End of life care co-ordination
Record keeping guidance

National Information Standard ISB 1580
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About NHS Improving Quality (NHS IQ)

NHS IQ is a new body, which brings together a number of improvement bodies—including the former National End of Life Care Programme—in order to drive improvement consistently across the NHS in England. NHS IQ has worked with PHE in the ongoing development of National Information Standard ISB 1580. NHS IQ is working to improve quality in end of life care as part of its dedicated Long Term Conditions Programme. Find out more at www.nhsiq.nhs.uk

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Foreword

The co-ordination of care is key to providing person-centred care across professional and organisational boundaries. One reason why services might fail to meet an individual’s needs is that professionals may not have access to information about a person’s preferences and wishes for their care: this prevents effective decision making and good care at a time when they need it most.

At the other end of the spectrum, a person may encounter many different health and social care professionals who cannot access previous information recorded about that person, simply because the professional is operating in a different part of the care system. This can lead to frustration, lack of co-ordination and poor care.

An electronic palliative care co-ordination system (EPaCCS) can solve this problem by allowing cross-boundary access to information about the person’s preferences and wishes, provided, of course, that the person is willing to have this information shared with relevant professionals.

The End of Life Care Strategy (2008) states that “all people approaching the end of life, and their carers, should be entitled to know that systems are in place to ensure that information about their needs and preferences can be accessed by all relevant health and social care staff with their permission”.

The Quality Standard for End of Life Care, published in 2011 by the National Institute for Health and Care Excellence (NICE), includes a definitive statement on this issue: “People approaching the end of life receive consistent care that is co-ordinated effectively across all relevant settings and services at any time of day or night, and delivered by practitioners who are aware of the person’s current medical condition, care plan and preferences.”

To achieve this, the “end of life care co-ordination information standard” provides a consistent safe and reliable way of recording and communicating this information, so that professionals deliver high quality, co-ordinated end of life care.

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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.

Whilst 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—End of life care co-ordination: Core content—identifies the key information that should be held in the end of life 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 as part of an initiative led by the National End of Life Care Programme and the Department of Health to provide an information standard for use in EPaCCS. Health and social care professionals, and their professional organisations, helped to develop the guidance.

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 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.¹

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 is the major aim of the end of life and palliative care strategies in all four countries of the UK.²,³,⁴,⁵,⁶

¹ Treatment and care towards the end of life: good practice in decision-making General Medical Council (2010)
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)
People’s preferences for end of life care should be recorded in a consistent way to support communication (with the person’s permission) 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 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 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 end of life care and a person’s inclusion on a register.

Communication may be achieved by keeping the record in the person’s home or current home (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 recording and communication of 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 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 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 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 end of life care for adults. Principles for record keeping for advance care planning are included together with recommended core record content to support 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 end of life 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 the full end of life care pathway 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 led by the English National End of Life Care Programme and the Department of Health to develop an information standard for use in EPaCCS to support the recording and communication of end of life care preferences and wishes. 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 core content for end of life care co-ordination. 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.

From April 2013, Public Health England through the National End of Life Care Intelligence Network and NHS England through NHS Improving Quality are supporting 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 end of life care process, for example, the Gold Standards Framework, Preferred Priorities for Care and Integrated Care Pathways for the Dying Person (see Glossary).

Planning for your future care by NEoLCP/University of Nottingham/NCPC (2012) summarises the care process for making end of life care choices from the person’s perspective:

- Opening the conversation
- Exploring your options
- Refusing specific treatment, if you wish to
- Identifying your wishes and preferences
- Letting people know your wishes
- Appointing someone to make decisions for you using a Lasting Power of Attorney
- Identifying who you would like to be consulted on your behalf

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:

- **Capacity, care planning and advance care planning in life limiting illness: A Guide for Health and Social Care Staff**, NEoLCP (2012)

- **The NICE Quality Standard for End of Life Care for Adults**, National Institute for Health and Care Excellence (2011)
• **Common core competences and principles for health and social care workers**, NEoLCP/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.

• **e-ELCA e-learning resources** that include modules on advance care planning and communication are freely available to health and social care staff.

• **Finding the Words**, NEoLCP (2011). A training DVD and workbook to support staff in end of life care conversations.

