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

Change specification

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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About NHS Improving Quality (NHS IQ)

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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SCCI Standardisation Committee for Care Information

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.

Document information:

Title	Previously: End of life care co-ordination: core content Now: Palliative care co-ordination: core content
SCCI reference	SCCI1580 Amd 11/2015
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Approvals:

Name	Organisation	Version	Date
Julia Verne	Public Health England	1.0	12.06.2015
Maggie Morgan-Cooke	NHS Improving Quality	1.0	12.06.2015

Glossary of terms:

Term	Definition
Acute hospital (NEW)	Acute hospitals provide a wide range of specialist care and treatment for patients. Services offered in acute hospitals include: • 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 www.nrls.npsa.nhs.uk/resources/healthcare-setting/acute-hospital
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 (‘health and welfare’ and/or ‘property and affairs’) **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 Mental Capacity Act 2005 Code of Practice. Ministry of Justice 2007

Term	Definition
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 • 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** 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 Mental Capacity Act 2005Code of Practice. Ministry of Justice 2007. Advance decisions to refuse treatment NEoLCP (2013)

Term	Definition
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** 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
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 check list of common factors that must always be considered when trying to work out someone's best interests. Reference: Mental Capacity Act (2005) Code of Practice. Ministry of Justice 2007

Term	Definition
Cardiopulmonary resuscitation decision	**Cardiopulmonary resuscitation** Emergency treatment that supports the circulation of blood and/or air in the event of a respiratory and/or cardiac arrest. **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. **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. **Sources** Decisions relating to cardiopulmonary resuscitation. Guidance 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 north east initiative for making care decisions in advance. Northern England Strategic Clinical Networks. (2014)
Carer	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.) 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.
Care workers	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.

Term	Definition
Community hospital (NEW)	The community hospital is a service that offers integrated health and social care and is supported by community-based professionals (Meads, G. Participate. University of Warwick, 2004).
Core content	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.
Disability	Functional or cognitive impairments that affect a person's ability in communication, understanding, decision making or self-care.
End of life	The General Medical Council defines people as 'approaching the end of life' as those 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, general frailty and co-existing conditions that mean people are expected, to die within 12 months, existing conditions if people are at risk of dying from a sudden acute crisis in their condition and 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 (EoLC)	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)
End of life care diagnosis	Primary diagnosis: the diagnosis that is 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.

Term	Definition
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.
Frailty	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. **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.
Gold Standards Framework (GSF)	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. www.goldstandardsframework.org.uk
Hospice (NEW)	Hospice includes NHS and voluntary specialist palliative care inpatient beds, including those located in NHS hospitals and on NHS hospital grounds.
Just-in-case box/anticipatory medicines	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.
Key worker	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.

Term	Definition
Lasting Powers of Attorney (LPA)	There are two different types of LPA. A Property and Financial Affairs LPA: 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. A Personal Welfare LPA: this must be made 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. It can be extended to life-sustaining treatment decisions (Personal Welfare LPA 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 Mental Capacity Act 2005 Code of Practice. Ministry of Justice 2007 Deciding right - a north east initiative for making care decisions in advance. Northern England Strategic Clinical Network (2012)
Lead clinician	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.

Term	Definition
Mental capacity	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: • 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? Reference: Mental Capacity Act 2005 Code of Practice. Ministry of Justice 2007.
Palliative care co-ordination (previously called End of life care co-ordination)	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.
Preferred Priorities for Care (PPC)	The PPC is an EoLC tool which 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 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. **Source:** Preferred Priorities for Care, NEoLCP (2011)
Prognosis (end of life)	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.

