consideration as to the text here would be beneficial as extremely important to the standards. Reference again to addressing people’s concerns are highlighted in holistic assessment section, there may be areas that cannot be addressed so giving reference to this would be beneficial also to support practitioners from feeling they have to remedy everything rendering the task meaningless. (N&M) |
| 201 | NHS England and NHS Improvement | Statement 3 | Does this apply only to carers providing care at home and not those who continue to provide care to those in care homes or hospitals etc as this would severely disadvantage some? In the quality measures also the term ‘helped’ is ambiguous and suggest would need clarity – supported may be a better term. Is there also consideration as to the variance in outcomes and themes for learning as focusing upon the proportion who are satisfied may lead you to miss the true value in a smaller number who are dissatisfied or ambivalent, but this may have a profound impact? (N&M) |
| 202 | NHS England and NHS Improvement | Statement 3 | Suggest there is a role for commissioners in ensuring that commissioned services work in an integrated and cohesive way. Include ICS’s as an example also. (N&M) |
| 203 | NHS England and NHS Improvement | Statement 3 | ED&I – suggest carers must be provided with information in a way that is appropriate for them and not “should”. (N&M) |
| 204 | NHS England and NHS Improvement | Statement 3 (measure) | Any information and support to both patients and carers needs to be offered in different formats taking into account IT literacy, language, culture etc (10 Care) |
| 205 | NHS England and NHS Improvement | Statement 3 (measure) | Support should be available 24/7 (10 Care) |
| 206 | Rowcroft Hospice, Devon | Statement 3 | We suggest considering how this statement relates to inpatient care also. Being in hospital or other inpatient care settings does not automatically mean carers have access to services they require to support them in their caring role. |
| 207 | Royal College Of Nursing | Statement 3  (measures) | CSNET tool used to assess carer strengths and needs is recognised as a valuable resource used to understand these issues more fully.  (Ewing G and Grande GE. Providing comprehensive, person-centred assessment and support for family carers towards the end of life: 10 recommendations for achieving organisational change. London: Hospice UK, 2018) |
| 208 | Royal College of Occupational Therapists | Statement 3 | Carers providing end of life care to people at home are supported to access local services that can provide assistance.  Occupational therapists provide carers with emotional and practical support to care for the person approaching the end of their life, for example providing palliative care at home and help to use equipment and adaptations.  Occupational therapists have a unique role within palliative care as their dual training in physical and mental health enables them to support people through their illness and any resulting disability.  In recent years there has been an increased awareness of the importance of palliative rehabilitation as an aspect of palliative care.  Palliative rehabilitation is a whole-team philosophy for use with people at end of life which integrates rehabilitation, enablement and self-management. It ensures that the individual is supported in living life as fully and meaningfully as possible, until the end of life.  This aligns well with occupational therapy's core philosophy of enabling and enhancing a person's engagement in meaningful and purposeful occupations to improve their health and well-being.  Position statement from World Federation of Occupational Therapists (WFOT):  Death is an unavoidable and natural conclusion of life, and occupational therapy practitioners have a unique role in supporting participation in desired occupations for people who are dying and their families.  Occupational therapy practitioners understand the transactional relationship between person, environment, and occupation to support ongoing performance in desired occupations that promote quality of life for people who are dying, as well as for their loved ones (Pickens, O’Reilly, & Sharp, 2010).  Regardless of clients’ life expectancy, occupational therapists provide a unique service that enables function, comfort, safety, autonomy, dignity, and social participation through engagement in occupation.  <https://wfot.org/assets/resources/Occupational-Therapy-in-End-of-Life-Care.pdf>  Measuring the Efficacy of Occupational Therapy in End-of-Life Care: A Scoping Review: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7018467/>  Professional perspectives of rehabilitative palliative care: <https://www.hospiceuk.org/what-we-offer/clinical-and-care-support/rehabilitative-palliative-care/professional-perspectives-of-rehabilitative-palliative-care/palliative-care-occupational-therapist>  Improvement Hub » The Route to Success in End of Life Care – Achieving Quality for Occupational Therapy:  <https://www.england.nhs.uk/improvement-hub/publication/the-route-to-success-in-end-of-life-care-achieving-quality-for-occupational-therapy/>  Occupational therapists have a key role in identifying priorities and helping the person to set occupational goals. The role will also include facilitating the person to die at home, if this is their choice.  The social care framework highlights that if people can stay in their own homes for longer they are likely to retain better quality of life right up until the point of death.  For many people, their home is their care home, so enabling people to remain or return there is important.  Occupational therapists working in acute care will have a key role in discharge planning;  those working in social services, in assessing for and recommending housing adaptations,  if appropriate. This role requires effective coordination and liaison with other services once the person’s permission has been obtained.    <https://www.england.nhs.uk/improvement-hub/wp-content/uploads/sites/44/2017/11/End-of-Life-Care-Route-to-Success-Occupational-Therapy.pdf> |
| 209 | The Royal Marsden NHS Foundation Trust | Statement 3 | **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?**  Carer support- most secondary care teams would need a way to collect data on support for carers using existing trust records |
| 210 | Royal Pharmaceutical Society | Statement 3 | The stresses and emotional toll of caring for a loved one undergoing palliative or end of life care cannot be underestimated. It’s therefore essential that the local services and resources are in place to support families and carers at this difficult time.  As the most accessible healthcare professional who will come in to contact with carers, pharmacists and the pharmacy teams are ideally placed to highlight sources of support for a person and their families. They can also appropriately refer to other sources of health and social care support that are open to their patients. |
| 211 | South West End of Life Network | Statement 3 | This statement makes the assumption that services do exist to support carers. We agree that knowledge of what is available is valuable. |
| 212 | The GSF Centre in End of Life Care | Statement 3 Question 1 | * Note that improving carers’ support also **helps to reduce hospitalisation and crises** -carers finding it difficult to cope is one of the key reasons for people being admitted to hospital or are unable to die at home / in their preferred place of care * **A key area of support for carers could be that they are individually assessed eg use of Carers Needs Assessment Tool** to ensure their needs are discussed , identified , recognised , provided for or signposted . eg CAT tool attached or Carers Needs assessment tools are excellent in this area , with better preparedness , ability to cope and reduced crises * (page 15) need to add the need for **respite care** for some carers eg nightsitting , home siting , hospice respite care etc * Need to enlarge this area in line with the Care Act and rights of carers , so to cross reference this- and at minimum assess the needs of each carer * Important to cross reference **with bereavement support for carers in the local signposting** directory, even if not directly included here in this measure and QS * This we suggest, needs to be in line with NICE guideline NG150 (specifically recommendation 1.3.1.) and the Care Act 2014, so the need for cares assessment is more important than satisfaction , which is unlikely to be accurate measure .   So instigating improved access to and routine use of Carers needs assessments is vital here |
| 213 | The GSF Centre in End of Life Care | Statement 3 Question 2 | **Measures-** process (page 13)   * nos signposted / the denominator nos carers at home- suggest not robust enough and I suggest could be * **numbers of carers assessed using a carers’ needs assessment tool / identified carers on registers** – this register/ database is possible via QOF data ie GP practice registering carers and completing the pall care QOF register accurately * Suggest also measurement of evidence of giving **carers proactive guidance** eg leaflet on ‘ What to do in a crisis ‘ – to include both general and specific recommendations (as in below) |
| 214 | The GSF Centre in End of Life Care | Statement 3 Question 3 | **Resources** needed   * Use of needs assessments eg <https://www.england.nhs.uk/publication/the-carer-support-needs-assessment-tool-csnat-for-use-in-palliative-and-end-of-life-care-at-home-a-validation-study/> and Edge Hill uni CAT tool * Enhanced directory/ database of carers – already recommended * Use of EpaCCs to ensure proxy spokesperson/ LPOA is noted on EPaCCS in an emergency * Workforce training in assessment of carers needs * Signposting directory or on line resource in each area showing available local resources and support including voluntary sector, church/faith groups and national on-line groups   Need to include social prescribing as part of PCNs provision o this support and signposting and may need further training |