• **Difficult Conversations for Dementia**, NCPC (2011). A short booklet to support those caring for someone with dementia to open up conversations about end of life wishes and preferences.

Discussions with people at the end of life about their preferences and choices are extremely sensitive. The process of planning for end of life care is often an ongoing 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 formal paid carers, health and social care staff 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 has 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.

\(^7\) The differences between general care planning and decisions made in advance, NEoLCP (2010).
- 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.

6.2 Record keeping practice principles

General record keeping principles stipulated by the GMC (2013), NMC (2010), HCPC (2008), AoMRC (2008), AoMRC and NHS (2008) 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 end of life 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, DNACPR 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).

Whilst 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*, NEoLCP (2012):

- 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**, NEoLCP (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**, NEoLCP (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 end of life 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, a life expectancy of 12 months provides some guidance on the optimum timescale for introducing the topic of end of life care planning.

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 end of life 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 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 The code: Standards of conduct, performance and ethics for nurses and midwives, Nursing and Midwifery Council (2008).

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

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Not all people will want to have discussions about 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 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 carers, the person him/herself and relatives or informal 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 DNACPR opinion 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.9

It is recommended that data entry and changes to the DNACPR and ADRT fields are restricted to or reviewed by one named professional responsible clinician, for example, a person’s GP. The electronic registers should have within their specification a feature to notify this clinician automatically when the record has been modified. 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 6.12 Core content for end of life 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: A joint statement from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing (2007).
6.5 How do professionals know that an end of life care record has been created?

Local systems will be necessary to ensure that the relevant staff groups are able to identify individuals with an end of life 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 responsible 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 and formal carers.

To avoid confusion, it is important to close the record when a person dies. It is suggested that the person’s GP has responsibility for ensuring that the record is updated with the place and date of death.

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, DNACPR, 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 treatment\textsuperscript{10} 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

**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 DNACPR policies in place and an example protocol is provided in Appendix 3. 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 should not be instigated in the event of a cardiopulmonary arrest. 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 DNACPR recommendation, if the clinician assesses that CPR has a realistic chance of success then the patient must consent to CPR if they have capacity for this decision. If they do not have capacity, the decision is made using the best interests process of the Mental Capacity Act (2005). If CPR has no realistic chance of success then CPR is not an option and consent for CPR is not possible, but open dialogue is important, although many patients at the end of life understand that CPR is not an option.

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.)

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.

“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, 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, NEoLCP (2012).
6.9 Consent

Not all people will want to be included on the register and are 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 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. When possible, staff should seek consent each time the record is viewed.

An example of a consent model is London’s Co-ordinate my care programme.

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 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.

6.10 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. The information standard requires separate explicit informed consent for creation and sharing the end of life care co-ordination record.

New terminology, as detailed below, has been developed to provide clarity of the consent that has been granted (ie whether explicit, best interest decision, Lasting Power of Attorney consent) and where consent has been withdrawn. These codes, published in October 2013 become mandatory for completion on 01 June 2014

- consent given for sharing end of life care co-ordination record
- withdrawal of consent for sharing end of life care co-ordination record
- best interest decision taken (Mental Capacity Act 2005) for sharing end of life care co-ordination record
- consent given by appointed person with Lasting Power of Attorney for personal welfare (Mental Capacity Act 2005) for sharing end of life care co-ordination record

There are two timing options for seeking consent for the sharing of the EPaCCS section of a wider clinical record:

1. Include specific informed consent for creation and sharing end of life care preferences at the time of creating a shared record. 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 end
of life care preferences, a conversation then takes place with the person at that time to seek specific consent for the EPaCCS content.

6.11 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.

6.12 Core content for end of life care co-ordination

The Academy of Medical Royal Colleges and the Royal College of Nursing recommend that records should have a standardised structure (AoMRC 2008,11, RCN (2010).12 New Standards for the Clinical Structure and Content of Patient Records were published by AoMRC and HSCIC in July 2013. Please note that the next version of the information standard will be aligned with the Clinical Documentation and Generic Record Standards headings specified in this guidance.

The following table provides defined content “headings” for structuring the information deemed to be essential for effective end of life 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 end of life care.

