NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Health and social care directorate

Quality standards

Briefing paper

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| Quality standard topic: End of life care for adults (QS update)  Output: Prioritised quality improvement areas for development.  Date of Quality Standards Advisory Committee meeting: 8 September 2020 |

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* + 1. Introduction

This briefing paper presents a structured overview of potential quality improvement areas for end of life care for adults (QS update). It provides the committee with a basis for discussing and prioritising quality improvement areas for development into draft quality statements and measures for public consultation.

* 1. Structure

This briefing paper includes a brief description of the topic, a summary of each of the suggested quality improvement areas and supporting information.

If relevant, recommendations selected from the key development source below are included to help the committee in considering potential statements and measures.

* 1. Development source

The key development source referenced in this briefing paper is:

[End of life care for adults: service delivery (2019) NICE guideline NG142](https://www.nice.org.uk/guidance/ng142)

Published October 2019.

* + 1. Overview
  1. Focus of quality standard

This quality standard will cover end of life care services, which provide care and support to adults (aged 18 or over) with progressive life-limiting conditions in the final weeks and months of life (or for some conditions, years). It will cover planning and preparation, but it will not cover care of dying adults in the last days of life. This area is covered by a separate [NICE quality standard for Care of dying adults in the last days of life (QS144)](https://www.nice.org.uk/guidance/qs144).

This quality standard will replace the existing [NICE quality standard for End of life care for adults (QS13)](https://www.nice.org.uk/guidance/qs13). It will be updated using [new guidance on End of life care for adults: service delivery (NG142)](https://www.nice.org.uk/guidance/ng142).

* 1. Definition and service delivery

End of life care encompasses care and support for people approaching the end of life. People who are approaching the end of life include those in the final weeks and months of life, although for people with some conditions, this could be months or years.

This includes people with:

* advanced, progressive, incurable conditions
* general frailty and coexisting conditions that mean they are at increased risk of dying within the next 12 months
* existing conditions if they are at risk of dying from a sudden acute crisis in their condition
* life-threatening acute conditions caused by sudden catastrophic events.

End of life care may be delivered by disease-specific specialists and their associated teams; by generalists such as primary care teams or hospital-based generalists (for example, elderly care); or by palliative care specialists in hospices, hospitals and community settings. Giving this type of care can ensure that people live well until they die.

Care that is given alongside, and to enhance, disease modifying and potentially life-prolonging therapies, often for years, can be called 'supportive care'.

Care that is primarily conservative and aimed at giving comfort and maintaining quality of life in the last months of life is commonly referred to as palliative care. Palliative care particularly aims to provide relief from pain and other distressing symptoms, integrate the psychological, social and spiritual aspects of the person's care, and continue to offer a support system to help people to live as actively as possible until their death.

[End of life care for adults: service delivery (2019) NICE guideline NG142](https://www.nice.org.uk/guidance/ng142) refers to end of life care as both supportive and palliative care.

* 1. Population

According to the [palliative and end of life care atlas of variation](https://fingertips.phe.org.uk/profile/atlas-of-variation) (PHE, 2018), approximately half a million people die in England each year. The majority are aged 75 years and older (68% in 2016) which has changed little over recent years. However, the age at which people die has substantially increased (Figure 1).

**Figure 1 Number of deaths by age at death, England 2006 - 2016**



Improvements in health care are leading to more people living longer but often with multiple comorbidities. Over the last 10 years the number of people dying with dementia has been increasing considerably. The future is likely to see this trend continue due to the expected increase in the number of people dying in their late 80s or later. This will impact on the health and social care services that will be required to deliver high quality end of life care.

* 1. Current context

[NHS England established an End of Life Care Programme (2018/19)](https://www.england.nhs.uk/eolc/what-nhs-england-doing-to-improve-end-of-life-care/) which aims to:

* increase the percentage of people identified as being in their last year of life so that their end of life care can be improved by personalising it according to their needs and preferences and
* secure strong clinical engagement and support in improved end of life care by working with NHS England regional networks.

The programme is aligned to the [Ambitions for Palliative and End of Life Care](http://endoflifecareambitions.org.uk/resources/) framework which supports national and local health and care system leaders to take action to improve end of life care.

It outlines six ambitions:

* Each person is seen as an individual
* Each person gets fair access to care
* Maximising comfort and wellbeing
* Care is coordinated
* All staff are prepared to care
* Each community is prepared to help
  1. Resource impact for the guideline

The recommendations from NICE’s guideline on [end](http://www.nice.org.uk/guidance/ng142) of life care for adults: service delivery that we think will have the greatest resource impact nationally (for England), and will need the most additional resources to implement or potentially generate are:

* Providing multipractitioner care **[recommendation 1.9]**
* Providing end of life care coordination **[recommendation 1.10]**
* Transferring people between care settings **[recommendation 1.11]**
* Providing out-of-hours care **[recommendation 1.12]**

The estimated total annual cost of providing end of life care (EOLC) services for a population of 500,000 is estimated at £2.3 million. Most areas will have a significant part of these services already in place. Clinical opinion suggests it is likely to be specialist areas that require the greatest increase in investment. There is high variability in services provided across different regions. For a health economy with 80% of services already in place, the resource impact of moving to 100% of services would be around £469,000.

Table 1 below shows a range of investment of the likely resource impact for implementing the guideline (excluding ambulance services).

Table 1 Potential resource impact of providing end of life care for adults for a population of 500,000 using NICE recommendations.

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Description** |  |  |  |  |
| Percentage of service already in place | 70% | 80% | 90% | 100% |
| **Potential incremental resource impact (£000s)1** | **704** | **469** | **235** | **0** |

1 Based on an estimated total annual cost of providing EOLC services of £2.3m

Discussions with experts from the guideline development committee indicate that one integrated service model is needed to deliver the recommendations outlined above. The resource impact template supporting the guidance provides an example of resources needed to provide the services included in these recommendations.

From the table above it can be estimated that for every 10% of additional service needed, the potential incremental cost is £235,000 for a population of 500,000. This is based on a total baseline cost of service of £2.3 million, however within the services provided, there could be variations, for example care coordination services may already be staffed at 100%, whilst other services such as out-of-hours care may be staffed at 70%.

Investment in ambulance services should be considered locally as this may involve the commissioning of additional ambulances and may have set up costs including the cost of the vehicles and training of additional staff.

Services are commissioned by NHS England, clinical commissioning groups (CCGs), and Local Authorities. Providers of NHS commissioned services are hospital trusts, community providers, and the voluntary sector.

* + 1. Summary of suggestions
  1. Responses

In total 33 registered stakeholders, the National Clinical Director for End of Life Care and 9 specialist committee members responded to the engagement exercise which was extended because of the impact of the coronavirus pandemic. We also received comments from 3 non-registered stakeholders and 2 comments from individuals. The responses have been merged and summarised in table 2 for further consideration by the committee.

Full details of all the registered stakeholders’ suggestions are given in appendix 2 for information.

### Table 2 Summary of suggested quality improvement areas

|  |  |
| --- | --- |
| Suggested area for improvement | Stakeholders |
| Identification | APM, BGS, BPS, BSHF, BSG, BTS, FICM, GSF, HUK, NCD, RCP, SAM, SCM1, SCM2, SCM4, SCM6, SCM7, SCM8, SCM9 |
| Needs assessment   * Holistic needs assessment * Reviewing needs and treatment | BDA, BGS, BPS, BSHF, HUK, MC, MSAT, RCN, RCOT, RCSLT, SBNS, SCM5, SCM6, SCM7, SCM8 |
| Advance care planning | APM, BGS, BPS, BSHF, CID, DUK, FICM, GSF, HUK, MC, MNDA, MSAT, NHSB&T, RC, RCGP, RCN, RCP, SAM,  SCM2 – SCM9 |
| Coordinated care   * Coordination and information sharing * Providing multipractitioner care * Transfers between care settings | ABN, AFTSP, APM, BGS, BPS, BTS, CID, FASO, FICM, GSF, HUK, KCUK, MSAT, NCD, RCGP, RCN, RCOT, RCP, SAM, SCM1 - SCM7, THB |
| Out of hours care | APM, BPS, FICM, MC, NCD, RCP, SCM1, SCM2, SCM6, SCM7, SCM9, |
| Support for carers   * Supporting carers * Bereavement care | AFTSP, CBC, DUK, FICM, MSAT, NCD, RCN, SCM1, SCM2, SCM4 - SCM6, UCLH |
| Additional areas   * COVID-19 * Shared decision making * Last days of life * Decision making and mental capacity * Specific populations * Reablement * Access to funding * OACC measures | ABN, APM, BGS, BPS, BTS, CID, DUK, FASO, FICM, GSF, HUK, KCUK, MNDA, MSAT, NCA, NHSB&T, RCGP, RCN, RCOT, RCP, RCSLT, SAM, SCM1, SCM3, SCM5, SCM7, SCM9, THB, UCLH, UE |
| Abbreviations:  ABN, Association of British Neurologists, Quality Committee  AFTSP, Association for Family Therapy and Systemic Practice UK  APM, Association for Palliative Medicine of Great Britain and Ireland  BDA, Oncology Specialist Group on behalf of the BDA  BGS, British Geriatric Society  BPS, The British Pain Society  BSG, British Society of Gastroenterology  BTS, British Thoracic Society  BSHF, British Society for Heart Failure  CBC, Cruse Bereavement Care  CID, Compassion in Dying  DUK, Dementia UK  FASO, False Allegations Support Organisation  FICM, Faculty of Intensive Care Medicine  GSF, The Gold Standards Framework CIC  HUK, Hospice UK  KCUK, Kidney Care UK  MC, Marie Curie  MNDA, Motor Neurone Disease Association  MSAT, Multiple System Atrophy Trust  NCA, National Care Association  NCD, National Clinical Director for Palliative and End of Life Care  NHSB&T, NHS Blood and Transplant  RCGP, Royal College of General Practitioners  RC, Resuscitation Council UK  RCN, Royal College of Nursing  RCOT, Royal College of Occupational Therapists  RCP, Royal College of Physicians  RCSLT, Royal College of Speech and Language Therapists  SAM, Society for Acute Medicine  SBNS, Society of British Neurological Surgeons  SCM, Specialist Committee Member  THB, Trinity Hospice Blackpool  UCLH, University College London Hospitals NHS Foundation Trust  UE, University of Essex | |

* 1. Identification of current practice evidence

Bibliographic databases were searched to identify examples of current practice in UK health and social care settings; 3098 papers were identified for end of life care. In addition, 67 papers were suggested by stakeholders at topic engagement and 77 papers internally at project scoping.

Of these papers, 12 have been included in this report and are included in the current practice sections where relevant. Appendix 1 outlines the search process.

* 1. Priorities for committee discussion

The format of this briefing paper has been amended to support the move to virtual committee meetings. Table 3 summarises the availability of information presented in the briefing paper for each suggested quality improvement area. We have used this to suggest priority areas for the quality standards advisory committee to discuss. The areas that are not suggested as a priority for discussion are shaded in grey within the briefing paper. These are suggestions only however and the committee on 8th September 2020 will decide which areas it wishes to discuss.

Table 3 Summary of information available for suggested areas for improvement

| Suggested area for improvement | In scope | Guideline recs | Current practice evidence | Existing QS statement | Priority to discuss? |
| --- | --- | --- | --- | --- | --- |
| Identification | Yes | Yes | Yes | No | **Yes** |
| Needs assesment   * Holistic needs assessment * Reviewing needs & treatment | Yes  Yes | Yes  Yes | Limited  No | No  No | **Yes**  **Yes** |
| Advance care planning | Yes | Yes | Yes | No | **Yes** |
| Coordinated care   * Coordination and information sharing * Providing multipractitioner care * Transfer between settings | Yes  Yes  Yes | Yes  Yes  Yes | Yes  No  No | No  No  No | **Yes**  **Yes**  **Yes** |
| Out of hours care | Yes | Yes | Limited | No | **Yes** |
| Support for carers   * Supporting carers * Bereavement care | Yes  Yes | Yes  No | Yes  Limited | Yes – separate quality standard  No | **Yes**  **No** |
| Additional areas   * COVID-19 * Shared decision making * Last days of life * Decision making and mental capacity * Specific populations * Reablement * Access to funding * Outcome Assessment and Complexity Collaborative | Yes  Yes  No  Yes    Yes  Yes  No  Yes | No  No  Yes  Yes  Yes  Yes  No  No | N/A  N/A  N/A  N/A  N/A  N/A  N/A  N/A | No  No  Yes  Yes  Yes  Yes  No  No | **No**  **No**  **No**  **No**  **No**  **No**  **No**  **No** |

* + 1. Suggested improvement areas
  1. Identification

Summary of suggestions

### Identification

Stakeholders suggested that timely recognition and identification of people approaching the end of life is a key area for quality improvement.

Stakeholders said that people who are recognised and identified as approaching the end of life have opportunities to make informed decisions about their care and make plans for their future. They can access palliative and specialist palliative care services, and their carers and people important to them are more likely to be offered support. Without the identification, people only have access to generic services.

Stakeholders suggested that recognition of people approaching the end of life remains suboptimal and inconsistent. They raised specific concerns about inequity in identification of people approaching end of life and provision of palliative care to people with life limiting health conditions other than cancer. Specific groups highlighted by stakeholders included those living with frailty, motor neurone disease, heart, renal or liver failure and people from underserved populations who are even less likely to be identified.

Selected recommendations from development source

Table 4 highlights recommendation that has been provisionally selected from the development source that may support potential statement development. These are presented in full after the table to help inform the committee’s discussion.

### Table 4 Specific areas for quality improvement

|  |  |
| --- | --- |
| Suggested quality improvement area | Suggested source guidance recommendations |
| Identification | NICE NG142 [Recommendation 1.1.1](https://www.nice.org.uk/guidance/ng142/chapter/Recommendations#identifying-adults-who-may-be-approaching-the-end-of-their-life-their-carers-and-other-people) |

### Identification

NICE NG142

Recommendation 1.1.1

People managing and delivering services should develop systems to identify adults who are likely to be approaching the end of their life (for example, using tools such as the Gold Standards Framework, the Amber Care Bundle or the Supportive and Palliative Care Indicators Tool [SPICT]). This will enable health and social care practitioners to start discussions about advance care planning, provide the care needed, and to support people's preferences for where they would like to be cared for and die.

Current UK practice

[The Community Care Pathways at the End of Life (CAPE) study](https://spcare.bmj.com/content/9/4/468) investigated primary care provision for patients in the final 6 months of life. The study looked at the records of 400 recently deceased patients in 20 GP practices in the East of England. There was no evidence of end of life care planning for 31% of the deaths which were considered “unanticipated” by healthcare services.

[According to an article by Keri Thomas](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5819956/), the founder and National Clinical Lead at The Gold Standards Framework Centre, 98% of UK general practices have QOF palliative care registers, and regular meetings to proactively discuss EOLC, based on the basic level Gold Standards Framework (GSF). The author highlights that 2009 GSF national survey demonstrated that only a quarter of patients who died were identified on the register, and only a quarter were non-cancer patients. Data published by PHE in 2018 indicates that QOF average identification rate was 34%. This is a significant progress but also an indication that many people are still not recognised early enough to plan proactive care.

A large thematic review carried out by CQC and summarised in a report: [A different ending: addressing inequalities in end of life care (2016)](https://www.cqc.org.uk/publications/themed-work/different-ending-end-life-care-review) highlighted that people with diagnoses other than cancer and older people were not always able to access the right care at the right time. The review highlighted that healthcare professionals sometimes found it difficult to identify when people who have conditions other than cancer, including frailty and dementia, were likely to be in the last 12 months of life. What is more, healthcare professionals do not always recognise dementia as a life limiting condition which means the person may lose the opportunity to discuss end of life care wishes and preferences before the last year of life as they progressively lose capacity to make decisions.

### Committee discussion

|  |
| --- |
| For discussion |
| * What is the priority for improvement? * What is the key action that will lead to improvement? * Can we develop a specific, measurable statement? |
| For decision |
| * Should this area be prioritised for inclusion in the quality standard? |

* 1. Needs assessment

Summary of suggestions

### Holistic needs assessment

Stakeholders suggested that carrying out a person-centred holistic needs assessment is a key area for quality improvement.

Stakeholders suggested that a holistic needs assessment leads to personalised care and better care planning. It facilitates identifying and responding to needs and can bring quicker relief to those who need help in end of life care and their carers.

They suggested that a person-centred assessment should be based on what matters to the person and include activities the person wants to do and needs they have. They specifically highlighted the importance of social care support in meeting needs beyond healthcare.

Stakeholders suggested that needs assessments are not carried out consistently and that many people do not have their needs recognised. Particular concerns were raised around people who are transgender.

### Reviewing needs & treatment

Stakeholders suggested that reviewing needs and treatment is a key area for quality improvement.

They highlighted that needs and effectiveness of treatments can change very quickly among people at the end of life. They suggested regular reviews are necessary to respond to these changes and amending or withdrawing ineffective treatments, medication or artificial nutrition when they no longer benefit the person. Changes to communication needs were specifically highlighted.

Selected recommendations from development source

Table 5 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development.

### Table 5 Specific areas for quality improvement

|  |  |
| --- | --- |
| Suggested quality improvement area | Selected source guidance recommendations |
| Holistic needs assessment | NICE NG142 [Recommendation 1.2.1](https://www.nice.org.uk/guidance/ng142/chapter/Recommendations#assessing-holistic-needs) |
| Reviewing needs & treatment | NICE NG142 [Recommendations 1.5.1, 1.5.2, 1.5.3](https://www.nice.org.uk/guidance/ng142/chapter/Recommendations#reviewing-current-treatment)  NICE NG142 [Recommendation 1.7.1](https://www.nice.org.uk/guidance/ng142/chapter/Recommendations#reviewing-needs) |

### Holistic needs assessment

NICE NG142

Recommendation 1.2.1

If it is thought that an adult is approaching the end of their life, carry out an initial holistic needs assessment with the person and document this. This will enable the right support to be provided when it is needed.

### Reviewing needs & treatment

NICE NG142

Recommendation 1.5.1

For advice on reducing treatment burden and reviewing medicines and other treatments, see the NICE guidelines on multimorbidity and medicines optimisation.

Recommendation 1.5.2

Develop policies for reviewing treatment within all specialties to meet the changing needs of adults approaching the end of their life and to reduce the burden of unhelpful treatments. Different services should work together and share information about treatment reviews (see section 1.10 on providing end of life care coordination).

Recommendation 1.5.3

The lead healthcare professional should ensure that the person approaching the end of their life is offered opportunities to discuss their existing treatment plans with a healthcare professional. The person's carers and other people important to them should be included in the discussions, if the person agrees. This should include discussing:

* any changes that could optimise care and improve their quality of life (for example, reducing the number of unnecessary routine appointments, organising appointments close to the person's home, starting new treatments or stopping unhelpful treatments)
* community support available to help with their treatment.

Current UK practice

### Holistic needs assessment

A large thematic review carried out by CQC and summarised in a report: [A different ending: addressing inequalities in end of life care (2016)](https://www.cqc.org.uk/publications/themed-work/different-ending-end-life-care-review) highlighted specific issues relevant to people from BME groups, Gypsy and Traveller communities and others:

* organisational lack of familiarity with people’s cultural preferences
* staff making assumptions about their preferences - people less able to make choices
* lack of understanding of what was important to people, including their relationships

The same report highlighted concerns that LGBT partners were often not involved in care in the same way that a heterosexual partner would be.

The case note review carried out as part of this work showed that for 76% of the overall sample, the health and care professionals had considered the individual’s communication needs, however, this dropped to 45% for people with dementia.

### Reviewing needs & treatment

No published studies on current practice were highlighted for this suggested area for quality improvement. This area is based on stakeholder’s knowledge and experience.

### Committee discussion

|  |
| --- |
| For discussion |
| * What is the priority for improvement? * What is the key action that will lead to improvement? * Could we focus on a specific audience or setting? * Can we develop a specific, measurable statement? |
| For decision |
| * Should this area be prioritised for inclusion in the quality standard? |

* 1. Advance care planning

Summary of suggestions

### Advance care planning

Stakeholders suggested that advance care planning is a key area for quality improvement.

They highlighted that advance care planning gives people the opportunity to engage in making specific decisions and plans for their future care. Early planning for care at the end of life ensures that families and professionals are aware of a person's wishes before communication or cognitive changes make this difficult or impossible.

Stakeholders suggested that professionals across health and social care still do not support people at the end of life and those close to them to have conversations regarding end of life care choices.

More specifically, stakeholders suggested that Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) is sometimes brought up in isolation without a sensitive and well-structured conversation and has been particularly poorly handled in the context of COVID-19 pandemic.

Selected recommendations from development source

Table 6 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development.

### Table 6 Specific areas for quality improvement

|  |  |
| --- | --- |
| Suggested quality improvement area | Selected source guidance recommendations |
| Advance care planning | NICE NG142 [Recommendations 1.6.1, 1.6.2, 1.6.3](https://www.nice.org.uk/guidance/ng142/chapter/Recommendations#advance-care-planning) |

### Advance care planning

NICE NG142

Recommendation 1.6.1

Service providers should develop policies to ensure that advance care planning is offered to adults who are approaching the end of their life. Policies should take into account under-served and vulnerable groups.

Recommendation 1.6.2

Service providers should develop processes to support carers and other people important to the person to be involved in advance care planning, if the person approaching the end of their life agrees.

Recommendation 1.6.3

Service providers should have systems in place to ensure that adults approaching the end of their life each have a copy of their advance care plan available in their place of residence or with them if admitted to a hospital, care home or hospice.

Current UK practice

[A national survey carried out by the Multiple System Atrophy Trust](https://www.msatrust.org.uk/cause-and-cure/msa-needs-surveys/) (2019) found that only 37% of 284 respondents had discussed with their doctor end of life care. Of those who had not had this discussion, almost two thirds (62%) would like to have this discussion.

In terms of formal advance care planning, the most commonly reported were:

* A will (79% have a will, further 10% are considering this).
* Lasting Power of Attorney (POA) for property and finance (60% have one in place, further 19% are considering this).
* Lasting POA for health and welfare (54% have one in place and a further 21% are considering this).