| 215 | The GSF Centre in End of Life Care | Statement 3 Question 4 | **COVID impac**t- Again the importance of supporting carers , helping them know early what to look out for , teaching them skills and use of pulse oximetry can help better home support  The inclusion of **COVID virtual wards** in some areas for people living with COVID at home has been excellent eg Southampton Primary care Group |
| 216 | The GSF Centre in End of Life Care | Statement 3 Question 6 | See Carers needs assessment tool attached – and there are others eg https://www.england.nhs.uk/publication/the-carer-support-needs-assessment-tool-csnat-for-use-in-palliative-and-end-of-life-care-at-home-a-validation-study/ |
| 217 | The GSF Centre in End of Life Care | Statement 3 Additional note | * Cares UK guidance on implementation of the Carers Act to be referenced   NICE NG 150 carers cross references with carers support . |
| 218 | University of Cambridge | Statement 3 | Quality statement 3 refers to carers being “supported to access local services that can provide assistance”. There is no mention of any assessment of their needs. Health and social care practitioners cannot direct carers to appropriate services if they have not undertaken any assessments to identify what carers’ support needs are. In the 2011 Quality Standard, Quality Statement 7 referred to carers being “offered comprehensive holistic assessments in response to their changing needs and preferences and holistic support appropriate to their current needs and preferences”. Further, stakeholders in the current NICE Quality Standards Briefing paper highlight that carers should have their needs assessed and receive support accordingly (4.6 Support for carers). The current statement needs to return to a wording encompassing more holistic assessment and support. |
| 219 | University of Cambridge | Statement 3 - rationale | The Rationale to Quality Statement 3 refers to “practical and emotional support for carers” being crucial to help them to continue to care. Carers’ support needs are broader than the practical and emotional support highlighted in the quality statement and also individual to each carer and their situation. The above concerns are supported by the NICE Quality Standards Briefing paper stakeholder comments for Support for Carers, which clearly states  “Stakeholders suggested that despite an increasing awareness of carers’ needs, the support available is still insufficient. They felt that there is more focus on information needs rather than on addressing wider needs of the person with caring responsibilities. (page 29)  The “wider needs of the person with caring responsibilities” referred to by stakeholders in the briefing document have been well evidenced in the research literature, and that carers need to be supported both as ‘co-workers’ but also as ‘clients’ themselves to carry on their caring role and this extends beyond practical and emotional support referenced in the standard.4,5,6,7  Even if referred for a statutory carer assessment under the Care Act 2014, this addresses only carers’ support needs that arise from their ‘client’ role, such as need for a break from caring. In an end of life care context, carers also have support needs as ‘co-workers’ to enable them to care for the patient, such as support in managing symptom and medicines, in understanding the patient’s illness and with knowing what to expect in the future. These type of support needs require input from healthcare professionals, not from local authority assessors. Thus addressing the wider needs of carers is essential, particularly in the light of clear research evidence that a large proportion of ‘inappropriate/ avoidable’ terminal admissions to hospital are family initiated.8,9  Service providers, healthcare practitioners as frontline staff and Commissioners of service need clear standards regarding identifying and assessing carers. Firstly, to enable them to rapidly identify and address carers’ support needs (as co-workers) where healthcare rather than social care input is required. Secondly, to ensure speedier and consistent referral to statutory assessment in cases where some of the carers’ needs can be met by support offered through statutory assessment.  4 Stajduhar KI, Nickel DD, Martin WL, et al. Situated/being situated: client and co-worker roles of family caregivers in hospice palliative care. Soc Sci Med 2008; 67: 1789–1797.  5 Ewing G, Grande GE. Development of a Carer Support Needs Assessment Tool (CSNAT) for end of life care practice at home: a qualitative study. Palliat Med 2013; 27: 244-256.  6 Micklewright K & Farquhar M. Does the Carer Support Needs Assessment Tool cover the established support needs of carers of patients with chronic obstructive pulmonary disease? A systematic literature search and narrative review. Palliat Med 2020; 34(10):1305-15.  7 Ewing G, Croke S, Rowland C, Grande G. Suitability and acceptability of the Carer Support Needs Assessment Tool (CSNAT) for the assessment of carers of people with MND: a qualitative study. BMJ Open 2020;10:e039031. doi:10.1136/bmjopen-2020-039031.  8 Gott M, Frey R, Robinson J, Boyd M, O’Callaghan A, Richards N, et al. The nature of, and reasons for, ‘inappropriate’ hospitalisations among patients with palliative care needs: a qualitative exploration of the views of generalist palliative care providers. Palliat Med. 2013;27(8):747–56.  9 Reyniers T, Deliens L, Pasman HR, Vander Stichele R, Sijnave B, Houttekier D, et al. Appropriateness and avoidability of terminal hospital admissions: results of a survey among family physicians. Palliat Med 2017; 31(5):456–64. |
| 220 | University of Cambridge | Statement 3 - Quality measures | Quality statement 3 proposes that the denominator for measurement of this statement should be the number of carers providing end of life care to people at home. Data sources proposed for this denominator are local carer experience surveys, audits of referrals to social prescribing and community support and NHS Digital’s Personal social services of adult carers. However, this approach will miss a very large proportion of carers. Again this stresses the need for carers to be consistently identified and recorded alongside the identification of persons approaching end of life, to provide a comprehensive, reliable data on the ‘carer denominator’ for measurement. |
| 221 | Weldmar Hospicecare | Statement 3 | The quality standard on carers 93) is quite challenging. It mentions practical level of support and there are many challenges around resourcing this eg lack of packages of care, strain on district nursing service and equipment delivery logistics in a large rural area. Given the stress and potential bereavement carers are facing we have concerns about how measureable this standard is. |
| Statement 4 | | | |
| 222 | Association for Palliative Medicine | Page 18  Quality statement 4 | Numerator – as per earlier comment this is difficult to capture as not a single conversation. |
| 223 | British Association of Social Workers | Statement 4 | BASW England members said that sharing information can be problematic when using different IT systems to capture and store data, reliant on professionals or other involved to share information as systems do not talk to each other. Systems need to capture conversations with people about their views, wishes and advanced care planning and decision making.  Consideration should also be given to how information sharing can take place safely in line with GDPR across different organisations given the sensitivity of what it may contain. Information sharing across organisations without named workers from social care and health involved will be problematic as services and organisational systems are not aligned.  Co-ordinated care is fully reliant on the relationships developed between organisations, partnership agreements, and good multi-agency and multi-disciplinary working. Currently, IT systems across organisations do not communicate with each other which makes record sharing and viewing and accessing up to date information problematic.  Consideration should be given in relation to how multi-practitioner teams can function effectively and work together when they are not co-located, given the issues with different IT systems and organisational policies, procedures and working arrangements and requirements. This would require in some cases a full-service re-design to enable multi-practitioner working to be effective in the way this quality standard envisages. |
| 224 | British Association of Social Workers | Statement 4 | Members said that at present, services and organisational systems are not aligned, which means that sharing information across organisations in the absence of named workers from health and social care will be problematic.  Currently, co-ordinated acre is fully reliant on the relationships developed between organisations, partnership agreements, and good multi-agency and multi-disciplinary working. Currently, IT systems across organisations do not communicate with each other which makes record sharing and viewing and accessing up to date information problematic.  Consideration should be made as to how multi-practitioner teams can function effectively and work together when they are not co-located. Given the issues with different IT systems and organisational policies, procedures and working arrangements and requirements a full-service re-design would need to take place to enable multi-practitioner working to be effective in the way this quality standard envisages.  Examples of where this works well in practice could be included to show organisations how this is possible to achieve.  This statement should also focus on current issues around increasing accessibility to formal care services and including family and informal support network. In addition, it should improve the use of technology as a means of checking in with people, this is less invasive and different way of providing emotional support to the cared for person and any informal carers. |
| 225 | British Geriatrics Society | Statement 4 | The role of paramedics is vital and evidence should include ways of Woking that include but go beyond Electronic Palliative Care Coordination Systems |