References:
12 Nursing Content of eHealth records (2010). Royal college of Nursing eHealth Publications
NMC (2009) Record keeping: Guidance for nurses and midwives
<table>
<thead>
<tr>
<th>Content heading/subheading</th>
<th>Definition/illustrative description of the type of information to be recorded under each heading</th>
</tr>
</thead>
<tbody>
<tr>
<td>1  Consent status*</td>
<td></td>
</tr>
<tr>
<td>2  Record creation* and record amendment* dates</td>
<td></td>
</tr>
<tr>
<td>3  Planned review date*</td>
<td>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 end of life care.</td>
</tr>
<tr>
<td>4  Person’s details</td>
<td>Note: Gender is self-declared gender.</td>
</tr>
</tbody>
</table>
|     Name* including preferred name | No/Yes Pick list of languages  
<p>|     Date of birth*    | Functional or cognitive impairments that affect a person’s ability in communication, understanding, decision-making or self-care. |
|     Usual address*   |                                                                                               |
|     NHS number      |                                                                                               |
|     Telephone contact details |                                                                                               |
|     Gender (self-declared) |                                                                                               |
|     Need for interpreter |                                                                                               |
|     Preferred spoken language |                                                                                               |
|     Functional status and disability |                                                                                               |
| 5  Main informal carer     | This is the individual, excluding paid carers or carers from voluntary agencies, nominated by the person to hold major responsibility for providing their informal care and support. |
|     Name                 | Note: The main informal carer will be identified by the person’s GP or key worker if the person lacks capacity to identify one for him/herself. |
|     Telephone number     | A prognosis is a judgement about the likely outcome of a health condition or situation. Regarding end of life care, awareness of the prognosis is taken to mean awareness that the life span is limited. |
|     Availability of Informal Carer Support* |                                                                                               |</p>
<table>
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<tr>
<th>Content heading/subheading</th>
<th>Definition/illustrative description of the type of information to be recorded under each heading</th>
</tr>
</thead>
</table>
| **6** GP details           | Name of usual GP*  
Practice name, address, telephone and fax numbers*                                                                 |
| **7** Key worker           | Name  
Telephone number  
A health or social care professional who, with the person approaching the end of life’s consent and agreement, takes a key role in co-ordinating their care and promoting continuity, ensuring the person knows who to access for information and advice. |
| **8** Formal carers involved in care | Name  
Professional group  
Telephone number  
Health and social care professionals and staff, including carers from voluntary agencies, providing care and support for the person. Lead clinician(s) should be clearly indicated within this list. |
| **9** Medical details      | Primary end of life care diagnosis*  
Other relevant end of life care diagnoses and clinical issues  
Allergies or adverse drug reactions  
The diagnosis that is the main contributing factor to the need for end of life care.  
Relevant diagnoses and medical problems that need to be taken into account when making end of life care decisions. This includes mental health issues such as depression, anxiety and dementia.  
Relevant drug and non-drug allergies, as well as adverse drug reactions, sensitivities and intolerances. |
| **10** “Just in case box”/anticipatory medicines | Whether they have been prescribed  
Where these medicines are kept  
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. |
| **11** End of life care tools in use | Name of tools, eg Gold Standards Framework, Integrated Care Pathway, Preferred Priorities for Care  
See Glossary. The name of the tool is recorded eg GSF, Integrated Care Pathway, PPC etc. |
| **12** Advance statement   | Requests or preferences that have been stated  
See Glossary. Free text fields |
<table>
<thead>
<tr>
<th>Content heading/subheading</th>
<th>Definition/illustrative description of the type of information to be recorded under each heading</th>
</tr>
</thead>
<tbody>
<tr>
<td>13 Preferred place of death 1st and 2nd choices if made</td>
<td>This is key information to support people’s preferences. Professionals may wish to rephrase this question 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 structured list of responses below is used to support outcome evaluation, with the addition of free text for specific detail, eg which hospice. 1 Hospital 2 NHS hospice/specialist palliative care unit 3 Voluntary hospice/specialist palliative care unit 4 Person’s own home 5 Care home 6 Other plus free text 7 Usual place of residence</td>
</tr>
<tr>
<td>14 Do not attempt cardiopulmonary resuscitation (DNACPR) decision made Whether a decision has been made, the decision, date of decision, location of documentation and date for review.</td>
<td>See Glossary. Recording of an opinion in the case of a clinician or a decision in the case of ADRT about cardiopulmonary resuscitation, the decision, date of decision, the location of the document and the review date.</td>
</tr>
<tr>
<td>15 Person has made an advance decision to refuse treatment (ADRT) Whether a decision has been made, the decision, date of decision and the location of the documentation</td>
<td>See Glossary. Record of whether an ADRT has been made and the location of the document where the decisions are recorded</td>
</tr>
<tr>
<td>16 Lasting Power of Attorney (LPA) for personal welfare?</td>
<td>See Glossary. Recording of whether a LPA has been appointed and the authority of the LPA: • with authority for life sustaining decisions or • without authority for life sustaining decisions.</td>
</tr>
<tr>
<td></td>
<td>Name and contact details of LPA</td>
</tr>
</tbody>
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### Content heading/subheading