A report [“I wish I had known” produced by Compassion in Dying (2018)](https://compassionindying.org.uk/library/i-wish-i-had-known/) found that whilst 87% of people over 65 years old think it is important that healthcare professionals know about their preferences for treatment and care, only 4% have made an Advance Decision and just 7% have appointed a Lasting Power of Attorney for Health and Welfare. According to the report based on the charity’s experience of supporting 25,000 people at the end of life, people:

* often do not feel supported to make the decisions they are faced with
* are not always given an honest prognosis
* do not know what options and choices are available
* do not know the right questions to ask their doctor

[A systematic review carried out by the National Institute for Health Research](https://www.ncbi.nlm.nih.gov/books/NBK355498/) (2016) which synthesised evidence of processes, barriers and facilitators related to do-not-attempt-cardiopulmonary-resuscitation decisions (DNACPR) decision-making and implementation found evidence of variation and suboptimal practice in relation to DNACPR across health-care settings. The review looked at reports from NHS trusts, the National Reporting and Learning System, the Parliamentary and Health Service Ombudsman, the Office of the Chief Coroner, trust resuscitation policies and telephone calls to a patient information line.

[Since the outbreak of Covid-19, concerns have been raised about blanket applications of DNACPR orders to groups of people, including people with a learning disability and autism](https://www.nursingtimes.net/news/policies-and-guidance/government-promises-new-national-guidance-on-dnacpr-orders-14-07-2020/). A Department of Health and Social Care spokesperson said: “We have made clear that it is completely unacceptable for DNACPR orders to be applied in a blanket fashion to any group of people. The government has taken consistent action on a number of fronts to prevent this from happening and NHS England is currently creating patient-facing guidelines on how to challenge a DNACPR and access support”.

### Committee discussion

|  |
| --- |
| For discussion |
| * What is the priority for improvement? * What is the key action that will lead to improvement? * Can we develop a specific, measurable statement? |
| For decision |
| * Should this area be prioritised for inclusion in the quality standard? |

* 1. Coordinated care

Summary of suggestions

### Coordination and information sharing

Stakeholders suggested coordination and information sharing is a key area for quality improvement.

Stakeholders highlighted that people at the end of their life are more likely to receive care from a range of services, in a number of settings. Coordination of these services is necessary to ensure that the person receives end of life care that reflects their needs and preferences. They suggested that identifying a key coordinator or key worker who can facilitate wrapping care around the person at the end of their life can be helpful in removing barriers across the system.

Stakeholders also suggested that information sharing systems need to be clear and IT systems that are used to communicate decisions and information about people at the end of life need to be fit for purpose and interoperable.

Stakeholders suggested that patients still experience suboptimal coordination of their care, between different services and also between their condition specific specialist and that of their palliative care teams.

The importance of documenting and sharing information about people at the end of life and their preferences has been particularly highlighted during the COVID-19 pandemic where people were often treated in isolation with no input from friends and family.

### Providing multipractitioner care

Stakeholders suggested providing multipractitioner care as a key area for quality improvement.

Stakeholders felt that multipractitioner care is necessary to enable people approaching the end of life to be supported and have their health and social care needs met in the place of their preference.

They highlighted increasing numbers of people reaching the end of life with more than one disease. This introduces the need for close collaboration between disease specific specialists who need to be supported by multidisciplinary teams and palliative care specialists to achieve the best outcomes and experience for the person at the end of life.

### Transfer between care settings

Stakeholders suggested transfers between care settings is a key area for quality improvement.

Stakeholders highlighted that developing systems to support smooth and rapid transfer between settings is vital to maximise the chance of a person being cared for and dying in their preferred place. These systems should include transport available to move people between care settings without delay, availability of care packages at home and information on the person’s plan of care and changing needs that would accompany them at the point of transfer to allow for smooth transition.

Stakeholders suggested that delayed discharge to a place where people want to die, and unwanted and medically unnecessary hospital admissions occur because care packages for those wishing to die at home are unavailable.

Selected recommendations from development source

Table 7 below highlights recommendations that have been provisionally selected from the development source.

### Table 7 Specific areas for quality improvement

|  |  |
| --- | --- |
| Suggested quality improvement area | Selected source guidance recommendations |
| Coordination and information sharing | NICE NG142 [Recommendations 1.8.1, 1.8.2](https://www.nice.org.uk/guidance/ng142/chapter/Recommendations#communicating-and-sharing-information-between-services), [1.10.1, 1.10.3, 1.10.4](https://www.nice.org.uk/guidance/ng142/chapter/Recommendations#communicating-and-sharing-information-between-services) |
| Providing multipractitioner care | NICE NG142 [Recommendations 1.9.1, 1.9.2](https://www.nice.org.uk/guidance/ng142/chapter/Recommendations#communicating-and-sharing-information-between-services) |
| Transfer between care setting | NICE NG142 [Recommendations 1.11.2, 1.11.3](https://www.nice.org.uk/guidance/ng142/chapter/Recommendations#transferring-people-between-care-settings) |

### Communicating and sharing information

NICE NG142

Recommendations 1.8.1

Adults approaching the end of their life should have care that is coordinated between health and social care practitioners within and across different services and organisations, to ensure good communication and a shared understanding of the person's needs and care.

Recommendations 1.8.2

Use electronic information-sharing systems that are accessible between different services and organisations to enable information to be reviewed, updated and shared efficiently within and between multipractitioner teams, across different services and organisations.

### End of life care coordination

NICE NG142

Recommendations 1.10.1

Provide end of life care coordination for adults who are approaching the end of their life through:

* community and primary care services for adults, provided by the person's GP or another health or social care practitioner in the primary or community care team
* hospital services for adults whose treatment is based in secondary or tertiary care, provided by health and social care practitioners based in hospices or disease-specific specialists in hospitals.

Recommendations 1.10.3

Ensure that there is good communication between health and social care practitioners coordinating community-based care and health and social care practitioners coordinating hospital care.

Recommendations 1.10.4

Health and social care practitioners providing end of life care coordination should:

* offer information to the person approaching the end of their life, their carers and others important to them, about who the multipractitioner team members are (including the lead healthcare professionals in each setting responsible for their care), the roles of the team members and how services are accessed
* ensure that holistic needs assessments are offered, and the person's wishes and needs are discussed and acted on whenever possible
* ensure that care is coordinated across and between the multipractitioner teams and between care settings
* ensure that regular discussions and reviews of care, holistic needs and advance care plans are offered
* share information about the person's care between members of the multipractitioner teams.

### Providing multipractitioner care

NICE NG142

Recommendation 1.9.1

Provide access to the expertise of highly skilled health and social care practitioners, when needed, for adults approaching the end of their life, their carers and other people important to them. They should have the skills to:

* meet complex care and support needs
* anticipate and prevent or minimise crises
* support people's preferences for where they would like to be cared for and die, if possible.

Recommendation 1.9.2

Health and social care practitioners should have the skills to provide care for adults approaching the end of their life who need support in the following areas:

* disease-specific, including symptom management, hydration and nutrition, and access to medication
* physical
* psychological
* social, including support and advice (for example, signposting advice on benefits, finance and third-sector, local or national support services)
* support with activities of daily living, including access to equipment and rehabilitation services
* pastoral, religious and spiritual
* cultural.

### Transfer between care settings

NICE NG142

Recommendation 1.11.2

Develop systems to support smooth and rapid transfer between care settings for adults approaching the end of their life. For example, organise services so that:

* ambulances or other transport services can move people between care settings without delay and in an efficient and compassionate way
* care packages and equipment are available to enable adults approaching the end of their life to move to the place where they would like to be cared for and die.

Recommendation 1.11.3

Develop an agreed transfer policy between ambulance service providers and acute care providers to enable the rapid transfer of adults approaching the end of their life to the place where they would like to be cared for and die whenever rapid transfer is a priority.

Current UK practice

### Coordination and information sharing

A large thematic review carried out by CQC and summarised in a report: [A different ending: addressing inequalities in end of life care (2016)](https://www.cqc.org.uk/publications/themed-work/different-ending-end-life-care-review) highlighted that:

* some people felt end of life care was often not well-coordinated and that having a number of different people involved in different aspects of care was confusing; people often had to repeat information multiple times and care provided by different staff and services was not consistent; the impact was increased burden on the carers trying to coordinate care and a loss of focus on the person and their wishes.
* underdevelopment of Electronic Palliative Care Coordination Systems (EPaCCS) was a significant barrier to effective information sharing; where EPaCCS were in use, there was a sense that the system was not properly embedded; although commissioners often felt that EPaCCS were a key tool, staff who were using the system had difficulties.

[The National Survey of Bereaved People (VOICES, 2015)](https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/nationalsurveyofbereavedpeoplevoices/england2015#coordination-of-care-in-the-last-3-months-of-life) collected information on bereaved people’s views on the quality of care provided to a friend or relative in the last 3 months (21,320 respondents). 9,287 respondents answered a question about whether community services worked well together. 41% said that the services definitely worked well together (see Figure 2). This was significantly higher for people who died at home (55%) compared with those who died in a hospice (37%), hospital (33%) or care home (31%)

**Figure 2 Coordination of care between care services in the last 3 months, England, 2015**



### Providing multipractitioner care

No published studies on current practice were highlighted for this suggested area for quality improvement. This area is based on stakeholder’s knowledge and experience.

### Transfer between care settings

No published studies on current practice were highlighted for this suggested area for quality improvement. This area is based on stakeholder’s knowledge and experience.

Resource impact

The potential resource impact of providing multi-practitioner care, care coordination and transfer between care settings depends on the level of service already in place. This was assessed as part of an integrated care model alongside out of hours care which together may have impact on service capacity (see 2.5 above).

### Committee discussion

|  |
| --- |
| For discussion |
| * What is the priority for improvement? * What is the key action that will lead to improvement? * Can we develop a specific, measurable statement? |
| For decision |
| * Should this area be prioritised for inclusion in the quality standard? |

* 1. Out of hours care

Summary of suggestions

### Out of hours care

Stakeholders suggested availability of out of hours care as a key are for quality improvement.

Stakeholders felt that rapid access to services is essential to support people at the end of life. They highlighted that for people near the end of life, unexpected crises are common and lack of out of hours care can lead to consequences such as avoidable A&E visits and hospital admissions as well as unnecessary suffering.

Stakeholders felt that people should have access to a healthcare professional available 24 hours a day, 7 days a week, who can access the person's records and advance care plan and make informed decisions about changes to care.

Stakeholders suggested that only minority of trusts and services based in the community provide access to out of hours care which remains a source of anxiety and suboptimal experience for people at the end of life, their families and carers.

Selected recommendations from development source

Table 8 below highlights recommendations that have been provisionally selected from the development source/sources that may support potential statement development.

### Table 8 Specific areas for quality improvement

|  |  |
| --- | --- |
| Suggested quality improvement area | Selected source guidance recommendations |
| Out of hours care | NICE NG142 [Recommendation 1.12.1](https://www.nice.org.uk/guidance/ng142/chapter/Recommendations#providing-out-of-hours-care) |

### Out of hours care

NICE NG142

Recommendation 1.12.1

Adults approaching the end of their life, their carers and other people important to them should have access to:

* a healthcare professional available 24 hours a day, 7 days a week, who can access the person's records and advance care plan, and make informed decisions about changes to care
* an out-of-hours end of life care advice line
* an out-of-hours pharmacy service that has access to medicines for symptom management in adults approaching the end of their life.

Current UK practice

[A study which explored commissioning of specialist palliative care services in England (2017)](https://spcare.bmj.com/content/8/1/93) based on information obtained through the Freedom of Information Request sent to 209 CCGs, found that commissioning of 24/7 specialist palliative care services varied widely.

* 172 CCGs (84.31%) commissioned 7- day access to some form of specialist palliative care, ranging from providing a telephone advice line to a 24-hour on-call specialist palliative care team
* 169 CCGs (82.84%) commissioned 7-day specialist palliative care services for patients in their own homes, ranging from advice lines to dedicated night care teams
* 163 CCGs (79.90%) commissioned 24/7 specialist palliative care advice; of these:
* 123 (75.46%) provided advice from a consultant to all other out-of-hours’ healthcare professionals in the area
* 117 (71.78%) provided advice directly to patients and their carers

[A national survey of Hospice at Home (HAH) services (2019)](https://spcare.bmj.com/content/early/2019/11/13/bmjspcare-2019-001818) found that out of the 70 services that responded (54.7% response rate), rapid response (within 4 hours) was available in 65.7% and hands-on care 24 hours a day was available in 52.2%.

Resource impact

The potential resource impact of out-of-hours care depends on the level of service already in place. This was assessed as part of an integrated care model alongside other areas of the guidance that may have impact on service capacity (see 2.5 above).

### Committee discussion

|  |
| --- |
| For discussion |
| * What is the priority for improvement? * What is the key action that will lead to improvement? * Can we develop a specific, measurable statement? |
| For decision |
| * Should this area be prioritised for inclusion in the quality standard? |

* 1. Support for carers

Summary of suggestions

### Supporting carers

Stakeholders suggested supporting carers as a key area for quality improvement.

Stakeholders suggested that carers should have their needs assessed and receive support accordingly. They highlighted that providing support to carers can reduce the level of stress and illness, and allow them to continue to care for the person and improves the end of life experience for the person.

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.

### Bereavement care

Stakeholders suggested bereavement support as a key are for quality improvement.

They suggested that provision is very disjointed between settings with pockets of high quality support rather than consistent provision.

Stakeholders also suggested that COVID-19 has had an impact on people’s experience of grief, bereavement and loss. Deaths from Covid-19 are considered to be traumatic given the situations in which people are dying and the wider contextual situation in which people are grieving. Stakeholders anticipated an increase in incidence of complicated grief, post-traumatic stress and other poor bereavement outcomes as a result of family isolation during the dying process.

Stakeholders also highlighted that whilst bereavement care for carers and family members is considered, the psychological impact on staff caring for severely unwell patients with COVID-19 should also be addressed. Stakeholders felt that staff are experiencing increased burden of dying patients and raised particular concerns about those who are not experienced in caring for patients at the end of their lives.

**Please note:** NICE is currently developing a quality standard on supporting adult carers. The draft quality standard is expected to go out to public consultation in October.

Selected recommendations from development source

Table 9 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development.

### Table 9 Specific areas for quality improvement

|  |  |
| --- | --- |
| Suggested quality improvement area | Selected source guidance recommendations |
| Supporting carers | NICE NG142 [Recommendation 1.3.1](https://www.nice.org.uk/guidance/ng142/chapter/Recommendations#supporting-carers) |
| Bereavement care | Not directly covered in NICE NG142 and no recommendations are presented |

### Supporting carers

NICE NG142

Recommendation 1.3.1

People managing and delivering services should think about what practical and emotional support can be provided to carers of adults approaching the end of their life and review this when needed.

Current UK practice

### Supporting carers

[Carers UK State of caring report 2019](https://www.carersuk.org/for-professionals/policy/policy-library/soc-19) found that the majority of carers in England who had been assessed / reassessed in the last year felt that their needs were not given sufficient consideration. 25% of carers who were not yet retired and had an assessment in the last year felt that their need to combine paid work and caring was sufficiently considered in their carer’s assessment.

[A national survey of Hospice at Home (HAH) services (2019)](https://spcare.bmj.com/content/early/2019/11/13/bmjspcare-2019-001818) found that out of the 70 services that responded (54.7% response rate) two thirds of services provided respite care to support carers (n=52, 74.3%). Fewer services (n=15, 21.4%) provided practical support (household tasks, e.g., shopping) directly for family members or carers.

[Carers UK Missing Out: Research briefing on the State of Caring 2019](https://www.carersuk.org/for-professionals/policy/policy-library/missing-out-research-briefing-on-the-state-of-caring-2019-survey) (based on survey responses from over 7,000 carers) found that over half of all carers (55%) took over a year to recognise their caring role and 23% took over 5 years to recognise themselves as a carer. 36% of carers said they missed out on financial support as a result of not identifying as a carer and 47% said they missed out on practical support.

The CQC review [A different ending: addressing inequalities in end of life care (2016)](https://www.cqc.org.uk/publications/themed-work/different-ending-end-life-care-review) highlighted feedback from some LGBT people who felt that their partners were often not involved in their care in the same way that a heterosexual partner would be.

### Bereavement care

[The National Survey of Bereaved People (VOICES, 2015)](https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/nationalsurveyofbereavedpeoplevoices/england2015#coordination-of-care-in-the-last-3-months-of-life) collected information on bereaved people’s views on the quality of care provided to a friend or relative in the last 3 months (21,320 respondents).

* 76% bereaved carers stated that they were involved in decisions about the care provided to the patient as much as they wanted to be
* 59% said that they had definitely been given enough support at the time of the death
* when asked whether they had talked to anyone from any support services since the death, most respondents reported that they had not, and did not want to (66%). however, 21% said that they had not, but would have liked to.

### Committee discussion

|  |
| --- |
| For discussion |
| * What is the priority for improvement? * What is the key action that will lead to improvement? * Can we develop a specific, measurable statement? * Separate QS on supporting carers is being developed. Is there an element of supporting carers at this specific time that we could focus on? |
| For decision |
| * Should this area be prioritised for inclusion in the quality standard? |

* 1. Additional areas

### Summary of suggestions

The improvement areas below were suggested as part of the stakeholder engagement exercise. However, they were felt to be either unsuitable for development as quality statements, outside the remit of this particular quality standard referral or need further discussion by the committee to establish potential for statement development.

There will be an opportunity for the committee to discuss these areas at the end of the session on 8 September 2020.

### COVID-19

At topic engagement we asked stakeholders to tell us if there were any particular issues relating to COVID-19 that we should take into account when developing this quality standard. Some of the issues have already been highlighted as particularly relevant to areas for quality improvement discussed earlier in the paper.

However, there were also additional themes highlighted by stakeholders that are not currently covered by NICE guidelines:

* need for evidence around impact of lockdown, social distancing rules and use of Personal Protective Equipment (PPE) on end of life care; particular concerns about people with dementia
* need for integrated models of palliative care in care homes
* benefits and issues associated with using remote communication to discuss end of life care
* benefits and potential of using online tools for patient care including assessments
* issues around supporting healthcare staff working during the pandemic; some of the specific issue included:
  + staff burnout, moral distress, fatigue, and exhaustion especially among staff not normally working with people at the end of life
  + need for training and support for staff members redeployed from variety of clinical backgrounds to providing end of life care
  + compassionate employers

These suggestions have not been progressed as evidence-based guidelines need to be developed before specific quality statements can be considered.

### Shared decision making

Shared decision making was suggested as an area for quality improvement. This suggestion has not been progressed. Shared decision making and involving people in designing their care is a principle applicable to all quality standards as set out in [the NHS Constitution for England](https://www.gov.uk/government/publications/the-nhs-constitution-for-england). NHS England is supporting the implementation of shared decision making across care pathways at national and local level through its NHS RightCare [shared decision making programme](https://www.england.nhs.uk/rightcare/useful-links/shared-decision-making/) and NICE is currently developing a [guideline on Shared decision making](https://www.nice.org.uk/guidance/indevelopment/gid-ng10120). This area may be referred to in audience descriptors.

### Last days of life

Specific issues around supporting people in the last days of life and those important to them were highlighted as an area for quality improvement. This was specifically suggested in the context of the COVID-19 pandemic by some of the stakeholders. This suggestion has not been progressed. Last days of life are covered by a separate [NICE quality standard Care of dying adults in the last days of life (QS144)](https://www.nice.org.uk/guidance/qs144).

### Decision making and mental capacity

Specific issues around decision making and mental capacity were highlighted as an area for quality improvement. This suggestion has not been progressed. Decision making and mental capacity is covered by a separate [NICE quality standard Decision making and mental capacity (QS194)](https://www.nice.org.uk/guidance/qs194).

### Specific populations

Issues around end of life care among specific populations were highlighted as an area for quality improvement. This suggestion has not been progressed. NICE has published quality standards that specifically address support for the groups highlighted by stakeholders:

* [End of life care for infants, children and young people (QS160)](https://www.nice.org.uk/guidance/qs160)
* [Learning disability: care and support of people growing older (QS187)](https://www.nice.org.uk/guidance/qs187)
* [Promoting health and preventing premature mortality in black, Asian and other minority ethnic groups (QS167)](https://www.nice.org.uk/guidance/qs167)
* [Motor neurone disease (QS126)](https://www.nice.org.uk/guidance/qs126)

Inequality issues specific to end of life care can be highlighted within the inequalities considerations for each quality statement.

### Reablement

Availability of strength-based exercise within the community was suggested as an area for quality improvement. This suggestion has not been progressed. Reablement is covered by a separate [NICE quality standard Intermediate care including reablement (QS173)](https://www.nice.org.uk/guidance/qs173).

### Access to funding

Improving access to specific funding streams was suggested as an area for quality improvement. This suggestion has not been progressed. NICE quality standards focus on actions that demonstrate high quality care or support, not specific funding arrangements.

### Outcome Assessment and Complexity Collaborative (OACC)

Implementation of OACC suite of measures was suggested as an area for quality improvement. This suggestion has not been progressed. NICE quality statements focus on actions that demonstrate high quality care or support, not measures used for monitoring quality. Existing measures, such as OACC, can be used for monitoring implementation of quality statements where appropriate.