| 226 | Compassion in Dying | Statement 4 Audience(pg 19) | The list of health and social care practitioners should also include ambulance trusts so that DNACPR forms, ReSPECT forms and Advance Decisions are easily accessible. |
| 227 | Faculty of Intensive Care Medicine | Statement 4 | See 1-3 |
| 228 | Greenwich & Bexley Community Hospice | Statement 4 | More reference to the use of Local Care Networks would be helpful in this standard. This would provide a useful focus for multi-practitioner reviews and collection of case studies/ reviews with action plans which might be a better qualitative measurement of how the system is working with regard care coordination. |
| 229 | Greenwich & Bexley Community Hospice | Statement 4 | The importance of investment and training in hospital discharge planning at end of life should be strengthened in this model to support increased numbers of people to be discharged well and to enable this to be done more quickly. It is unlikely that hospital SPC teams will be involved in PCNs, so this needs some thought and reference in the standards. Greenwich & Bexley Community Hospice has evaluated the impact of discharge coordination on overall care coordination and place of care/ death, demonstrating a positive impact of such a role. See attached document |
| 230 | Hospice UK | Quality Statement 4  General | This quality statement does reflect the identified key areas for quality improvement |
| 231 | Hospice UK | Quality Statement 4  Measures | In: Process  ‘the number in the denominator whose advance care plan is shared with the practitioners involved in their care’ – this line perhaps leaves too much ambiguity, should the line read ‘is shared with the practitioners across **all** of the services and organisations involved in their care’ |
| 232 | Hospice UK | Quality Statement 4  General | The quality statement repeatedly states that the benefit of information sharing is that patients ‘do not have to repeatedly provide information that can be shared’ – while this is a benefit, the quality statement would be strengthened by also including other benefits of information sharing such as ensuring that an individual is flagged for any extra support across multiple services, and that they, and their carers, are not missed off any systems. |
| 233 | Hospice UK | Quality Statement 4  Measures | It is worth reiterating that an overreliance on patient experience surveys as a measure could be problematic given their sporadic roll-out currently, and concerns about statistical significance and ethical implications. |
| 234 | Hospice UK | Quality Statement 4  Measures | The use of ‘preferred place’ as a substitute for a successful end of life experience can raise issues, circumstances can change rapidly at the end of life, particularly for those being cared for at home, and it is not always possible to achieve care or death in a preferred place. This does not necessarily mean that a person’s care was coordinated badly or that their care was below standard. |
| 235 | Hospice UK | Quality Statement 4  Question 3 – resourcing | We welcome the recommendation to ensure that electronic information-sharing systems are in place across local health systems. It is important to establish where the resourcing responsibilities for this will lie, who ‘leads’ on the information-sharing, and at what level the decisions on which data system to use are taken. If services have to switch over to a new system to mirror those of others within their locality there will inevitably be a resourcing and training need attached to implementing that new system. |
| 236 | Kidney Cancer Support Network |  | **Adults approaching the end of their life receive care that is coordinated between health and social care practitioners within and across different services and organisations. [2011, updated 2021]**  As detailed above, there was NO communication between services whatsoever. The GP would only react once the discharge letter had been obtained. The discharge letters were usually inaccurate. Follow-up was rarely arranged without chasing and reminders.  I think that if it would have been someone else in my shoes as a carer/partner, with no medical knowledge, then his last months would have been significantly worse. Good for X but a heavy responsibility, intense stress and always a “am I doing the right thing” concern as carer with no one to ask or obtain advice from of any great use.  Incredibly hard to be both partner and patient.  Incredibly hard to act both as partner and carer. |
| 237 | King’s College Hospital NHS Foundation Trust | Quality statement 4 (process) | **Co-ordination: Denominator: “the number of adults approaching the end of their life who have an advance care plan”.**  This should instead read “evidence that end-of-life planning has been offered”. Advanced care planning is not mandated and only offered clinically. It is voluntary and a patient or relative-led discussion- and there are incidents where these groups decline the conversation. Therefore, recording that it has been offered and declined by the patient/relative is also a valid numerator. |
| 238 | King’s College Hospital NHS Foundation Trust | Quality statement 4 (process) | This numerator/denominator score is not going to be an accurate measurement of the quality of coordinated care for all the points already elaborated on above.  One measure of quality of coordinated care could be whether patients are offered education and empowered to access and coordinate their own care should they wish to. An example of this is myCMC (Coordinate My Care in the London area) where patients can start and edit their own advance care plan with support from their doctor or nurse. There needs to be evidence of an increasing uptake of these platforms and satisfaction of patients with these platforms could also be measured. https://www.coordinatemycare.co.uk/for-patients/mycmc/  Another measure of quality of coordinated care would be whether patients are aware of who to contact for support in co-ordination of their appointments/contacts.  Who their key worker/primary contact/ GP/ community support/secondary support is and potentially how satisfied they are with the support they are getting from them.  Evidence of systems that share information identifying adults who are likely to be approaching the end of their life between clinical settings is also important here. |
| 239 | Macmillan Cancer Support | Statement 4  (Co-ordinated Care) | Q1. Does this draft quality standard accurately reflect the key areas for quality improvement?   * The statement should explicitly state that end of life care services should be well led and multi-professional, demonstrate integrated and coordinated working and should encourage early referral into palliative care. Professionals we spoke to said that collaborative working at present relied heavily on the relationships between professionals. ‘Corridor conversations are really the only joined-up-ness for those conversations [about patient care]’[Healthcare professional]. This is unsustainable. Macmillan Cancer Support (2019) At the Crossroads: How can the NHS Long Term Plan improve end of life care in England? * The statement should state that services are able to respond rapidly to avoid crisis. Some rapid response teams have not been upskilled in palliative care. This hinders EOL conversations with patients and makes hospital admission more likely. Macmillan Cancer Support (2019) At the Crossroads: How can the NHS Long Term Plan improve end of life care in England? * Service providers should also make sure that any system being developed must work with all health and care providers, including private providers of care such as local 111 services or residential and care homes.   Q2. 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?  Use of electronic information-sharing systems (already recognised by NICE as a data source) would be one of the main ways in which services were able to evidence activity. Collecting data for this statement is therefore heavily reliant on services having in place information-sharing systems such as EPaCCs, and consistent use of these systems. It should be noted that these systems vary across services. We heard from professionals of some areas that had well-functioning systems, but also of many areas that did not. The main challenges were clinical buy-in, functionality and data sharing. Clinical Commissioning Groups (CCGs), and the Sustainability and Transformation Partnerships (STPs) and Integrated Care Systems (ICSs) they work with, must have plans in place to develop an EPaCCS system or an equivalent tool for coordinating palliative care. They need to show how they are considering the needs of end of life patients in wider plans for digitalisation and on data interoperability. Macmillan Cancer Support (2019) At the Crossroads: How can the NHS Long Term Plan improve end of life care in England?  Section 4b refers to the following quality measure: “evidence of local arrangements for relevant information about adults approaching the end of their life to be shared with the members of the malpractitioner team involved in their care”. We are not confident that this is something easy to control, measure or manage.  Q3. 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.   * It is significant that the stated resource impact for “Transfer between Care Settings”, within this statement, depends on the level of service already in place [NICE briefing document]. The levels of services vary across the country – for instance, regarding the availability of care packages to allow people to be transferred from hospital to the home safely, and also regarding the development of information sharing systems. Adding to these pressures, demand for end of life care in the community is increasing. Macmillan Cancer Support (2019) At the Crossroads: How can the NHS Long Term Plan improve end of life care in England? * There is therefore a resource requirement for resources for community teams providing out of hours end of life care, to ensure all services are adequately resourced.   