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<tr>
<th>Content heading/subheading</th>
<th>Definition/illustrative description of the type of information to be recorded under each heading</th>
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</thead>
<tbody>
<tr>
<td>17 Names and contact details of others (1 and 2) that the person wants to be involved in decisions about their care</td>
<td></td>
</tr>
<tr>
<td>18 Other relevant issues or preferences around provision of care?</td>
<td>This may include: 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.</td>
</tr>
<tr>
<td>19 Actual place of death</td>
<td></td>
</tr>
<tr>
<td>20 Date of death</td>
<td></td>
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* Completion of these items is mandatory.

### 6.13 Guidance

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

- **Record keeping: Guidance for nurses and midwives.** Nursing & Midwifery Council (2009)
- **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** (2012) 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)
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 AoMRC\textsuperscript{13} 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.

Review of this guidance

This guidance will be reviewed in 2016. 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

Thank you to everyone who supported the development of this guidance. Special thanks to Anne Casey, Stephen Lock, Professor Rob George, Dr Claud Regnard, Dr Julia Riley, Dr Patrick McDaid, Dr Julian Abel, Dr Chi Chi Cheung, Dr Caroline Tait, Dr Catherine Millington-Sanders and the National End of Life Care Programme team.

Katie Lindsey, National End of Life Care Intelligence Network, developed the national information standard for End of life care co-ordination: Core content.

The following professional organisations were consulted in the development of the national information standard for End of life 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

Health Professions Council

Joint RCGP/GPC IT Committee

Royal College of General Practitioners

Royal College of Nursing

Royal College of Physicians
## 10 Glossary

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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</table>
| **Advance care planning (ACP)** | 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. Under the terms of the Mental Capacity Act 2005, formalised outcomes of advance care planning might include one or more of the following:  
- 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) |
| **Advance decision to refuse treatment (ADRT)** | 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. An advance decision to refuse treatment:  
- can be made only by someone over the age of 18 who has mental capacity |
| **Advance statement** | 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.

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.

**Sources:**
Mental Capacity Act 2005 |
| **Advance decision** | 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

**Sources:**
Advance decisions to refuse treatment, NEoLCP (2013)
Mental Capacity Act 2005
| **Best interests** | 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.  

**Reference:**  
| **Disability** | Functional or cognitive impairments that affect a person’s ability in communication, understanding, decision making or self-care. |
| **Do not attempt cardiopulmonary resuscitation decision (DNACPR)** | **Cardiopulmonary resuscitation (CPR):** Emergency treatment that supports the circulation of blood and/or air in the event of a respiratory and/or cardiac arrest.  

**CPR decision:** An opinion, in the case of a clinician or a decision in the case of an ADRT for or against cardiopulmonary resuscitation. Such decisions only apply to restoring 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.  

**Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Decision:** Only covers views about withholding CPR in the event of a future arrest. It is completed by the clinician responsible for care.  

**Sources:**  
Decisions relating to cardiopulmonary resuscitation. A joint statement from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing (2007)  
Quality standards for cardiopulmonary resuscitation practice and training. Resuscitation Council (2013)  
Deciding right – a new north east initiative for making care decisions in advance NHS North East (2012) |
| **End of life** | 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.

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

| End of life care co-ordination (EoLCC) | 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.  