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# Appendix 1: Review flowchart

Records identified through topic engagement  
[n = 67]

Records identified through IS scoping search  
[n = 77]

Records identified through ViP searching  
[n = 3098]

Records excluded  
[n = 3027]

Records screened  
[n = 3242]

Citation searching or snowballing

[n=16]

Full-text papers excluded  
[n = 219]

Full-text papers assessed   
[n = 231]

Current practice examples included in the briefing paper  
[n = 12]

# Appendix 2: Suggestions from stakeholder engagement exercise – registered stakeholders

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **ID** | **Stakeholder** | **Key area for quality improvement** | **Why is this important?** | **Why is it key area for quality improvement?** | **Supporting information** |
| **Identification** | | | | | |
| 1 | Association for Palliative Medicine of Great Britain and Ireland | Improving recognition and identification of patients in the last year of life. | Patients who are recognised and identified as being in the last year of life have the opportunity to make informed decisions about their care and take opportunities to make decisions and plans for their future | Recognition of patients in the last year of life remains poor and generalists need support to improve practice in this area |  |
| 2 | British Geriatric Society | Competence in Frailty identification and management in stable and acute situations | Severe frailty is an End of Life condition . |  |  |
| 3 | British Society for Heart Failure | Improved access to palliative care for patients with long term conditions such as heart failure | Improved access to palliative care for patients with long term conditions such as heart failure | Approximately 4% of heart failure patients receive palliative care input. (2) 70% people cared for within hospice and palliative care teams are cancer patients. (3) Palliative care input can reduce heart failure re-admissions by 42%. (4) | Heart failure multidisciplinary teams should include specialist palliative care. (5) 25.4% of heart failure patients were referred to or discussed with the palliative care team prior to dying from heart failure. (5) https://www.ncepod.org.uk/2018report2/AHF%20executive%20summary.pdf |
| 4 | British Society of Gastroenterology | End stage liver disease immediately comes to mind | EOL care is poor for this group of patients at present |  |  |
| 5 | British Thoracic Society | More universal identification of those with significant palliative care needs by those in respiratory / caring for patients. Integration into chronic disease management. In line with the Long Term Plan. |  |  |  |
| 6 | Faculty of Intensive Care Medicine | Improved public and professional awareness that death isn’t necessarily a failure of medical treatment and palliative care referral is not necessarily an indication of imminent death |  |  | Positives: For some patients and teams there seemed to be greater willingness to discuss end of life issues and planning and potentially avoid referrals to ICU which in normal times they seem to struggle with. It should continue to be part of a wider on going discussion about what ICU can offer particularly those with chronic underlying conditions. Negatives: There were frustrations around the lack of a mandated clinical decision making tool for standardised risk stratification. (Sort of fits in with the above). Even within London it wasn’t possible to achieve. This raises concerns about equity of care and for some patients the denial of proper end of life planning. |
| 7 | Hospice UK | Identification | Identification of people with palliative and end of life care needs, while improved in recent years, still requires more attention.  During 2019/20, there were additional QoF points available for general practice which specifically sought to provide an incentive to improve identification. A renewed focus on identification in the updated quality standard would help to maintain progress and to increase the proportion of people being identified as having palliative or end of life care needs | Identification of people’s palliative and end of life care needs continues to be patchy, particularly for people with non-malignant disease, including those with complex co-morbidities. It is especially an issue where people may not have a need for referral to specialist palliative care services who are less likely to be identified. |  |
| 8 | SCM1 | Identifying adults who may be approaching the EOL 1.1.1 1.1.2 | Identification enables health and social care practitioners to start ACP discussions, provide the care needed and to support people’s preferences for where they would like to be care for at the end of their lives.  Without identification, people will only have access to generic services. | To enable CCG’s and service providers to plan and commission appropriate services for their local populations.\* To ensure that people have access to palliative and specialist palliative care services. To ensure timely access to welfare benefits. To improve uptake of ACP’s. LPA’s and will writing | The Gold Standards Framework – Prognostic Indicator Guidance. RCGP 2011 Dying Matters – Identifying End of Life patients. \* Numbers vary between CCG’s from 509 to 9,641 deaths in 2016. Atlas of variation for palliative and end of life care in England, NHS Right Care - October 2018 Capacity, care planning and advance care planning in life limiting illness – A guide for Health and Social Care staff June 2014. |
| 9 | SCM8 | Recognition of Severe Clinical Frailty (as diagnosed using a clinical frailty tool eg CFS or Edmonton) as being an end of life state.  The service provider should be able to demonstrate that all those recognised as living with Severe Frailty that Advance Care Planning has been offered as part of a Comprehensive Assessment (CGA) | Too often there is no trigger for advance care planning discussions in people approaching the end of their lives without a single lift limiting condition  The recognition of severe Frailty should prompt ACP discussions routinely as part of the pathway for those living with Severe Frailty | Advance care planning discussions will enable appropriate decisions to be made in the event of a deterioration in condition. This will result in a patient centred approach to care and avoid inappropriate interventions unwanted by patients and carers including resuscitation and hospitalisation  this will have an impact on rates of inappropriate admissions to hospital and improved rates of death in preferred place of care |  |
| 10 | National Clinical Director for Palliative and End of Life Care | Identification of people likely to be in their last year of life | Early identification enables personalised care and support planning (including advance care planning) conversations and preparations | There is evidence that this remains suboptimal, and also that it is a focus of inequity. Patients with a cancer diagnosis are more likely to be identified than those with a non-malignant disease. Some of our underserved populations (e.g. homeless, BME, etc.) are even less likely to be identified. |  |
| 11 | SCM2 | People approaching the end of life are identified in a timely way. | Systematic identification ensures that people can access services they need once identified, carers and people important to person approaching end of life can be supported, the person can advance plan and consider their wishes and preferences e.g. preferred place of care. These things will improve people’s experiences of end of life and of dying | If people do not know they are approaching the end of life they cannot make their wishes known, they will not be able to access specialist services, people important to the person will not be able to access support they need | NG142 – end of life adults – service delivery  National Audit Care at End of Life  NG31 – care of dying adult which showed some people experiences of dying could be improved |
| 12 | Royal College of Physicians (RCP) | Identifying patients in the last weeks and months – upskilling generalists | Any quality improvement in end of life care must start with identification of patients who may be at the end of life. | In order to improve care and support patient choice, to avoid overaggressive treatment at the end of life and support the appropriate use of resources | NACEL audit reveals that most people dying at the end of life do not have advance care plans https://s3.eu-west-2.amazonaws.com/nhsbn-static/NACEL/2020/NACEL\_2019\_Summary\_Report\_Final.pdf NACEL report 2019 recommends that there are processes in place to identify patients for advance care planning in order to deliver personalised care |
| 13 | SCM7 | Identification of people who may be entering the end of life [=last year of life] and their principal carers | The failure to identify when people may be transitioning from active [=curative, life-prolonging] aim of therapy to supportive and life-enhancing [including palliative] care is often the most important reason why people do not receive the right care as their illness progresses. It is actually somewhat easier in cancer, because advancing to stage 3 and 4 are clear signs of disease progression. It is less clear for many non-cancer conditions, eg single or multiple organ failure. Ensuring that HCPs and social care professionals are constantly aware of stage of disease, intention of treatment and when this moves away from life-prolonging is key to unlocking new appropriate services, and withdrawing form unnecessary treatments. | Earlier and more standardised identification of entering EOL could bring substantial savings for the NHS and also highlight when more support needs to be put in for family carers. | See evidence base for NICE 142 – Rec 1.1 Also NICE QS 13 (2017) – statement 1. |
| 14 | SCM9 | People with all conditions and of any age who live with conditions where they could benefit from supportive and palliative care should have those needs identified as early as possible | Early identification of palliative care need is associated with increased care co-ordination and an increased likelihood that a person will achieve their preferences for end of life care. | The numbers of patients identified on GP palliative care registers is still well below the number of people expected to die each year in the UK, and there is marked variability between practices, indicating ongoing unmet need. Patients are still more likely to be referred to specialist services if they have cancer than other conditions, which is not in keeping with the patient population. Around 20% of people who die receive no palliative care, either generalist or specialist. | Multi-morbidity predicted to increase over the next 20 years https://evidence.nihr.ac.uk/alert/multi-morbidity-predicted-to-increase-in-the-uk-over-the-next-20-years/ Inequities in palliative care https://www.mariecurie.org.uk/globalassets/media/documents/policy/campaigns/a042-equity-in-the-provision-palliative-eol-care-in-uk\_v11-copy.pdf |
| 15 | SCM9 | Patients who are identified and included on GP practice palliative care registers should be aware of the benefits of this, including how to access timely information and advice (for health, social and care needs) when they need it | We need to consider how this provides benefits to patients, and how it can be used to empower patients to make decisions about their care. There are new opportunities due to the COVID-19 pandemic and increased use of technology in healthcare consultations – perhaps to link a virtual MDT around a patient and to ensure they are aware of / have access to information and support structures provided by their healthcare teams and local communities | Data about practice palliative care registers is accessible and has been collated into the PEoLCIn Profiles previously https://fingertips.phe.org.uk/profile/end-of-life There is research in this area although this dates back to 2012 so more up to date understanding is needed  https://spcare.bmj.com/content/2/Suppl\_1/A89.1 https://bjgp.org/content/62/598/e344 |  |
| 16 | Society for Acute Medicine | Systems to recognise those likely to be in their last year of life | Well established evidence that early recognition of those likely to be within the last year of life allows early communication and discussion which in turn supports advance care planning and better patient-focussed outcomes with end of life care. | This is the most important step in providing end of life care. Without clear recognition then the ensuing steps to supporting people to die as they wish to cannot occur. Recognition needs to occur at a point whereby intervention can be made, allowing enough time to make preparations. Patients and carers often report not being given enough time to prepare for the end of life. | General medical council make clear definition for last year of life as a key point in which advance care planning conversations should be considered. https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life |
| 17 | SCM4 | Consistent use of the end of life care register, once patients have been identified as being in the last year of life. | As stated 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 as thought (by the GP practices) that a further 15% of deaths were predictable but not put on the register. It also showed that those included were more likely to receive well-coordinated care, have the opportunity to have ACP conversations, and to die in the preferred place. It also showed that carers/relatives were more likely to be offered bereavement support. | It is known that palliative care registers are used n very different ways within and between GP practices. It is very important that patients with non-cancer diagnoses have access to the same level of services as patients with cancer. If health care professionals working with these patients (eg community matrons, non-cancer specialist nurses) are trained to identify those in the last year of life and to consent patients with non-cancer diagnoses to the register, then there may be a decrease in the inequity of provision of services that still exists. | http://endoflifecareambitions.org.uk/wp-content/uploads/2016/09/ipsos\_mori\_eolc\_locality\_register\_final\_report\_2.pdf  https://spcare.bmj.com/content/2/Suppl\_1/A89.1 |
| 18 | SCM6 | Identifying adults who may be approaching the end of their life | This will enable health and social care practitioners to start discussions about advance care planning, provide the care needed, and to support people's preferences for where they would like to be cared for and die. | Evidence suggests that fewer people are being recognised to be approaching the end of life than they might be, with the potential for them to miss the opportunity to discuss this and plan ahead if they so wish |  |
| 19 | The British Pain Society | Identification of people who may be entering the end of life [=last year of life] and their principal carers | The failure to identify when people may be transitioning from active [=curative, life-prolonging] aim of therapy to supportive and life-enhancing [including palliative] care is often the most important reason why people do not receive the right care as their illness progresses. It is actually somewhat easier in cancer, because advancing to stage 3 and 4 are clear signs of disease progression. It is less clear for many non-cancer conditions, eg single or multiple organ failure. Ensuring that HCPs and social care professionals are constantly aware of stage of disease, intention of treatment and when this moves away from life-prolonging is key to unlocking new appropriate services, and withdrawing form unnecessary treatments. | Earlier and more standardised identification of entering EOL could bring substantial savings for the NHS and also highlight when more support needs to be put in for family carers. | See evidence base for NICE 142 – Rec 1.1  Also NICE QS 13 (2017) – statement 1. |
| 20 | The GSF Centre CIC | Key area for quality improvement 4. Identification (QS1) – the ability to identify decline in people earlier to ensure more proactive care and earlier appropriate treatment and referrals. This is not prognostication but early preparedness . (related to QS 1) and applies both in general and secondly COVID specific.  Thi was always key , but even more so in the light of COVID-19 | General  There is good evidence of the use of tools such as the GSF Proactive identification guidance , PIG to enhance earlier identification of people in all sectors leading to inclusion on GP’s registers and other digital sharing such as Electronic pall care Coordinating Systems /EPaCCS .   COVID –susceptibility predictions and trajectories of illness   COVID assessment tools | General The GSF PIG enables earlier identification of non-cancer patients with frailty, dementia and multimorbidity- the 75% population of people who die in usual circumstances .  COVID  In general, there seems to be an unpredictability of COVID susceptibility , but groupings into 6 clusters suggested , and most older, BAME and with underlying health conditions. This needs to be considered in areas like care homes  COVID related tools eg use of RESTORE2 for assessment of symptoms in care homes and use of pulse oximeter | General  Early identification of people not just those dying but those who might die in the next year or so , (QS 1) is recognised as being important for effective use of preventative shielding , proactive care , audit and inclusion in digital records eg EpaCCs .  The original updated tool developed with RCGP for BMA QOF from 2004 (reissued 3 -4 yearly) is the GSF Proactive Identification Guidance tool https://goldstandardsframework.org.uk/pig with strong international evidence base from across the world. Other tools do similar things, but the GSF PIG leads to needs based coding , needs support matrices and more advance care planning . See https://www.goldstandardsframework.org.uk/cd-content/uploads/files/1%20%20vs%204%20%20Evidence%20that%20use%20of%20GSF%20Improves%20identification.pdf NB needs to updated to include indications of COVID susceptibility COVID- Many studies showing susceptibility to COVID. Kings College London study of 6 cluster groups that might help earlier prediction (79%) - paper not yet published (Spector, Steves ) interesting  https://www.goldstandardsframework.org.uk/cd-content/uploads/files/COVID-19/CS49286-RESTORE2-full-version.pdf BGS helpful COVID resources – some quoted in https://www.goldstandardsframework.org.uk/cd-content/uploads/files/COVID-19/BGS%20Managing%20the%20COVID-19%20pandemic%20in%20care%20homes%20v3.pdf |
| **Needs assessment** | | | | | |
| 21 | British Geriatric Society | The utilisation of a comprehensive Geriatric assessment | which leads to personalised care including parallel planning and inclusion of end of life - ( not just function!) – links into new Care Home enhanced service delivery |  |  |
| 22 | Marie Curie | Social/Community Care | Social care is a crucial element of the care given to people at the end of their lives and should be considered as an integral part of public health. Adult social care provides numerous benefits for people and support to other services: it prevents emergency admissions and lengthy stays in hospital, alleviating some of the pressure on acute NHS services; improves the quality of care for people; allows people to be cared for in a setting better suited to their needs than a hospital, where appropriate; provides options for people to decide on where they want to be cared for; offers respite for overstretched carers and families. | Similar to the above key area, social care can ensure a better quality of care out of hospitals. Sometimes emergency admissions to hospitals are necessary, but at Marie Curie, we know that often they are stressful for the individual and their loved ones. In addition, Marie Curie’s own research into how the ageing population will impact on health services found a worrying upward trend towards rising costs as people in the last year of their lives are repeatedly admitted to hospital as an emergency. If social care is well implemented alongside palliative care in an area, it will be more cost-effective as it can, in some cases, prevent admissions and stays in acute hospitals as well as ensuring a better patient-centred care. Social care allows people with terminal illnesses to be cared for in a place of their choosing, be that in their own home or elsewhere in the community. The majority of people would prefer to spend their final days at home, and with the right community services in place those choices can be respected. In many cases, the Marie Curie Nursing Service would not be able to provide care in people’s homes without social care services already being in place. | Nuffield Trust, ‘Exploring the cost of care at the end of life’, September 2014, available online at http://www.nuffieldtrust.org.uk/sites/files/nuffield/publication/end\_of\_life\_care.pdf  Marie Curie, ‘Emergency admissions: Data briefing’, March 2018, available online at https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2018/emergency-admissionsbriefing-paper-2018.pdf |
| 23 | Royal College of Nursing | Diversity | Understanding the diverse needs of people from the transgender community, at end of life | We have focused on care for people with diverse needs continually but there appears to be little in relation to this group. |  |
| 24 | Royal College of Occupational Therapists | Person-centred approach focussing on the activities (occupations) that a person approaching the end of their life wants and/or needs to do. | Occupational therapists have been shown to have the range of skills required to provide symptom management, assessment of holistic needs and development of support plans that are based on what matters to the individual and cover physical and mental health needs.  Palliative care is considered as an approach whereby the person's physical, psychosocial and spiritual needs are considered.  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/ |  |
| 25 | SCM7 | Assessing and acting on holistic needs | Holistic needs assessment (HNA) has been part of cancer guidance since NICE 2004 (supportive care for adults with cancer). However, even now the implementation of HNA and the means of carrying it out, are variable and often almost entirely missing in secondary and tertiary level care. NICE NG 142 highlighted this area as a gap, although it stopped short of recommending specific technologies for doing HNA. What is also needed are more uniform ways of responding to identified unmet holist needs, ie to avoid/reduce postcode lottery. | Identifying and responding to unmet holistic needs could bring quicker relief to people who need help in EOL, as well as their carers. HNA can be done on paper or electronically to ease the workload on HCPs. It is likely to be cost-neutral to NHS, as although more unmet needs may be identified, it is likely that meeting these earlier can mitigate harmful and costly complications such as urgent admissions. | See evidence base for NG142 - Rec 1.2 Also QS 13 (2017) – statements 3, 4, 5, 6, 7 |
| 26 | Society of British Neurological Surgeons (SBNS) | Person centred care | Individual needs are variable | Seamless care |  |
| 27 | SCM5 | Assessing holistic needs | This one comes towards the start of the guideline and then feeds in to multipractitioner care because it will identify the practitioners who need to be involved or asked for their input. | A meaningful and useful needs assessment requires a skilled practitioner to undertake it. When done well it will ultimately save time by identifying who else should be involved and help to decision making on places of care. It will also identify those important to the person so they can be provided with support. Holistic assessment leads on to care planning. |  |
| 28 | SCM6 | If it is thought that an adult is approaching the end of their life, carry out an initial holistic needs assessment with the person and document this. | This will enable the right support to be provided when it is needed. | Provision of needs assessment may be patchy and people may fall through the net. Links with personalised care planning and NHS Long Term Plan | Needs assessment is being developed by a number of workstreams eg frailty, cancer, personalised care and support planning |
| 29 | The British Pain Society | Assessing and acting on holistic needs | Holistic needs assessment (HNA) has been part of cancer guidance since NICE 2004 (supportive care for adults with cancer). However, even now the implementation of HNA and the means of carrying it out, are variable and often almost entirely missing in secondary and tertiary level care. NICE NG 142 highlighted this area as a gap, although it stopped short of recommending specific technologies for doing HNA. What is also needed are more uniform ways of responding to identified unmet holist needs, ie to avoid/reduce postcode lottery. | Identifying and responding to unmet holistic needs could bring quicker relief to people who need help in EOL, as well as their carers. HNA can be done on paper or electronically to ease the workload on HCPs. It is likely to be cost-neutral to NHS, as although more unmet needs may be identified, it is likely that meeting these earlier can mitigate harmful and costly complications such as urgent admissions. | See evidence base for NG142 - Rec 1.2 Also QS 13 (2017) – statements 3, 4, 5, 6, 7 |
| 30 | British Society for Heart Failure | Appropriate medication review for deprescribing towards the end of life for people with long term conditions | Heart failure patients often have polypharmacy regimens for treatment of heart failure and co-morbid disease | Rationalising medications and making deprescribing decisions can be difficult to implement in clinical practice. |  |
| 31 | Hospice UK | Interventions: non-medical & managing polypharmacy | Appropriate/effective management of poly-pharmacy, and reducing inappropriate medications in end of life care. |  |  |
| 32 | SCM8 | Develop policies for reviewing treatment within all specialties to meet the changing needs of adults approaching the end of their life and to reduce the burden of unhelpful treatments. A Systematic Medication review should be undertaken for anyone who is thought to be approaching with end of their lives to consider stopping medication of limited value in this situation ( eg Statins ) | A standard approach to medication review will reduce inappropriate prescribing and waste whilst reducing tablet burden and reduce the prescribing of medication which will become increasingly unsafe as the persons condition deteriorates eg prophylactic anticoagulation and burdensome antihypertensives | An easy to measure parameter it will improve safety for individuals whilst reducing the cost of prescribing and the complications associated with high risk drugs such as bleeding and falls |  |
| 33 | Multiple System Atrophy Trust | Adults in the later stages of life should have easily available equipment, such as specialised beds, syringe drivers, hoists, provided appropriately and speedily to enable them to be cared for at home. |  |  |  |
| 34 | Oncology Specialist Group on behalf of the BDA | Where a person is receiving Artificial Nutrition Support, an individualised care plan should include discussion of a person’s preferences and decisions regarding if and when this support should be stopped. This should be recorded in the advance care plan. |  | Clinically-assisted nutrition and hydration, BMA https://www.bma.org.uk/canh ESPEN guideline on ethical aspects of artificial nutrition and hydration, 2016 https://www.espen.org/files/ESPEN-Guidelines/3\_\_ESPEN\_guideline\_on\_ethical\_aspects\_of\_artificial\_nutrition\_and\_hydration.pdf |  |
| 35 | Oncology Specialist Group on behalf of the BDA | In addition to a review of hydration and artificial hydration support, that artificial nutrition support should also be reviewed (much in the same way that medication is reviewed and any medications no longer indicated are stopped. The rationales for the above are as follows  1 to prompt healthcare professionals to review artificial nutrition support, preferably as a multidisciplinary team including a dietitian. 2 to ensure a person’s wishes are observed as far as is practical. 3 to allow healthcare professionals to provide information and support to relatives regarding what is an emotive issue and a potential source of conflict. |  |  |  |
| 36 | Royal College of Speech and Language Therapists | Maintaining even basic communication until the end. | This requires staff and family members to be informed of the best way of communicating with the patient i.e. this might be through limiting vocabulary, tone of voice, gesture facial expression--- also staff and family members need to be clear with regard to the level of comprehension of the patient. If a person is not understanding much then tone of voice, facial expression and touch become much more important. Even a patient who is not fully conscious can appreciate and understand basic interactions which can be comforting and reduce fear. It is important not to assume that a patient is not understanding. |  |  |