Q4. Do you think the end of life care service delivery (excluding care in the last days of life) has substantially changed during the COVID-19 pandemic? Can you describe any positive changes that have been introduced as a result of the COVID-19 pandemic?   * Macmillan surveyed healthcare professionals in July 2020 on the impact of COVID-19 on NHS services, including support for end of life care. Respondents to our survey recognised significant disruptions to end of life care because of the pandemic. There were reports of difficulties in organising care packages to support transfer of patients, with this stemming from social care workforce shortages and NHS staff sickness. * Pockets of good practice also existed: * A respondent to our Health and Care Professional survey highlighted the innovative ways of integrated working that emerged during the pandemic. They told us how a new model emerged of rapid and intensive support. The support was mobilised for care homes experiencing an outbreak of Covid. In addition, local Covid pathways for patients with frailty were developed to manage care out of hospital where hospital was deemed unnecessary or inappropriate. Services provided both acute and end of life care management. * We have also heard how in several areas services had been trying for years to make improvements, such as setting up single point of access and co-ordination centres; due to Covid-19 they have been able to carry these forward with success. One professional told us how the pandemic “kick started EOL improvements” with EPaCCS sped up in their area.   Q.5 For draft quality statement 4: Is there a specific aspect of coordination of care that this quality statement should focus on? If so, please provide details.   * All aspects stated are important. Given that NHSE has committed to rolling out information sharing systems as part of the NHSE long-term plan, if any were to be emphasised it would make sense to focus on “Communication and Sharing Information”. As highlighted above, we know that variation exists between local areas in terms of the development of information sharing systems. It would be useful for this part of the statement specifically to highlight the need for Advance Care Plans to be sharable on such systems. |
| 240 | Marie Curie | Statement 4 Question 4 | The suspension of CHC fast-track funding has seen many of our community nursing services across England become more involved in the management of referrals and coordination of care packages. Benefits seen include:  • More flexible and responsive care packages delivered at the right time.  • Closer multidisciplinary team working  • Much faster funding decisions, meaning that care can be delivered sooner, and patients spend less time in hospital, with fewer delayed discharges. |
| 241 | NHS England and NHS Improvement | Quality Statement 4 – Rationale | Suggest there may need to be reference to the role of a care co-ordinator, someone identified to help coordinate the care of the individual. The rationale seems more focused on sharing of information. (PC) |
| 242 | NHS England and NHS Improvement | Statement 4 Quality measures | Rather than ‘multipractitioner team’, should this be ‘multi-disciplinary team’? This is a more widely used term. (PC) |
| 243 | NHS England and NHS Improvement | Statement 4 What the quality statement means for different audiences | Suggest including the need to identify a lead practitioner on behalf of the multi-disciplinary team who will help to facilitate improved care coordination for the patient. (PC) |
| 244 | NHS England and NHS Improvement | Statement 4 What the quality statement means for different audiences | Should include a clear single point of contact for the person, who can be relied upon to update all other professionals that are involved. This may include calling/speaking with other professionals to resolve any issues and not just updating a care plan (PC) |
| 245 | NHS England and NHS Improvement | Quality Statement 4 – Rationale | This statement is achievable as in a number of organisations they are undertaking joint working with hospices using GP MDT template which will assist with this – Locala organisation have an RI event with hospice planned 12th Jan to include shared communications etc (N&M) |
| 246 | NHS England and NHS Improvement | Statement 4 Rationale/process | This is a key area for improvement. The description equates co-ordination with information sharing and appointment/multiple visits. Whilst there is no consensus on the term ‘co-ordination’ these are but 2 elements. It is generally accepted the term co-ordination also is about the delivery of care at the right time, in the right order and the right setting and the contributions of different services and health professionals being timely and well organised to meet patient’s needs and delivering an agreed plan of care. Of course, to carry out a professional role well this does rely on adequate exchange of information but if this statement relies on this aspect alone, along with appointment coordination, there is a risk it misses essential elements perceived by patients to comprise co-ordination. It is possible to conduct surveys of patients experience and level of satisfaction with care co-ordination. (N&M) |
| 247 | NHS England and NHS Improvement | Statement 4 Outcome | Suggest consideration as to experience of family and carers also to ensure groups aren’t marginalised or excluded from sharing their feedback. This may need to be posthumously also as need to consider the impact people/families etc may feel for giving negatively perceived feedback at the time of a persons impending death upon the care they are currently receiving. (N&M) |
| 248 | NHS England and NHS Improvement | Statement 4 Outcomes | “ensure that electronic information-sharing systems are in place so that all practitioners providing care can access up-to-date records and advance care plans” possibly will be outside of the remit of all service providers and may need reconsideration. For example, care homes, independent providers may rely upon commissioners or other agencies to ensure this is coordinated and facilitated across sectors. (N&M) |
| 249 | NHS England and NHS Improvement | Statement 4 | This statement is achievable. Evidence from providers of how we have progressed detailed below:   1. Yes, reflects key area for improvement; In Locala service level agreement and joint working agreement overnight being re-visited. Electronic data sharing has potential to be improved as work on different systems- Care First and SystmOne. Link meetings take place and information is uploaded to communication template on S1. 2. Local structure in place to collect data- Joint service overnight- Integrated night service and programme of care provided by Kirklees, care plans added to S1 and care identified as social care, evidence of joint working and communication/review. 0-2hr visits response recorded for palliative care. Compliments submitted.   Evidence of practice that underpins standard 4- Integrated night service and delivery of both health and social care to the patient by joint service – the health/social team best placed to deliver care required overnight undertakes visit (N&M) |
| 250 | NHS England and NHS Improvement | Statement 4 Quality measures structure data source | Evidence of local arrangements – should mention need for this to be across sectors and teams as co-ordination and information sharing are not just across organisational issues. (N&M) |
| 251 | NHS England and NHS Improvement | Statement 4 Quality measures process | 1. Would also sharing of a care plan, not just an advance care plan be a signal of co-ordination   Data source what evidence would an auditor be looking for to demonstrate care coo ordination in a record. This is ambiguous and have ramifications for the feasibility and reliability and validity of data collection. (N&M) |
| 252 | NHS England and NHS Improvement | Statement 4  (measure) | Process measure (a) focuses on advance care plans only. To achieve coordinated care without the person repeatedly having to convey information, key information about current personalised care and support plans are also important to be shared. There should be an additional process measure to capture this or it should be incorporated explicitly in process measure (a). **(BW)** |
| 253 | NHS England and NHS Improvement | Statement 4  (measure) | Process measure (b) – I don’t think you can measure this meaningfully as a process measure. Why not turn this into an outcome – to be measured through patient and carer experience tools? **(BW)** |
| 254 | North West Boroughs Health | Statement 4 pg. 18 | Sharing of information must be with the persons consent. |
| 255 | North West Boroughs Health | Statement 4 Pg.18 | Patient experience surveys specifically linked to End of Life Care are not in use within the Trust. This would be only achievable with significant financial investment. |
| 256 | North West Boroughs Health | Statement 4 Pg.19 | ACP documents should be left with the patient as they are a patient held record, they can be updated and reviewed whenever there is a change in condition or circumstance. If they are stored in the persons electronic record the latest version may not be uploaded and the person may have changed their mind. |
| 257 | Rowcroft Hospice, Devon | Statement 4 | We suggest considering measurement of the % of late referrals to specialist palliative care services as a measure of coordination of care. |
| 258 | Rowcroft Hospice, Devon | Statement 4 | Not dying in the persons original preferred place of care is not always a measure of success. In some instances, this may be to the person’s detriment. We know that peoples’ preferences change over time and it could be worth considering instead whether the person died in the best place for them at the time. |
| 259 | Royal College Of Nursing | Statement 4  (rationale) | The intention to have IT systems which communicate between care providers is a great aspiration, but clear direction and appropriate funding needs to be given to this to enable the success of implementation and sustainability |
