



Public Health
England

NHS

Improving Quality

Protecting and improving the nation's health

National End of Life Care Intelligence Network

Palliative care co-ordination: core content

Record keeping guidance

National Information Standard (SCCI1580)

About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. It does this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. PHE is an operationally autonomous executive agency of the Department of Health.

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NHS Improving Quality works to improve health outcomes across England by providing improvement and change expertise to help the acceleration of learning to enable whole system change across England. It brings together knowledge, expertise and experience from across the NHS, to help re-shape the healthcare improvement landscape.

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This information standard (SCCI1580) has been approved for publication by the Department of Health under [section 250 of the Health and Social Care Act 2012](#).

Assurance that this information standard meets the requirements of the Act and is appropriate for the use specified in the specification document has been provided by the Standardisation Committee for Care Information (SCCI), a sub-group of the National Information Board.

This information standard comprises the following documents:

- Requirements Specification
- Change Specification (this document)
- Implementation Guidance
- Guidance to Implementing Changes.

An Information Standards Notice (SCCI1580 Amd 11/2015) has been issued as a notification of use and implementation timescales. Please read this alongside the documents for the standard.

The controlled versions of these documents can be found on the [HSCIC website](#).

Date of publication 18 September 2015.

The intelligence networks

Public Health England operates a number of intelligence networks, which work with partners to develop world-class population health intelligence to help improve local, national and international public health systems.

National End of Life Care Intelligence Network

The National End of Life Care Intelligence Network (NEoLCIN) aims to improve the collection and analysis of information related to the quality, volume and costs of care provided by the NHS, social services and the third sector to adults approaching the end of life. This intelligence will help drive improvements in the quality and productivity of services.

National Cancer Intelligence Network

The National Cancer Intelligence Network (NCIN) is a UK-wide initiative, working to drive improvements in standards of cancer care and clinical outcomes by improving and using the information collected about cancer patients for analysis, publication and research.

National Cardiovascular Intelligence Network

The National Cardiovascular Intelligence Network (NCVIN) analyses information and data and turns it into meaningful timely health intelligence for commissioners, policy makers, clinicians and health professionals to improve services and outcomes.

National Child and Maternal Health Intelligence Network

The National Child and Maternal Health Intelligence Network provides information and intelligence to improve decision-making for high-quality, cost-effective services. Its work supports policy makers, commissioners, managers, regulators, and other health stakeholders working on children's, young people's and maternal health.

National Mental Health, Dementia and Neurology Intelligence Network

The National Mental Health Intelligence Networks (NMHDNIN) brings together the distinct National Mental Health Intelligence Network, the Dementia Intelligence Network and the Neurology Intelligence Network under a single programme. The Networks work in partnership with key stakeholder organisations. The Networks seeks to put information and intelligence into the hands of decision makers to improve mental health and wellbeing, support the reduction of risk and improve the lives of people living with dementia and improve neurology services.

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Foreword

Co-ordinated care remains a cornerstone of high quality health and social care. A recurrent problem reported by those who experience poor care is that of fragmented care, where inadequate information continuity plays a major part. This is particularly true in palliative and end of life care where care and support are often provided by a range of organisations: NHS, social services and third sector, as well as the person's own family and friends.

As the person's condition progresses, they become weaker and often, though not always, lack the physical and mental energy to repeat information about their care, treatment, needs and preferences. In some situations, they may lack mental capacity to make decisions. Whether this is a temporary or permanent lapse, it would be much better if decisions that need to be made about their care and treatment during that period could be informed by their known views, preferences and priorities, provided the person wishes this to discuss and record these beforehand.

One way of facilitating co-ordination of care through information sharing is by the use of electronic palliative care co-ordinating systems (EPaCCS). Different localities may use different platforms and systems to provide an EPaCCS for their local population, for example through the summary care record (additional information dataset) or standalone systems, but the palliative care co-ordination information standard (previously known as the end of life care co-ordination information standard) provides a consistent, safe and reliable set of key information to be recorded and communicated so that information continuity can be secured, especially across time and organisational boundaries.

This document provides guidance for record keeping in line with the palliative care co-ordination information standard. It reminds staff and professionals about the importance of skilful and sensitive communication in the way information is ascertained, discussed and recorded. It facilitates the process of information sharing and should lead to an experience of care that feels more 'joined up' for people who are approaching the end of their lives, those important to them and all those involved in caring for them.

Professor Bee Wee
National Clinical Director for End of Life Care
NHS England

Disclaimer

This publication contains information, advice and guidance to support implementation of electronic palliative care co-ordination systems (EPaCCS) in England. The information has been compiled by Public Health England and NHS England, with contributions from NHS Improving Quality and the Health and Social Care Information Centre, and in consultation with others.

While every effort has been made to ensure the guidance provides accurate and expert information and guidance, we cannot guarantee its correctness and completeness. We do not accept responsibility for any loss, damage or expense resulting from the use of this information.

Endorsement

This publication has been endorsed by the following organisations:



1. Introduction

The aim of this guidance is to improve the co-ordination and quality of care provided for people at the end of life and to enable more people to die in the place of their choosing and with their preferred care package.

Access to reliable and timely person information is essential for the provision of quality, safe and efficient care by health and social care staff. To this end, a national information standard has been developed to support the recording and communication of people's end of life care choices and preferences. This standard – Palliative care co-ordination: core content – identifies the key information that should be held in the palliative care co-ordination record and it provides structures and definitions for consistency and reliability of the content. The standard was developed to support electronic palliative care co-ordination systems (EPaCCS), but it is also relevant for paper-based co-ordination systems.

The guidance was developed to support implementation of the information standard through EPaCCS. Health and social care professionals, and their professional organisations, helped to develop the guidance.

This guidance has been approved by the Clinical and Professional Assurance Group that holds responsibility for the clinical safety of the information standard. This group is chaired by the president of the Association for Palliative Medicine of Great Britain and Ireland, or their representative, and has representation from ten professional bodies: Royal College of Nursing; Royal College of General Practitioners; Royal College of Physicians; Royal College of Emergency Medicine; College of Occupational Therapists, Chartered Society of Physiotherapy; Association of Directors of Adult Social Care; College of Paramedics; British Geriatrics Society.

2. Context

The General Medical Council defines people as 'approaching the end of life' when they are likely to die within the next 12 months. This includes individuals whose death is imminent (expected within a few hours or days); those with advanced, progressive, incurable conditions; those with frailty and co-existing conditions that mean they are expected to die within 12 months; those at risk of dying from a sudden acute crisis in an existing condition; and those with life-threatening, acute conditions caused by sudden catastrophic events.¹

¹Treatment and care towards the end of life: good practice in decision-making. General Medical Council (2010)

These people need a combination of health and social care services often provided by a wide range of professional and staff groups. Improving the co-ordination and quality of this care remains the major aim of the palliative care approaches in all four countries of the UK.^{2,3,4,5,6} People's preferences for care as they approach the end of life should be recorded in a consistent way to support (with the person's permission) communication between professional teams.

Access to this information is required at any time, day or night, so that those delivering care to the person, including unscheduled care providers and emergency services, have the relevant information to support communication of the person's preferences and wishes for care. This will help to avoid the initiation of inappropriate treatments.

3. Purpose

This guidance is for use by health and social care professionals, educators, and others concerned with the quality of care for people at the end of life. It should be used in conjunction with the extensive guidance available to support clinical practice, advance decision making and palliative and end of life care service provision.

The overall aim is to improve the co-ordination and quality of care provided for people at the end of life and to enable more people to die in the place of their choosing and with their preferred care package. Staff must continue to use best judgement to act in a person's best interests at all times and not just follow the recorded information.

Once the person has been identified as approaching end of life (this timing will vary depending on the type of illness, but is generally between six and twelve months before death), any preferences or decisions agreed with that person and/or those caring for him/her, should be recorded and communicated, with the person's consent, so that any provider who then sees the person is aware of this information, and is able to access it. Staff must exercise judgement about when or whether to initiate discussions about palliative and end of life care and about establishing a palliative care co-ordination record, but must default in favour of discussion unless to do so would harm the person in some way.

Communication may be achieved by keeping the record in the person's home or current residence (which could be a care home, hostel, supported housing or prison setting), by providing access to an electronic palliative care co-ordination system or other local means for

² [Living and dying well](#). A national action plan for palliative and end of life care, Scottish Government (2008).