| 37 | Society of British Neurological Surgeons (SBNS) | Responsive to changes | The needs can vary from day to day | Care tailored to need |  |
| 38 | Society of British Neurological Surgeons (SBNS) | Daily review of clinical condition and care priorities | The clinical condition can improve or worsen | Care tailored to clinical need |  |
| **Advance care planning** | | | | | |
| 39 | Association for Palliative Medicine of Great Britain and Ireland | Advance care planning. Increasing the uptake of advance care planning by empowering generalists to initiate conversations | Advance care planning enables patients to have the opportunity to engage in making specific decisions and plans for their future care | A significant proportion of patients who come in to hospital acutely are in the last year of life. These patients need to be identified and offered the opportunity for advance care planning | Royal College of Physicians | Our Future Health. Talking about dying: How to begin honest conversations about what lies ahead. London: RCP, October 2018. www.rcplondon.ac.uk/talking-about-dying |
| 40 | British Geriatric Society | ACP as conversation over time and involvement of all key decision makers |  |  |  |
| 41 | British Society for Heart Failure | Dying in the preferred place of care for patients with long term conditions and heart failure. | Heart failure patients should have the same access to services as cancer patients | The majority of heart failure patients die in hospital. | Comprehensive cardiology and palliative holistic assessment of patient and family. This includes finding out what is most important to the person with heart failure rather than the professionals’ agenda. (3) |
| 42 | British Society for Heart Failure | Increased education, training and resources to up-skill in advanced care planning | Heart failure mortality is high: Inpatient mortality 9.4% 30-day mortality ~15% 1-year mortality 23.3% (6) | Heart failure specialist teams managing these patients need the required skills to provide appropriate care planning. | Heart failure management plans and medical advance care plans. All patients should have patient specific tailored plans to fit the medical, device and palliative needs of the patient and family. (3) |
| 43 | Compassion in Dying | Clarity that preferences for care are not limited to place of care | Through supporting over 56,000 people to plan ahead, we have learned that people are willing to accept the reality that they may need to be moved from home to a different care setting.  However, many are not willing to accept CPR or CANH in certain situations.  Therefore, discussing advance care planning only in reference to place of care disregards many other aspects of end-of-life care that people may wish to prioritise | The focus on place of care disregards the fact that socio-economic status, plays a significant role in determining where someone is cared for. (e.g. “My home is not a nice place to live, she said, let alone a nice place to die.” – Tessa Morgan, Caring is a Feminist Issue, Cicely Saunders Institute, March 2020) - Davies JM, Sleeman KE, Leniz J, Wilson R, Higginson IJ, et al. (2019): Socioeconomic position and use of healthcare in the last year of life - New research – Dying in the Margins http://endoflifestudies.academicblogs.co.uk/new-esrc-funded-project-dying-in-the-margins-investigates-how-socio-economic-deprivation-effects-end-of-life-experiences-and-ability-to-die-at-home/  Therefore, if honest and meaningful conversations about care planning are to take place, they must cover all treatment preferences and not just location.  By only focussing on place of care the guideline risks undermining the NHS comprehensive model of personalised care and could deny many people the opportunity to express a preference about the aspects of their care that truly matter to them. | Useful information on place of care and death are below  - Home care and end-of-life hospital admissions - Perspectives of bereaved relatives of patients with haematological malignancies concerning preferred place of care and death |
| 44 | Compassion in Dying | Unambiguous and specific information on what advance care planning means. | Not specifying the legal mechanisms available for documenting treatment and care preferences risks denying people the ability to make decisions about their care in a meaningful way.  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 therefore an essential component of any end-of-life care document. | When professionals are not aware of advance care planning tools it can have tragic consequences as highlighted in the recent cases of Brenda Grant [2017] (who was given life prolonging treatment against her wishes for 22 months) and Jillian Rushton [2018] (whose clearly expressed treatment wishes were disregarded, resulting in her being provided with the very treatment she had taken steps to refuse). The Departure Lounge evaluation report noted that: - Participants would appreciate assistance for the person dying around setting their affairs in order. Participants prioritised the opportunity to ‘make their wishes known’ - There is need for more information on - Inspiring and reassuring examples of ways in which people can retain agency, personality and dignity at end of life Given the potential benefits to be gained from getting this right, it does not seem sufficient to only make reference to advance care planning tools via links to the Mental Capacity Act 2005 and the NICE guideline on decision-making and mental capacity. Every opportunity to be clear and specific about the tools available for advance care planning must be maximised.  A clear example of the consequences of not being clear about what the advance care planning tools are and how they are used can be found in the poor practice of blanket DNACPR forms being issued to some people during the Covid 19 pandemic. Having clarity around how CPR decisions are made including the need for consultation but not consent would have prevented much of the distress that occurred.  A summary of the situation that arose can be found here https://medium.com/death-dying-and-digital/dnacpr-in-the-news-like-never-before-c104142b5ceb Compassion in Dying’s letter on CPR decisions to the Secretary of State for Health and Social Care further explains how - Patients are distressed when doctors do not comply with the law  - Patients feel abandoned when their treatment preferences are ignored by healthcare professionals  - Lack of clarity about the different advance care planning tools leads to disjointed and inefficient care https://compassionindying.org.uk/wp-content/uploads/2020/05/Letter-to-SSHSC.pdf | The House of Commons Health Select Committee Report on End of Life Care. This report recommended the Government ‘considers how it can further raise awareness of the mechanisms available to patients and carers under the Mental Capacity Act 2005 to make their wishes clear about end of life care. This should also include information about Advance Decisions to Refuse Treatment’ Also see our Freedom of Information report on the lack of uniform commitment to the Mental Capacity Act and the poor care that results as a consequence of that. – e.g. “I completed my Advance Decision form and went to see my GP to discuss it with him. He basically said it’s a waste of time, to come back when I have one of the conditions on the form so that we can then fill in one of their in-house DNAR forms.” A subsequent piece of research with GPs highlighted key areas for improvement.  - One GP told us that offering an Advance Decision or DNAR form would be “opening up a can of worms” - “It was my understanding that they are not a legal document. An Advance Decision is an informal statement of wishes, whereas a DNAR is a proper form” - Most of the GPs we interviewed had not received formal training on Advance Decisions since medical school, with one GP asking “do we need formal training on that?” Those who said they’d received some training on the Mental Capacity Act still lacked specific knowledge of what an Advance Decision is and how the people they support could make one. One of our key observations was that GPs may not be best suited to support people through the end-to-end process of making an Advance Decision due to a lack of time and specialist knowledge. However, there are third sector organisations, such as Compassion in Dying, ready to help. GPs, community link workers and social prescribers should know who they are and signpost to them.  The 2019 YouGov research – “What Matters to Me” - found that respondents associated a ‘good death’ with being pain-free, but around two-thirds (64%) felt they did not have enough information and support to achieve a good death. |
| 45 | Dementia UK | Advance care planning and dementia at a time of COVID-19 | The COVID-19 pandemic has highlighted existing and new advance care planning challenges for people living with dementia such as carrying out conversations early in the diagnosis, as well as negotiating social distancing and visiting restrictions which hinders supporting conversations or honouring previously expressed wishes and decisions such as to be present at the time of dying. | In 21 worldwide COVID-19 guidance documents concerning palliative or end-of-life care in nursing homes, advance care planning it is discussed in a very limited way. The emphasis lies on treatment preferences in writing (i.e., do-not-hospitalize or DNR), while the actual communication process is less frequently mentioned (Gillisen et al 2020).Family carers may not have the time to process the information that is given to them to make informed choices or to discuss decisions with other family members such as siblings (Moore et al 2020). It has sometimes been difficult to have discussions face-to-face, due to shielding measures affecting residents, and family members and friends who may act as consultees (Gordon et al 2020). Healthcare professionals may not have time or capacity to develop relationships with older people or family carers; most of whom they are unable to meet face to face prior to having these challenging and often difficult conversations. Professionals engaging in difficult conversations often rely on in-person and nonverbal cues to facilitate discussion of sensitive subjects; however, telephone conversations hinder this, and some people may not have access or the skills to use technologies such as video calling (Moore et al 2020) | Joni, Gilissen, Pivodic Lara, and T. Unroe Kathleen. "International COVID-19 palliative care guidance for nursing homes leaves key themes unaddressed." Journal of Pain and Symptom Management (2020).  Gordon, A.L., Goodman, C., Achterberg, W., Barker, R.O., Burns, E., Hanratty, B., Martin, F.C., Meyer, J., O’Neill, D., Schols, J. and Spilsbury, K., 2020. Commentary: COVID in care homes—challenges and dilemmas in healthcare delivery. Age and Ageing.  Moore KJ, Sampson EL, Kupeli N, Davies N. Supporting families in end-of-life care and bereavement in the COVID-19 Era. International Psychogeriatrics. 2020 Apr 30:1-0. |
| 46 | Faculty of Intensive Care Medicine | Public empowerment to raise issues such as DNACPR |  |  | Kate Masters, Compassion in Dying and Leigh-Day Law Firm |
| 47 | Faculty of Intensive Care Medicine | Professionals in treatment specialties (especially cancer services) to have mandatory parallel discussions (cure vs. palliation) from the time of diagnosis. | When such patients fall acutely ill and loses capacity it is often too late for acute specialties such as Emergency Medicine and Intensive Care Medicine to provide true individualised care |  |  |
| 48 | Hospice UK | Communication / Effective Care Planning | Quality communication and care planning is critical to good outcomes and experiences of care. In the current quality standard, there is limited reference made to advance care planning which is vital to support effective communication and care planning | Advance care planning, and personalised care and support planning are critical tools to improving people’s experiences of care, and ensuring that care meets people’s individual needs. They are recognised as such in both the NHS Long Term Plan and the Ambitions for Palliative & End of Life Care, both of which have been published since the quality standard was last reviewed. During the pandemic, the importance of communicating with those important to the person who is dying and providing them with support has become a major issue, particularly as a result of visiting restrictions and the availability and use of PPE.  The pandemic has also highlighted the critical role of ensuring that information is available in a variety of formats and languages. For example, public information on shielding (relevant to people affected by terminal illness) was not available in community languages or different formats. |  |
| 49 | SCM8 | All people resident in CQC registered Care Homes for Older People should have the opportunity to have a discussion about wishes and preferences within 14 days of admission to the care home | People living in Care homes for Older People tend to be living with a degree of frailty and hence more likely to be approaching the end of their lives. They should be offered an opportunity to discuss their wishes and preferences as a standard part of the admission process led by Care Homes Staff and supported by Primary Care and Community Team | As above – making ACP port of the routine admission process will make it part of common practice and not something done at the last minute and too late. |  |
| 50 | SCM8 | All people diagnosed as living with dementia should be offered a conversation to discuss issues relating to Advance Care Planning and giving Power of Attorney to someone. (This conversation should be recorded and shared and revisited if the individual is not yet ready to engage). | Early decision making is important following a diagnosis to dementia to avoid the loss of opportunity to express wishes and preferences once the person loses capacity. | If the opportunity to express wishes and preferences is lost and the person doesn’t have a health attorney family members and care givers may be uncertain of the person’s wishes and preferences leaving room for disagreement and disharmony. Knowing that the person has made decision themselves helps to reduce the burden of guilt on family members who feel they are being asked to make decisions about the person and subsequently may feel they have failed their family member if a best interest decision is taken that they don’t feel is what the person would have wanted. |  |
| 51 | SCM8 | All people being advised to take out power of attorney for health should be offered advice on matters to discuss with their attorney when they no longer have capacity to make decisions | People may be advised to take out power of attorney for health but are not usually supported to have conversations about what they would or wouldn’t want. Without prior knowledge or appropriate advice conversations don’t happen which meant that the Attorney often doesn’t know what the donor wants when they have lost the capacity to decide | It’s impossible to have a useful conversation without an appropriate amount of experience – having guidance in the form of written or spoken communication one to one or in a group setting would enable patients and their family members to understand the kinds of things they would want to have an opinion about |  |
| 52 | Marie Curie | Advanced Care Planning | Advance care planning (ACP) is crucial to ensure personalised care for people at the end of their lives. However, there are still many incidents taking place with ACP putting the quality of life and care at risk for terminally ill people. | In the study on patient safety incidents in ACP for serious illness, the researchers found 70 incident reports in which ACP caused a patient safety incident across three categories: -ACP not being completed despite being appropriate  -ACP completed but not accessible or miscommunicated between professionals --ACP completed and accessible but not followed  The reasons for this included staff lacking knowledge, confidence, competence or belief in trustworthiness of prior documentation to create or enact ACP | Dinnen, Toby et al.(2019) Patient safety incidents in advance care planning for serious illness: a mixed methods analysis. BMJ Supportive and Palliative Care 0:1-8 http://dx.doi.org/10.1136/bmjspcare-2019-001824 |
| 53 | Motor Neurone Disease Association | Early identification of respiratory impairment and preference for Non-Invasive Ventilation (NIV) | It is important to undertake regular assessment of respiratory function and to know the person’s wishes for Non-Invasive Ventilation (NIV) as respiratory function may decrease rapidly. | Effective respiratory management is essential and there must be a plan in place to monitor respiratory function and ensure that the person’s wishes are taken into account, including at end of life stage. 5% of people with MND had difficulty accessing breathing support in 2019. Have a protocol in place to assess regularly and monitor respiratory function. Ensure the person’s wishes and preference for NIV is recorded. | https://pathways.nice.org.uk/pathways/motor-neurone-disease/assessing-and-managing-respiratory-function-in-motor-neurone-disease https://static.mndassociation.org/app/uploads/2015/04/19135930/mnd-respiratory-pathway-v1-1-070615.pdf https://www.mndassociation.org/professionals/management-of-mnd/management-by-symptoms/respiratory-symptoms-in-mnd/ Royal Free London NHS Foundation Trust (2018) Development of a multidisciplinary respiratory assessment tool to facilitate early identification of respiratory impairment in clients with motor neurone disease: https://www.nice.org.uk/sharedlearning/development-of-a-multidisciplinary-respiratory-assessment-tool-to-facilitate-early-identification-of-respiratory-impairment-in-clients-with-motor-neurone-disease  Dorset (June 2018) -Respiratory Care Pathway, NIV Multi Disciplinary Pan Dorset MND Group Information sheet 8C https://static.mndassociation.org/app/uploads/2012/03/09164035/Respiratory-Care-Pathway-NIV-Dorset-June-2018.pdf  https://www.mndassociation.org/improving-mnd-care-survey-2019/ |
| 54 | Motor Neurone Disease Association | Advance care plans to be in place, which may include Advance Decision to Refuse Treatment (ADRT), Lasting Power of Attorney (LPA), preferred place of care, Do Not Attempt CPR (DNACPR). | Early planning for care at the end of life ensures that families and professionals can be made aware of a person's wishes for end of life care before communication or cognitive changes make this difficult or impossible. | The 2019 MND Improving Care Survey found that only 36% were given the opportunity to discuss an Advance Care Plan. Staff working with people with MND must be confident to recognise that a person is approaching the end of their life and act on this understanding. Staff must feel equipped to engage effectively with patients/carers to discuss end of life care. Ensure that advance care plans are recorded in a timely manner and ensure this is known to the family and carers as well as held by all agencies the person engages with. | http://mnd.rcnlearning.org.uk/caring-for-people-with-mnd/planning-ahead/ https://static.mndassociation.org/app/uploads/2017/05/19140014/eol09-advance-care-planning-and-advance-decisions.pdf https://www.england.nhs.uk/improvement-hub/publication/advance-decisions-to-refuse-treatment-a-guide-for-health-and-social-care-professionals/ https://www.mndassociation.org/improving-mnd-care-survey-2019/ Pathway and guidelines for withdrawing non-invasive ventilation(NIV) in patients with Leicestershire and Rutland MND Supportive and Palliative Care Group https://www.mndassociation.org/app/uploads/2015/02/leicestershire-and-rutland-pathway-and-guidelines-for-withdrawing-niv.pdf |
| 55 | Multiple System Atrophy Trust | Early counselling and support to facilitate and enable discussions about advance care planning and end of life wishes. | Multiple System Atrophy is a terminal progressive neurological condition. Mean duration of symptom onset to death is around 7 years. Given this rapid progression the ability to communicate can be lost before end of life discussions or counselling to cope with this diagnosis. At present there is no pathway to access counselling support, making a journey with MSA much harder than it should be. In addition, failure to instigate early discussion around end of life care and Advance Care Planning can mean that people are unable to articulate their needs at this crucial time. Adults with a progressive illness should also be encouraged to discuss end of life care and advance care planning when they face new interventions, such as ventilation or gastrostomy, or when they face triggers that suggest that end of life is close – such as aspiration pneumonia. See MSA Trust Needs Survey on the proportion of people who have not had End of Life discussions but who would want to.  This has a negative impact on both the person with MSA and their carers. We have found that there is a real problem as to whose responsibility it is to initiate discussions on Advance Care Planning and End of Life issues and also how to initiate these discussions. | See MSA Trust Needs Surveys- the largest ever study of people living with MSA and Former Carers. https://www.msatrust.org.uk/cause-and-cure/msa-needs-surveys/ https://www.msatrust.org.uk/wp-content/uploads/2020/02/MSA-TRUST-PEOPLE-LIVING-WITH-MSA-FULL-TECHNICAL-REPORT-FINAL.pdf see section 3.7.2 |  |
| 56 | SCM2 | Ensure all people approaching end of life have an Advance Plan that they have been involved in creating (and is updated regularly) | Helps people to achieve the care that they want, especially if they lose the capacity to be involved in discussions at a later stage  Will help people to experience a better end of life and will support carers in advocating for the person | Although the evidence is sparse, the NG142 and NG31 agreed that advance planning is a useful tool in ensuring care meets the needs and desires of people at the end of life and who are dying. It is also a useful way to provide some control to the person at end of life. If a person loses capacity it means there is information from the person at end of life as to what they had described they wanted The National Audit for Care at End of Life is still identifying people who do not have an advance plan at their last admission | NG142 – end of life adults – service delivery  National Audit Care at End of Life  NG31 – care of dying adult which showed some people experiences of dying could be improved |
| 57 | NHS Blood and Transplant | Increased use of and access to advance care planning, including Advance Decisions to Refuse  Treatment (ADRT) and Do Not Attempt Resuscitation (DNACPR) orders, and Lasting Power of Attorney | The guidance supports the use of advance planning for end of life care and knowledge of a patients wishes and preferences helps the wider care team in the community and in hospital to make decisions consistent with the individual’s choices. However it is not clear whether this advice is being followed and who should be driving this. Certainly, advanced care planning documents remain unusual in ICU and ED patients where many patients lack capacity and such plans would be particularly helpful. A patient\*s values and preferences continue to be primarily established with the family. | Current studies (German) in ICU suggest that Advance Care Plans are having little impact on the decision making in the ICU. Standardised documents with specific bespoke goals and electronic access to them when the patient is admitted to secondary care with help the planning of end of life care of many who are admitted as emergencies | See also Faculty of Intensive Care Guidance  https://www.ficm.ac.uk/sites/default/files/ficm\_care\_end\_of\_life.pdf |
| 58 | Resuscitation Council UK | Discussions and recommendations about cardiopulmonary resuscitation (CPR) should be conducted in a structured, person-centred way, contextualising resuscitation within overall goals of care | There is good evidence that a structured, holistic, person-centred approach to planning for a future emergency is superior to considering and recording whether or not someone should have cardiopulmonary resuscitation attempted in isolation. It is important to consider the person’s broader care and treatment needs to understand what the individual’s goals of care are, and to understand whether the patient would want cardiopulmonary resuscitation attempted and could be helped by it.  Such a person-centred approach, based on well-informed discussion between patients and clinicians, is consistent with recommendations in the national guidance ‘Decisions relating to CPR’, with guidance from the GMC, and with the NICE-accredited Resuscitation Council UK national guidelines on resuscitation. The ReSPECT process (Recommended summary plan for emergency care and treatment), developed by Resuscitation Council UK working with a range of other organisations, patient and public representatives and clinical experts, is such an approach that has been developed and adopted widely within England and Scotland. However, there is still evidence of practice where Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) is recommended in isolation, without sensitive and well-structured conversation as part of a defined process. | An NIHR study (published 2016) showed evidence of variation and suboptimal practice in relation to DNACPR decisions across healthcare settings. There were deficiencies in considering, discussing and implementing the decision, as well as unintended consequences of DNACPR decisions on other aspects of patient care. DNACPR recommendations were documented in different organisations and different geographical areas on widely differing forms, which were often not used or accepted in other organisations or areas.  During the COVID-19 pandemic we have been informed of numerous instances in which • attempts were made to pressurise patients into agreeing to have a DNACPR recommendation recorded, without any informed discussion • DNACPR forms were completed without any discussion with patients or their proxies • Untrained staff were instructed to complete forms for patients (e.g. in care homes) recording a DNACPR recommendation for a doctor to sign. Proper adoption of the ReSPECT process and education of all health and social care staff in its use could have avoided the majority of these instances, many or all of which were unprofessional, unethical and probably unlawful. | Please see: NIHR study report: Perkins GD, Griffiths F, Slowther A-M, et al  Do-not-attempt-cardiopulmonary-resuscitation decisions: an evidence synthesis Source: Centre for Reviews and Dissemination Health Technology Assessments - CRD HTA - 12 April 2016 - Publisher: Centre for Reviews and Dissemination. Available via the NICE website. This highlights the many problems with the use of a DNACPR approach, and possible solutions. The development of the ReSPECT process arose directly from the evidence that emerged from this study.  Please see also: Decisions relating to cardiopulmonary resuscitation 2016. British Medical Association, Resuscitation Council UK and Royal College of Nursing.  https://www.resus.org.uk/library/publications/publication-decisions-relating-cardiopulmonary GMC guidance: https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life UK resuscitation guidelines: Subsection - ‘Discussing decisions about CPR’: https://www.resus.org.uk/library/2015-resuscitation-guidelines/prevention-cardiac-arrest-and-decisions-about-cpr https://www.resus.org.uk/respect |
| 59 | Royal College of General Practitioners | Advanced care planning quality and the communication of this to all who might be involved   Advance care planning is recommended in NICE guidance NG142 section 1.6 https://www.nice.org.uk/guidance/ng142/chapter/Recommendations#advance-care-planning | It is essential that patient choice is at the heart of their own care and advanced care planning has increased over recent months with COVID-19. The quality of these care plans has yet to be determined and unless these advanced choices are shared with the appropriate health, social care and caring teams the care we give will never meet the patient wishes. |  |  |
| 60 | Royal College of Nursing | Advance Care Planning | Despite government directives to support conversations at end of life, there is still evidence that professionals across the health and social care setting do not support patients and their loved ones to have conversations regarding end of life care choices. Building on the work that has already been completed we need to continue to drive this forward. | Conversations relating to end of life care do not always happen in a timely manner. All members of the multi-professional team must be supported to acquire the skills needed to undertake this conversation, with compassion and competence. This is especially important when people are given a life changing diagnosis where decisions around their wishes should be instigated early in the disease trajectory (i.e. at memory clinics and neurology outpatient clinics). | https://www.rcn.org.uk/clinical-topics/end-of-life-care/advance-care-planning   https://www.alzheimers.org.uk/categories/support/advance-care-planning |