**Source:**  
*End of life care strategy: promoting high quality care for adults at the end of their life*  
Department of Health (2008) |
<table>
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<tbody>
<tr>
<td>End of life care (EoLC)</td>
<td>A means of sharing information, using electronic or paper based systems, about an individual's preferences and choices for care at the end of life between those caring for the person in order to improve communication, co-ordination and quality of their care.</td>
</tr>
</tbody>
</table>
| End of life care diagnosis | Primary diagnosis: The diagnosis that is the main contributing factor to the need for end of life care.  
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) | A new term to replace “locality registers”. 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. |</p>
<table>
<thead>
<tr>
<th><strong>Formal carers</strong></th>
<th>Health and social care professionals and staff, including carers from voluntary agencies, providing care and support for the person.</th>
</tr>
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<tbody>
<tr>
<td><strong>Gold standards framework (GSF)</strong></td>
<td>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. <a href="http://www.goldstandardsframework.org.uk">www.goldstandardsframework.org.uk</a></td>
</tr>
<tr>
<td><strong>Integrated care pathway (ICP)</strong></td>
<td>A tool that consists of a systematic and structured multidisciplinary approach to care and documentation of care.</td>
</tr>
<tr>
<td><strong>Just-in-case box/anticipatory medicines</strong></td>
<td>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.</td>
</tr>
<tr>
<td><strong>Key worker</strong></td>
<td>A health or social care professional who, with the person approaching the end of life’s consent and agreement, takes a key role in co-ordinating their care and promoting continuity, ensuring the person knows who to access for information and advice.</td>
</tr>
</tbody>
</table>
| **Lasting Powers of Attorney (LPA)** | There are two different types of LPA:  
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.  
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.  
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.  
Sources:  
Mental Capacity Act 2005  
<table>
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<tbody>
<tr>
<td><strong>Lead clinician</strong></td>
</tr>
<tr>
<td><strong>Locality register</strong></td>
</tr>
<tr>
<td><strong>Main informal carer</strong></td>
</tr>
<tr>
<td><strong>Mental capacity</strong></td>
</tr>
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<td></td>
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<tr>
<td></td>
</tr>
<tr>
<td><strong>Preferred priorities for care (PPC)</strong></td>
</tr>
<tr>
<td><strong>Prognosis (end of life)</strong></td>
</tr>
</tbody>
</table>

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.
Appendix 1: Additional content for end of life 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.