³ [Understanding palliative and end of life care](#), Northern Ireland

⁴ [Dying Well Matters. One Wales: 3 years on](#) (2008-2011)

⁵ [End of Life Care Strategy: third annual report](#) (2011)

⁶ [End of Life Care Strategy: promoting high quality care for adults at the end of their life](#) (2008)

recording and communication of palliative and end of life care decisions and wishes. Whether the information is recorded on paper or in an electronic system, its purpose is to:

- I. **Support identification and communication of people's wishes and preferences.** The core content details an individual's wishes and preferences for care and enables consistent documentation and communication.
- II. **Inform those caring for people approaching the end of life** and their families and carers of the decisions that have been made about palliative and end of life care preferences, choices, and the plans that are in place. This includes whether a person has made an advance statement, an advance decision to refuse treatment, whether a person has appointed someone with Lasting Power of Attorney and any wishes for organ donation. The current choices of an individual with capacity will always take precedence, but should they lose capacity these advance decisions are a key part of the best interests process.
- III. **Support co-ordination of care** using information that includes palliative and end of life care decisions and preferences. The information is used by the person, family, informal carers and a wide range of professional staff to guide them in delivery of appropriate care. Should the individual lose capacity, the information ensures that palliative and end of life care decisions and preferences are taken into account in the best interests process.

Standardised, unambiguous record content in electronic systems also supports extraction and analysis of data for secondary uses such as audit, service improvement and planning.

4. Scope

The scope of the guidance is co-ordination of palliative and end of life care for adults particularly as they approach the end of life. Principles for record keeping for advance care planning are included together with recommended core record content to support palliative and end of life care co-ordination. This core content includes essential demographic information in case the EPaCCS has to be managed separately from the main care record(s). It also includes details of advance care planning choices and decisions.

The core content is not a substitute for the full record and free text fields should not be used to add detail that is better recorded elsewhere. Misuse of the palliative care co-ordination record in this way could introduce safety risks, for example, medications being recorded in several places and not being synchronised.

Additional content that has been identified to support palliative and end of life care is provided in Appendix 1 (additional content). This has been tested and refined through piloting and

consultation and could be used to inform the development of both paper and electronic record systems.

The guidance is based on work undertaken in England and refers to English law where relevant. The principles for record keeping practice and the rest of the core content are consistent with regulatory and professional body guidance that is applicable across the UK.

5. How the guidance was developed

This guidance was developed as part of an initiative to develop an information standard to support the recording and communication of palliative and end of life care preferences and wishes in EPaCCS. The work was based on the result of piloting in eight sites across England of end of life care locality registers (now called EPaCCS).

The findings from the pilot projects are reported in the [End of Life Locality Registers Evaluation: Final Report](#), Ipsos MORI (2011). This includes reviews of practice and service guidance, existing record keeping practices and related initiatives such as the electronic palliative care summary that has been implemented across Scotland.

Extensive consultation was undertaken to refine the proposed dataset. Patients, carers and the public were invited to feedback on proposals via an online survey. Consultation with relevant professional organisations included feedback on the full content items. The results of the consultations were considered by an expert group and a final draft prepared for approval/endorsement by the professional organisations listed in the endorsements.

Since April 2013, Public Health England through the National End of Life Care Intelligence Network and NHS England have supported implementation and maintenance of the information standard.

6. Record keeping practice

6.1 The care process

A number of tools are available to support the process for a person's palliative care as they approach the end of life, for example, the Gold Standards Framework and Preferred Priorities for Care. (See Glossary).

Planning for your future care by NHS Improving Quality/University of Nottingham/NCPC (2014) summarises the care process for making end of life care choices from the person's perspective:



Staff must be aware that not everyone will choose to have these conversations and this must be respected. Those who do need to be supported by health and social care staff with the appropriate knowledge and skills.

Guidance is available for health and social care staff to respond to or initiate conversations with people approaching the end of their lives, including:

- I. **Capacity, care planning and advance care planning in life limiting illness: A Guide for Health and Social Care Staff**, NHS Improving Quality (2014).
- II. **The NICE Quality Standard for End of Life Care for Adults**, National Institute for Health and Care Excellence (2011).
- III. **Common core competences and principles for health and social care workers**, NEEoLCP/DH/Skills for Health/Skills for Care (2009). This identifies the core competences that are required to underpin delivery of end of life care. These include specific dimensions for communication skills and advance care planning.
- IV. **e-ELCA e-learning resources** that include modules on advance care planning and communication are freely available to health and social care staff.
- V. **Finding the Words**, NEEoLCP (2011). A training DVD and workbook to support staff in end of life care conversations.

- VI. **Difficult Conversation Series** (Heart Failure, Young Adults, Dementia, Chronic Obstructive Pulmonary Disease. Motor Neurone Disease), NCPC. Short booklets to support those caring for someone with specific illnesses to open up conversations about palliative and end of life wishes and preferences.
- VII. Guidance from British Medical Association, Resuscitation Council (UK) and Royal College of Nursing: **Decisions relating to cardiopulmonary resuscitation 3rd Edition 2014**.

Discussions with people at the end of life about their preferences and choices are extremely sensitive. The process of planning for palliative and end of life care should be a continuing dialogue with a person and those close to them about how to meet their current needs with general care planning and needs that can be anticipated in the future.⁷

Advance care planning is a voluntary process of discussion and review to assist an individual with capacity to think about how their condition may affect them in the future and, if they wish, to set on record choices about their care and treatment and/or an advance statement or advance decision to refuse a treatment in specific circumstances. These should be referred to by those responsible for their care or treatment (whether, health and social care professionals and staff, voluntary sector workers or family carers) in the event that the individual loses capacity to make contemporaneous decisions as their illness progresses.

It is important that staff understand that any choice or advance decision to refuse treatment recorded in advance of loss of capacity only becomes relevant when a person loses capacity to decide on these issues. Where an individual maintains the capacity to decide, those involved within their care must check and agree the content of any care planning record.

Outcomes of advance care planning may include:

- advance statements – these statements are not legally binding, but should a person lose capacity, carers are required under the Mental Capacity Act 2005, to take the statements into account when considering the individual's best interests and they should inform subsequent decisions
- valid and applicable advance decisions to refuse treatment (including DNACPR) that are legally binding
- appointment of person(s) with Lasting Powers of Attorney

See Glossary for definitions of these terms.

⁷ **The differences between general care planning and decisions made in advance**, NEoLCP (2012).

6.2 Record keeping practice principles

General record keeping principles stipulated by the GMC (2013), NMC (2015), NMC (2012) HCPC (2008), AoMRC (2008), AoMRC and NHS (2008), NHS (2010) and AoMRC (2013) apply—including all entries and amendments being dated and timed, confidentiality, accuracy and timeliness of content. It must be clear who made or amended any entry or, in the case of current medications that are automatically updated, the date of the last update. Appendix 2 provides further advice on accountability considerations related to palliative care co-ordination records.

In its [guidance on decision-making in end of life care](#), the General Medical Council (2010) requires doctors to:

- I. Make a record of the decisions made about a person's treatment and care, and who was consulted in relation to those decisions.
- II. Do your best to make sure that all those consulted, especially those responsible for delivering care, are informed of the decisions and are clear about the goals and the agreed care plan, unless the person indicates that particular individuals should not be informed.
- III. Check the handover arrangements where you work, and use the available records and arrangements for information storage and exchange, to ensure that the agreed care plan is shared within the healthcare team. This will include both paid and unpaid carers outside the team and other health professionals involved in providing the person's care. This is particularly important when people move across different care settings (hospital, ambulance, care home) and during any out-of-hours period. Failure to communicate some or all relevant information can lead to inappropriate treatment being given (for example, cardiopulmonary resuscitation decisions or opinions not being known about) and failure to meet the people's needs (for example, their wish to remain at home not being taken into account).

While these duties of care rightly sit within the guidance of regulatory bodies, they should also be reflected in the policies and operating procedures that ensure proper governance of clinical decision making at the end of life, including procedures to ensure that dying people are not vulnerable, through poor communication, inadequate or absent documentation, to inappropriate interventions when they are in transit between settings.