| 61 | Royal College of Physicians (RCP) | Advance care planning – Supporting generalists to have conversations about disease extent, future progression and treatment choices | Patients must be offered a conversation about their health when they are identified as EOL in order that they are able to make informed choices about their future including healthcare choices | Healthcare staff remain reluctant to start these conversations both in hospital, in outpatients and in the community. The multi-factorial barriers need to be urgently addressed. | Royal College of Physicians | Our Future Health. Talking about dying: How to begin honest conversations about what lies ahead. London: RCP, October 2018. www.rcplondon.ac.uk/talking-about-dying |
| 62 | SCM7 | Conducting and acting on advance care planning | People approaching EOL need to be offered easy and updatable ways of making advance care plans and sharing these with the health and social care teams. The COVID-19 crisis has shown that NHS is unprepared for large numbers of people who have to rapidly make decisions on escalation and ceiling of treatment, preferences about being transferred to hospital etc.  The RCP EOLC audit (2016) showed very poor uptake of ACP for people who were clearly approaching EOL, and who died in hospital. There are now several ways of helping people make ACPs, but there needs to be better monitoring of how these are implemented and equally importantly, acted on, especially in a crisis. | When people have not made clear their preferences and advance plans, or if these have been made but not communicated, then it can lead to great distress towards the EOL, especially if patients are admitted urgently to hospital against their wishes.  The NHS is likely to benefit in terms of saving resources on unnecessary hospital visits and admissions.  NB: This QS needs to be implemented also in care homes, where many eligible patients are residing. | See NICE NG142 – Rec 1.6 evidence base Also RCP Dying in Hospital Audit (2016) and subsequent NACEL reports. |
| 63 | SCM9 | People with palliative care needs should be supported to consider and make care plans that respect their autonomy and choices where possible (including the nature of documentation of those care plans) | Care planning, where patients have the opportunity to consider and plan their care towards the end of life, is considered best practice in palliative care. | Many different documents to support Advance Care Planning have been devised over recent years. There is often a treatment or organisation focus on these documents (e.g. emphasis on avoiding hospital admission). There is a lack of patient choice in terms of the types of documents that are “accepted” at local hospital trusts. A broader and more personalised approach to care planning is needed | There is much more work needed to understand patient experiences, acceptability, impact and outcomes associated with advance care planning. |
| 64 | Society for Acute Medicine | Advance care planning established within acute hospital settings | Advance care planning has a clear and well-established impact on people achieving their preferred place of care and death. | Hospital clinicians hold a privileged position with respect to trust and confidence of patients &/or their families. Often the responsibility for advance care planning is placed on the community sector/general physicians. Hospital admissions are clear intervention points where end of life conversations could be initiated. |  |
| 65 | SCM4 | Education on how to deliver effective and timely advance care planning, including to those with specific communication needs. | As discussed in the Evidence Review “Advance Care Planning”, health care professionals continue to find some conversations difficult, and the implementation of careful, sensitive and timely advance care planning is inconsistent across the UK. | The committee agreed in the evidence review “Advance Care Planning” that training programmes for HCPs could help facilitate the process. | https://spcare.bmj.com/content/1/1/71.1 https://www.nhs.uk/planners/end-of-life-care/documents/planning-for-your-future-care.pdf https://www.hospiceuk.org/what-we-offer/courses-conferences-and-learning-events/conferences/hospice-uk-national-conf/abstracts/details/development-of-an-advance-care-planning-training-programme-utilising-online-learning?secured=false |
| 66 | SCM5 | Advanced care planning | This is probably the first point in the guidance and is often undertaken by individual disease groups at different times. For example Dementia it started at diagnosis whereas for renal failure it may be some way through the length of the disease when it becomes apparent that there are no further treatment options.  For others it may not start until a move from home to care home or sheltered accommodation. | There are a number of indicators to start advanced care planning and many different types of plan. This is an area requiring considerable more work and research to identify the optimum times and types of plan. To make it most effective it needs and should encourage joint working. |  |
| 67 | SCM6 | Service providers should develop policies to ensure that advance care planning is offered to adults who are approaching the end of their life | Enables people to consider and record their wishes and preferences for treatment in advance, which may have a bearing on the choices that they have on the setting in which they receive care and treatment. | A number of approaches have been tried, but evidence suggests that it is underutilised. Links in with treatment escalation plans eg ReSPECT | Digital interoperability between service providers continues to be a challenge |
| 68 | The British Pain Society | Conducting and acting on advance care planning | People approaching EOL need to be offered easy and updatable ways of making advance care plans and sharing these with the health and social care teams. The COVID-19 crisis has shown that NHS is unprepared for large numbers of people who have to rapidly make decisions on escalation and ceiling of treatment, preferences about being transferred to hospital etc.  The RCP EOLC audit (2016) showed very poor uptake of ACP for people who were clearly approaching EOL, and who died in hospital. There are now several ways of helping people make ACPs, but there needs to be better monitoring of how these are implemented and equally importantly, acted on, especially in a crisis. | When people have not made clear their preferences and advance plans, or if these have been made but not communicated, then it can lead to great distress towards the EOL, especially if patients are admitted urgently to hospital against their wishes.  The NHS is likely to benefit in terms of saving resources on unnecessary hospital visits and admissions.  NB: This QS needs to be implemented also in care homes, where many eligible patients are residing. | See NICE NG142 – Rec 1.6 evidence base Also RCP Dying in Hospital Audit (2016) and subsequent NACEL reports. |
| 69 | The GSF Centre CIC | Advance care Planning discussions offered to people approaching their final year/s of life. (included in QS 2 and 3 but not very specific so suggest to be enhanced . ) | Offering and recording specific advance care planning (ACP) discussions to all people across all settings is internationally recognised as best practice. | Offering ACP discussions (also sometimes called Personalised Care and Support Planning ) are important part of the NHSE Long Term Plan and Universal Care plans, to enable more personalised care Shown to be cost efficient also and reduce hospitalisation .   Very relevant and made even more vital during the COVID 19 pandemic , and the sometimes blanket DNAR agreements initially suggested by some GP practices .  Routine ACP discussion with generalist staff eg by care home staff with every resident , could lead to appropriate hospitalisation. | Offering ACP discussion to every relevant person / resident is a key measured part of GSF in all settings – see BMJ article primary care , and in publication use of GSF in hospitals (can send on ) . See the Advance Care Planning International group- since 2010, sharing good practice across the world. https://www.acp-i.org/ And EAPC https://www.sciencedirect.com/science/article/abs/pii/S147020451730582X Also see widely referenced ACP section of GSF website https://www.goldstandardsframework.org.uk/advance-care-planning See chapters on evidence base of ACP and Economic benefit in Oxford University Press Book- edited by Thomas K Lobo B Detering K Advance Care Planning in End of Life Care ISBN 978-0-19-880213-6 Several references from systematic reviews available and could send including  • Ch 4 Josey Dixon  • Systematic review of economic evidence of ACP (2015) Dixon J Matosevic T and Knapp M The economic benefit evidence for advance care planning :systematic review of evidence Pall Med 29 (10) 869-84 –  • varied cost-saving studies- around half included RCT and concluded that ACP lead to healthcare/ hospital -based cost savings (didn’t always take into account community costs) ie reduced hospitalisation , length of stay, and fewer invasive interventions. Included people with dementia, in care homes and high areas of EOLC need .  • Strong evidence that it provides person-centred care in advanced illness at EOL and emerging evidence more generally ie promotes more of care they want and less of care they don’t want , higher carer satisfaction and some reduced hospital cost savings. Though economic benefit complex to measure- and its not all about saving money-( she says more on this and types of economic evaluations eg cost minimisation, cost saving, cost utility , cost benefit etc – page 42 )   Sarah Russell (ch 2)  • Cites extensive evidence demonstrating its benefit  Karen Detering  • The original RCT 2010 Detering KM et al The impact of ACP on end of life care in elderly patients; a randomised controlled trial BMJ 340 (1) :c1345- More recent  • ACP facilitators programme https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-019-4192-0 This is even more relevant now since the COVID crisis exposed the need for more consistent ACP discussions with all care homes residents and identified hospital patients . |
| 70 | SCM3 | Advance Care Planning | Planning ahead is evidenced to reduce anxiety, promote communication and improve patient and carer experience at End of Life | Numbers of completed advance care plans remains low nationally, despite the benefits of the document. | Advance Care Planning – Gold Standards Framework Advance Care Planning – NICE Making an Advance Care plan – Compassion in Dignity |
| **Coordinated care** | | | | | |
| 71 | Association for Palliative Medicine of Great Britain and Ireland | IT systems that are used to communicate decisions and information about patients in the last year of life need to be fit for purpose and interoperable | It is important to document patients key information and preferences for end of life care and this needs to be accessible to all potentially involved in their care | Currently systems are not reliably interoperable and there is significant risk of information not being known and accessible to those who need to know. | Impact of electronic palliative care coordination systems (EPaCCS) on care at the end of life across multiple care sectors, in one clinical commissioning group area, in England: a realist evaluation protocol. Lucy Pocock1,  1. Lydia French, Michelle Farr, Richard Morris, Sarah Purdy 2020 10(3) http://dx.doi.org/10.1136/bmjopen-2019-031153 |
| 72 | British Geriatric Society | Care co-ordination/use of Electronic care systems. | For example My CMC which enable people and their families as well as the wider whole care team to support the goals of care for that individual – MDT needs to include mental health professionals- geriatricians, Allied Health Professional’s community, paramedics and care homes |  |  |
| 73 | Compassion in Dying | Documentation and record sharing | The Covid 19 pandemic highlighted the importance of documenting and not only discussing end-of-life care preferences because many individuals had to be treated in isolation, without family and friends around to speak on their behalf. The current approach to sharing patient records is inconsistent (i.e, not in every region, not across all services such as GPs, care homes, ambulance trusts and hospitals) and thus impacts negatively on care. | The importance of not only talking about end of life preferences and the experiences of our callers when preferences are and are not written down are set out here :https://medium.com/death-dying-and-digital/we-need-to-do-more-than-talk-about-death-56893516a36  For example: “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.” “How will the hospital know about my Advance Decision?” is one of the most common questions we receive on our information line.  Only 46% of the CCGs (96 out of 207) reported that GP practices in their area have systems for recording the existence of a person’s Advance Decision and 32 of those responses mentioned the use of Electronic Palliative Care Co-ordination Systems (EPaCCS).  (Finding from an FOI sent to 207 CCGs in England in January 2018. 100% response rate) Only 7 out of 13 Ambulance Trusts are able to upload advance care plans on to their systems. (Findings Finding from an FOI sent to all 13 Ambulance Trusts January 2018. 100% response rate) The Brenda Grant and Jillian Rushton cases mentioned above demonstrate the urgent need for improving the system for sharing patient records in a timely and meaningful way. | Shared records was one of the foundations of the Ambitions Framework http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf   Lessons learned from the Coordinate My Care system can be found here - https://www.coordinatemycare.co.uk/category/articles/   https://www.coordinatemycare.co.uk/wp-content/uploads/2016/09/bmjspcare-2015.pdf   The PRSB recently documented information-sharing related challenges faced during the pandemic - https://theprsb.org/2020/05/twitter-chat-report-now-live/ |
| 74 | Kidney Care UK | Communicating and sharing information between services and specialisms. | See above re symptom control |  |  |
| 75 | National Clinical Director for Palliative and End of Life Care | Communicating and sharing information between services | This is crucial if the patient is to experience joined up care. | The ability to share information across organisations boundaries remains a barrier to providing efficient and seamless care for patients. It is unacceptable for patients to have to repeatedly provide information that can be shared between services. |  |
| 76 | Royal College of Physicians (RCP) | IT systems which are intraoperable to communicate decisions | We must be able to share the choices patients make in a robust and secure manner. The current electronic system of EPaCCS is unfit for purpose as there is insufficient interoperability of IT systems which leads to patient wishes not being carried out. | We cannot support patient wishes unless we communicate them effectively between settings and organisations. | Electronic palliative care coordination system (EPaCCS): Interoperability is a problem. Pablo Millares Martin BMJ 2018 8(3) https://spcare.bmj.com/content/8/3/358 Impact of electronic palliative care coordination systems (EPaCCS) on care at the end of life across multiple care sectors, in one clinical commissioning group area, in England: a realist evaluation protocol. Lucy Pocock1,  1. Lydia French, Michelle Farr, Richard Morris, Sarah Purdy 2020 10(3) http://dx.doi.org/10.1136/bmjopen-2019-031153 |
| 77 | Society for Acute Medicine | Systems for clear information sharing between healthcare sectors | Clear systems must be in place to share important end of life care information and decisions. This is already within the NICE End of life care for adults quality standard [QS13] yet information is still difficult to access | Detailed information for many patients is missed due to lack of easily accessible data sharing. To be clinically useful this information needs to be available at every stage of patient-healthcare interaction (home, primary care, secondary care, etc). |  |
| 78 | SCM4 | Electronic IT system accessible by different services and across organisations. | It is well-known that electronic information sharing is the quickest, most easily accessible and safest (in terms of data protection) method of facilitating well-coordinated care.  The Health and Social Care Act 2015 legally requires health and social care services to share information where this will facilitate care.  The NICE committee concluded in the Evidence Review “Information Sharing” that use of electronic information-sharing methods, in the long-term, would be likely to reduce costs . | It is known that there is variability in the implementation of IT-based systems used in end of life care services across the UK. The Evidence Review “Information sharing”   The implementation of an electronic information sharing system would be in line with the NHS Long Term Plan. | <https://spcare.bmj.com/content/8/4/447> |
| 79 | SCM5 | Communicating and sharing information between services | This is an area where there could be a great deal of improvement assisted by technology. | If the same advanced care plan followed by a needs assessment and then a day to day care plan are shared between practitioners and services. This will facilitate many of the other areas in the guidance for example, the review of current treatment and stopping what is no longer beneficial or necessary. Identification of the most appropriate person to meet needs. Transferring of people between care settings, especially to the ordering and supply of equipment | • Too often people have to wait for equipment and services to be ordered to be able to transfer from one setting to another By using the same or linked technology this could be quicker. • Having the same criteria for access to equipment and services would help transfer of people. • All areas have access to CHC funding but very different forms and criteria for provision, some areas provide live in carers others do not and the forms are different across the country. |
| 80 | The GSF Centre CIC | Additional developmental areas of emergent practice | Use of digital systems to improve communication eg EPaCCs , cloud/ websites eg ACP discussions and possibility of AI support in future eg AI for ACP discussions |  |  |
| 81 | SCM3 | EPaCCS – Electronic Palliative Care Co-ordination System | Due to national Health IT systems inability to communicate to the wider MDTeam involved in patient care this system allows communication with the patient and beyond | Patient Safety Improved patient and carer experience  Improved job satisfaction for staff | Electronic Palliative Care Coordination System – England Electronic Palliative Care – NHS Digital |
| 82 | Trinity Hospice Blackpool | Development of usable EPaCCS system in all localities (possibly the development of a national system), involving primary care and palliative care services to develop an effective system with a set number of key criteria included. | Electronic palliative care coordination systems are going to be key in facilitating patient choice at end of life and in providing good and appropriate care. This has been recognised in all seminal documents and plans from the last decade including One Chance to get it right (LACDP 2014) | Research already carried out, evaluating the Coordinate my care system, demonstrates the benefit of EPaCCS systems in avoiding unnecessary hospital admissions and facilitating the meeting of a patient’s expectations and preferences around their care at end of life. However these systems are highly variable and have been developed in an ad hoc fashion locally, with variable amounts of useful information. Some for example omit ceilings of treatment. The development of a usable system in all localities is a key area for quality improvement. | Please see:  Riley et al 2019. Advance care planning: the impact of Ceiling of Treatment plans in patients with Coordinate my Care. BMJ Support & Palliative Care.9:267-270 & Riley et al 2018. Crash course inEPaCCS (electronic Palliative Care Coordination Systems): 8 years of successes and failures in patient data sharing to learn from. BMJ Support & Palliative Care. 8:447-455 |
| 83 | Hospice UK | Additional developmental areas of emergent practice: Promoting quality care in non-specialist palliative care settings | The vast majority of people approaching the end of life will have limited involvement of specialist palliative care services, and will instead rely on mainstream generalist care. There is an opportunity with the refresh of the quality standard to bring a new focus on non-specialist palliative care including primary care, district and community nursing, social and personal care, care homes and other settings. |  |  |
| 84 | Hospice UK | Additional developmental areas of emergent practice: Care coordination | Identifying a key coordinator and wrapping care around the person who is dying and their family helps to remove the barriers across the system. The system has provided that this can be achieved during the pandemic, and should now be mainstreamed. |  |  |
| 85 | Multiple System Atrophy Trust | People should have a clinically competent key worker as a constant point of contact to keep abreast of changing situations, anticipatory care and co-ordinating and accessing appropriate support | Co-ordination of care and support is a problem for people with MSA throughout their journey and especially at end of life. Due to the nature of their condition, support requires a multi- disciplinary approach. This is often lacking because of no one worker having responsibility for overall co-ordination. |  |  |
| 86 | National Clinical Director for Palliative and End of Life Care | Providing end of life care coordination | This is linked to the 3rd area for QI listed above. | There is evidence to show that patients still experience coordination of their care being suboptimal – between different services and also between their condition specific specialist and that of their palliative care teams. |  |
| 87 | Royal College of Occupational Therapists | Lead healthcare professional A lead healthcare professional is a member of the multidisciplinary team who assumes overall clinical responsibility for the delivery of care to a patient. They are usually a senior doctor or senior nurse; however occupational therapists have the skills to undertake these roles. | The lead healthcare professional should ensure that the person approaching the end of their life is offered opportunities to discuss their existing treatment plans with a healthcare professional. | 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 |  |
| 88 | SCM7 | Providing coordinated care for EOL for patients and carers | In spite of local plans and policies being made in specific settings (community, acute, care homes etc) patients and families are let down because of lack of joined up care. This is particularly seen when the patient has a crisis, eg sudden deterioration in underlying condition like COPD, or an incidental event such as fall and fracture.  Lack of coordination is often cited by patients and families as a source of distress and wasted time, eg delayed or inappropriate transfer between settings. | Even though many places have good or excellent parts of EOLC services, patients can be let down if there is poor coordination between them, especially across settings.  The NHS wastes resources on carrying out unnecessary tests or repeating them because information has not been passed between service providers. | See NICE NG 142 – Rec 1.10 evidence base Also QS13 (2017) – statement 8. |
| 89 | SCM6 | Ensure that there is good communication between health and social care practitioners coordinating community-based care and health and social care practitioners coordinating hospital care. | Information on their plan of care and changing needs should accompany the person at the point of transfer to permit as smooth a transition in care as possible | People in the last year of life are more likely to receive care in a number of settings - information on their plan of care and changing needs should accompany the person at the point of transfer but often is insufficient |  |
| 90 | The British Pain Society | Providing coordinated care for EOL for patients and carers | In spite of local plans and policies being made in specific settings (community, acute, care homes etc) patients and families are let down because of lack of joined up care. This is particularly seen when the patient has a crisis, eg sudden deterioration in underlying condition like COPD, or an incidental event such as fall and fracture.  Lack of coordination is often cited by patients and families as a source of distress and wasted time, eg delayed or inappropriate transfer between settings. | Even though many places have good or excellent parts of EOLC services, patients can be let down if there is poor coordination between them, especially across settings.  The NHS wastes resources on carrying out unnecessary tests or repeating hem because information has not been passed between service providers. | See NICE NG 142 – Rec 1.10 evidence base Also QS13 (2017) – statement 8. |
| 91 | The GSF Centre CIC | Population-based integrated end of life care –across whole system and population | Whole system care through ICSs needs to be developed to ensure joined up care for people on the receiving end. There is a need to focus on integrated provision in practice and include health and social care provision. | A need to measure effectiveness and integration of a wider system across health and social care as in the developing ICSs . Not many metrics have been developed though some used by PHE EOLC Intelligence Network . there needs to be increasing concordance of health and social care assessments and metrics . | BJGP Editorial article Thomas K Gray Population based End of Life Care  Pilot use of EOLC Metrics submitted to NHSE from the GSF Cross Boundary Care Sites -see attached unpublished data sent and used by NHSE and other STPs/OCSs – showing key EOLC metrics and measurables suggested for wider population areas eg STP/ICSs . Further updated information on their use through collating information from EPaCCS is available from us eg Nottinghamshire CCGs/ ICS. |
| 92 | The GSF Centre CIC | Key area for quality improvement 1 Enhancing Generalists’ provision of end of life care (EOLC) for people in the last year/s of life across all health and social care providers (possibly in Sect 15 Workforce training or 10 Specialist Pall care sections ). | Most care provision for people in the final years of life is given by generalist frontline staff , in health and social care – estimated about 2.5 million staff . The significance of the contribution of social care staff in care homes, but also in domiciliary care and retirement villages, was recognised and exposed during the COVID crisis. Therefore, to improve EOLC received by more people earlier in their decline , enhancement of generalist skills is vital. | There is little evidence included so far of the beneficial effect of generalists’ training in improving care, reducing hospitalisation and improving outcomes for people eg enabling more to die where they choose. The GSF Centre has focussed on this area , with much experience over the last 20 years in enabling over 3500 teams improve care . Experience from GSF accredited teams and from ‘Frontrunners’ in different sectors is available, demonstrating what is possible to achieve . This aligns with Sect 1.42 of the NHSE Long Term plan in seeking proactive, person-centred coordinated care ie focussing on generalists’ skills of  • early identification – proactive care .  • Assessment of personal and clinical needs – personalised care  • Planning better outcomes and reducing avoiding hospitalisation | There are many examples of evidence of experience of benefit through GSF training in all areas of health and social care eg Frontrunners in primary care , hospitals care homes , Accreditation evidence etc and more available on request https://www.goldstandardsframework.org.uk/evidence |
| 93 | Association for Family Therapy and Systemic Practice UK | Increasing skill and capacity for specific clinical staff to talk with families about death, dying, bereavement and relationships. | ICU clinicians and care home staff should all be provided with training on systemic ideas. Currently these clinical sites manage a large proportion of mortality. | Even within oncology, which is typically seen as the natural home of good communication, clinicians often offer suboptimal communications with families 1 yet family therapy techniques are recognised to have potential salience and support in cancer communication 2 | Death/mortality registries would presumably collect data on place of death (ICU. Care home) and location of care prior to a hospital death (again, care homes). |