Contents

1 Overview

1.1 Summary

Standard	
Standard number	SCCI1580
Standard title	Previously: End of life care co-ordination: Core content Now: Palliative care co-ordination: Core content
Description	Improving the co-ordination and quality of care provided for people at the end of life is a priority for NHS England. The information standard specifies the core content to be held in EPaCCS and supports NHS England's objective to increase the use of technology to help people manage their health and care. Palliative and end of life care is often delivered by a range of professional groups across care settings and sectors including out-of-hours doctors and ambulance services. Approaches to communication between providers of end of life care vary and depend on local service and system configuration. EPaCCS offers an approach to manage the sharing of palliative care information (with the person's consent) with the professionals caring for the individual and so help providers better manage communication and co-ordination of patient care. The core content includes palliative and end of life care decisions and preferences and the standard supports accurate and consistent recording of this information. Timely access to reliable and up to date information through EPaCCS will support people to die in the place of their choosing and with their preferred care package.
Release	
Release number	Amd 11/2015
Release title	Version 4
Description	Following feedback from implementers, national consultation, national review and phasing out of the Liverpool Care Pathway, changes to the national information standard SCCI1580 – Palliative care co-ordination: core content are required to ensure that the standard continues to meet user needs and remains fit for purpose. The changes are: **1. Change of title of the information standard** The title of the information standard has been changed to palliative care co-ordination: core content to improve clarity that EPaCCS records are to be

used for people who receive palliative care and not just for those in the last weeks/days of life. The name change also aligns with EPaCCS and the proposed Palliative Care Clinical Data Set.

2. Coding updates

Updating the Requirements specification with the new codes which were not available at time of publication of Amd16/2013, but have subsequently been published April 2014.

- disability
- functional status
- is main carer aware of person’s prognosis?

3. Correction

Correction of minor printing error in current Requirements specification.

4. New data items

- new data item to record NHS number status indicator code
- new data item to record the likely prognosis
- new data item to record awareness of cardiopulmonary resuscitation decision

5. Amendment to current data items

- changed terminology for informal and formal carers
- changed title of data item: DNACPR decision made
- changed categories for preferred place of death and actual place of death
- summary table of data items has been aligned to the headings recommended in the standards for the clinical structure and content of patient records published by Academy of Medical Royal Colleges (AoMRC). July 2013
- changed the data entry status for data item: NHS number from required to mandatory
- removal of ‘on integrated care pathway’ from data item: EoLC tool in use
- updated to new NHS Data Model and Dictionary terminology for Gender
- note added to Requirements Specification regarding timescales for withdrawal of maintenance for Read terminology
- updated SNOMED terminology where required
- changed definitions for key worker and carer in line with new NHS Data Model and Dictionary definitions

6. Updating of guidance documents and other changes

	• updating of the guidance documents • minor changes to guidance on consent that is provided in the implementation and record keeping guidance • recommendation that EPaCCS systems should include reporting functionality • risks and issues have been added to the Implementation guidance • ordering and numbering of the data items has been changed • information regarding mandatory collection of NHS number • maintenance section has been updated • the glossary has been updated
Conformance date	1 March 2016

1.2 Supporting products

Ref #	Title	Reference
1	Palliative care co-ordination: core content. Record keeping guidance	www.endoflifecare-intelligence.org.uk/resources/publications/record_keeping_guidance
2	Palliative care co-ordination: core content. Implementation guidance	www.hscic.gov.uk/isce/publication/scci1580
3	Guidance on information governance	http://systems.hscic.gov.uk/qipp/library/epaccsig.pdf
4	Care co-ordination interoperability	http://developer.nhs.uk/library/interoperability/care-co-ordination-interoperability/
5	Information sharing patterns summary	http://developer.nhs.uk/library/architecture/integration-patterns/information-sharing-patterns-summary/
6	Clinical safety report	www.hscic.gov.uk/isce/publication/scci1580

1.3 Related standards

Reference	Title
ISB 1500 to 1507	Common User Interface standards for entry and/or display of: patient name, address, telephone number, sex and gender, NHS number; date; time; patient banner
ISB 0129	Clinical Risk Management: its Application in the Manufacture of Health IT Systems
ISB 0160	Clinical Risk Management: its Application in the Deployment and Use of Health IT Systems
ISB 0149-02	NHS number for secondary care
ISB 0149-01	NHS number for general practice
ISB 1552 & 1553	Read Codes
ISB 0034	SNOMED CT
ISO/IEC 27001:2005	Information technology – security techniques – information security management systems – requirements www.iso.org/iso/catalogue_detail?csnumber=42103
ISB 0090	Organisation Data Service (ODS)

2 Change Specification

This section details the Amd11/2015 changes to the information standard. A summary table of the changes to the data set is included in Appendix 2. For full information about the information standard, please refer to the Palliative care co-ordination Requirements specification.