Record keeping practice principles for advance care planning are summarised in the executive summary of [Capacity, care planning and advance care planning in life limiting illness](#), NHS Improving Quality (2014):

- should an individual with capacity wish to record choices about their care and treatment, or an advance decision to refuse treatment, in advance of losing capacity, they should be guided by a professional with appropriate knowledge and this should be documented according to the requirements of the Mental Capacity Act 2005
- any choices or advance decisions to refuse treatment recorded in advance of loss of capacity only become relevant when a person loses the capacity to decide about those issues
- where an individual has capacity to decide, then they should check and agree the content of any care planning record
- staff should make or share records of any discussion only with the person's permission or if, in the case of someone who lacks capacity, this is judged to be in their best interests
- there should be locally agreed policies about where care planning documentation (including any formalised outcomes of advance care planning) is kept and systems in place to enable sharing between the health and social care professionals involved in the care of the individual, including out-of-hours providers and ambulance services
- the person concerned should be encouraged to regularly review any care planning documentation, to update this as appropriate, and to ensure that revisions are shared with those they wish to involve in their care

Two examples where local policy supports the storing and sharing of documentation are:

- [Making the case for change](#) NEdLCP (2012), appendix 5, EPaCCS case study: Impact in Practice (Somerset) where shared access to a person's end of life care preferences enabled a person to achieve a dying wish
- [Making the case for change](#), NEdLCP (2012) appendix 4, Integration of end of life care services in Bedfordshire – Partnership for Excellence in Palliative Support (PEPS)

Based on these principles and associated guidance materials, record content must support the recording, updating and communication of the person's choices and advance decisions to guide decision-making by all those providing care.

6.3 When is the palliative care co-ordination record created/updated?

The record holds specific information, including preferences, which have relevance for co-ordination of care, particularly across settings and organisational boundaries. Local policy will determine the accountability, the processes and authority for creating and updating the record and for the sharing of information.

Records are made and shared with the person's permission. Consideration needs to be given to the point at which people should be asked if they would like to have their details included in the record. Although often impossible to predict with confidence, a life expectancy of 12 months provides some guidance on the optimum timescale for introducing the topic.

A review date should be set at the time of record creation and also at each review date. A maximum review period of three months is set. When possible the person should be involved in deciding the timing of the next review. Communication with the other members of the team will be important to ensure a co-ordinated approach for review and to avoid duplication. Where consent for the record was a best interest decision, a person's lack of capacity to give this consent should be checked at the review. All staff have a responsibility for ensuring that the record is kept up to date and reflects the current wishes of the person. They also need to promptly remove a person's details from the record if they withdraw consent. Where palliative care co-ordination information forms part of a wider clinical record, a discussion should be had with the patient about what (if any) information about their palliative and end of life care preferences they would like to have removed (or made inaccessible) from the wider record when consent is withdrawn.

Staff must adhere to their relevant professional codes of practice, eg [NMC Code: Professional standards of practice and behaviour for nurses and midwives](#), Nursing & Midwifery Council (2015).

Staff must be aware of the human rights and equalities legislation in relation to advance care planning and the recording of information in EPaCCS. They need to address any barriers for inclusion that may be caused by negative attitudes or lack of access or support.⁸

Not all people will want to have discussions about palliative and end of life care choices and this needs to be respected. It is the responsibility of professionals to ensure that the record is updated with any changes to a person's preference for care. In addition, as part of the initial

⁸ [A Clinician's Guide to Record Standards – Part 1: Why standardise the structure and content of medical records?](#) Academy of Medical Royal Colleges (2008).

conversation, patients need to be reassured that having their choices recorded does not mean they cannot change their preferences at any time.

6.4 Who can make or update the core content?

Generally a health or social care professional that delivers care to the person will complete the record, with a person's permission, although this will be a local decision and administrative staff may have the task to input some (non-clinical) data. In most cases, a medically qualified or specialist palliative care professional will identify the person as approaching the end of life.

Anyone involved in the care of the person should be able to contribute to the record. This includes professional and voluntary carer workers, the person him/herself and relatives or carers contributing to care and decisions. Local decisions will be made on the way that people and their carers contribute to. In some instances this will be by discussion with staff and in others by having direct access to edit specific fields in their record.

Clinical data fields, including diagnoses and clinical issues, allergies and adverse drug reactions and medication details are to be completed by a clinician. Unless a DNACPR decision forms part of a person's ADRT, a decision about attempting cardiopulmonary resuscitation can only be given by the senior responsible clinician or their delegate, in discussion with the individual wherever possible and appropriate. It is the responsibility of this clinician to decide how or whether the decision is discussed with the person and their family, based on established principles, but they must default in favour of discussion unless there is a real risk that a conversation will result in harm.⁹

The electronic registers should have within their specification a feature to notify lead clinicians (eg GP, district nurse, key worker) automatically when the record has been modified. This would support the updating of any local records. Where no explicit decision has been made in advance, there should be an initial presumption in favour of CPR.

Not all content items apply to all situations and some may be completed as the conversations with the person proceed over time. Local policies/system design will dictate whether these items are left blank or a note made that an item has not yet been discussed/is not relevant. Items in the core content (see 6.13 Core content for palliative care co-ordination) that are marked * must always be populated when the record is created.

Please refer to Appendix 2 for considerations on accountability for completion of the record.

⁹ Decisions relating to cardiopulmonary resuscitation. Guidance from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing. 3rd edition. October 2014.

6.5 How do professionals know that a palliative care record has been created?

Local systems will be necessary to ensure that the relevant staff groups are able to identify individuals with a palliative care record. This may be by provision of a simple list of people with a record that can be checked whenever staff initiate an encounter with a person or by flagging in other databases.

6.6 Responsibility for the record

Staff have individual responsibility for completing and updating the record and for ensuring continuity of care for an individual. Local policy will determine the staff with overall responsibility for the record: this would usually be the key worker or GP. The policy will need to take account of variations in care setting.

All staff need to understand their role and responsibility relating to the record. GP responsibilities for identifying people in need of palliative care or support are specified in the [Quality and Outcomes Framework](#) and they need to be made aware if any of their patients are added to the record.

The lead clinician has overall responsibility for the clinical care of the person and they can be accessed through the key worker, relevant health and social care staff and carers.

To avoid confusion, it is important to document the date and place of death when a person dies. It is suggested that the person's GP has responsibility for ensuring that the record is updated with this information. IT systems should allow for data to be maintained for audit and clinical governance.

6.7 Advance decision documentation

Advance care planning is a voluntary process of discussion and review. Where people have made decisions about their future wishes and choices, they may want these to be documented.

There is opportunity to record the wishes and preferences, beliefs and values of a person in the event that s/he does not have capacity, in the form of advance statements within the record.

Advance decision documents (ADRT, cardiopulmonary resuscitation decisions, LPA, advance statements) that may accompany the co-ordination record need to be accessible (with the person's permission) to those who may need to act on them. There should be locally agreed policies about where care planning documentation is kept and appropriate systems in place to enable sharing between the health and social care professionals involved in the care of the individual 24/7.

Where possible, it is recommended that advance decision documents are stored together. In an electronic record, such as within an EPaCCS, electronic copies of these documents could be linked to the item indicating that the particular advance decision document exists. Where this is the case, a process needs to be in place to ensure that the documents are up to date. With due consideration to information governance and data protection, a hard copy of the original documentation should remain with the person at home, at the bedside or where it can be easily accessed by relevant carers.

An advance decision to refuse treatment¹⁰ is a decision to refuse a specific treatment made in advance by a person who has capacity to do so. This decision only applies at a future time when that person lacks capacity to consent to, or refuse, the specified treatment. This is set out in Section 24 of the Mental Capacity Act. Specific rules apply to advance decisions to refuse life-sustaining treatment.

An advance decision to refuse treatment:

- can be made only by someone over the age of 18 who has mental capacity
- is a decision relating to refusal of specific treatment and may also include specific circumstances
- can be verbal, but if an advance decision includes refusal of life sustaining treatment, it must be in writing, signed and witnessed and include the statement 'even if life is at risk'
- will only come into effect if the individual loses capacity
- only comes into effect if the treatment and any circumstances are those specifically identified in the advance decision
- is legally binding if valid and applicable to the circumstances
- can be overridden by the Mental Health Act, but only for psychiatric treatment

¹⁰ [Advance Decisions to Refuse Treatment: A Guide for Health and Social Care Professionals](#). NHS Improving Quality (2014).