<table>
<thead>
<tr>
<th>Content heading/subheading</th>
<th>Definition/illustrative description of the type of clinical information to be recorded under each heading</th>
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</thead>
<tbody>
<tr>
<td>Consent</td>
<td>Recording of a person’s consent for inclusion in the record and for sharing information with health and social care professionals.</td>
</tr>
<tr>
<td>Religious, spiritual and cultural requirements</td>
<td>The core data set provides opportunity for recording these requirements (other relevant issues or preferences about provision of care: data item 47) but consideration could be given to a separate field.</td>
</tr>
<tr>
<td>Current medication</td>
<td>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 autogeneration of the record from the details held in the Summary Care Record or GP record.</td>
</tr>
<tr>
<td>Next of kin</td>
<td>The name and contact telephone number of next of kin identified by the person.</td>
</tr>
<tr>
<td>Person lives alone</td>
<td>The core data set provides opportunity to record this (other relevant issues or preferences about provision of care: data item 47) but consideration could be given to a separate field.</td>
</tr>
<tr>
<td>Sexual orientation</td>
<td>Sexual orientation refers to the general attraction a person feels towards one sex or another (or both). An optional field may be considered.</td>
</tr>
<tr>
<td>Syringe driver at home</td>
<td>The syringe driver is a small, portable battery-driver infusion pump, used to give medication subcutaneously via a syringe usually over 24 hours.</td>
</tr>
<tr>
<td>Content heading/subheading</td>
<td>Definition/Illustrative description of the type of clinical information to be recorded under each heading</td>
</tr>
<tr>
<td>---------------------------</td>
<td>---------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Other equipment at home</td>
<td>To include catheter/continence products at home.</td>
</tr>
<tr>
<td>Expressed wish for organ donation</td>
<td>The core data set provides opportunity for recording these requirements (other relevant issues or preferences about provision of care: data item 47) but consideration could be given to a separate field.</td>
</tr>
<tr>
<td>Carer’s assessment carried out</td>
<td></td>
</tr>
<tr>
<td>Bereavement risk assessment</td>
<td></td>
</tr>
<tr>
<td>Person’s wishes of things to be avoided</td>
<td>The core data set provides opportunity for recording these requirements (other relevant issues or preferences about provision of care: data item 47) 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.</td>
</tr>
<tr>
<td>Preferred place of care</td>
<td>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.</td>
</tr>
<tr>
<td>Plans for verification of death</td>
<td>To include permission/suitability for nurse verification of death.</td>
</tr>
<tr>
<td>Treatments that have been refused and circumstances of refusal</td>
<td></td>
</tr>
<tr>
<td>Resuscitation discussed with person and date. If not – why?</td>
<td></td>
</tr>
<tr>
<td>Resuscitation discussed with family and date. If not – why?</td>
<td></td>
</tr>
<tr>
<td>Details of social care plan and location of document</td>
<td>Written agreements setting out how care will be provided within the resources available for people with complex needs. (Care Quality Commission)</td>
</tr>
<tr>
<td>Completion of form DS1500</td>
<td>Fast track application for benefits for people that are terminally ill.</td>
</tr>
<tr>
<td>Content heading/subheading</td>
<td>Definition/Illustrative description of the type of clinical information to be recorded under each heading</td>
</tr>
<tr>
<td>---------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Has person been accepted for Continuing Health Care funding</td>
<td>NHS continuing healthcare is a package of continuing care provided outside hospital, arranged for people with ongoing 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.</td>
</tr>
<tr>
<td>Reason for variance between actual and preferred place of death</td>
<td>Locally determined pick list of reasons why the person did not die in their preferred place of death.</td>
</tr>
<tr>
<td>Should person’s GP be contacted out-of-hours? Telephone numbers</td>
<td></td>
</tr>
<tr>
<td>Whether the person/family has been given a copy of the record</td>
<td>It is good practice to offer a copy of the record or access to it.</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>This could be considered to support equality monitoring.</td>
</tr>
<tr>
<td>Whether GP will sign death certificate in normal circumstances</td>
<td></td>
</tr>
<tr>
<td>Date person added to Gold Standard Framework register</td>
<td>Please refer to Glossary for definition.</td>
</tr>
<tr>
<td>Date of last discharge from hospital/hospice</td>
<td>The date of discharge from the most recent admission to hospital or hospice.</td>
</tr>
</tbody>
</table>
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/pages/dnar.pdf](http://www.resus.org.uk/pages/dnar.pdf)

**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 DNACPR decision is responsible for updating the EPaCCS record and for notifying the person’s GP as soon as possible. Staff cannot change a DNACPR 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.
Appendix 3: Example of DNACPR Policy

UNIFIED DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION (DNACPR)
In the event of cardiac or respiratory arrest no attempts at CPR will be made. All other appropriate treatment and care will be provided.

Notes: This form should be completed legibly in black ball point ink
- The patient’s full name, NHS or Hospital number, date of birth and address should be written clearly.
- The date of writing the decision should be entered.
- If the decision is cancelled the form should be crossed through with 2 diagonal lines in black ball point ink and “CANCELLED” written clearly between them, signed and dated by the healthcare professional.
- It is the responsibility of the healthcare professional cancelling the DNACPR decision to communicate this to all parties informed of the original decision (see section 4 on form)
If the original form is leaving the trust with the patient, please photocopy and file the copy in the patient’s notes for audit purposes.