| 94 | Association of British Neurologists, Quality Committee | Recognition of role of district nurse to increase their resources. | District nurses know the family and deliver daily care in palliative care. | The district nurse service needs to better resourced to deliver this care in the community. | https://www.goldstandardsframework.org.uk/cd-content/uploads/files/Library%2C%20Tools%20%26%20resources/ABC%20Palliative%20Care.pdf Although GPs may feel pressurised by time constraints, the primary care team, particularly the district nurses, are in a key role to perform this function, and often they are the mainstay of care at this most crucial time. This is in line with the “cradle to grave” concepts inherent in primary care; knowledge of context and community and of continuing supportive relationship and care of the dying is close to the heart of most people working in primary care. As Gomas (1993) said “Palliative care at home embraces what is most noble in medicine: sometimes curing, always relieving, supporting right to the end.” |
| 95 | British Thoracic Society | Access to multidisciplinary team meetings including palliative care input for those managing chronic disease. |  |  |  |
| 96 | British Thoracic Society | Access and provision of specialist palliative care services in an integrated manner for those where required so as to provide ongoing care by the respiratory team but input from pall care |  | At moment there is little provision for palliative care to get involved and experience differs when it does. This often requires separate visits to different people at different sites. |  |
| 97 | British Thoracic Society | Training for respiratory (and cardiac etc) staff in palliative care across the MDT job roles but also within UG / training curriculum. |  |  |  |
| 98 | Faculty of Intensive Care Medicine | Improved training and psychological support (at undergraduate and postgraduate level) for those involved in caring for dying patients |  |  |  |
| 99 | Hospice UK | Workforce Planning and Training | Since the quality standard was published, there have been considerable workforce changes, and the availability of training and education particularly for the ‘generalist’ workforce. | There is an opportunity to reflect on new roles in the health and care workforce and how they relate to the delivery of quality palliative and end of life care (such as nurse associates). Also important to reflect the considerable challenges associated with recruitment and retention of the workforce, especially in ‘generalist’ services such as care homes.  It is also important to ensure access to training and education for staff who sometimes find it hard to access (e.g. domiciliary care, personal assistants, care home staff etc). Education and training has had to adapt to the pandemic, for instance with the rapid expansion of online training programmes. |  |
| 100 | SCM1 | 1.9 Providing multipractitioner care | To enable people approaching the end of their lives to be supported and have their needs fully met in the place of their preference. In 2008 the first national strategy for end of life care in England galvanised the health and social care system with three key insights: that people didn’t die in their place of choice; that we needed to prepare for larger numbers of dying people and that not everybody received high-quality care. ‘Some people experience excellent care in hospitals; hospices; care homes and in their own homes. But the reality is that many do not’ | In order to meet peoples wishes we need: Rapid access to social care Person Centred Care Integrated Care Fair Access to Care Specialist Palliative Care Rehabilitative Palliative Care All stated in the Ambitions document but not yet a reality in many areas. Without providing the right resources, from the right people, at the right time, we will continue to have avoidable hospital admissions. | Ambitions for palliative and end of life care; A national framework from local action 2015- 2020  The role of social workers in palliative, end of life and bereavement care: Hospice UK/BASW   NHS England Specialist Level Palliative Care: Information for commissioners April 2016  Social care and hospital use at the end of life – The Nuffield trust December 2010 |
| 101 | Kidney Care UK | Symptom control | People with conservatively managed end-stage kidney disease have considerable symptom control needs, similar to advanced cancer populations. However, specialists outside of kidney care can be hesitant to prescribe some painkillers which are contraindicated for kidney patients. Collaboration between renal specialists and palliative care specialists is key. | Patients with advanced kidney disease have significant symptom control needs. Symptoms are poorly addressed due to poor recognition and anxiety about prescribing. Russon L and Mooney A, Clin Med (Lond). 2010 Jun; 10(3): 279–281 Patients report to Kidney Care UK varying quality of palliative care, with a number reporting no access to palliative care specialists. |  |
| 102 | Royal College of Nursing | Education: Staff training | Access to appropriately trained staff to support patients and families across the whole life span. Infancy, childhood, transition and adulthood  Training should be expanded to include training and support of general symptom management in non-specialist settings?  Given the recent hype and attention around the opioid crisis this is increasing the fear around administering opioids and sedative medications in non-specialist centres.  The use of technology to support learning should be embedded within all organisations in order to facilitate easy access to high quality learning | Transition from childhood to adulthood can be especially challenging for people with palliative and end of life care needs. Staff should have the knowledge base to support this in a seamless manner that leaves the person and their families supported and cared for. Learning opportunities should be accessible to all who provide care irrespective of grade or specialist status.  Care home and domiciliary carers are often the people who provide the consistency in the persons care provision and as such should be equipped with an agreed core competency. Project ECHO is receiving increased attention as a methodology in the provision of education in end of life care | Project Echo Transitions Hospice UK are developing a national Transitions community of practice see link below  https://www.hospiceuk.org/.../project-echo/get-involved/transitions-project-echo-networks  Cancer Pain management among oncology nurses: Knowledge, attitude, related factors, and Clinical recommendations : a systematic review . Bouya et al (2019) Cancer education 34(5) 839 -846  There is a plethora of education packages available in various different formats, how do we ensure that the education is quality assured and giving learners the  most up to date and patient focused information? This should be guided by a core standard of education.  Below is an example of available education  https://www.scie.org.uk/person-centred-care/older-people-care-homes/end-of-life-care  https://www.hospiceuk.org/what-we-offer/clinical-and-care-support/project-echo/about-project-echo |
| 103 | SCM5 | Providing multipractitioner care | Increasing numbers of people reaching the end of their lives have more than one disease and if practitioners from the various specialties work together the effects of the action taken in one area can be assessed by those with more knowledge in another. For example someone with long standing Parkinson’s disease may develop an untreatable cancer and to the titration of the Parkinson’s disease drugs is important for the comfort of the patient. | Joint working between specialities is important to maximise the physical, social and psychological care for example end of life care and renal care, end of life care and dementia care, end of life care and having a learning disability, end of life care for the homeless. By working together practitioners can learn from each other and then transfer this learning to the next person with that combination of circumstances. It improves trust between practitioners. This whole area spills over into the next section of end of life care coordination because specialist practitioners work across end of life care settings particularly between primary, community and secondary care. |  |
| 104 | Trinity Hospice Blackpool | Improved provision of physical care for patients at end of life at home. | It is consistently reported that close to 80% of people wish to be in their own homes when they die, as described in VOICES survey (ONS 2015). Yet less than a quarter actually do die in their own home. One barrier to this is the absence of sufficient care at end of life (dedicated specialist nurses and carers) | Preference around place of death has consistently been recognised as a factor in providing good quality care at end of life and has been regarded as a surrogate marker as such. Anecdotally the absence of sufficient care provision at end of life has been a significant barrier to meeting this unmet need. | Please see VOICES survey of bereaved people (ONS 2015). https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/nationalsurveyofbereavedpeoplevoices/england2015#preferences-and-choice-at-the-end-of-life |
| 105 | Association of British Neurologists, Quality Committee | Oncology-palliative care workstream needs to improve patient journey especially for patients with terminal brain tumours. | Paul Kallanithi recognised the importance of this: “Who is the captain of the ship (WICOS)?” | Patients and families struggle at this time to receive clear information. Brain tumour patients in NI may attend 3 different hospitals (Neurologist in DGH, Oncologist and neurosurgeon in different hospitals) before palliative care involvement. Multidisciplinary meetings have not been translated into a smooth pathway. Joint palliative care- neuro-oncology workstream could be improved. | <https://en.wikipedia.org/wiki/Paul_Kalanithi> |
| 106 | False Allegations Support Organisation | A Management plan between prison and NHS on structure of access for a prisoner in end of life care. | There is good evidence that appropriate and effective NHS standard support can drive significant improvements in the quality of life and health status of prisoners within the prison estate | The National Audit should be mandatory at all individual prisons and working with their local NHS service regardless whether it is public or private prison. All prisons care facilities should be part of  The NHS system and staff accountable to the NHS standards (Dr’s, nurses and auxiliaries) regardless. | Prison health care should be accountable to the NHS not the prison authorities be they private or public prisons. |
| 107 | SCM1 | Transferring people between care settings 1.11.2 | Care packages and provision of equipment is essential to enable people and those important to them to live and die in a supported and safe manner according to their preferred priorities of care. | People may need formal care and support to enable them to live at home. Equipment can help both formal carers and relatives to safely cate for people i.e. hoists, profiling beds, wheelchairs.  Care agencies will need to adhere to moving and handling policies. Holistic needs assessment will determine the level and type of care required. Health and social care practitioners need to ensure that they are undertaking sexual orientation monitoring. This was commented upon by LGBT Foundation in the stakeholder comments - no 109. | There’s no place like home: Making the case for free social care at the end of life. Macmillan cancer Support 2013. How could free social care at end of life work in practice. OPM June 2014 Mapping the scope of occupational therapy practice in palliative care: A European Association for Palliative Care cross-sectional survey Palliative medicine 2018 32 (5) 960 – 968 National Framework for Continuing Healthcare November 2012, Updated 11th March 2019 SNAP – Support Needs Approach for Patients https://thesnap.org.uk  https://www.rcgp.org/uk/clinical-and-research/resources/a-to-z-clinical-resources/daffodil-standards.aspx ‘Hiding who I am’ The reality of end of life care for LGBT people. Marie Curie 2016 |
| 108 | SCM2 | Specialist transport services are available for people at end of life | This will enable people to be cared for (and die) in their preferred place of care – in a compassionate and speedy way  This will help people to experience an improved experience of end of life and death – and reduce stress for carers | NG142 committee agreed that the availability of efficient and timely transfer is important to ensure that people can be moved quickly, when needed, to where they would like to be cared for and die. It will also mean that care is provided in appropriate places and that beds are freed up in inappropriate places of care 2017 QS for end of life stated Many people receive high-quality care in hospitals, hospices, care homes and in their own homes but a considerable number do not. Up to 74% of people say they would prefer to die at home, but currently 58% of people die in hospital. There s no evidence to show this has changed | NG142 – end of life adults – service delivery  National Audit Care at End of Life  NG31 – care of dying adult which showed some people experiences of dying could be improved |
| 109 | Royal College of General Practitioners | Choice of place of death | Aiming to increase the proportion of patients who die in their chosen place is key to improving the experience of dying. |  |  |
| 110 | Society for Acute Medicine | Systems for rapid discharge towards the end of life | Patients who wish to die outside of the hospital setting are often unable to be discharged due to lack of support available in their preferred place of death. This could be due to complicated systems for discharge and involvement of multiple individual teams | There is great variance across acute trusts over the responsibility for fast track discharges towards the end of life. Within the community sector, the teams responsible for end of life care varies between geographical areas/clinical commissioning groups leading to wide variance in the availability and quality of end of life care. Referral processes to community teams when rapidly discharging patients is complex and there is again wide variance across clinical commissioning groups over how the process works . In urban areas where one hospital collaborates with multiple geographical areas this makes the process difficult to navigate & slow |  |
| 111 | SCM4 | Availability of care packages for those wishing to die at home. | Delayed discharge from hospital or hospice to home, where a majority of people wish to die, often occurs because of a lack of availability of care provision at home. It is also known that unwanted/medically unnecessary hospital admissions often occur because of challenges in home care provision. | There is evidence that the absence of sufficient domiciliary care to address a patient’s needs can be the reason why patients are either admitted to hospital/hospice or cannot be discharged from hospital/hospice.  Developing a more cohesive and consistent approach to the organisation of care services, would lead to 1. A higher probability that patients would die in their preferred setting, and 2. More crucial hospital beds being made available for medical reasons. | <https://bjgp.org/content/69/685/e561> |
| 112 | SCM4 | Transfer of patients between settings. | Recommendation 11 discusses the need to develop systems to support smooth and rapid transfer between settings. This is vital to ensure that there is maximum chance of a patient being able to be cared for and die in their preferred place. | There is a wide variation between the availability and response times of ambulance services attending those at end of life across the UK. The reasons for this are complex and need further analysis. Barriers for delay, non-conveyance or non-attendance include lack of availability (particularly out-of-hours), limited available patient information and service emphasis on emergency situations. Some areas have a dedicated ambulance service (eg The Leeds Palliative Care Ambulance and the Welsh Ambulance Services NHS Trust) and these have been shown to have an effect on the number of people who are able to die in their preferred setting.  Work is needed in order to bring equity of this service to other areas of the UK. Potentially, by having a dedicated ambulance service to transport patients from hospital to either home or hospice (if that is the preferred setting), vital hospital beds could be made available more quickly. | https://www.england.nhs.uk/publication/inter-facility-transfers-framework/  https://spcare.bmj.com/content/4/Suppl\_1/A8.2  https://www.nice.org.uk/sharedlearning/end-of-life-care-rapid-transport-service  https://journals.sagepub.com/doi/full/10.1177/0269216318779238 |
| **Out of hours care** | | | | | |
| 113 | Association for Palliative Medicine of Great Britain and Ireland | Improving access to specialist palliative care. this includes the specialist nursing workforce and palliative care Doctors | We know that patients have improved care when they have 24/7 access to specialist palliative care services. | There is much disparity geographically and even within regions regarding availability and access to specialist palliative care services | APM workforce report demonstrates that there are less trainees entering the speciality than those leaving the specialty https://apmonline.org/wp-content/uploads/2019/08/palliative-medicine-workforce-report-2019-2.pdf Foster A, Livingstone T, Cadell G (2011) Partnership working to deliver seven day access to specialist palliative care. BMJ Supportive & Palliative Care 2011;1:203. NHS England Specialist Level Palliative Care: Information for commissioners (2016) NHS England https://www.england.nhs.uk/wp-content/uploads/2016/04/speclst-palliatv-care-comms-guid.pdf |
| 114 | Faculty of Intensive Care Medicine | Improved palliative care services (NACEL Audit Report 2 states that only one-third of community and hospital NHS Trusts have 7-day palliative care services. This to include psychological support for patients and their families |  |  |  |
| 115 | SCM1 | 1.12 Providing out of hours care | Without OOH care, the default position in to call an ambulance and be conveyed to hospital. If we are supporting people to live and die at home then rapid access to services is essential. | It is crucial that people approaching the end of their lives have rapid access to a clinical review of their condition including symptoms. They may also need rapid access to equipment i.e. pressure relieving equipment, hoists , commodes and carers support i.e. carers, Hospice at Home, District Nurses.  24/7pharancy is essential. | Dying out-of-hours 24/7 care at the end of life conference report – Macmillan Cancer Support 2011  Out-of-hours primary care use at the end of life: a descriptive study – British Journal of General Practice September 2016 66 (650) |
| 116 | Marie Curie | Out of hours palliative and end of life care | The study on “Quality improvement priorities for safer out of hours palliative care” found many problems in the out of hours palliative care that need to be addressed. In this study, almost two-thirds of the patient described safety incidents as “actual harm” with reports citing emotional and psychological distress to patients, families and carers. These incidents of harm included errors in prescribing, dispensing or administering of medications or delays in access to timely care or advice. More serious consequences happened in 129 (12%) of the cases, such as hospital admission and untimely death. Commonly identified contributory factors to these incidents were a failure to follow protocol, lack of skills/confidence of staff and patients requiring medication delivered via a syringe driver. | Williams, Huw et al (2018) Quality improvement priorities for safer out of hours palliative care: Lessons from a mixed methods analysis of a national incident reporting database. Palliative Medicine 33(3):346-356  https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6376594/ |  |
| 117 | National Clinical Director for Palliative and End of Life Care | Out of hours care | Unscheduled needs that occur out of hours can cause huge anxiety and distress if the provision of out of hours care is patchy or non-existent. | Patient experience feedback indicate that this remains a source of anxiety and suboptimal experience. |  |
| 118 | SCM2 | Ensure people have access to 24-hour specialist palliative care services | Provides reassurance to people and ensure they have access to the care they need at end of life  This will help people to experience a better end of life | The evidence considered by NG142 showed some benefit in supporting people to stay where they wish to be cared for by providing an out-of-hours service. The committee agreed that the services described in the studies reflected existing out-of-hours services in areas of good practice. However, there was evidence that elements of service provision important for people approaching the end of their life may be variable or lacking. The current National Audit for Care at End of Life is demonstrating not all NHS settings have access to this care | NG142 – end of life adults – service delivery  National Audit Care at End of Life  NG31 – care of dying adult which showed some people experiences of dying could be improved |
| 119 | Royal College of Physicians (RCP) | Increasing resource for specialist palliative care teams to provide 24/7 advice and support | Patients receive better care when they are able to access specialist palliative care but access is still below levels mandated by multiple national reports, guidance documents and standards. Community palliative care is patchy and funding mostly from charitable donation. | Drive forward implementation of recommendations on availability, staffing and funding of specialist palliative care services in all settings | NHS England Specialist Level Palliative Care: Information for commissioners (2016) NHS England https://www.england.nhs.uk/wp-content/uploads/2016/04/speclst-palliatv-care-comms-guid.pdf Improving supportive and palliative care for adults with cancer. (2004) Guidance on Cancer Services, the Manual. National Institute for Clinical Excellence Foster A, Livingstone T, Cadell G (2011) Partnership working to deliver seven day access to specialist palliative care. BMJ Supportive & Palliative Care 2011;1:203.  More Care, Less Pathway. A Review of the Liverpool Care Pathway (2013) https://www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients  Parliamentary and Health Service Ombudsman (2015)Dying without dignity. Investigations into complaints about end of life care |
| 120 | SCM7 | Providing more round the clock services for EOLC | For people near the EOL [=last year of life], unexpected crises are common and lead to dire consequences such as potentially avoidable A&E visits and admission to hospital. Crises of symptoms lead to unnecessary suffering owing to lack of 24 hour pharmacy services and specialist advice.  The RCP Dying in Hospital Audit (2016) showed that only a small minority of hospital trusts offered a 24/7 bedside specialist service. This will be even worse in the community.  It is unacceptable that patients still do not access to comfort and specialist care in all locations near the EOL. | This is primarily a humanitarian issue, ie the unnecessary suffering of patients and by implication, their families, when 24/7 services are lacking. It is a disgrace that the NHS does not provide this for people at EOL.  Providing 24/7 cover is said to be expensive in manpower but the NHS could potentially save resources from avoidable admissions to hospital, using telephone and video calling. | See NICE NG 142 – rec 1.12 evidence base Also QS13 (2017) – statement 9. |
| 121 | SCM9 | People approaching the end of life who experience a crisis at any time (24/7) should receive prompt care that is appropriate to their needs and preferences. This may include the identification of their supportive and palliative care needs. This may also now include access to telephone advice virtual consultations | Use of urgent and emergency healthcare rises as patients approach the end of life | There is an ongoing need to improve access to support for patients in crisis at the end of life. Even with comprehensive care plans, unforeseen moment of crisis arise and there needs to be a robust system around patients to ensure that they can access the health and social care that they require, as their needs change, even in emergencies. | This paper outlines the need for more proactive identification of need https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2749774 Acute healthcare use and costs of care have been considered previously in this Nuffield report https://www.nuffieldtrust.org.uk/research/exploring-the-cost-of-care-at-the-end-of-life |
| 122 | SCM6 | A healthcare professional available 24 hours a day, 7 days a week, who can access the person's records and advance care plan, and make informed decisions about changes to care | Essential to ensure that care can be provided to support the person in their setting of choice | Differing service configurations operate across the country, and funding per CCG varies widely |  |
| 123 | The British Pain Society | Providing more round the clock services for EOLC | For people near the EOL [=last year of life], unexpected crises are common and lead to dire consequences such as potentially avoidable A&E visits and admission to hospital. Crises of symptoms lead to unnecessary suffering owing to lack of 24 hour pharmacy services and specialist advice.  The RCP Dying in Hospital Audit (2016) showed that only a small minority of hospital trusts offered a 24/7 bedside specialist service. This will be even worse in the community.  It is unacceptable that patients still do not access to comfort and specialist care in all locations near the EOL. | This is primarily a humanitarian issue, ie the unnecessary suffering of patients and by implication, their families, when 24/7 services are lacking. It is a disgrace that the NHS does not provide this for people at EOL.  Providing 24/7 cover is said to be expensive in manpower but the NHS could potentially save resources from avoidable admissions to hospital, using telephone and video calling. | See NICE NG 142 – rec 1.12 evidence base Also QS13 (2017) – statement 9. |
| **Support for carers** | | | | | |
| 124 | Association for Family Therapy and Systemic Practice UK | When adults are receiving end of life care, procedures should be in place to identify children and young people in the family, assess the impact on them, and provide pathways to support | When parents are facing their own death or the death of a partner it may be difficult to have space to recognise and respond to the impact upon children and young people in the family. At this time it is important to create a space where parents, grandparents and other members of the family might think about the needs of children and young people. |  |  |
| 125 | Association for Family Therapy and Systemic Practice UK | Support for families in a wide sense, thinking about how to explain death and how to include children and young people in events and rituals celebrating the life and marking the death of a parent or other close family member, but also thinking of the needs of older generations who may have lost an adult child. | It is important that children and young people’s needs are not overlooked, especially since they may find it hard to articulate or make their needs known. If this can be thought about proactively it can reduce additional unnecessary suffering. There may be assumptions that children should not attend funerals, but it is important to think about how to discuss these events and ways to include children in appropriate ways. Grandparents (older adults in families) can be a rich resource since they are most likely to have previously lived through a grief and can help children by normalising this as an event in life, witnessing survival and validating the difficult emotions. Older adults losing their grown up children face particular challenges of managing the sense of survivor guilt and “out of timing” for their predicted generational and family narrative |  |  |