Case Study

A young man, whose friend died after prolonged hospital treatment, makes a signed and witnessed, treatment-specific, advance decision and statement refusing any treatment to keep him alive by artificial means if he is injured in this way. A few years later, he is seriously injured in a road traffic accident and is paralysed from the neck down and is only able to breathe with artificial ventilation.

Initially he remains conscious and is able to consent to treatment on being taken to hospital. He participates actively in a rehabilitation programme. Some months later, he loses consciousness. It is at this point that his written advance decision is located, though he has not mentioned it during his treatment.

His consent to treatment and involvement in rehabilitation after his injury is clearly inconsistent with his prior advance decision and statement to refuse any treatment to keep him alive by artificial means if he was injured in the same way. Anyone assessing the advance decision would need to make careful consideration of the considerable doubt this inconsistency puts on its validity.

Key points

The validity and applicability of any advance decision to refuse treatment must be carefully considered and, where there is concern, professional/legal advice should be sought.

There should be local policies about attempting cardiopulmonary resuscitation in place. Clinicians must follow local and national guidance and professional codes of conduct when making and recording decisions about attempting cardiopulmonary resuscitation.

A CPR decision can only be made if an arrest is anticipated in the current circumstances. A DNACPR recommendation is made by the senior responsible clinician or delegate to provide their opinion that cardiopulmonary resuscitation attempts should not be instigated in the event of a cardiopulmonary arrest. Any decision must adhere to procedures described in the [Resuscitation Council's Guidelines](#). It is the responsibility of this clinician to ensure that the opinion is recorded and that the record kept up to date.

A DNACPR recommendation does not absolve the attending clinician from assessing the patient at the time of a cardiopulmonary arrest because there may be a clear and simply reversible cause, such as major airway obstruction. A DNACPR decision made by the person, that is part of a valid and applicable ADRT, is binding.

When making a CPR recommendation, if the clinician assesses that CPR has a realistic chance of success and the benefit of attempting CPR has been assessed to outweigh the risks and burdens for the individual, there should be a presumption in favour of involvement of the person in the decision-making process. If she or he lacks capacity, those close to them must be involved in discussions to explore the person's wishes, feelings, beliefs and values in order to reach a 'best-interests' decision. (Mental Capacity Act. 2005). It is important to ensure that they understand that (in the absence of an applicable power of attorney) they are not the final decision-makers.

Even if CPR is not an option because there is no realistic chance of success, open dialogue and communication with the patient (where possible) and those close to him/her remain important. The availability of those identified as important to the person should not delay a decision not to attempt resuscitation.

Making a decision not to attempt CPR that has no realistic prospect of success does not require the consent of the patient or of those close to the patient, however there is a presumption in favour of informing a patient of such a decision. It is important that staff do not engage the person in discussion about resuscitation if the individual has indicated that s/he does not want to discuss CPR or when the person lacks capacity and it is not in the person's best interests. The question whether, when and how to consult and notify the patient requires sensitivity, care and skill, and must be undertaken by those who are competent to do so. When a person is not aware of the DNACPR decision, staff must record the reason(s) for this in order to explain why this decision was made without the person's knowledge, so that this is clear to other professionals involved in the person's care.

Full guidance is available in the Guidance from the British Medical Association, the Resuscitation Council (UK), and the Royal College of Nursing (previously known as the 'Joint Statement') 2014 – [Decisions relating to cardiopulmonary resuscitation \(3rd edition\)](#).

It is important that staff read and follow this guidance which includes the importance of involving people (or their representatives if they are unable to make decisions for themselves) in the decision-making process and communication and documentation of CPR decisions.

The guidance includes [DNACPR model forms](#) and recommended standards for recording decisions.

6.8 Mental capacity and best interests decisions

A person may lack capacity to make some or all decisions or to consent to actions connected with health and social care provision. These individuals will be reliant on staff to follow a careful process of care planning and decision-making that maximises their ability to participate in care planning and make associated decisions (even if this is partial) and protects their best interests.

For decisions made on behalf of a patient either temporarily or permanently lacking the mental capacity to make their own decisions, a decision should be sought from a Court of Protection appointed person (if any) with welfare decision responsibilities^[2] - there may be more than one. (See Court of Protection website if further guidance needed.) If such a person has not been appointed or is not available a 'best interest decision' should be taken and recorded in accordance with the Mental Capacity Act and associated professional guidance.

'Best interests' should be determined by following the process defined in the Mental Capacity Act 2005, Code of Practice (chapter 4), which requires that all relevant circumstances are taken into account.

The 'decision-maker' is usually the person responsible for the person's care at that time. This can be a relative or partner, but is often a health or social care professional responsible for the individual's care at the time (Mental Capacity Act 2005, Code of Practice, chapter 5).

Relatives or partners must be consulted as part of the process of determining best interests and in order to enable them to understand the care and treatment decision making process. The views of other people who are close to the person who lacks capacity should be considered, as well as the views of any deputy or attorney.

If a person lacks mental capacity, and in the absence of a person legally appointed by the Court of Protection to make welfare decisions a clinician or social worker is allowed to act in their best interests and add their information to EPaCCS.

Further guidance on best interests decisions can be found in: [Capacity, care planning and advance care planning in life limiting illness](#), NHS Improving Quality (2014).

6.9 Likely Prognosis

It is important that the staff caring for an individual are kept informed if a person is approaching the last phase of life to support their decision making. The creation of a palliative care co-ordination record indicates that a person is likely to be in their last year of life (sometimes longer). A data item likely prognosis allows staff to document when they consider a person to

^[2] This may be Lasting Power of Attorney (historical – if welfare responsibilities include), Enduring Power of Attorney (if includes welfare responsibilities) or Welfare Deputy.

be in the last days, weeks or months of life. It is appreciated that it is very difficult for clinicians to predict the prognosis with accuracy and this must be taken into account by all staff that access the record. This field is to be completed by doctors only. The doctor needs to have full information about the patient's current condition.

It is important that this information is kept up to date and it is recommended that the prognosis is reviewed monthly for people with a likely prognosis of months, weekly for people with a likely prognosis of weeks and daily for people with a likely prognosis of days.

6.10 Consent

Discussions with people at the end of life about their preferences and choices can be sensitive. Generally, they are not one-off discussions and need to take place over a number of visits.

Not all people will want to have an EPaCCS record and they must be free to withhold consent. Staff must exercise judgment on whether it is appropriate or timely to initiate these discussions and must always act in the person's best interests.

Separate explicit consent for creation of the record and for sharing information is required because the palliative and end of life care record contains information of a sensitive nature and is shared across organisational boundaries. Consent involves a person being fully informed about why information needs to be shared, what information will be shared, who will see their information, what will be done with the information and the implications of sharing that information and of non-disclosure on their care and treatment.

People need to be informed of any secondary use of non-identifiable information, eg for reporting or for research. Secondary use of identifiable information needs separate explicit consent. The individual needs to have the capacity to understand the consent they are giving and for that consent to be freely given.

Explicit consent is given by a person agreeing actively, orally or in writing. People generally have a right to object to the use and disclosure of their own confidential information and have a right to withdraw their consent at any time, other than where there is a statutory basis for the use or disclosure. It is also important to note that consent to share does not mean all information pertaining to that individual. Clarity is required to ensure which areas the individual is happy to share and with whom.

The record records the consent given for creation and sharing the record. This includes whether explicit consent has been given, whether it was a best interest decision or whether the decision was made by a personal welfare Lasting Power of Attorney. The record also records if consent for the record has been withdrawn. This provides clarity of the consent for the record and where consent was a best interest decision or granted by a Lasting Power of Attorney, it

alerts care professionals that there may be mental capacity issues to be taken into consideration.

The record may contain names and contact details of a person's main family member or informal carer, an appointed Lasting Power of Attorney and others that the person has identified that they wish to be involved in decisions about their care. In general, these individuals will be aware that their details are included on the record and the information is unlikely to be confidential or sensitive in nature, however, it is suggested that when staff add these details to the record, the person is asked whether these individuals have been informed.

Exceptionally, the person may not wish the named individual(s) to know that they have been referenced in the record at the current time. In this instance, there should be a means of recording this decision not to inform relatives or carers. Staff can then be aware of the need to continue the discussion about the importance of relatives and carers knowing about their inclusion on the record so that they do not inadvertently breach the person's trust or, if it becomes necessary, can do so knowingly in the best interests of the person if they lose capacity.