| 260 | Royal College of Occupational Therapists | Statement 4 | Adults approaching the end of their life receive care that is coordinated between health and social care practitioners within and across different services and organisations.  Occupational therapists work with other members of the multi-disciplinary team to coordinate the care of adults who are approaching the end of their life. They ensure that all relevant information is added to the person’s record and advance care plan so that it can be accessed by other practitioners involved in the person’s care when needed. |
| 261 | Royal College of Physicians and Surgeons of Glasgow | Statement 4 | This is possibly the most difficult practice to implement. Co-ordinated care between health and social care services is frequently poor, and at times virtually absent. This is especially true when dealing with people with chronic, progressive, physical and mental health disabilities. Training and education in proper co-ordinated care needs much improvement. Effective management of such services is also key. |
| 262 | Royal Pharmaceutical Society | Statement 4 | Co-ordination of care across health and social care is vitally important in ensuring that a person’s death is as peaceful, symptom and stress-free as possible. This is a responsibility and should be the goal of health and social care professionals. It requires both robust systems to be in place as well as input and team working from across the multidisciplinary team.  Pharmacists should be embedded in all multidisciplinary palliative care teams to input expertise on prescribing, deprescribing and use of medicines. Pharmacists and the pharmacy team have particularly important roles following a person’s diagnosis of a palliative illness to ensure that the medicines regimen is optimised, as well as to help coordinate the care and medicines supply for patients as they move from one care setting to another. Specialist palliative care pharmacist teams should also be in place in all localities and known to generalist practitioners as a source of advice on medicines issues. |
| 263 | South West End of Life Network | Statement 4 | “Adults approaching the end of their life receive care that is coordinated between health and social care practitioners within and across different services and organisations.” Is there a simpler way to say this, in a way that could be understood by anybody? |
| 264 | South West End of Life Network | Statement 4 (measure) | Concern has been raised by some members of the South West End of Life Network that “Preferred place of care achieved” may be limited as a data outcome measure - as it is not always available or appropriate use of scarce resource. However we acknowledge that it can be relevant to many. |
| 265 | South West End of Life Network | Statement 4 (measure)  and other measures | “When a measure becomes a target, it ceases to be a good measure” (Marilyn Strathern, after Charles Goodhart). For any of the measures chosen, we need to avoid turning them into a target, as this will inevitably distort performance and have unintended adverse consequences. |
| 266 | The GSF Centre in End of Life Care | Statement 4 Question 1 | * Good definitions in QS * Additional tighter suggestions below as measures as yes, I think there is something missing here that describes effective coordination of care , though hard to define   and to link up with **goal concordant care** in line with ACP discussion |
| 267 | The GSF Centre in End of Life Care | Question 2 – statement 4 | Missing piece here I suggest are new outcomes and process measures :-  **Outcome Measures**   1. Evidence of people dying in preferred place of care ie nos PPOC attained / nos recorded 2. Evidence information -sharing eg preferred place of care , LPOA and DNAR/ Treatment Escalation plans 3. Evidence of decreased crisis emergency admissions (and ? out of hours calls for GPs) ie nos unplanned admission/ nos identified in hospitals 4. EOLC metrics CCG/ICS -wide in line with 5 Ps (see GSF EOLC Metrics paper) 5. Goal concordant care evidenced 6. Hospital bed days used per identified patient could be accessed in hospitals and/ or HBD and numbers emergency admissions/ identified patient (NAO Office Report 2009 indicated 203/ person in final year of life) , so in an effort to tangibly reduce hospitalisation , these are useful at wider EPaCCs/ CCG/ICS level 7. At a local organisation level (eg when training a care home, GP practice etc ) we use run charts, tracker tools and bi-annual hospital audits to assess progress in reducing hospitalisation , but this would need to be conflated for greater numbers in an area , so maybe feasible at local audits for progress mainly and then reflect in EPaCCs wider are data later . 8. See ‘5 Ps’ summary in EOLC Metrics Paper attached, and to note that we also included here a qualitative feedback report as the 5th P , indicating if the service did feel to be well coordinated to the bereaved carer , Also links with Family Perceptions of care Tool attached , and could link with VOICES though think that has discontinued and in some ways was always flawed .   **Process Measures**   1. Evidence of giving **carers proactive guidance** eg leaflet on ‘ What to do in a crisis ‘ – to include both general and specific recommendations 2. Evidence of MDT discussions between health and social care settings eg meetings with GPs and Care Homes staff , GP practices GSF/ Supportive care meetings etc 3. Key coordinator - orchestration of services in line with preferences eg key coordinator role or via coordinating hub 4. Evidence of use of EPaCCs across sectors 5. Workforce-Empowered staff to reduce hospitalisation, especially in social care (as described in NAO 2008 EOLC report) , so confidence of staff before and after training can demonstrate this .   Pt satisfaction is flawed as a measure in itself though VOICEs, bereavement survey etc contribute some part but not all the picture .  Dying in preferred place of choice or care can be attained and though not perfect is a good indication o success for many , though the greater one would enlarge into goal concordant care . Still to be develop in the UK I think  noa in PPC  (Numbers of people explaining their condition/ information repeatedly is relevant of course for some to note but not to measure I feel, as in the scheme of things it is a mild measure and might lead to difficulty in implementing . In the end more people would rank higher that they prefer to live and die as they choose, symptom free , where they want to be , with reduced crises , peacefully ‘ no heroics’ etc .)  Some of this overlap with QS 4 on coordination and some metrics could be similar |
| 268 | The GSF Centre in End of Life Care | Statement 4 Question 3 | Resources –   * **Workforce training** – we have examples of single sector and multi sector training in GSF cross boundary care days plus others will . training , informing , resourcing and enabling in QI processes like this will take small resources , but well worth the investment – without such workforce training this whole system transformation might not be effective . * **Digital**- improved uptake and interoperability of EPaCCs   **Personnel-** Might need local ICs audit support to ensure such data is collected (as in Nottinghamshire example where audit lead supports measurement of progress |
| 269 | The GSF Centre in End of Life Care | Statement 4 Question 4 | COVID coordination centres have shown improvements during COVID such as the 4 Birmingham Hospices hub <https://www.birminghamhospice.org.uk/hospices-launch-hobs/>  Virtual wards eg in Southampton have evolved well and these gains should not be lost . |
| 270 | The GSF Centre in End of Life Care | Statement 4 | NOTE in the above . YES there was an omission , but Coordination is difficult to describe , but crucial to get right . Its described sometimes as changing the culture of care and can partly be tangibly measured both quantitatively and qualitatively , and partly though individual stories qualitatively . Practical suggestions above on improving measures and encouragement that there are several doing this already . |
| 271 | The Royal Marsden NHS Foundation Trust | Statement 4 | **Do you think the end of life care service delivery (excluding care in the last days of life) has substantially changed during the COVID-19 pandemic? Can you describe any positive changes that have been introduced as a result of the COVID-19 pandemic?**  Coordinated care has improved with greater cross boundary working eg. Virtual meetings and shared documents |
| 272 | Weldmar Hospicecare | Statement 4 | We are still struggling to get the different electronic systems communicate to each other and therefore this will be challenging to ensure the data is measuring the same in each organisation.  The specific aspect as requested is the IT provision. As an organisation we are investing in changing to SystmOne as our local GP population all use this. |
| Question 5 – statement 4 | | | |
| 273 | Association for Palliative Medicine |  | The co-ordination of care should focus on the recording and sharing of wishes and preferences in relation to a patient’s care. |
| 274 | Motor Neurone Disease Association |  | We believe advanced care planning is the responsibility of the whole team of people involved in someone living with MND’s care, not any one individual within it, and it is an iterative process. Importantly, there needs to be ease of access to this information across providers and services. |
| 275 | Multiple System Atrophy Trust |  | Adopting the “Team around the Family” –(TAF) concept into adult end of life care would help to address co-ordination and communication. |
| 276 | Multiple System Atrophy Trust |  | Coordination and continuity of care is essential, and we agree that having a key identified person who can ensure timely reviews, updates and can delegate for planned absences is needed. However, a “key team” is also needed so that there is always somebody who knows what’s happening 24/7. Physical visiting is important to provide this support to ensure a” holistic” picture. |
| 277 | Royal College of Occupational Therapists |  | An identified health/social care practitioner should be given the role of co-ordinating a person’s end of life care, ensuring that the person approaching the end of their life is at the centre of all decisions (if they wish to be). Occupational therapists have the skills to undertake this role. |