<table>
<thead>
<tr>
<th>1.</th>
<th>Reason for DNACPR decision</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.A</td>
<td>CPR is unlikely to be successful</td>
<td>Summary of the main clinical problems and reasons why CPR would be inappropriate, unsuccessful or not in the person’s best interests. Be as specific as possible. In this situation discussion with patient / relevant other about CPR is not necessarily needed, but patient / relevant other should be aware of goals of care. Record the details of discussion or the reason for not discussing in the person’s notes.</td>
</tr>
<tr>
<td>1.B</td>
<td>CPR may be successful, but may be followed by a length and quality of life which would not be of overall benefit to the patient</td>
<td>Summary of communication with patient... State clearly what was discussed and agreed. If this decision was not discussed with the patient state the reason why this was inappropriate. If the patient does not have capacity, do they have a valid and applicable advance decision to refuse treatment? If not, their relatives or friends should be asked what the patient’s wishes might have been. If there is no one appropriate to consult and the patient lacks capacity then an instruction to an IMCA should be considered. If the patient has made a Lasting Power of Attorney (LPA), appointing a Welfare Attorney to make decisions on their behalf, that person must be consulted. A Welfare Attorney may be able to refuse life-sustaining treatment on behalf of the patient if this power is included in the original LPA. You need to check this by reading the LPA. If the patient has capacity ensure that discussion with others does not breach confidentiality. State the names and relationships of relatives / relevant others with whom this decision has been discussed. More detailed description of such discussion should be recorded in the clinical notes where appropriate.</td>
</tr>
<tr>
<td>1.C</td>
<td>DNACPR is in accord with the recorded, sustained wishes of the patient who is mentally competent</td>
<td>Record the assessment of capacity in the clinical notes. Ensure that any advance decision to refuse treatment is valid for the patient’s current circumstances. If this decision has not been discussed with the patient or Welfare Attorney state the reason.</td>
</tr>
</tbody>
</table>

2. Healthcare professional making this DNACPR decision/verification

State names and positions. In general this should be the most senior healthcare professional immediately available. The decision must be verified by the most senior healthcare professional responsible for the patient’s care at the earliest opportunity (within 48 hours in Acute Trusts). If the person making the decision is the most senior person, verification is not required.

3. Review

A fixed review date is not recommended. This decision should be “INDEFINITE” unless:
- i) a definite review date is specified
- ii) there are changes in the patient’s condition and CPR is likely to be successful
- iii) their expressed wishes change and CPR is likely to be successful
Reviewer needs to complete all details on the form and document the outcome in the notes.

4. Who has been informed of this DNACPR decision?

Please ensure that all Health Care Professionals who have been informed are aware of their responsibility to document the decision in their own records, as the original stays with the person.

5. Ambulance crew instructions

These should be completed by a doctor prior to ambulance transfer. Section c) is the name and telephone number of the destination and Next Of Kin (NOK). Section e) to be completed by the doctor.
**UNIFIED DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION (DNACPR)**

In the event of cardiac or respiratory arrest, no attempts at CPR will be made. All other appropriate treatment and care will be provided.

<table>
<thead>
<tr>
<th>Name</th>
<th>Address</th>
</tr>
</thead>
</table>

**Date of birth**

| NHS or hospital number | Date of DNACPR decision: __/__/___ |

**1. Reason for DNACPR decision:**

- **A)** CPR is unlikely to be successful due to
  - [ ] This decision has been discussed with the patient
  - [ ] This decision has been discussed with relevant other
  - [ ] Name of relevant other

- **B)** CPR may be successful, but followed by a length and quality of life which would not be of overall benefit to the patient.
  - [ ] Patient involved in discussions?
  - [ ] Patient lacks mental capacity and has a legally appointed Welfare Attorney: Name
  - [ ] Patient lacks mental capacity and does not have a legally appointed Welfare Attorney. Decision is made on the balance of overall benefit to the patient in discussion with:
  - [ ] Name(s)

- **C)** DNACPR is in accord with the recorded, sustained wishes of the patient who is mentally competent.
  - [ ] Valid and applicable Advance Decision to Refuse Treatment (ADRT) seems?

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
<th>Date / /</th>
<th>Time</th>
</tr>
</thead>
</table>

**2. Healthcare professional making this DNACPR decision:**

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Signature</th>
<th>Date / /</th>
<th>Time</th>
</tr>
</thead>
</table>

Healthcare professional verifying this DNACPR decision if original decision made by a professional without overall responsibility for the patient’s care:

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Signature</th>
<th>Date / /</th>
<th>Time</th>
</tr>
</thead>
</table>

**3. Review:**

This is an indefinite decision / needs review (delete as appropriate)

<table>
<thead>
<tr>
<th>Review date if appropriate / /</th>
<th>Outcome of review: DNACPR to continue?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name Position Date / / Time</td>
<td>Yes</td>
</tr>
</tbody>
</table>