6.11 Managing consent for EPaCCS when it forms part of a wider electronic clinical record

Where EPaCCS is established as a subset of a wider electronic clinical record, for example a long-term conditions (LTC) electronic record, consideration needs to be given to the consent model. There are two timing options for seeking and recording consent for the sharing of the EPaCCS section of a wider clinical record:

1. Include specific informed consent for creation and sharing future palliative and end of life care preferences at the time of creating a shared record. The clinician would record both the general consent and the EPaCCS consent at the point of record creation. Professionals responsible for seeking consent will need to carefully consider the way that this is communicated in order to avoid causing anxiety or distress. Consent given at this time would allow any EPaCCS information captured from that point on to be shared.
2. Alternatively, seek consent only for sharing of the general information at the time of creating a shared clinical record. At a later date, if there is a need to start capturing and sharing palliative and end of life care preferences, a conversation then takes place with the person at that time to seek specific consent for the EPaCCS content and record this in the record.

Exceptionally at the point at which there is a need to start capturing and recording end of life information, the clinician may feel that previous discussions with the patient have made it clear that they consent to having an EPaCCS record, and they may choose to record the EPaCCS consent in the record on behalf of the patient. The clinician would need to be confident that the

patient had fully understood and agreed to this, and they would be responsible for ensuring this was the case.

6.12 Other information governance considerations

Health records contain confidential and personal information. It is essential that all staff with access to the records have a full understanding of the information governance requirements to maintain security and protection of personal information held about individuals. Staff need to abide by the law, local employment conditions and their professional code of conduct regarding confidentiality, and must respect the conditions attached to permissions assigned to them for access to the record. Staff should be aware that serious breaches of the Data Protection Act 1998 could result in a fine from the Information Commissioner's Office.

Staff have a responsibility for accuracy of the record and, depending on their administration rights, will be responsible for updating or amending the record or for notifying the GP or key worker when changes need to be made. They are responsible for security of personal information when using the record and if transferring information by email, fax or phone.

6.13 Core content for Palliative care co-ordination

The Academy of Medical Royal Colleges and the Royal College of Nursing recommend that records should have a standardised structure (AoMRC 2008¹¹, RCN (2015)).¹² The information standard aligns with the headings specified in Clinical Structure and Content of Patient Records (AoMRC & HSCIC 2013).

The following table provides defined content 'headings' for structuring the information deemed to be essential for effective palliative care co-ordination. Layout of the information will depend on whether, for example, it is integrated with the GP record, is part of the person-held record or forms the content of an EPaCCS.

Information recorded against each heading may also be structured, using standard terms and codes if it is recorded in an electronic system. Codes are applied where possible; however, there will always be a need for some free text fields to ensure that the person's preferences are adequately communicated. The related **information standard** provides recommended terms and codes for use in systems supporting palliative and end of life care.

11 **A Clinician's Guide to Record Standards – Part 1: Why standardise the structure and content of medical records?** Academy of Medical Royal Colleges. (2008)

12 **Nursing Content of eHealth records** (2010). Royal College of Nursing eHealth Publications
NMC Code: Professional standards of practice and behaviour for nurses and midwives. NMC (2015)

Content heading/subheading		Definition/illustrative description of the type of information to be recorded under each heading
1	Consent Consent status*	
2	Record creation* and record amendment* dates	
3	Plan and requested actions Planned review date	Date set at creation of the care co-ordination record and at subsequent review by professional (normally key worker or GP) in consultation with the person for a review of the person's preferences and choices for palliative and end of life care.
	Cardiopulmonary resuscitation decision – whether a decision has been made, the decision, date of decision, location of the documentation and date for review.	
4	Person demographics Person name* including preferred name Date of birth* Person address* NHS Number* and NHS number status indicator code* Person telephone number Gender Relevant contacts	Note: gender is self-declared gender.
	Main carer name and contact details. Availability of carer support*.	Note: the main carer will be identified by the person's GP or key worker if the person lacks capacity to identify one for him/herself.

Content heading/subheading	Definition/illustrative description of the type of information to be recorded under each heading
<p>5 Special requirements Need for interpreter</p> <p>Preferred spoken language</p> <p>Functional status</p> <p>Disability</p> <p>End of life care tools in use eg Gold Standards Framework</p>	<p>No/yes</p> <p>Pick list of languages</p> <p>Uses Australian modified Karnofsky Performance Scale</p> <p>Functional or cognitive impairments that affect a person's ability in communication, understanding, decision-making or self-care. The name of the tool is recorded (See Glossary).</p>
<p>6 Information and advice given Is main carer aware of person's prognosis?</p> <p>Is person aware of the cardiopulmonary resuscitation clinical decision?</p> <p>Family member/carers informed of cardiopulmonary resuscitation clinical decision</p>	<p>A prognosis is a judgement about the likely outcome of a health condition or situation. Regarding palliative and end of life care, awareness of the prognosis is taken to mean awareness that the life span is limited.</p>
<p>7 GP Practice GP name* GP practice details*</p>	
<p>8 Key worker Name Telephone number</p>	<p>A key worker is a care professional who takes a key role in co-ordinating the care of the patient and promoting continuity, ensuring the patient knows who to access for information and advice.</p>
<p>9 Services and care Name of health and social care staff and professionals involved in care. Professional group. Telephone number.</p>	<p>Health and social care professionals and staff, including care workers from voluntary agencies, providing care and support for the person. Lead clinician(s) should be clearly indicated within this list.</p>

Content heading/subheading	Definition/illustrative description of the type of information to be recorded under each heading
<p>10 Diagnoses Primary end of life care diagnosis*</p> <p>Other relevant end of life care diagnoses and clinical issues</p> <p>Likely prognosis</p>	<p>The diagnosis that is the main contributing factor to the need for end of life care.</p> <p>Relevant diagnoses and medical problems that need to be taken into account when making palliative and end of life care decisions. This includes mental health issues such as depression, anxiety and dementia and may include:</p> <ul style="list-style-type: none"> • any religious/spiritual/cultural needs • other instructions from the person about their care • organ donation decision • lives alone • preference for renal dialysis • other social issues <p>This is a clinical judgement indicating the anticipated period of time until death. There is recognition of the uncertainty related to such a judgement. To be completed by a doctor who has full information about the patient's current conditions.</p>
<p>11 Allergies or adverse reactions</p>	<p>Relevant drug and non-drug allergies, as well as adverse drug reactions, sensitivities and intolerances.</p>
<p>12 Medications and medical devices Whether a 'just in case box' or anticipatory medicines have been prescribed. Where these medicines are kept.</p>	<p>Anticipatory prescribing of medicines commonly prescribed in palliative care with a 'just in case box' placed in the person's home, providing rapid access to these medications if required during the terminal phase of a person's illness.</p>

Content heading/subheading	Definition/illustrative description of the type of information to be recorded under each heading
<p>13</p> <p>Legal information</p> <p>Advance statement Requests or preferences that have been stated</p> <p>Advance decision to refuse treatment (ADRT) Whether a decision has been made, the decision, date of decision and the location of the documentation</p> <p>Lasting Power of Attorney or similar Name and contact details of person appointed with Lasting Power of Attorney (LPA) for personal welfare</p> <ul style="list-style-type: none"> • without authority to make life-sustaining decisions • with authority to make life-sustaining decisions 	<p>See Glossary</p> <p>Free text fields</p>
<p>14</p> <p>Person and carers' concerns, expectations and wishes Preferred place of death 1st and 2nd choices if made</p> <p>Names and contact details of others (one and two) that the person wants to be involved in decisions about their care</p> <p>Other relevant issues or preferences around provision of care?</p>	<p>Professionals may wish to rephrase the question about preferred place of death when discussing these wishes with a person as the terminology may be a barrier to communication. A suggested approach could be to ask the preferred place for care when dying. It is recommended that the responses are used to support outcome evaluation. It is important that these choices are reviewed and kept updated as people may change their minds as their illness progresses.</p>
<p>15</p> <p>Actual place of death</p>	<p>It is important that this data item is completed when a person dies</p>
<p>16</p> <p>Date of death</p>	<p>It is important that this data item is completed when a person dies</p>

* Completion of these items is mandatory.