| 126 | Association for Family Therapy and Systemic Practice UK | Support and training for GPs and other primary care professionals who might be supporting a dying individual to think about the wider family in terms of supports that might be needed. | End of life care is not always in hospices or specialist facilities. People may be dealing with end of life issues in their own homes, and may be supported by primary care and / or hospice at home professionals. The focus of care is often the individual person who is facing the end of their life, but they are linked with other people in the contexts of families and close relationships, and these needs do not end when the person dies. To think about and include wider family relationships is likely to make it easier for people to access further support, as needed. Times of grief and loss can also raise difficult previously masked or subsumed familial issues or disputes and disequilibrium. Helping grieving adults recognise and contain the effects of grief in their relating is important. GP’s etc also aware that somatisation may well occur in children and other adults as expression of grief and possibly association with the person being lost |  |  |
| 127 | Association for Family Therapy and Systemic Practice UK | Support and training for GPs and other primary care professionals around how children’s understanding of death to be able to support talking about this, and advising others to talk, in a developmentally appropriate way | Children’s understanding of death can be very different to that of adults and depends upon stage of development. If professionals who support the family have good knowledge of how death may be understood by children, then they will be more helpful and be less likely to compound difficulties by assuming a level of understanding which is not there, yet.  If children have cared for loved ones they may be knowledgeable and appear very mature and may need encouragement to consider their own grief and need |  |  |
| 128 | Association for Family Therapy and Systemic Practice UK | Additional developmental areas of emergent practice: Integrate systemic theories and systemic family therapists into clinical practice. This will enable services to enact the World Health Organisation’s definition of palliative care as encompassing the wider family and system | At present, much palliative care is still disease focused and targeted to individuals with the life-limiting condition. Yet, the WHO explicitly states that palliative and end of life care should encompass the wider system. At present therefore the health service system in England/Wales fails to deliver on this internationally recognised marker of quality care. Without incorporating the wider family network, there are considerable missed opportunities to a) support informal care provision b) reduce complex bereavement c) enact psychosocial care at end of life.  Unlike a birth plan, when it comes to dying, there are no do-overs.  It is important that we get this right every time, for every one. | RCTs of family therapy have demonstrated improvements for families most at risk of adverse outcomes in bereavement 7. | Systemic theories are applied in other areas of clinical work – e.g. in liaison psychiatry, child/adolescent mental health and so forth. They are also used in oncology  Grief is a family and relational issue 3.  The death of a friend can reverberate for up to four years impacting health and social outcomes 6.  Yet therapeutic conversations can improve outcomes for bereaved families 4 and family therapy specifically can increase communication at end of life 5.  References: 1. Lavallée JF, Grogan S, Austin CA. Cancer patients' family members' experiences of the information and support provided by healthcare professionals. Health Education Journal 2019; 78(4): 416-27. 2. Rauscher EA, Dean M, Campbell-Salome G, Barbour JB. "How do we rally around the one who was positive?" Familial uncertainty management in the context of men managing BRCA-related cancer risks. Social Science & Medicine 2019; 242: N.PAG-N.PAG. 3. Breen LJ, Szylit R, Gilbert KR, et al. Invitation to grief in the family context. Death Studies 2019; 43(3): 173-82. 4. Petursdottir AB, Svavarsdottir EK, Haraldsdottir E. The impact of implementing an educational intervention to enhance a family‐oriented approach in specialised palliative home care: A quasi‐experimental study. Scandinavian Journal of Caring Sciences 2019; 33(2): 342-50. 5. Zaider TI, Kissane DW, Schofield E, Li Y, Masterson M. Cancer-related communication during sessions of family therapy at the end of life. Psycho-Oncology 2020; 29(2): 373-80. 6. Liu W-M, Forbat L, Anderson K (2019) Death of a close friend: Short and long-term impacts on physical, psychological and social well-being. PLoS ONE 14(4): e0214838. https://doi.org/10.1371/journal.pone.0214838 7. Kissane, D. W., McKenzie, M., Block, S., Moskowitz, C., McKenzie, D. P., & O'Neill, I. (2006). Family Focused Grief Therapy: A Randomized, Controlled Trial in Palliative Care and Bereavement. The American Journal of Psychiatry, 163(7), 1208–1218. https://doi.org/10.1176/appi.ajp.163.7.1208 |
| 129 | SCM1 | Assessing carers needs 1.2.3 1.3.1. 1.3.2 | There are policy drivers for assessing carers needs. Care Act 5YFV Children’s and Families Act Carers strategy New models of Care and vanguards Commitment to Carers published 2014 | Carers are an essential component in enabling people to live and die at home. 80% people want to die at home 50% carers support this 5% feel that they have the skills N. Guberman (2006) | Development of a Carer Support Needs Assessment Tool (CSNAT) for End of Life care practice at home: A qualitative study. Gail Ewing and Gunn Grande Palliative medicine 27 (3) 244 – 256 Examining the perspectives of family members involved in the delivery of palliative care at home Journal of Palliative Care 19 (1) 27 -35 Family Caregiver Burden Dumont S Burden Scale (2008)  Journal of Palliative Care 24:3 151 – 161 Supporting carers in end of life care: an introductory programme for support workers and volunteers. Seymour et al. Nottingham University Supporting Adult Carers – NICE Guideline (NG150) |
| 130 | Multiple System Atrophy Trust | The families and carers of adults in the last days of life should be offered an assessment of their needs and the necessary support for them, including support for the care of the person who is dying, so that they are able to be present as family and close friends rather than providing physical care. | People with MSA and their carers report problems with the fast track assessments for NHS Continuing Healthcare, with delays and poor quality assessments. Covid-19 and problems around face to face assessments seem to have exacerbated this. In addition, there are often problems accessing the care and support services required as a result of a successful assessment. | https://www.parkinsons.org.uk/get-involved/continuing-healthcare-alliance https://www.msatrust.org.uk/wp-content/uploads/2020/02/MSA-TRUST-FORMER-CARERS-FULL-TECHNICAL-REPORT-FINAL.pdf 45% of people with MSA did not die where they wanted to |  |
| 131 | National Clinical Director for Palliative and End of Life Care | Supporting carers | Carers have a dual impact – they are part of the core care team and also facing bereavement as an individual. Their needs are often secondary to that of the patient. | There is evidence to demonstrate that although there is an increasing awareness of carers’ needs, this is still lagging behind. There appears to be more focus on information needs now, but less on addressing the whole person needs of the carers. |  |
| 132 | SCM2 | Ensure support (especially practical) is provided to carers/the people important to the person at end of life | By providing this support it will enable carers to manage better hence allowing person at end of life to continue to be cared for/die in their place of choice It will also reduce stress and illness of carers and improve the person at end of life experience | NG142 found that carers have better outcomes, such as maintaining quality of life and reduced carer burden, when supported.  It highlighted that some investment made be needed to facilitate this as experiences differ across settings. National Audit of Care at End of Life also highlighted inconsistencies in practical support provided for carers | NG142 – end of life adults – service delivery  National Audit Care at End of Life  NG31 – care of dying adult which showed some people experiences of dying could be improved |
| 133 | SCM4 | Supporting carers | Supporting carers and those important to the patient is key to enabling patients to die in their preferred place, reduce inappropriate hospital admissions and pressure on the NHS. As noted by the committee this should go further than strict statutory carers’ assessment to include respite, psychological support and the varied needs of different carer groups should be taken into account. | Carers are vital in providing support and taking the burden of care for patients. In Carers UK ‘State of Caring Survey’ 2019 key finding were: • Every day another 6,000 people take on a caring responsibility – that equals over 2 million people each year. • 58% of carers are women and 42% are men. • 1.3 million people provide over 50 hours of care per week. • Over 1 million people care for more than one person • As of 2019 there could be as many as 8.8 million adult carers in the UK. We need to develop key measures for success in carer support to identify effectiveness. | <https://www.carersuk.org/news-and-campaigns/press-releases/facts-and-figures> |
| 134 | SCM5 | Supporting carers | This area helps the person undertaking the assessment and planning the care identify whether there are carers, a significant number of people do not have any immediate carers. It will also identify the age and abilities of carers and different provisions need to be made for them as identified in the guidance | By supporting carers appropriately their long term health may benefit.  The information section also fits well in to this standard. It is often the carer who reads patient information and translates it appropriately for the person who is dying. |  |
| 135 | SCM6 | People managing and delivering services should think about what practical and emotional support can be provided to carers of adults approaching the end of their life and review this when needed[1]. | Carers have better outcomes, such as maintaining quality of life and reduced carer burden, when supported. | Differing localities and services have developed differing models of support, however there are likely to be significant gaps in provision. There may be scope for sharing good practice |  |
| 136 | Cruse Bereavement Care | Bereavement Care Having quality standards for bereavement care will also support care of the dying person for the following reasons:  (1) Contributing to their mental wellbeing, to know their loved ones will have the support they need after they have died, which may therefore be said to contribute towards them having a ‘good death’.  (2) Support those dying and bereaved, particularly in traumatic circumstances. | The impact of Covid-19, with multiple deaths and the inability for relatives/ friends to visit those who are dying, see the body of the person who has died after death, or hold/attend full funeral services is expected to have a long term impact on those who are nearing the end of their lives and on those who are bereaved, with an anticipated rise in complicated grief.  With an average of 6 people suffering intense grief as a result of a traumatic death, there is a need to ensure that the holistic support for the person who is dying and the important people in their lives includes bereavement care provision. Deaths from Covid-19 are considered traumatic given the situations in which people are dying and the wider contextual situation in which people are grieving | Bringing about a good death for the person who is dying will also benefit their carers (Kreicbergs et al 2005, McCarthy et al 2010, van der Geest et al 2014, Jalmsell et al 2010, Wright et al 2008) Whilst this references suicide, it highlights special attention needed by people bereaved traumatically (Helping people bereaved by suicide: Their needs may require special attention, Keith Hawton, Sue Simkin, BMJ. 2003 July 26; 327(7408): 177–178). |  |
| 137 | Dementia UK | Grief, bereavement and loss during and post the COVID-19 period for those living with dementia. | COVID-19 has had an impact on the experience of grief, bereavement and loss e.g. anticipatory, disenfranchised, complicated and pre-loss grief. This has been exacerbated for people with dementia and their families due to social distancing and visitor restriction requirements. Many documents highlight that the restriction of visits can be lifted for dying residents (although strict criteria apply) but fail to provide guidance on supporting family, especially regarding bereavement—although measures, such as physical distancing, might negatively impact the grieving process (Wallace et al 2020 | Social distancing and visitor restrictions policies and practices, have complicated issues of grief (Wallace et al 2020). Older adults and those with multimorbidities might be particularly affected by issues including isolation, loneliness, end of life care, and bereavement, which may be exacerbated by the so-called digital divide (Holmes et al 2020) Some grief processes are novel related to social distancing/isolation, uncertainty/self-blame related to infection, and inability to implement usual burials/funerals (Wallace et al 2020). Others are typically experienced near end of life but are occurring on an unprecedented scale that has the potential to have devastating individual/societal effects in the short and long term (Wallace et al 2020). | Holmes, E.A., O'Connor, R.C., Perry, V.H., Tracey, I., Wessely, S., Arseneault, L., Ballard, C., Christensen, H., Silver, R.C., Everall, I. and Ford, T., 2020. Multidisciplinary research priorities for the COVID-19 pandemic: a call for action for mental health science. The Lancet Psychiatry.  Wallace, C.L., Wladkowski, S.P., Gibson, A. and White, P., 2020. Grief during the COVID-19 pandemic: considerations for palliative care providers. Journal of Pain and Symptom Management. |
| 138 | Faculty of Intensive Care Medicine | Issues related to COVID19 - Family isolation during the dying process (at best one named family member in PPE) is likely to increase the incidence of Complicated Grief |  |  |  |
| 139 | Faculty of Intensive Care Medicine | Issues related to COVID19 -Additional support in the community and educational establishments for the bereaved |  |  |  |
| 140 | Royal College of Nursing | Bereavement support | Bereavement care and support | There appears to be a disjointed approach to bereavement support across all settings, with pockets of high-quality support . This should be the norm not the exception | SWAN model of care ( Manchester – now being adopted in other regions) https://www.pat.nhs.uk/patients-and-visitors/swan-model-of-care.htm  Similar models are being used in Barts Health  Dandelion Bereavement model in Basildon & Thurrock University Hospital Trust |
| 141 | University College London Hospitals NHS Foundation Trust | Staff support | The psychological impact on staff caring for severely unwell patients with COVID-19, and the increased burden of dying patients, was recognised, especially for those who are not experienced in caring for patients at the end of their lives. | Though the well-being of individuals who are dying and their families is recognised (‘End of Life Care Core Skills Education and Training Framework’ (2017)), the well-being of staff is often overlooked. During COVID-19, staff well-being came to the forefront (‘The Psychological Needs of Healthcare Staff as a Result of the Coronavirus Pandemic’, British Psychological Society (2020)), ensuring organisations support staff mental health and anticipate psychological reactions over time. | The TEOLCT worked closely with the Clinical Psychology and staff well-being teams to facilitate regular staff support sessions within the trust. A rota covering all the COVID-19 wards provided staff drop-in sessions for open discussions. Some themes which emerged from these sessions included staff difficulty adjusting to lockdown, their fears of contracting the virus and infecting family members, witnessing high death numbers (secondary trauma) particularly in context of restricted visiting and rapid deterioration, and some grieving for family, friends or colleagues who had died from COVID-19. The feedback for the sessions was positive and we are working to continue supporting those clinical areas with an ongoing need. |
| 142 | University College London Hospitals NHS Foundation Trust | Bereavement support and follow-up | As detailed above, COVID-19 and restricted visiting presented challenges in providing bereavement support for families and friends on dying patients. | Evidence highlights that families of those who died from COVID-19 are at risk of prolonged grief disorder, post-traumatic stress, and other poor bereavement outcomes (Selman et al. Journal of Pain and Symptom Management, 2020). Therefore, they are in need of support during and following the death of a patient. | Working closely with the Specialist Palliative Care team (and using their model for bereavement support and follow-up) and parent teams of hospitalised patients, we have provided bereavement follow-up for all patients who have died since that nationwide lockdown (23rd March 2020). The next of kin are called and offered condolences, provided an opportunity to discuss their deceased relative’s care, and offered signposting to bereavement services. As these calls do not have a set agenda, they are adaptable to need of the person being contacted. Feedback has been overwhelmingly positive, with family members feeling recognised and supported. |
| **Additional areas** | | | | | |
| 143 | Hospice UK | Holistic Support /Evidence-Based Co-Design | Strengthening the role that people’s experience of care has is vital, and has been shown to deliver considerable benefits to service improvement. | There is an opportunity to further strengthen co-design, for example by encouraging shadowing and similar initiatives that aim to give a voice to patient journeys to improve the individual experience of the person, carer, relative or friend. |  |
| 144 | Kidney Care UK | Shared decision making – explaining options, giving information in a timely way, supporting people to make fully informed decision. In the case of kidney care and end of life care, decisions regarding whether to start or to continue dialysis. | The importance of shared decision making is highlighted in NICE end of life care and kidney care guidance. The population of people with end stage kidney disease is ageing and decisions about whether dialysis is appropriate are particularly important, given uncertainty about the balance of benefit over burden. | Research has found access to and awareness of conservative management for older adults varies nationally, and depends partly on the degree to which conservative management is an  established pathway within each unit. Bristowe K, et al Ann Palliat Med, 2019;8(2):121-129 The Kidney Patient Reported Experience of Kidney Care in the UK 2019 received responses from 16,469 from 70 adult renal units across the UK. It found ‘sharing decision about your care’ was the second lowest rated area of kidney care. This has been among the lowest rated area for all three years that the survey has been running (2017-2019). | Kidney Patient Reported Experience of Kidney Care www.renalreg.org/projects/prem Renal Registry www.renalreg.org |
| 145 | Royal College of General Practitioners | End of Life conversations - a willingness to discuss death and dying in an open way with the patient and those important to them | “Networks of support of family, friends, neighbours and community members, are the foundation of what matters most to those undergoing experiences of death, dying, loss and care giving. This is as true for the person with the illness as it is for those who make up the caring network. These experiences are not the sole domain cared for by professional health and social care services. They are social and cultural, involving all of us and are part of our cultural heritages” https://www.compassionate-communitiesuk.co.uk |  |  |
| 146 | Association of British Neurologists, Quality Committee | Access to visitors on hospital sites | Palliative care for non-Covid-19 neurological care suffered during the pandemic surge. | Dying patients and their families were denied meeting one another in the final days of life. | Media recognition of this apparent cruelty. |
| 147 | Society for Acute Medicine | Embedded mandatory training for multidisciplinary team members to talk about end of life concepts | Clear and well-informed communication is critical to allowing patients/families/those important to them to understand the concepts and issues when approaching the end of life. There is no system for communication in place and is not part of mandatory training for healthcare professionals - yet every healthcare professional is expected, at some point, to care for people who are nearing the end of their life. | Poor communication - through avoidance or unclear information - is a key driver for complaints and dissatisfaction in end of life care. Often non-doctor healthcare professionals are better placed to initiate conversations around death and dying and feel inhibited to do so. Particularly pertinent to the COVID-19 response was the drive to telephone patients to discuss resuscitation decisions somewhat “out of the blue” highlighting the anxiety faced by healthcare professionals when not prepared for conversations and the impact that has on patients. | Communication from GPs during COVID: https://www.hsj.co.uk/primary-care/gps-contacting-patients-about-do-not-resuscitate-forms/7027279.article End of life care as everyone’s business: https://www.rcplondon.ac.uk/news/end-life-care-can-it-be-everyones-business https://journals.rcni.com/cancer-nursing-practice/end-of-life-care-is-everyones-business-cnp.16.2.41.s22 |
| 148 | Motor Neurone Disease Association | Anticipatory medication to be prescribed for at home to patients with MND | Suitable anticipatory medicines and routes should be prescribed as early as possible so that the person has them available to manage symptoms likely to occur during their last days of life. | MND can involve rapid progression and it is essential to think ahead and plan for symptom management across the pathway, including end of life care. Have a process in place to ensure that suitable anticipatory medicines and routes are prescribed as early as possible. Review these medicines as the person's needs change. | https://www.mndassociation.org/professionals/management-of-mnd/management-by-symptoms/palliative-and-end-of-life-care/ Guidance for professionals: MND care at end of life https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/condition-specific-short-guides/motor-neurone-disease https://static.mndassociation.org/app/uploads/2017/05/19135954/end-of-life-guide.pdf |
| 149 | Multiple System Atrophy Trust | Adults with progressive disease such as Multiple System Atrophy who are likely to require medication to ease symptoms and distress at the end of life should have early discussions about anticipatory medication, for use at the end of life, with individualised indications for use, dosage and route of administration. | End of life care for people with MSA often turns into a crisis for them and their carers so early anticipatory planning is needed to avert this. |  |  |
| 150 | University College London Hospitals NHS Foundation Trust | Communicating with families of dying patients | Due to national hospital visiting restrictions and shielding measures imposed during COVID-19, frequently family of those who were dying could not attend. Often, wards were too busy to proactively call next of kin to keep them updated. However, families and friends were reliant on calls from the ward to update them on the progress of the patient. | The trust disseminated the visiting policies, reflecting the NHS England and NHS Improvement ‘Visiting Guidance’ (2020), enforcing a no visiting policy, except for exceptional circumstances, including a patient in the last days of life. Ensuring family and friends of the dying person were aware that the person was dying and understand the focus of care was imperative, especially when the dying person was not able to engage in conversations themselves. In some clinical areas, staff found not having their patient’s family with them when they were dying difficult and even dehumanising. | During our staff training sessions, we ensured staff were mindful of calling family and friends of their patients. Training included having difficult conversations over the phone. A guidance document was disseminated across the trust detailing good practice in communicating with next of kin, including information following a death.  Video calls were used to facilitate virtual visits. Family members may have made audio/ video recordings of these visits when the patient lacked mental capacity to provide consent. A trust-wide policy was issued with guidance on how to decide whether such recordings would be in the best interests of the patient and how staff may be protected in such circumstances.  Communicating with family members was often time consuming, and therefore, additional dedicated staffing was required to manage the need. It was important that these staff members received appropriate training and support to carry out their role. |
| 151 | University College London Hospitals NHS Foundation Trust | Symptom control and guidance on withdrawal of non-invasive ventilation | Those dying due to COVID-19 experienced a variety of symptoms, often more severe and rapidly than seen previously. The Northern Care Alliance NHS Group and the Association for Palliative Medicine of Great Britain and Ireland (APM) produced the ‘COVID-19 and Palliative, End of Life and Bereavement Care in Secondary Care’ (2020) guidance which detailed the symptoms patients were experiencing in the last days of life and best practice for managing symptoms. | Though clinical guidance was available for symptomatic management of patients with COVID-19 in the last days of life, often the clinical picture varied. Therefore, the trust leads developed clinical guidance, based on the trust’s experience, in line with the APM guidance and provided guidance for patients having non-invasive ventilation (such as continuous positive airway pressure (CPAP)), especially as staff caring for these patients were often not experienced in providing this level of care. | It became clear that patients with COVID-19 could deteriorate rapidly, and therefore ensuring they were comfortable at the end of their lives required early intervention with continuous subcutaneous infusions of end of life care medications (i.e. opiates for breathlessness and pain, benzodiazepines for terminal agitation), and administrating larger doses of anticipatory medications than what clinicians were used to prescribing or giving. Therefore, staff training highlighted these principles whilst we supported medical prescribing and nursing administration on the wards. In collaboration with other clinical teams, we created trust-wide guidance for symptom control at the end of life, including for those patients who were being weaned off CPAP prior to death. |
| 152 | Compassion in Dying | Clarity that decision-making pathways depend on whether or not the patient has capacity to make decisions about their end-of-life care. | To ensure person-centred decision-making, health and care professionals must have clear protocols to follow based on whether or not the patient can consent to and/or refuse treatment. | Our experience from supporting 56,000 people to plan ahead and receive the end-of-life care that is right for them has demonstrated that the quality of capacity assessments and the subsequent actions taken need urgent improvement.  Priority areas for improvement include professionals understanding the legal framework of the Mental Capacity Act 2005 particularly: - The presumption of capacity  - People having the right to make decisions that others might regard as unwise or eccentric - When and how best interests decisions should be made Our Freedom of Information request completed by all CCGs in 2018 highlights areas needing urgent improvement, set out in our report: - “The GP thought that my Advance Decision meant I did not want any further treatment as of now! I explained that it was a refusal of treatment for when I lost capacity to make decisions myself.” - “My GP said not to bother doing an Advance Decision, it is not legally binding” - “My GP told me that I can only have an Advance Decision if I had a pre-existing  - condition like cancer” - 87% of CCGs (180 out of 207) provide information to GP practices on advance care planning. However, not all CCGs consistently and explicitly covered the topics of Advance Decisions, Lasting Powers of Attorney and Do Not Attempt Resuscitation orders. | The recent Royal College of Physicians’ guidance on CANH and PDOC provide very useful information on person-centred care that can be replicated and/or adapted for this purpose |
| 153 | Royal College of Speech and Language Therapists | Being clear of mental capacity of the patient. | This is important in these circumstances in order to assure informed consent is given the different interventions. Assessing mental capacity of a severely ill patient may have communication difficulties should be done with the assistance of someone specifically trained /informed |  |  |