**4. Who has been informed of this DNACPR decision?**

Please inform all relevant parties and tick when informed:

- [ ] Patient
- [ ] GP
- [ ] Nursing Home
- [ ] Relative (Name)
- [ ] Ambulance
- [ ] Community Hospital
- [ ] Hospice
- [ ] Out of Hours
- [ ] Acute Trust (Name contact)
- [ ] Other (please state)

<table>
<thead>
<tr>
<th>Name</th>
<th>Signature</th>
<th>Date</th>
</tr>
</thead>
</table>

**5. Ambulance crew Instructions:**

(Please fax a copy of this form to GWAS on 08451 204340 or email a copy to ......................)

- [ ] All other supportive care should be given.
- [ ] If whilst in transit the patient suddenly deteriorates, continue journey and try to contact destination:
  - Destination name & telephone no.
  - Next of kin name & telephone no.
- [ ] If whilst in transit the patient dies continue to / return to acute setting.

<table>
<thead>
<tr>
<th>Name</th>
<th>Signature</th>
<th>Date</th>
</tr>
</thead>
</table>

DNACPR unified form draft 28.3.11, Author Dr R McGubbie

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Appendix 4: DNACPR Decision pathway


Making a CPR decision

If you cannot anticipate what you would write on the death certificate if the patient arrested it is not possible to make a CPR decision in advance. If you cannot anticipate on arrest, consent for (or refusal of) CPR cannot be obtained since any arrest will be unexpected.

Consequences:
- The young person or adult with capacity must be given opportunities to receive information or an explanation about any aspect of their treatment. If the individual wishes, this may include information on the CPR treatment and its likely success in different circumstances.
- Continue to communicate progress to the individual (and to the partner/family if the individual agrees).
- Review regularly to check if circumstances have changed.

In the event of an unexpected arrest, carry out CPR if there is a reasonable possibility of success (if in doubt, start CPR and call for help from colleagues, arrest team or paramedics).

If it is likely that the individual is going to die naturally because of an irreversible condition. Consent is not possible since CPR is not an available option, but communication about end of life issues should continue.

Consequences:
- Document the reason why there is no realistic chance that CPR could be successful, e.g., “Deterioration caused by advanced cancer.”
- Continue to communicate progress to the patient (and to the partner/family if the patient agrees or if the patient lacks capacity). This explanation may include information as to why CPR treatment is not an option.
- Continue to elicit the concerns of the individual, partner, family or parents.
- Review regularly to check if circumstances have changed.
- To allow a comfortable and natural death effective supportive care should be in place, with access if necessary to specialist palliative care, and with support for the partner, family or parents. The latest Liverpool Pathway (v12) can be used as a quality framework.
- If a second opinion is requested, this request should be respected, wherever possible.

In the event of the expected death, AND (Allow Natural Dying) with effective supportive care in place, including specialist palliative care if needed.

In children: discuss the options with the parents who can consent for CPR treatment.

In adults: check if there is a valid and applicable Advance Decision to Refuse Treatment (ADRT) refusing CPR, a registered and signed Personal Welfare (Health & Welfare) Lasting Power of Attorney order (with its accompanying third party certificate) with the authority to decide on life-sustaining treatment, or a court-appointed deputy is involved. The most recent order takes precedence. Otherwise make a decision in the patient’s best interests, following the Best Interests process as required by the Mental Capacity Act.

When there is only a small chance of success and there are questions whether the burdens outweigh the benefits of attempting CPR the involvement of the individual in making the decision is paramount if they have the capacity to make the decision. When the individual is a child, those with parental responsibility should be involved in the decision where appropriate. When a young person or adult does not have capacity for this decision, the CPR decision is made according to the requirements of the Best Interests process as required by the Mental Capacity Act.

In the case of serious doubts or disagreement further input should be sought from an IMCA, local Clinical Ethics Advisory Group or, if necessary, the courts.

- Decisions about CPR can be sensitive and complex and should be undertaken by experienced members of the healthcare team and documented carefully.
- Decisions should be reviewed regularly and when the circumstances change.
- Advice should be sought if there is any uncertainty over a CPR decision.