6.14 Guidance

Health and social staff should be aware of the following guidance to support record keeping in palliative and end of life care:

- **NMC Code: Professional standards of practice and behaviour for nurses and midwives.** Nursing & Midwifery Council (2015)
- **Delegating record keeping and countersigning records. Guidance for nursing staff.** Royal College of Nursing (2013)
- **A Clinician's Guide to Record Standards – Part 1: Why standardise the structure and content of medical records?** Academy of Medical Royal Colleges (AoMRC) (2008)
- **A Clinician's Guide to Record Standards – Part 2: Standards for the structure and content of medical records and communications when patients are admitted to hospital.** Academy of Medical Royal Colleges (AoMRC) (2008)
- **Standards for the clinical structure and content of patient records.** AoMRC and HSCIC (2013)
- Further examples can be found at **NHS Improving Quality**. This includes record keeping principles for advance care planning in **Capacity, care planning and advance care planning in life limiting illness** (2014) and recording written and verbal advance decisions to refuse treatment, provided on Page 15 and 16 of **Advance Decisions to Refuse Treatment: a Guide for Health and Social Care Professionals** (2013)
- **Record Keeping Guidance.** The Chartered Society of Physiotherapy (2012)
- **Caldicott review: information governance in the health and care system** (2013)
- **College of Occupational Therapists' Record Keeping Guidance** (2010)

7. Audit

An audit trail will be available of the details, dates and person viewing the record, making entries or amendments.

An audit of records against standards by NHS trusts is recommended by AoMRC¹³ to demonstrate compliance with NHS Litigation Authority Risk Management Standards and for inspections by the Care Quality Commission. Access to the records and the consent process need to be monitored and audited.

8. Review of this guidance

This guidance will be reviewed in 2018. If you would like to provide feedback or comment on this guidance or on your experience in using it, please contact neolcin@phe.gov.uk

9. Acknowledgements

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The following professional organisations were consulted in the development, review and update of the national information standard for Palliative care co-ordination: core content:

Association of Directors of Adult Social Services
Association for Palliative Medicine of Great Britain & Ireland
British Geriatrics Society
British Medical Association: General Practitioner Committee
Chartered Society of Physiotherapy
College of Emergency Medicine
College of Occupational Therapists
College of Paramedics
Joint RCGP/GPC IT Committee
Royal College of General Practitioners
Royal College of Nursing
Royal College of Physicians

¹³ A Clinician's Guide to Record Standards – Part 1: Why standardise the structure and content of medical records? Academy of Medical Royal Colleges (2008).

10. Glossary

Term	Definition
Acute hospital	<p>Acute hospitals provide a wide range of specialist care and treatment for patients. Services offered in acute hospitals include:</p> <ul style="list-style-type: none"> • consultation with specialist clinicians (consultants, nurses, dieticians, physiotherapists and a wide range of other professionals) • emergency treatment following accidents • routine, complex and life-saving surgery • specialist diagnostic, therapeutic and palliative procedures <p>www.nrls.npsa.nhs.uk/resources/healthcare-setting/acute-hospital</p>
Advance care planning (ACP)	<p>A voluntary process of discussion and review to help an individual who has capacity to anticipate how their condition may affect them in the future and, if they wish, set on record choices or decisions relating to their care and treatment so that these can then be referred to by their carers (whether professional or family carers) in the event that they lose capacity to decide once their illness progresses.</p> <p>Under the terms of the Mental Capacity Act 2005, formalised outcomes of advance care planning might include one or more of the following:</p> <ul style="list-style-type: none"> • advance statements to inform subsequent best interests decisions • advance decisions to refuse treatment which are legally binding if valid and applicable to the circumstances at hand • appointment of Lasting Powers of Attorney (for health and welfare and/or property and affairs) <p>Sources</p> <p>Capacity, care planning and advance care planning in life limiting illness. A Guide for Health and Social Care Staff, NHS Improving Quality (2014)</p> <p>Mental Capacity Act 2005</p> <p>Mental Capacity Act 2005 Code of Practice. Ministry of Justice 2007</p>

Term	Definition
<p>Advance decision to refuse treatment (ADRT)</p>	<p>An advance decision to refuse treatment (ADRT) is a decision to refuse a specific treatment made in advance by a person who has capacity to do so. This decision only applies at a future time when that person lacks capacity to consent to, or refuse, the specified treatment. This is set out in Section 24 of the Mental Capacity Act. Specific rules apply to advance decisions to refuse life-sustaining treatment.</p> <p>An advance decision to refuse treatment:</p> <ul style="list-style-type: none"> • can be made only by someone over the age of 18 who has mental capacity • is a decision relating to refusal of specific treatment and may also include specific circumstances • can be verbal, but if an advance decision includes refusal of life-sustaining treatment, it must be in writing, signed and witnessed and include the statement ‘even if life is at risk’ • will only come into effect if the individual loses capacity • only comes into effect if the treatment and any circumstances are those specifically identified in the advance decision • is legally binding if valid and applicable to the circumstances • can be overridden by the Mental Health Act, but only for psychiatric treatment <p>Sources</p> <p>Capacity, care planning and advance care planning in life limiting illness. A Guide for Health and Social Care Staff, NHS Improving Quality (2014)</p> <p>Advance decisions to refuse treatment, NHS Improving Quality (2014)</p> <p>Mental Capacity Act 2005</p> <p>Mental Capacity Act 2005 Code of Practice. Ministry of Justice 2007</p>

Term	Definition
Advance statement	<p>This is a written statement (either written down by the person themselves or written down for them with their agreement) the person might make before losing capacity (Mental Capacity Act Code of Practice 2007, P291) about their wishes and feelings regarding issues they wish to be considered in the case of future loss of capacity due to illness, such as the type of medical treatment they would want or not want, where they would prefer to live or how they wish to be cared for.</p> <p>Advance statements should be used to help find out what somebody's wishes and feelings might be, as part of working out their best interests when they have lost capacity to decide. They are not the same as advance decisions to refuse treatment and are not binding.</p> <p>Sources Capacity, care planning and advance care planning in life limiting illness. A Guide for Health and Social Care Staff, NHS Improving Quality (2014) Mental Capacity Act 2005</p>
Best interests	<p>Under the Mental Capacity Act 2005, any decision made or any action done for or on behalf of a person who lacks capacity must be done or made in their best interests. Decision makers must take into account all relevant factors that would be reasonable to consider. Section 5.13 of the Mental Capacity Act Code of Practice sets out a non-exhaustive checklist of common factors that must always be considered when trying to work out someone's best interests.</p> <p>Reference Mental Capacity Act (2005) Code of Practice. Ministry of Justice 2007</p>

Term	Definition
<p>Cardiopulmonary resuscitation decision</p>	<p>Cardiopulmonary resuscitation Emergency treatment that supports the circulation of blood and/or air in the event of a respiratory and/or cardiac arrest.</p> <p>Cardiopulmonary resuscitation decision A clinical opinion, for or against an attempt at cardiopulmonary resuscitation. Such decisions only apply to attempts to restore circulation or breathing. They do not decide the suitability of any other type of treatment, and never prevent the administration of basic comfort and healthcare needs.</p> <p>Do not attempt cardiopulmonary resuscitation (DNACPR) decision Only covers views about withholding attempts at cardiopulmonary resuscitation in the event of a future arrest. It is made by the clinician responsible for care. This decision can also be made by the person themselves as part of ADRT.</p> <p>Sources Decisions relating to cardiopulmonary resuscitation. A joint statement from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing (2014) Quality standards for cardiopulmonary resuscitation practice and training. Resuscitation Council (2013) Deciding right – a new north east initiative for making care decisions in advance Northern England Strategic Clinical Networks (2014)</p>
<p>Carer</p>	<p>A carer is a person who is either providing or intending to provide a substantial amount of unpaid care on a regular basis for someone who is disabled, ill or frail. A carer is usually a family member, friend or neighbour and does not include care workers. (Carers (Recognition and Services) Act 1995.)</p> <p>Note: The main carer will be identified by the individual or the person's GP or key worker if the person lacks capacity to identify one themselves.</p>
<p>Care workers</p>	<p>A care worker is employed to support and supervise vulnerable, infirm or disadvantaged people, or those under the care of the state. They can be volunteers who provide care as part of their work for the voluntary organisation or paid workers who are providing care by virtue of a contract of employment or any other contract.</p>
<p>Core content</p>	<p>The data and information that is recommended to be collected and held in electronic palliative care co-ordination systems for all people receiving palliative and end of life care.</p>