| 278 | RCP |  | Statement 4: Is there a specific aspect of coordination of care that this quality statement should focus on?   * Yes should focus on transfer of information around identification of patients approaching the end of life, and advance care planning conversations between care settings |
| 279 | Society for Acute Medicine |  | This quality statement should focus on a single point of access for information sharing across clinical and community areas. In particular it needs individualised plans of care to be clearly flagged and accessible when immediately needed (such as to attending paramedic crews, 111 operators and hospital emergency departments). It is much more difficult to change a person’s management plan once it has started. If this information is readily available then it will help to empower clinicians to keep dying people in their preferred place of care and death – the default is to convey to hospital and initiate active and invasive treatment. |
| 280 | Society for Acute Medicine |  | Yes. Coordinate My Care is an internet-based secure database of advance care plans for those felt to be dying. It is used London-wide and allows all healthcare workers to access the same care plan from wherever they work. An automatic flag has been built in to 111 and paramedic service systems, community (GP and community palliative care systems) and hospital systems. It allows early flagging of advance care plans and is being more frequently used as clinicians become more aware of it. |
| 281 | The GSF Centre in End of Life Care |  | Examples  See the ‘5 Ps ‘ included on the GSF EOLC Metrics Report attached that were feasible to obtain , and thought to be realistic even then, 3 years ago, especially from those with good EPaCCS . this is possible and can indicate population wide metrics of good EOLC.  Also, in our experience , we have worked closely with 10 GSF Cross Boundary care Sites . These were the areas invited to run the EOLC Metrics pilot – report attached , demonstrating progress in this area of large scale population based CCG/STP.ICS coordination )  The GSF Cross Boundary care areas use GSF across wider areas to improve integrated delivery of care eg the **Jersey Island** wide project, **Nottinghamshire** etc – see poster and videos describing experiences on  <https://www.goldstandardsframework.org.uk/cross-boundary-care-training>  Example of best practice -include the **Airedale Gold Line** as an excellent example , <http://www.airedale-trust.nhs.uk/services/the-gold-line/> where all settings were trained in GSF (primary care , care homes, hospitals ) and then built on this 24/7 Gold line hub.  Other good examples where this has been used and hubs are developing that we are aware of in our work across the country include eg Morecombe Bay Gold patients, Southport, Bedfordshire Pall Care/ Hospice Help line    Many use the term ‘ **Gold’ patients** to name those people identified on the register , which patients like , and have a gold card with emergency number of this , affirming the value of people at this stage of life – see -  <https://www.goldstandardsframework.org.uk/what-are-gold-or-gsf-patients> |
| Statement 5 | | | |
| 282 | Association for Palliative Medicine | Page 21  Quality statement 5 | Not specific enough what the support needs to be. Does not always need to be specialist palliative care. District nurses, GPs etc have a role in providing generalist palliative care. |
| 283 | Association for Palliative Medicine | Page 21  Quality statement 5 | Having access to a co-ordinated patient record is absolutely key |
| 284 | Association of British Neurologists | Statement 5 | Often the outcome suggested does not relate to the standard being assessed. e.g. Standard 5 Coordination of social care and health care. The evidence for that is to be that people die in the their preferred place of death. This is not directly related. Perhaps for all the standards the evidence requirement should be reduced e.g. for standard 5 organisations demonstrate they have a system for co-ordination between social and health care. Without  realistically achievable processes services will not engage with the standards which will be a shame given the important areas they cover. |
| 285 | British Association of Social Workers | Statement 5 | Members said that in relation to out of hours care, the 24 /7 arrangements described in this quality standard can be achieved will be dependent on the quality of commissioning arrangements in the local area. This will require pooled budgets from health and social care to allocate enough funds to enable good quality, responsive services that can work flexibly and provide a high level of quality, person centred support.  Members added that specialist providers for this type of support need to be identified, and multi-professionals involved need to have knowledge of who they are and how to engage them in the person's care and when. The 24-hour helpline is a good idea in theory, but questions remain as to how will this be commissioned and quality assured. |
| 286 | British Geriatrics Society | Statement 5 | Vital and should evidence a single point of contact for patients/families- |
| 287 | Faculty of Intensive Care Medicine | Statement 5 24/7 Support | This remains aspirational outside the acute care setting. NACEL reports that most regions and individual NHS Trusts can provide 7-day support but this is usually a day-time provision. Out-of-hours may be available but not necessarily reflective of an individual dying patient’s needs |
| 288 | Hospice UK | Quality statement 5  Measures | It is worth noting that ‘the proportion of adults approaching the end of their life who **have access to** a healthcare professional’ or ‘an out of ours end of life care advice line’ if it is interpreted as the number of people who live in an area which is technically served by an out-of-hours service, does not necessarily equate to a patient knowing about and feeling supported to use such a service. |
| 289 | Hospice UK | Quality Statement 5  Question 4 – COVID-19 | Hospices have been successfully providing their local areas with out-of-hours end of life care advice lines since before the pandemic.  During the pandemic, hospice and end of life care services have been rapidly adapted in order to be compliant with the latest regulations. This switch to online delivery of support and services has been a positive aspect of the pandemic response and has ensured that patients and their carers have continued to have access to support during this time. It would be valuable if commissioners sought to replicate these services on a longer-term basis. |
| 290 | Kidney Cancer Support Network | Statement 5 | **Adults approaching the end of their life have access to support 24 hours a day, 7 days a week. [2011, updated 2021]**  As detailed above. Support is there during office hours (e.g., GP/ oncology secretary and OPD clinics) but not over times such as the summer holidays (we experienced 3 delayed MDTs prior to treatment for this reason) and festive periods.  After hours services are often limited to advice to “go to A&E” or wait until your clinic opens in the morning. I remember disagreeing with someone on the ECHO line about needing to take an exhausted, frail man to A&E at 8pm on a Saturday night on a freezing cold night. I was told it was ultimately our decision, but I would have to take responsibility for this decision if anything went wrong and that were no other options available. So off to A&E we went where he sat, or tried to, for the next 4 hours until he was seen and a further 4 hours until he was admitted. Totally irrational for a patient with potential neutropenic sepsis to be sitting in the same cold, packed waiting room as a young student with suspected meningitis symptoms.  During the day but only during the week, an oncology patient can be seen urgently at the Day Unit, but come 5pm or the weekend, A&E becomes the only option at their busiest time.  Whilst we met and X was treated by some wonderful, caring people across all the healthcare sectors, he was failed in many aspects by the NHS.  This caused unnecessary delays in management and treatment decisions, minimal palliative care and very poor communication. As an end-of -ife experience it fell below any acceptable standards and made me feel ashamed to belong to the medical profession.  I am also incredibly grateful that he died just before lockdown – I cannot begin to imagine how all of this would have worked with limited access for spouses/relatives/carers during these COVID-19 times. |
| 291 | King’s College Hospital NHS Foundation Trust | Quality statement 5 | Healthcare professionals should also include the Ambulance Service, in addition to GPs, specialists and nurses.  The ambulance service also needs access to the patient’s records and advance care plan. |
| 292 | Macmillan Cancer Support | Statement 5  (Out of hours care) | Q1. Does this draft quality standard accurately reflect the key areas for quality improvement?   * 24/7 telephone end of life care advice should be made available for professionals providing this care.   Q3. 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.   * It is significant that the stated resource impact for “Out of Hours Care” within this statement depends on the level of service already in place [NICE briefing document]. Quality is varied across the country – for instance in relation to access to 24/7 support, and to care provided by urgent and community response. We have heard from professionals how some areas have fully established multi-disciplinary teams providing urgent care in the community, some areas where there were features of a rapid response service (such as a triage number for people to call) and some areas with no features of an adequate level of service. Macmillan Cancer Support (2019) At the Crossroads: How can the NHS Long Term Plan improve end of life care in England? * As with Statement 4, there is therefore a resource requirement for community teams providing out of hours end of life care.   Q4. Do you think the end of life care service delivery (excluding care in the last days of life) has substantially changed during the COVID-19 pandemic? Can you describe any positive changes that have been introduced as a result of the COVID-19 pandemic?   * During the pandemic pockets of good practice to meet increased demand have emerged. These include: * The upskilling of an ambulance service in relation to end of life care. * Nursing services which supported care homes lacking nurses, being extended to support both care homes with nurses and local hospices, merging to provide 24hour access to specialist palliative care.   Specifically, to address increased demand from care homes, one healthcare professional highlighted to us targeted education and training initiatives, and another reported a model that had emerged with rapid, intensive support mobilised to meet demand for end of life care in care homes. Ultimately, services will need to be supported to retain and share these cases of good practice. |