Please note that some codes required to support the revised standard will not be published until October 2015. These are specified in the information below. TRUD will issue a notification on release of the codes and they will be provided as corrigendum for the standard on the SCCI website.

2.1 New items

2.1.1 New data item: to record the Likely prognosis

Data item title	Likely prognosis
Description	A clinical judgement indicating the anticipated period of time until death
Requirement	Used to denote those who are nearing their last months/weeks/days of life but with recognition of the uncertainty related to such a judgement Last days of life (definition: death is likely in <1 week) Last weeks of life (definition: death is likely in <1 month) Last months of life (definition: death is likely in <1 year)
Format	Coded in SNOMED CT/Read CTV3/Read V2. (Suggest that codes conform to SNOMED classifications)
Source	Manual Note: this data item can only be completed by key worker, GP or responsible clinician
SNOMED CT	511401000000102 | Last days of life (finding) 955231000000109 | Last weeks of life (finding) | | Last months of life (finding) | (Code to be published October 2015)
Read CTV3	XaQg1 | Last days of life | XacFk | Last weeks of life | | Last months of life | (Code to be published October 2015)
Read V2	2JE.. | Last days of life 2Jf.. | Last weeks of life | | Last months of life | (Code to be published October 2015)

Data entry status	Optional
Note	To be completed by a clinician

2.1.2 New data item: NHS number status Indicator code

Data item title	NHS number status indicator code
DD Element name	NHS number status indicator code
DD Note	www.datadictionary.nhs.uk/data_dictionary/data_field_notes/n/nhs/nhs_number_status_indicator_code_de.asp?query=nha
Format	01 Number present and verified 02 Number present but not traced 03 Trace required 04 Trace attempted – no match or multiple match found 05 Trace needs to be resolved – (NHS number or patient detail conflict) 06 Trace in progress
Description	Status of the NHS number recorded in the record
Requirement	To support completion and verification of NHS number
Source	Manual
Data entry status	Mandatory

2.1.3 New data item: Awareness of cardiopulmonary resuscitation decision

- this includes new terminology for ‘family member/carer informed of cardiopulmonary resuscitation clinical decision’
- terminology recording whether the person is aware of the cardiopulmonary resuscitation decision has been moved from the data item: ‘cardiopulmonary resuscitation decision’ to this data item to improve clarity

Data item title	Awareness of cardiopulmonary resuscitation decision
Description	Whether the person and their family member or carer have been informed of the clinical decision made regarding cardiopulmonary resuscitation
Requirement	To provide clarity for staff on the information that has been given to the person and their family and carers to support their conversations with people and their families
Format	Coded in SNOMED CT/Read CTV3/Read V2. (Suggest that codes conform to SNOMED Classifications)
Source	Manual
SNOMED CT	845151000000104 | Not aware of do not attempt cardiopulmonary resuscitation clinical decision (finding) | | Family member informed of cardiopulmonary resuscitation clinical decision (situation) | (Code to be published in October 2015) | Carer informed of cardiopulmonary resuscitation clinical decision (situation) | (Code to be published in October 2015)
Read CTV3	XaZZn | Not aware of do not attempt cardiopulmonary resuscitation clinical decision | | Family member informed of cardiopulmonary resuscitation clinical decision | (Code to be published in October 2015) | Carer informed of cardiopulmonary resuscitation clinical decision | (Code to be published in October 2015)
Read V2	9NgV. | Not aware of do not attempt cardiopulmonary resuscitation clinical decision | | Family member informed of cardiopulmonary resuscitation clinical decision | (Code to be published in October 2015) | Carer informed of cardiopulmonary resuscitation clinical decision | (Code to be published in October 2015)
Data entry status	Optional
Notes	Not aware of do not attempt cardiopulmonary resuscitation clinical decision relates to the individual ie the patient is not aware of the decision. More than one option can be selected for this data item.