Term	Definition
Disability	Functional or cognitive impairments that affect a person's ability in communication, understanding, decision making or self-care.
End of life	<p>The General Medical Council defines people as 'approaching the end of life' when they are likely to die within the next 12 months. This includes individuals whose death is imminent (expected within a few hours or days); those with advanced, progressive, incurable conditions; those with general frailty and co-existing conditions that mean they are expected, to die within 12 months; those at risk of dying from a sudden acute crisis in an existing condition; and those with life-threatening, acute conditions caused by sudden catastrophic events.</p> <p>Source Treatment and care towards the end of life: good practice in decision making. General Medical Council (2010)</p>
End of life care (EoLC)	<p>Care that helps all those with advanced, progressive and terminal conditions to live as well as possible until they die. It enables the supportive and palliative care needs of both the individual and family to be identified and met through the last phase of life and into bereavement. It includes the physical care, management of pain and other symptoms and provision of psychological, social care, spiritual and practical support.</p> <p>Source End of life care strategy: promoting high quality care for adults at the end of their life. Department of Health (2008)</p>
End of life care diagnosis	<p>Primary diagnosis: the diagnosis that is the main contributing factor to the need for end of life care.</p> <p>Other relevant diagnoses and clinical problems: relevant diagnoses and medical problems that need to be taken into account when making end of life decisions.</p>
End of life care tools	Tools that health and social care professionals use to support provision of the best possible care for people who are nearing the end of their life.
Electronic Palliative Care Co-ordination Systems (EPaCCS)	Electronic systems linking care providers across a locality. By holding key information, centred on a core data set, for individuals who have been identified as approaching the end of life, the EPaCCS enables co-ordination of care for these people, and their families and carers.

Term	Definition
Frailty	<p>Frailty is a distinct health state related to the ageing process in which multiple body systems gradually lose their in-built reserves. Around 10% of people aged over 65 years have frailty, rising to between a quarter and a half of those aged over 85 years. Older people living with frailty are at risk of adverse outcomes such as dramatic changes in their physical and mental wellbeing after an apparently minor event which challenges their health, such as an infection or new medication.</p> <p>Source Fit for Frailty - consensus best practice guidance for the care of older people living in community and outpatient settings - a report from the British Geriatrics Society 2014.</p>
Gold Standards Framework (GSF)	<p>A recommended EoLC tool developed originally for use in primary care; it can also be used in care homes. It helps to identify people who are approaching the end of life, assess their needs and preferences, plan care and communicate across agencies.</p> <p>www.goldstandardsframework.org.uk</p>
Hospice	<p>Hospice includes NHS and voluntary specialist palliative care inpatient beds, including those located in NHS hospitals on NHS hospital grounds.</p>
Just-in-case box/anticipatory medicines	<p>Anticipatory prescribing of medicines commonly prescribed in palliative care with a 'just in case box' placed in the person's home, providing rapid access to these medications if required during the terminal phase of a person's illness.</p>
Key worker	<p>A key worker is a care professional who takes a key role in co-ordinating the care of the patient and promoting continuity, ensuring the patient knows who to access for information and advice.</p>

Term	Definition
<p>Lasting Powers of Attorney (LPA)</p>	<p>There are two different types of LPA:</p> <p>An LPA for property and financial affairs: This replaces the previous Enduring Power of Attorney and does not have power to make health decisions. Please note Enduring Powers of Attorney were replaced by Lasting Powers of Attorney but may still be used if made and signed before October 2007.</p> <p>An LPA for personal welfare: This LPA must be appointed while the individual has capacity, but only becomes active when the individual lacks capacity to make the required decision.</p> <p>The LPA must act according to the principles of best interests. The LPA's role can be extended to life-sustaining treatment decisions (LPA for personal welfare including health), but this must be expressly contained in the original application. A personal welfare LPA (PW-LPA) only supersedes an ADRT if the PW-LPA was appointed after the ADRT was made, and if the conditions of the PW-LPA cover the same issues as in the ADRT.</p> <p>Sources Mental Capacity Act 2005 Mental Capacity Act 2005 Code of Practice. Ministry of Justice 2007 Deciding right – a new north east initiative for making care decisions in advance Northern England Strategic Clinical Networks (2014)</p>
<p>Lead clinician</p>	<p>The most senior clinical decision maker responsible for the person. This could be a consultant, GP or nurse consultant. In some situations, there may be more than one lead clinician, each for a different discipline, eg a lead specialist palliative care physician, lead medical oncologist, lead geriatrician.</p>

Term	Definition
Mental capacity	<p>Mental capacity is the ability to make a decision. An assessment of a person's capacity must be based on their ability to make a specific decision at the time it needs to be made, and not their ability to make decisions in general. Under the Mental Capacity Act 2005 (England and Wales), anyone assessing someone's capacity to make a decision for themselves should use the two-stage test of capacity:</p> <ul style="list-style-type: none"> • does the person have an impairment of the mind or brain, or is there some sort of disturbance affecting the way their mind or brain works? (It doesn't matter whether the impairment or disturbance is temporary or permanent.) • if so, does that impairment or disturbance mean that the person is unable to make the decision in question at the time it needs to be made? <p>Reference Mental Capacity Act 2005 Code of Practice. Ministry of Justice 2007</p>
Palliative care co-ordination Previously called End of life care co-ordination	<p>A means of sharing information, using electronic or paper based systems, about an individual's preferences and choices for care when approaching the end of life between those caring for the person in order to improve communication, co-ordination and quality of their care.</p>
Preferred priorities for care (PPC)	<p>The PPC is an EoLC tool that essentially serves three purposes. It facilitates discussion(s) around end of life care wishes and preferences. The PPC can enable communication for care planning and decisions across care providers. And, thirdly, should the person lose capacity to make a decision about issues discussed, a previously completed PPC acts as an advance statement. This means that the information included within the PPC can be used as part of an assessment of a person's best interests when making decisions about their care.</p> <p>Source: Preferred Priorities for Care NHS Improving Quality (2014).</p>
Prognosis (end of life)	<p>A judgement about the likely outcome of a health condition or situation. Note: regarding end of life care, awareness of the prognosis is taken to mean awareness that the life span is limited.</p>

Appendix 1: additional content for palliative care record: extended data set

The core data set can be supplemented with additional information. These data items were identified by the Locality Registers Pilot sites. They were part of the consultation during the development of the information standard and can be considered for inclusion locally.

Content heading/subheading	Definition/illustrative description of the type of clinical information to be recorded under each heading
Religious, spiritual and cultural requirements	The core data set provides opportunity for recording these requirements but consideration could be given to a separate field. (data item: 'Other relevant issues or preferences about provision of care')
Current medication	Due to the potential difficulty of keeping a current medications field up to date, this has not been included in the core data set, however details of the current medications prescribed for the person can be included if the IT system allows auto generation of the record from the details held in the summary care record or GP record.
Next of kin	The name and contact telephone number of next of kin identified by the person.
Person lives alone	The core data set provides opportunity to record this within the main carer data item but consideration could be given to a separate field.
Sexual orientation	Sexual orientation refers to the general attraction a person feels towards one sex or another (or both). An optional field may be considered.
Syringe driver at home	The syringe driver is a small, portable battery-driver infusion pump, used to give medication subcutaneously via a syringe usually over 24 hours.
Other equipment at home	To include catheter/continence products at home.
Expressed wish for organ donation	The core data set provides opportunity for recording these requirements but consideration could be given to a separate field. (data item: 'Other relevant issues or preferences about provision of care')
Carer's assessment carried out	
Bereavement risk assessment	