| 293 | Motor Neurone Disease Association | Statement 5 Question 3 | In relation to Statement 5, 24/7 specialist palliative care is not universally available. NACEL found that two thirds of hospitals lack face-to-face specialist palliative care provision seven days a week. |
| 294 | NHS England and NHS Improvement | Statement 5 Quality Measures (c) | Out of hours pharmacy is referenced here but not in the rationale. Would be helpful to clarify that 24/7 support includes out of hours pharmacy services. (PC) |
| 295 | NHS England and NHS Improvement | Statement 5 What the quality statement means for different audiences | It is really important to emphasise not only ensuring this service is available, but that patients and their carers are clearly and consistently told how to access the service. (PC) |
| 296 | NHS England and NHS Improvement | Statement 5 Definition of Out of hours support | Would be useful to provide more detail on the out of hours advice line to differentiate between the other types of support, perhaps with some examples. (PC) |
| 297 | NHS England and NHS Improvement | Statement 5 Equality and Diversity Considerations | Accessibility of information also needs to take into consideration levels of health literacy. (PC) |
| 298 | NHS England and NHS Improvement | Quality statement 5 | This statement is achievable. In some services all EoL patients and families given SPOC number for 24hr support and advice line for hospice also 24hr if appropriate. (N&M) |
| 299 | NHS England and NHS Improvement | Quality statement 5 | In Locala organisation, there is an opportunity as an organisation to invest funds to upgrade SystmOne SPICT platinum member, this would allow colleagues to have access on their mobile phones also.  In Kirklees patient/carer has 24/7 access to support and advice via SPOC. OOH will receive a call-back/visit for advice and support from nursing service. If specialist advice required Kirkwood helpline available 24/7 and we can assist in facilitating this and liaising Kirkwood and with OOH GP service. Aim to avoid hospital admission. Liaise with ICCT caseload holders – via task/call. Evidence of local arrangements- Integrated Night Service (joint health and social care), Marie Curie (also call on night service to assist and support when with a patient), OOH GP service, WYMAS, Kirkwood help line and doctor available for advice/support overnight, EPaCCs  OOH GP access to anticipatory medication,  Evidence via patient feedback/positive experience. Compliments. 0-2hr response data and SPOC calls.  Resources- OOH GP – can experience long waits for call-backs/ visits which during covid has extended.  Capacity reduced in Night service and demand increased so again wait times extended -especially in highest demand time- late evening. Times are monitored and Datix submitted to capture data.  Information provided to patient and carer of 24/7 SPOC contact number so reassured of continual support available. Calls documented. (N&M) |
| 300 | NHS England and NHS Improvement | Statement 5 Definitions of terms used and quality measures | This is a key area for improvement. There is no definition of what the term ‘access’ means. This is critical if data collection is to be reliable and valid as all the measures of this standard use this term.  The definition of support does not currently include the facility for face to face assessment and intervention by a member of the multi practitioner team where this has been judged necessary, and as such should be achievable by local services so (confined to advice line and out of hours pharmacy service). (N&M) |
| 301 | NHS England and NHS Improvement | Statement 5 | Suggest this is more than “reassuring for carers” but a reflection of services being ‘wrapped-around’ the person and accessible in a way that meets their needs so possibly the terminology needs to reflect this? (N&M) |
| 302 | NHS England and NHS Improvement | Statement 5 Outcome | Suggest the number of people accessing hospital needs clarification as to what the learning is from this and what is inferred as this could be perceived as “hitting the target but missing the point” is construed incorrectly. (N&M) |
| 303 | NHS England and NHS Improvement | Statement 5 (measure) | Structure measure (a) – the evidence of local arrangements needs to include a second point, i.e. that there are local arrangements for the health care professional to access specialist palliative care advice if and when required on that same 24/7 - 7 days a week basis. This could be a separate structure measure or part of measure (a) but must be explicit. The assumption is that the first ‘health care professional’ might be a generalist who might not need to involve a specialist for every call, but must have access to the specialist advice whenever needed. **(BW)** |
| 304 | NHS England and NHS Improvement | Statement 5  (measure) | Process measure (b) – I wonder if this might be better as an outcome measure. Measuring access is always difficult – would it not be better to measure the extent to which people know they have access to an advice line and how to do so? Would that be better achieved through an experience tool/survey? – i.e. make this an outcome rather than process measure? **(BW)** |
| 305 | NHS England and NHS Improvement | Statement 5 (what the QS means for different audiences) | In this section, it must be stated that commissioners must commission specialist palliative care advice to be accessible 24/7 - 7 days/week, and that service providers must make this available. **(BW)** |
| 306 | Rowcroft Hospice, Devon | Statement 5 | It may be helpful to add the word ‘timely’ access to support 24 hours a day, 7 days a week and to have a measure that reports on how long it took to respond to an ask for support. There are 24/7 services available, but if the response is not ‘timely’ they are of no help and may predispose to an acute admission to hospital if kept waiting too long. |
| 307 | Royal College Of Nursing | Statement 5  (definitions) | Out-of-hours support – need to be clearer about this. If this is not face-to-face access then this should be said, if it is face-to-face (which we believe it should be) then this should be made explicit as well. |
| 308 | Royal College Of Nursing | Statement 5 Question 3 | “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”–  It would be impossible to provide the levels of care advised without investing. There are minimal twenty-four-hour services specifically for palliative or end of life care across the country, equally services are already stretched and underfunded. This area needs a full review and appropriate resourcing. |
| 309 | Royal Pharmaceutical Society | Statement 5 | A person requiring palliative or end of life care, and their families, must benefit from systems and practitioners that make sure the process of obtaining medicines, including urgent controlled medicines, is as easy and timely as possible. This will avoid any delay in treatment in all care settings and also help to ensure that a person can stay in their own homes, in comfort, without needing to be transferred to hospital for essential medicines.  Regardless of the services set in place on local levels, it’s important that both health care professionals and patients are aware of the processes that are in place to aid medicines supply in the community to avoid delays in treatment. This could be through extending existing services that are deemed to be best practice, or through improving communication regarding current systems of obtaining medicines that are in place. All prescribers issuing emergency prescriptions for end-of-life care should also take responsibility for making sure that the pharmacy they refer a person to does have stock of those prescribed medicines. At an emotional and difficult time any person and their families, sourcing important end of life medicines shouldn’t be an additional worry.  Pharmacists and pharmacy technicians must work with prescribers, nursing and care staff to ensure that the necessary medicines for a person in a timely manner. Pharmacists in the community should also make sure they communicate any services they provide that will aid medicines provision for palliative and end of life patients to local general practices. Examples of such services include just in case bags and community pharmacies that are commissioned by local health commissioning bodies to hold an extended list of essential end of life medicines. |
| 310 | South West End of Life Network | Statement 5 | The importance of access to out of hours pharmacy and medications for symptom control, as this often a significant challenge and sorting it out would reduce patient distress and hospital admissions; particularly challenging in rural areas |
| 311 | South West End of Life Network | Statement 5 | Concern raised by a member of the Network that it is not clear what “support” means here – thought to be an ambiguous term which needs some clarification. |