| 154 | Motor Neurone Disease Association | Patients with MND, carers & families given information and advice on legal rights and support services. | Ensure people are provided with information about MND and support at diagnosis or when they ask for it to support them as their condition deteriorates. | In 2019, only 48% of people with MND had the chance to discuss end of life care issues according to the MND Association Improving Care Survey. It is important to have a local directory of services and support available which enables ease of signposting or referral for people with MND to the services they may find useful, including the MND Association / helpline.  MND progresses rapidly in many cases and so these conversations should begin as early as possible. | Please see the NHS Rightcare Progressive Neurological Conditions Toolkit: https://www.england.nhs.uk/rightcare/wp-content/uploads/sites/40/2019/08/progressive-neuro-toolkit.pdf https://www.mndassociation.org/professionals/management-of-mnd/management-by-symptoms/palliative-and-end-of-life-care/  https://www.mndassociation.org/improving-mnd-care-survey-2019/ |
| 155 | Royal College of General Practitioners | End of life care for children and young adults. Provision of community and hospice services | End of life care does not just relate to those of advancing years. Children and young people must be given access to the best community and hospice care. |  |  |
| 156 | Royal College of Nursing | End of Life Care for people with cognitive impairment : aligned to the ambitions for end of life care | People with a cognitive impairment may be disadvantaged when accessing high quality end of life care:  Impairment of cognition can be the result of a multitude of diseases and disabilities | Evidence suggests people with a cognitive impairment may be disadvantaged when accessing end of life care. This includes accessing care across the range of settings from home, care homes and secondary care. | https://www.cqc.org.uk/sites/default/files/20160505 CQC\_EOLC...  https://www.ndti.org.uk/uploads/files/RA-End\_of\_Life.pdf  https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/equality-diversity/learning-disability  https://spcare.bmj.com/content/8/Suppl\_1/A42.3  https://www.alzheimers.org.uk/get-support/help-dementia-care/end-life-care |
| 157 | SCM7 | Developmental areas | The COVID-19 crisis has shown that people from certain minority ethnic groups are at higher risk of virus related illness and death. Other evidence shows further risks to specific ethnic groups, eg people with sickle cell disease, diabetes. There needs to be better monitoring of how these groups are being screened and care for. |  |  |
| 158 | SCM7 | Developmental areas | Need to document better the care given to people with learning disabilities who are entering EOL. This applies to children, TYA and those entering transition to adult care, as well as to older people. There is very good evidence that outcomes are poorer (higher death rates) for such people, and there is guidance but it is not followed. |  |  |
| 159 | The British Pain Society | Additional areas of emergent practice | Need to document better the care given to people with learning disabilities who are entering EOL. This applies to children, TYA and those entering transition to adult care, as well as to older people. There is very good evidence that outcomes are poorer (higher death rates) for such people, and there is guidance but it is not followed. |  |  |
| 160 | The British Pain Society | Additional areas of emergent practice | The COVID-19 crisis has shown that people from certain minority ethnic groups are at higher risk of virus related illness and death. Other evidence shows further risks to specific ethnic groups, eg people with sickle cell disease, diabetes. There needs to be better monitoring of how these groups are being screened and care for. |  |  |
| 161 | British Geriatric Society | Reablement/rehabilitation involving the community networks in which people live their and die overtime | The provision of strength based exercises- not available on the NHS- Allied Health Professional’s vital |  |  |
| 162 | Motor Neurone Disease Association | Access to continuing health care (CHC) | Access to CHC is an essential component of end of life support for many people, but this aspect is often overlooked. | In 2019, 35% of people with MND had problems with the Continuing Health Care application process. Frequently the eligibility assessment process (including end of life fast track) is difficult and problematic, and CHC funding is often not sufficient to meet assessed needs. | https://www.mndassociation.org/improving-mnd-care-survey-2019/ Continuing to Care, CHC Alliance 2016 https://static.mndassociation.org/app/uploads/2016/11/19135429/continuing-to-care-report.pdf https://www.nao.org.uk/report/nhs-continuing-healthcare-investigation/ |
| 163 | Royal College of Physicians (RCP) | Simplifying access to DS1500 and fast track funding | Equitable access to funding and care is essential to allow patients at the end of life live well until they die | DS1500 funding requires a declaration that the person may die in the next six months which denies access to many in need. Fast track funding at the end of life should enable trusted assessors in the acute and community sectors to identiy eligible patients. The current system is inconsistent and inequitable within and across health economies. | <https://www.mariecurie.org.uk/globalassets/media/documents/policy/appg/all-party-parliamentary-group-for-terminal-illness-report-2019.pdf> |
| 164 | False Allegations Support Organisation | Development plan |  |  |  |
| 165 | SCM3 | OACC suite of Measures – implementation | How do services know that they are making a difference? To use information to improve patient care by evaluating | Evaluations in the EOL area have always been limited. To set the standards of care we need appropriate tools to measure QoL outcomes and evidence the most effective models of care. How are we doing and what is working? | Kings College London – OACCs  Ehospice – OACC outcomes measures |
| 166 | Dementia UK | The impact of Personal Protective Equipment (PPE) on EoLC in all settings for people living with dementia and their care partners | PPE impacts upon people living with dementia in a variety of ways including understanding and remembering the necessity to wear it themselves, challenges of communication when health and social care staff are wearing PPE as well as physical interactions are through and/or restricted by PPE. | Wearing personal protective equipment can impact communication in healthcare environment (Hampton et al 2019) and there is evidence of its negative impact on end of life conversations (Selman et al 2020). For people living with dementia there is also evidence of the importance of therapeutic touch (Turner 2020). We need to urgently understand the impact of PPE on the experience of people living and dying with dementia. | Hampton, T., Crunkhorn, R., Lowe, N., Bhat, J., Hogg, E., Afifi, W., De, S., Street, I., Sharma, R., Krishnan, M. and Clarke, R., 2020. The negative impact of wearing personal protective equipment on communication during coronavirus disease 2019. The Journal of Laryngology & Otology, pp.1-11. Selman, L.E., Chao, D., Sowden, R., Marshall, S., Chamberlain, C. and Koffman, J., 2020. Bereavement support on the frontline of COVID-19: Recommendations for hospital clinicians. Journal of Pain and Symptom Management. Turner, T., 2020. Dementia care: an overview of available non-pharmacological therapies. Evaluation, 15, p.13. |
| 167 | Dementia UK | Palliative care, dementia, care homes and COVID-19 | COVID-19 mortality disproportionally affects nursing homes, where a significant number of residents live with dementia. There is a dearth of comprehensive international COVID-19 guidance on palliative care for nursing homes and for those living and dying with dementia from or at a time of COVID-19. | Most COVID-19 guidance on palliative care for nursing homes has a limited focus both regarding breadth of topics and recommendations made (Gillissen et al 2020). Furthermore, nonphysical (psychological, social, or spiritual) needs are hardly addressed and attention to dementia was limited to “wandering” residents (Gillissen et al 2020).The number of people dying in care homes trebled during the first 10 weeks of the COVID-19 pandemic in England and Wales; many of these deaths were ‘additional deaths’, that is associated with the COVID-19 pandemic but not directly as a result of COVID-19: integrated models of palliative care in care homes are urgently needed (Bone et al 2020) | Bone, A.E., Finucane, A.M., Leniz, J., Higginson, I.J. and Sleeman, K.E., 2020. Changing patterns of mortality during the COVID-19 pandemic: population-based modelling to understand palliative care implications. medRxiv.  Joni, Gilissen, Pivodic Lara, and T. Unroe Kathleen. "International COVID-19 palliative care guidance for nursing homes leaves key themes unaddressed." Journal of Pain and Symptom Management (2020). |
| 168 | Dementia UK | COVID-19 legacy on people with dementia living and dying well in care homes  (consequences of lockdown and social distancing) | Person centred care is a key requirement of end of life care and support for people living with dementia and their carers’ at and after COVID-19 is needed urgently. There is emerging evidence of the wide ranging negative impact of COVID-19 social distancing and lockdown requirements on care home residents with dementia (and their family carers) living and dying in care homes e.g. 1. disproportionately affected with atypical presentations 2. focus on biomedical vulnerability 3. loss of autonomy, challenge to human rights and shared decision making 4. risk assessment and management | Care home residents are disproportionately affected with atypical presentations, as well as restrictions of movement and subsequent loss of autonomy (Gordon et al 2020). Visiting restrictions place an enormous toll on people with dementia who are isolated, socially disconnected, and do not understand COVID-imposed restrictions (Lapid 2020). There is a need to balance risk - for example doing or not doing something may each have associated risks but it is about the right to choose. For example, during COVID-19 the family and the person may decide to maintain physical contact/visiting yet understand the risk this may impose to themselves. Often “there are no visiting relatives to provide companionship, reassurance, or help to relieve the strain. There are arguments that family carers are an invisible workforce (Phillips et al 2020). However, family carers are an integral part of the care system and when removed from that, the essential care and wellbeing of the individual suffers (One Voice 2020). Residents deprived of usual interaction with family and friends can become bewildered and depressed (Oliver 2020). Older persons face higher infection and mortality rates, ageism in public discourse, age discrimination in health care and triage decisions, neglect and domestic abuse at home, isolation without access to essential services, and greater exposure and poor treatment in care institutions (UN 2020). The COVID-19 pandemic in itself threatens the enjoyment of human rights, most prominently the right to life and the right to health. It also highlights how human rights are interdependent while at the same time reflecting competing interests that are sometimes hard to reconcile. Much of the COVID-19 discourse has been concerned with the biological vulnerability of specific groups of people and the distribution of resources such as ventilators, rather than the myriad of human rights issues especially for those in residential care (Peisah et al 2020). | Gordon, A.L., Goodman, C., Achterberg, W., Barker, R.O., Burns, E., Hanratty, B., Martin, F.C., Meyer, J., O’Neill, D., Schols, J. and Spilsbury, K., 2020. Commentary: COVID in care homes—challenges and dilemmas in healthcare delivery. Age and Ageing.  Lapid, M.I., Koopmans, R., Sampson, E.L., Van den Block, L. and Peisah, C., 2020. Providing quality end-of-life care to older people in the era of COVID-19: perspectives from five countries. International Psychogeriatrics, pp.1-8.  Oliver, D., 2020. David Oliver: Let’s not forget care homes when covid-19 is over. BMJ, 369.  One Dementia Voice (9th July 2020) An open letter to the Government - allow family carers key worker status  https://www.alzheimers.org.uk/news/2020-07-09/open-letter-secretary-state  Peisah, C., Byrnes, A., Doron, I.I., Dark, M. and Quinn, G., 2020. Advocacy for the human rights of older people in the COVID pandemic and beyond: a call to mental health professionals. International Psychogeriatrics, pp.1-13.  Phillips, D., Paul, G., Fahy, M., Dowling-Hetherington, L., Kroll, T., Moloney, B., Duffy, C., Fealy, G. and Lafferty, A., 2020. The invisible workforce during the COVID-19 pandemic: Family carers at the frontline. HRB Open Research, 3(24), p.24.  Spadaro, A., 2020. COVID-19: Testing the Limits of Human Rights. European Journal of Risk Regulation, pp.1-9.  United Nations (April 2020) COVID-19 and Human Rights We are all in this together (Click here)  Wang, H., Li, T., Barbarino, P., Gauthier, S., Brodaty, H., Molinuevo, J.L., Xie, H., Sun, Y., Yu, E., Tang, Y. and Weidner, W., 2020. Dementia care during COVID-19. The Lancet, 395(10231), pp.1190-1191. |
| 169 | Faculty of Intensive Care Medicine | Issues related to COVID19 - impersonal nature of telemedicine although paradoxically there is some (anecdotal) qualitative evidence to suggest that receiving bad news (albeit via video) in a home environment provided some comfort |  |  |  |
| 170 | National Care Association | COVID – 19 related death and rehabilitation. | There is no directive or recommendations on good practice relating this condition. Rehabilitation should be considered at all stages of this disease progression when symptoms present (The nation is fearful of the death process due to unaccompanied (family) support during the disease and at the last hours minutes of death). | National and statistics on deaths due to Pandemic/endemic status. Limited and poorly managed resources for rehabilitation within community settings i.e. nursing and residential homes. | Initial and continuing information overload leads to poor practice. PHE are allegedly the only point of information contact at his time which should improve communication and prevent confusion. NHS is a acute institution and works differently to Social Care in many ways due to psycho-social aspects. Guidance should be provided to direct good practice in the NHS a swell as Nursing Homes Residential Care Homes and LD Homes and not limited to the NHS practices only. Currently no published research to guide or direct good practice. NICE Guidance limited due to lack of published research. |
| 171 | NHS Blood and Transplant | Communicating with families remotely to discuss end of life care | The covid-19 pandemic highlighted the many challenges facing caregivers and families when face to face communication is not possible or severely restricted. This is particularly true when discussing poor prognosis, end of life care and related issues like organ donation. | Very little evidence at present as most is anecdotal and hearsay and many individual trusts developed their own strategies. Remote communication has great potential to improve communication in difficult situations and end of life care not just in pandemics. Some good practice guidance in this area would be beneficial |  |
| 172 | SCM7 | Developmental areas | Use of online tools for patient assessment and offering bedside advice, care and support. This has been highlighted by the COVID-19 crisis, where patients were isolated and were not being seen and cared for sufficiently, especially in community and care homes. |  |  |
| 173 | The British Pain Society | Additional areas of emergent practice | Use of online tools for patient assessment and offering bedside advice, care and support. This has been highlighted by the COVID-19 crisis, where patients were isolated and were not being seen and cared for sufficiently, especially in community and care homes. |  |  |
| 174 | Faculty of Intensive Care Medicine | Issues related to COVID19 - Support for staff and the risk of burn-out especially if no clear treatments plans and poor communication of uncertainty |  |  |  |
| 175 | SCM9 | Health and social care organisations should consider their role as compassionate organisations, reviewing their policies for staff support, including bereavement leave, and ensuring a member of the senior leadership team with responsibility for palliative and end of life care | This is a key area for consideration now as we enter the next phases of the covid pandemic, and health and social care staff experience fatigue and exhaustion | Improving palliative and end of life care for all will require fundamental culture shift across the healthcare service and social care systems. A quality standard that supported commissioners to hold organisations to account for structure and process that enable compassion would be helpful – nominated senior leaders, time and space for staff dealing with death and dying and robust bereavement policies are all worth considering | This aligns with some of the recommendations from the National Audit of Care at the End of Life (NACEL) audit  https://www.nhsbenchmarking.nhs.uk/nacel Daffodil Standard 8 outlines how organisations can become Compassionate Organisations and the role of general practice as a hub in a compassionate community https://www.rcgp.org.uk/clinical-and-research/resources/a-to-z-clinical-resources/daffodil-standards/the-daffodil-standards/standard-8-general-practice-being-hubs-within-compassionate-communities.aspx |
| 176 | The GSF Centre CIC | Key area for quality improvement 5 Enhancing wellbeing and resilience of staff , as well as that for patients and their carers/ families. | Enhancing staff resilience and selfcare became even more apparent and obvious especially during COVID crisis , and particularly in social care. | Staff wellbeing , self-care and compassion has always been important , and is included as part of GSF training and accreditation of all sectors. But the COVID pandemic has emphasised the importance of this, in maintaining mental health and wellbeing of staff across all sectors , and most importantly in care homes, where some have felt abandoned and unsupported . Some care homes staff have moved in to reduce the chance of spreading infection in the community, several for long periods of time. Many have developed their own QI solutions an shared good practice , but many others are grateful for more support from external supporters , facilitators , chaplains and others .  More should be included in this , in addition to psychological and emotional wellbeing of patients/people . .  A particular issue for families has been isolation and lack of visiting leading to complicated bereavement . | Our COVID experience relates to feedback from about 50+ care homes taking part in our GSF Support Calls for Care Homes run during the pandemic.  See GSF COVID 19 Support Calls - 3 weekly zoom calls , interaction, feedback powerpoints and supportive resources https://www.goldstandardsframework.org.uk/care-homes-covid-19-support-information-  British Psychological Society Covid 19 Staff wellbeing Group -The Psychological needs of healthcare staff as a result of the Coronavirus Pandemic   Get your Mind Plan NHSE https://www.goldstandardsframework.org.uk/cd-content/uploads/files/COVID-19/Psychological%20needs%20of%20healthcare%20staff.pdf https://www.goldstandardsframework.org.uk/cd-content/uploads/files/COVID-19/Psychological%20needs%20of%20healthcare%20staff.pdf Reflective debriefing tool – Hockley et al including Covid Support Reflective tool available on https://www.goldstandardsframework.org.uk/care-homes-covid-19-support-information |
| 177 | University College London Hospitals NHS Foundation Trust | Staff training | During COVID-19, redeployed staff were from a variety of clinical backgrounds with little or no training/ exposure to end of life care (i.e. outpatient department nurses, ophthalmology surgeons, dental clinicians). Therefore, redeployed staff were anxious about caring for dying patients. They required early training and support to quickly establish skills and build confidence. | Following the recommendations of the National Palliative and End of Life Care Partnership’s ‘Ambitions for Palliative and End of Life Care: A National Framework for Local Action 2015-2020’ and Health Education England’s ‘End of Life Care Core Skills Education and Training Framework’ (2017), all staff should have end of life care training depending on their level of exposure to dying patients in their role. However, redeployed staff were asked to work outside of their usual area of expertise and all needed a good standard of end of life care training to meet the complex needs of patients with COVID-19. | The Transforming End of Life Care team (TEOLCT) provided formal training through live-lectures and webinars which were available on the trust intranet. Ad hoc teaching for nursing staff covering the expanding number of COVID-19 wards, and one-to-one support was also provided. We signposted online learning resources to access up-to-date evidence and guidance. Frequently requested teaching topics included: • Difficult conversations (via telephone) • Cardio-pulmonary resuscitation (CPR)/ Treatment escalation planning (TEP) legal perspective and conversations • COVID-19 specific symptom control • Care of the dying patient • COVID-19 after death care • Self-care and well being |
| 178 | University of Essex | Helping health care staff to deal with moral distress | Moral distress is a painful feeling which arises when a person believes they know the right thing to do but feels hindered from doing it or feels involved in a wrong they cannot prevent. The shortages due to the COVID-19 crisis (e.g. of personal protective equipment, of medical equipment, of testing) have generated unprecedented levels of moral distress, in particular in relation to end-of-life care. This needs addressing urgently to prevent an increase in burnout and dropout rates in healthcare staff. | An IPPR/YouGov poll indicates that the COVID-19 crisis has made over one in five UK healthcare workers more likely to quit their role after the pandemic. A growing body of testimony attests that this is not simply due to stress or exhaustion but to a specific, moral form of distress first identified in US nursing studies in the 1980s: moral distress. In the context of end-of-life care, moral distress amongst staff was intensified by a number of factors, including: a) the inability to ensure that dying patients could be with their family, b) conversely, being unable to provide appropriate access to dying patients for their families; c) the wearing of PPE (when available) and the impossibility of making physical contact with patients, which both greatly hindered communication; d) concerns about potentially being a danger to patients due to the unavailability of PPE; e) short-staffing due to illness amongst staff.  See for example the following testimonies: https://www.theguardian.com/society/2020/jul/17/lambs-led-slaughter-life-inside-care-home-covid-19 https://www.theguardian.com/society/2020/jul/09/treating-dying-people-hospices-covid-19-breaking | See for example this report: ‘Care Fit for Carers: Ensuring the Safety and Well-Being of Carers During and After the Covid 19 Healthcare Crisis’.  https://www.ippr.org/research/publications/care-fit-for-carers For possible recommendations to alleviate moral distress, see for example: ‘Moral Distress Amongst Health Care Workers: Ethics Support is a Crucial Part of the Puzzle’, 23 June 2020, British Medical Journal: ‘https://blogs.bmj.com/bmj/2020/06/23/moral-distress-among-healthcare-workers-ethics-support-is-a-crucial-part-of-the-puzzle/ Recommendations See also: ‘Healthcare Professionals’ Moral Distress in Adult Palliative Care: A Systematic Review’ (2019), British Medical Journal, https://spcare.bmj.com/content/9/3/245 |
| **General** | | | | | |
| 179 | Compassion in Dying | General | Overall comment – The importance of reflecting patient voices Compassion in Dying strongly recommends that any guidance on end-of-life care must necessarily reflect and address the real concerns people have about their end-of-life care. For example, some of the questions we get asked on our free information line which supports people to plan for the end of life include: “I have Lasting Power of Attorney for Health and Welfare for my father, why are the doctors not listening to me?” “How do I make sure 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?” “I found a DNACPR form on my mother’s notes, what does that mean?” Our report - “I wish I had known…”- https://compassionindying.org.uk/library/i-wish-i-had-known/ (2018) outlines four key themes in terms of what our service users tell us they need from healthcare professionals:  • Conversations about the end of life  • Honest information so they can make informed decisions  • Recognition that priorities can differ • Support to plan before they reach the end of life  The 2019 YouGov research with people living with terminal and advanced illness found: • Over half (58%) disagreed that death and dying was a taboo subject for them. • Despite this, fewer than one in five (16%) said they have had a discussion with their doctor about what might happen as their condition progresses, particularly at the end of life. • Respondents associated a ‘good death’ with being pain-free, but around two-thirds (64%) felt they did not have enough information and support to achieve a ‘good death’. Paying attention to such findings will ensure that the Quality Standard reflects the realities faced by patients and supports the delivery of genuinely patient-centred care at the end of life. The importance of reflecting on patient experiences is highlighted in this article - https://www.careopinion.org.uk/blogposts/654/stories-the-original-data-for-improvement and Compassion in Dying would be delighted to share our learning with you as you progress this work. |  |  |
| 180 | False Allegations Support Organisation | Addressing Prison health care and access in: 1. compliance with NHS standards 2. the prisoners’ rights to regulated NHS facilities 3. access to end of life care in voluntary organisations | There is no legislation written for the prisoner held in the prison estate. | Varying Prison and Probation reports under the Health care report - dealing with health care. Normally produced at time of death of a prisoner. |  |
| 181 | Royal College of General Practitioners | General | The RCGP, in collaboration with Marie Curie, has developed the Daffodil standards. We recommend these be reviewed by NICE to quality improvement in this area | <https://www.rcgp.org.uk/clinical-and-research/resources/a-to-z-clinical-resources/daffodil-standards/quality-improvement-criteria-guidance.aspx> |  |
| 182 | Royal College of Physicians (RCP) | General | The RCP is grateful for the opportunity to respond to the above consultation. We have liaised with our JSC for Palliative Medicine and would like to make the following comments. |  |  |
| 183 | SCM5 | Development areas/emerging practice | I feel that there will be a lot of learning to come from the current management of Covid19. It may open up discussion of dying and death especially by and for those with comorbidities which is the group mostly covered by this guidance. |  |  |
| 184 | Trinity Hospice Blackpool | Improved recognition and reflection in national guidance that individualised patient centred care at end of life should never be standardised and that variation in practice is both desirable and optimal given the heterogeneous nature of the illnesses and patient priorities. | Patient choice at end of life has been recognised as vital in all relevant guidance from the last decade. Best described in More Care, less pathway and One chance to get it right. Patient choice has been described as affecting preferred place of care and death and other important aspects of care such as ceilings of treatment. However it also effects the therapeutic management of patients. Most medicines have a burden/benefit aspect to their use and a patients individual view and input on this and their priorities for care should effect dosages etc. | Recognition that individualised care at end of life will lead to variations in practice dependent on the patient being cared for and that this is both acceptable and appropriate for palliative care. So a key are for quality improvement would be a reflection in all guidance that the advice contained within is just that – guidance - and likely to vary for individuals. | See:-  ‘One chance to get it right’ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\_data/file/323188/One\_chance\_to\_get\_it\_right.pdf |