Content heading/subheading	Definition/illustrative description of the type of clinical information to be recorded under each heading
Person's wishes of things to be avoided	The core data set provides opportunity for recording these requirements but consideration could be given to a separate field. Definition could be extended to include the details of people that the person requests are not contacted. (Data item: 'Other relevant issues or preferences about provision of care')
Preferred place of care	To identify where an individual would preferred to be cared for. To select from NHS hospice/specialist palliative care unit, voluntary hospice/specialist palliative care unit, person's own home, hospital, care home, other.
Plans for verification of death	To include permission/suitability for nurse verification of death.
Treatments that have been refused and circumstances of refusal	
Details of social care plan and location of document	Written agreements setting out how care will be provided within the resources available for people with complex needs. (Care Quality Commission).
Completion of form DS1500	Fast track application for benefits for people that are terminally ill.
Has person been accepted for Continuing Health Care funding	NHS continuing healthcare is a package of continuing care provided outside hospital, arranged for people with on-going healthcare needs. Someone nearing the end of their life is likely to be eligible if they have a condition that is rapidly getting worse and may be terminal. It is agreed for 12 week periods and reviewed. It may also run in conjunction with other service supplied via the local authority for assessed needs.
Reason for variance between actual and preferred place of death	<p>Locally determined pick list of reasons why the person did not die in their preferred place of death.</p> <p>Can consider the community data set codes:</p> <p>01 Family decided to move individual to hospital 02 Individual was moved to hospital for clinical reasons 03 Individual changed their mind 99 Not known</p>
Should person's GP be contacted out-of-hours? Telephone numbers	

Content heading/subheading	Definition/illustrative description of the type of clinical information to be recorded under each heading
Whether the person/family has been given a copy of the record	As a minimum, the individual should be offered a copy of the record or access to it.
Ethnicity	This could be considered to support equality monitoring.
Whether GP will sign death certificate in normal circumstances	
Date person added to Gold Standard Framework register	Please refer to glossary for definition.
Date of last discharge from hospital/hospice	The date of discharge from the most recent admission to hospital or hospice.
Implanted devices	Details of any implanted devices that may require management (includes implantable cardiac defibrillators).

Appendix 2: accountability considerations

This section considers the accountability of staff in relation to the use of electronic palliative care co-ordination systems (EPaCCS) or other electronic record keeping. It considers issues which could give rise to action in court or where breaches of guidance could result in upheld complaints against staff.

It is based on advice developed for the summary care record in collaboration with the Medical Protection Society <http://systems.hscic.gov.uk/scr/staff/faqs/mpsfaqs>

Accuracy of the record

All those using the record are entitled to rely on the accuracy of the record. Accountability for an erroneous entry lies with the person who made the entry. If others reading the record are aware of any inaccuracies, they are duty bound to raise their concerns with the responsible clinician (GP or key worker), as soon as possible.

Creation and/or sharing of a record for a person, with mental capacity, who had not given consent or who withdraws consent

The person creating the record without taking consent may be accountable and subject to a complaint. In the same way, the person informed of withdrawal of consent is responsible for removal of the record and is accountable if this is not carried out in a timely manner.

EPaCCS and best interest decisions

Staff may consider that an EPaCCS would be in the best interest of a person without mental competence and yet their appointed adult (for example, a person with Lasting Power of Attorney for personal welfare) dissents on their behalf. A competent adult is entitled to make their own decision, even if this might appear foolish or unwise to others, providing they have been given sufficient information to make an informed decision. Such a refusal should be respected. Where the person is an incompetent adult then the provisions of the Mental Capacity Act 2005 will apply.

Accessing a person's EPaCCS record on behalf of another staff member providing care for the person and who has a legitimate reason for looking at the EPaCCS

For example, an out-of-hours member of NHS healthcare staff without access to EPaCCS telephones the out-of-hours GP who has access, and requests information held in an EPaCCS.

The person accessing the record is responsible for determining whether the person requesting information has a legitimate reason to access the information and that there is not a breach of confidentiality.

Staff deciding not to view the EPaCCS record of a person for whom they are delivering care in cases where they don't come to harm; where they do come to harm; and when they subsequently complain

This position is the same as with manual records. If staff decide not to view a person's EPaCCS record (where of course staff have permission to do so) then, were the person to come to harm or subsequently complain because of an issue that arose as a result, in general it might be quite difficult to defend the case.

Staff would have to justify not looking, though it would depend to a certain extent on the facts. For example, not looking at the records then failing to comply with a person's choices clearly recorded in the EPaCCS, would be difficult to justify.

Failing to view an EPaCCS for other reasons: including reasons beyond the staff member's control like an IT failure, and reasons within their control such as a forgotten password

The position is the same as with manual records. If notes have been lost or are inaccessible (for example through IT failure) the staff member cannot be held responsible.

In such circumstances, staff should be able to demonstrate that they made best effort to find out the information held in the record by referring to manual records and, if these are not available, discussion with the person or their carers. It is good practice to record that known records were not viewed, the reason for not viewing and the efforts made to access the information.

Acting on information in the EPaCCS that is later proved to be inaccurate eg incorrect diagnosis, incorrect recording of a person's preferences for care or not timely, eg information that is two months out of date

The position is the same as with manual records. It would depend upon the facts of the case and whether the member of staff's decision was reasonable in the circumstances. The date of the most recent amendment to the EPaCCS is indicated on the record and so it is clear when the information was last updated. It is reasonable to assume that the record is accurate and up-to-date. If staff have any doubt or concern about the accuracy, it is their duty of care to make reasonable efforts to rectify. If an error occurs, staff may need to demonstrate that they acted in good faith.

When a clinical DNACPR decision has been made that attempting cardiopulmonary resuscitation would be unsuccessful, it is generally good practice to inform people of the decision, however, it is important that staff do not engage the person in discussion about resuscitation when the individual has indicated that s/he does not want to discuss CPR or when the person lacks capacity and it is not in the person's best interests. When a person is not aware of the DNACPR decision, staff should record the reason(s) for this in order to provide clarity of the decisions made and of the person's knowledge and so support other professionals in their communication with the person. More guidance is available in the joint BMA, Resuscitation Council (UK) and RCN statement – Decisions relating to cardiopulmonary resuscitation. Available at www.resus.org.uk/dnacpr/decisions-relating-to-cpr

Inappropriate access of a person's record and actions that must be taken

A member of staff who has acted inappropriately is personally responsible for their own actions and must always be able to justify their decisions. Professional staff are bound to comply with their professional code of conduct. If, however, he or she is an employee, then there may be responsibility on the part of the employer on the basis of vicarious liability.

Similarly, if the employer had inadequate procedures or protocols in place, then they might find themselves responsible. It is also the case that if a member of staff had shared their log-in details or had left the system logged in so that inappropriate access of the system was made, they could be held responsible.

It is important that participating organisations have clear and robust procedures in place and that staff are aware of and comply with them. Failure to do so could leave the employee subject to disciplinary action by their employer.

Legal aspects of advance care planning

The Mental Capacity Act of 2005 (MCA), supported by a Code of Practice provides a legal structure for advance care planning to ensure that people make decisions for themselves wherever possible, and protects people who lack capacity by providing a flexible framework that ensures individuals' best interests must be the basis for the decision making process.

People with capacity can appoint a person to have authority to make a decision on their behalf if they do not have capacity to do so themselves at a future time. A power of attorney is a legal document that allows them to do so. It is registered with the Public Guardian. (Chapter 7 of the MCA Code of Practice).

An advance decision to refuse life-sustaining treatment is a legal document. The MCA imposes particular legal requirements and safeguards on the making of advance decisions to refuse life-sustaining treatment, (Section 9.4 of the MCA Code of Practice).

Responsibility for changing a 'Do Not Attempt Cardiopulmonary Resuscitation' (DNACPR) decision

The staff member who makes a decision to change a cardiopulmonary resuscitation decision is responsible for updating the EPaCCS record and for notifying the person's GP as soon as possible. Staff cannot change a cardiopulmonary resuscitation decision made as part of an ADRT. That can only be made by the person or their LPA, although the clinician may be the person who updates it.

Professional responsibilities in relation to advance decisions to refuse treatment (ADRT)

The Mental Capacity Act (2005) and Code of Practice (2007) clearly define that the responsibility for making an advance decision lies with the person making it. It will often be helpful for the person to discuss their advance decision with a healthcare professional. If necessary this professional may give advice or support during this process about how to make the advance decision and ensure that health and social care professionals are aware of it.

Chapter 9 of the Mental Capacity Act Code of Practice provides detailed advice about professional responsibilities and issues to consider in relation to advance decisions to refuse treatment, including how to check whether one exists and guidance on the making, updating and cancelling of advance decisions.