| 312 | The GSF Centre in End of Life Care | Statement 5 Question 1 | Suggest adding that routine use of **anticipatory medications** **or ‘ just in case’ boxes** of standardised 4 drugs with the authorization form for DNs to use (can send examples if needed , but commonly recommended and used for many years ) . This would prevent the need for the OOH pharmacist in section c) which, either way, could be combined with the function of a) the working hub or 24/7 information source.  Some of this overlap with QS 4 on coordination and some metrics could be similar . |
| 313 | The GSF Centre in End of Life Care | Statement 5 Question 2 | Suggest added measures , rather than just evidence of the presence of 24/7 hub ie  But could include:-   * numbers of emergency /999/ambulance calls out of hours / identified patient * numbers of crisis admissions to hospital / identified patient on register * or numbers seen in ED of identified patients (this has been tracked in some areas eg Notts * anticipatory medication or just in case boxes left / identified patient in final days of life (GSF red)   We do not think measure c) for pharmacists is strong – but preventing need for access to drugs in anticipatory medication is pre-emptive and better . So, a better measure is suggested here . In our experience, this is something you can see from Accreditation portfolio attached that we assess and is shown to be present as standard practice with GP practices that go through with GSF accreditation , but we know is relatively common elsewhere also as a measure of good practice . |
| 314 | The GSF Centre in End of Life Care | Statement 5 Question 3 | Although this is a process measure you could also include information given to carer / patient on what to do in a crisis – both general and specific . We developed several examples of this in the GSF Home Packs previously . |
| 315 | The GSF Centre in End of Life Care | Statement 5 Question 4 | COVID – as said about – importance of running ‘COVID virtual wards’ , routine use of pulse oximetry , REACT2 and NEWS tools have increased in home care , domiciliary care and care homes , so these improvements should be built upon .  We have found the GSF training helped staff in care homes, retirement villages , domiciliary care etc prepare well , notably with needs-based RAG coding and advance care planning for all residents, so when COVID hit , they were better able to cope- see ‘ Voices from the Frontline’ not yet published but in report form attached . |
| 316 | The GSF Centre in End of Life Care | Statement 5 Question 6 | As described for QS 4 in coordination , this also applies to access of support 24/7 , especially the Gold-Line |
| 317 | Weldmar Hospicecare | Statement 5 | It is good to see the need identified for those responding to people out of hours having access to the individuals medical records. Our 24 hr telephone advice line would be a good example of this in practice. |
| Additional areas | | | |
| 318 | BAME Health Collaborative | Medicine management | Availability of medication / Appropriate/effective management of poly-pharmacy, and reducing inappropriate medications in end of life care. I don’t see how we will achieve this aim if we do not have their input from pharmacy /Pharmacist. There must be better use of pharmacists in this endeavour, especially as 45% of those registered in the UK are of BAME origin and could also be used to give advice on ACP to BAME communities. |
| 319 | The Royal Marsden NHS Foundation Trust |  | **Does this draft quality standard accurately reflect the key areas for quality improvement?**  Agree. We thought missing education/training on delivery of end of life care for carers in peoples homes could be added |
| 320 | University of Cambridge |  | The quality statements require an additional statement of Holistic Needs Assessment for people approaching end of life and their carers. The current quality standard is intended to update the existing standard published in 2011, where the 2011 Standard Statements 3 and 7 do include comprehensive holistic assessments for both people approaching the end of life and their carers, respectively. The updating process therefore appears to be taking a backward step by omitting holistic assessment. Further, it also to fails to respond to the quality improvement areas currently recommended by stakeholders: Holistic Needs Assessment was a clear, suggested improvement area in the NICE Quality Standards Briefing paper. Stakeholders highlighted how such assessment enables person centred holistic delivery, facilitates identification and response to need and brings quicker relief both for adults at end of life and their carers. This is not just limited to ACP, but is essential for ensuring appropriate care and support throughout.  This update needs to take the approach of the 2011 Standard of separate quality statements about Holistic Needs Assessment for those approaching the end of life and their carers. It should be noted that Holistic Needs Assessments are often completed when a carer is present leading to an assumption that the assessment process also includes carers. However, the carer’s separate support needs are not being assessed in this case. Guidance from the National End of Life Care Programme on Holistic common assessment of supportive and palliative care needs for adults requiring end of life care makes clear that it is designed solely of the individual requiring end of life care. Provision therefore has to be made for separate holistic carer assessment. |
| Other | | | |
| 321 | Royal College of Physicians |  | We have liaised with the British Thoracic Society (BTS), the British Geriatrics Society (BGS) and our Joint Speciality Committee for Palliative Medicine, and would be happy to support the Quality Standard.  We would also like to endorse the comments submitted by the British Geriatric Society (BGS). |
| 322 | Care England |  | Apologies we do not have capacity to respond to this NICE consultation on this occasion. |

## Registered stakeholders who submitted comments at consultation

* Association for Palliative Medicine
* Association of British Neurologists
* BAME Health Collaborative
* British Association of Social Workers
* British Geriatrics Society
* Care England
* Compassion in Dying
* Faculty of Intensive Care Medicine
* General Medical Council
* Greenwich & Bexley Community Hospice
* Hospice UK
* Kidney Cancer Support Network
* King’s College Hospital NHS Foundation Trust
* Macmillan Cancer Support
* Marie Curie
* Motor Neurone Disease Association
* Multiple System Atrophy Trust
* National Bereavement Alliance
* NHS England and NHS Improvement
* North West Boroughs Health
* Rowcroft Hospice, Devon
* Royal College of Nursing
* Royal College of Occupational Therapists
* Royal Pharmaceutical Society
* Royal College of Physicians
* Royal College of Physicians and Surgeons of Glasgow
* Royal College of Speech and Language Therapists
* Society for Acute Medicine
* South West End of Life Network
* The GSF Centre in End of Life Care
* The Law Society
* The Royal Marsden NHS Foundation Trust
* University of Bedfordshire
* University of Cambridge
* Weldmar Hospicecare

1. Stroebe, M.S., Schut, H., and Stroebe, W (2007) Health outcomes of bereavement. *Lancet,* 370, 1960-73. <http://www.comsegovia.com/paliativos/pdf/Health%20outcomes%20of%20bereavement.pdf> [↑](#endnote-ref-1)
2. Stroebe et al (2007) ibid [↑](#endnote-ref-2)
3. Lloyd-Williams, M and Wilkinson, C and Lloyd-Williams, F (1998) Do bereaved children consult the primary health care team more frequently? *European Journal of Cancer Care* 7, 120-124 [↑](#endnote-ref-3)
4. Birrell et al (2013) Socio-Economic Costs of Bereavement in Scotland: Main Study Report. <https://www.artshealthandwellbeing.org.uk/sites/default/files/Socio-Economic%20Costs%20of%20Bereavement%20in%20Scotland.pdf> [↑](#endnote-ref-4)
5. Shear, K (2015) ‘Complicated Grief’, The New England Journal of Medicine, 372, 2, 153-60. [↑](#endnote-ref-5)
6. Lundorff, M., Holmgren, H., Zachariae, R., Farver-Vestergaard, I., & O’Connor, M. (2017). Prevalence of prolonged grief disorder in adult bereavement: A systematic review and meta-analysis. Journal of Affective Disorders, 212, 138-149. [↑](#endnote-ref-6)
7. Prigerson, H et al (2008) A case for inclusion of prolonged grief disorder in DSM-V. In Stroebe M et al (eds) *Handbook of Bereavement Research and Practice* Washington DC: American Psychological Association [↑](#endnote-ref-7)
8. Around 20% of people who register a death say that they would have liked to talk to someone about their feelings about the illness or death, but they did not get this chance. 13.3% did get to speak to someone, and 66.3% had not wanted to (Office for National Statistics (2015) [National Survey of Bereaved People (VOICES)](https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/datasets/nationalsurveyofbereavedpeoplevoices) 2015) [↑](#endnote-ref-8)
9. Sue Ryder found that only 9% of the adults they polled about their experiences of bereavement in the last 5 years had received any support aside from that provided by family or friends. 31% of those who did not receive any formal support said that it would have been helpful (i.e. 28% of those who had been bereaved). Sue Ryder (2019 [*A better grief*](https://www.sueryder.org/sites/default/files/2019-03/a-better-grief-report-sue-ryder.pdf)*).* [↑](#endnote-ref-9)
10. Lichtenthal WG, Nilsson M, Kissane DW, BreitbartW, Kacel E, et al. (2011) Underutilization of mental health

    services among bereaved caregivers with prolonged grief disorder. Psychiatr Serv. 62: 1225–

    1229. doi: 10.1176/appi.ps.62.10.1225 [↑](#endnote-ref-10)
11. Calanzani, N., Koffman, J., & Higginson, I. J. (2013). Palliative and end of life care for Black, Asian and Minority Ethnic groups in the UK. London: Marie Curie <https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/june-2013/palliative-and-end-of-life-care-for-black-asian-and-minority-ethnic-groups-in-the-uk.pdf> [↑](#endnote-ref-11)
12. Bignall T, Jeraj S, Helsby E and Butt J (2019) *Racial disparities in mental health: literature and evidence review* London: Race Equality Foundation [↑](#endnote-ref-12)
13. Baker C (2018) *Mental health statistics for England: Prevalence, services and funding* Briefing paper 6988. House of Commons library <https://commonslibrary.parliament.uk/research-briefings/sn06988/> [↑](#endnote-ref-13)