2.2 Amendments

2.2.1 Change of title of the information standard

The title of the information standard has been changed to Palliative care co-ordination: core content (SCCI1580).

2.2.2 Coding updates

The Requirements specification has been updated with the new codes which were not available at time of publication of Amd 16/2013. These code numbers were published April 2014.

Data item: Disability		
Read V2	Read CTV3	SNOMED CT
F49D. | Visual impairment | 13oB. | Difficulty communicating | 28E3. | Cognitive impairment | 1PA0. | Unable to summon help in an emergency | 13i2. | Impaired ability to recognise safety risks |	Xaato | Unable to summon help in an emergency | XabGs | Impaired ability to recognise safety risks |	914271000000103 | Impaired ability to recognise safety risks (finding) |

The previous SNOMED CT terminology for the following term has been retired and has been mapped to new international SNOMED code:

Data item: Disability	
SNOMED CT	
Amended as existing code has been retired and is now mapped to new international SNOMED code. **Remove:** 882831000000102 | Patient reports no current disability (situation) | **Replace with**: 703154009 | Patient reports no current disability (situation) |	
Read V2:	No change
Read CTV3:	No change

Data item: Functional status		
Read V2	Read CTV3	SNOMED CT
38QF. | Australia-modified Karnofsky Performance Status scale |	Xab0M | Australia-modified Karnofsky Performance Status scale |	901361000000101 | Australia-modified Karnofsky Performance Status scale (assessment scale) | 901541000000107 | Assessment using Australia-modified Karnofsky Performance Status scale (procedure) | 901671000000100 | Australia-modified Karnofsky Performance Status scale score (observable entity) |

The SNOMED CT codes for the following data item have been updated as below:

Data item: Is main carer aware of person’s prognosis?
SNOMED CT
Remove: 751941000000100 | Carer aware of prognosis (situation) | **Replace with:** 473301001 | Caregiver aware of prognosis (situation) | Preferred synonym | Carer aware of prognosis | (description ID 2956650010)* * Note: this will be updated as UK specified preferred term for the October 2015 release
Read V2: No change
Read CTV3: No change

2.2.3 Correction

Correction of minor printing error in current Requirements specification:

Data item: Functional status

Removal of words '*IP35, COM 32'* after Modified Karnofsky Performance Status Scale.

2.2.4 Change terminology for informal and formal carers

The terms for ‘main informal carer’ and ‘formal carer’ have been changed to ‘main carer’ and ‘care worker’, respectively. The following amendments have been made to support this change:

	Current	NEW
1	**Data item title:** Main informal carer **Definition:** The individual, excluding paid carers or carers from voluntary agencies, identified by the person to hold major responsibility for providing their informal care and support. Note: the main informal carer will be identified by the person's GP or key worker if the person lacks capacity to identify one themselves. **SNOMED CT** 751311000000102 | Has an informal carer (finding) | 751701000000100 | Does not have an informal carer (finding) | Unknown specified as free text **Read CTV3** XaX11 | Has an informal carer | XaX1P | Does not have an informal carer Unknown specified as free text **Read V2** 918u. | Has an informal carer | 91802 | Does not have an informal carer | Unknown specified as free text	**Data item title:** Main carer **Definition:** 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.) 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. **SNOMED CT** 184156005 | Has a carer (finding) | 414041006 | Does not have a carer (finding) | Unknown specified as free text **Read CTV3** 918F. | Has a carer | XaJvD | Does not have a carer | Unknown specified as free text **Read V2** 918F. | Has a carer | 918V. | Does not have a carer | Unknown specified as free text
2	Title: Main informal carer telephone numbers	Title: Main carer telephone numbers
3	Title: Is main informal carer aware of person’s prognosis?	Title: Is main carer aware of person’s prognosis?

	Current	**NEW**
4	Title: Formal carers involved in care: Name Description: The names of the health and social care professionals and staff, including carers from voluntary agencies, providing care and support for the person.	Title: Care workers involved in care: Name Description: The names of the health and social care professionals and staff, including care workers from voluntary agencies, providing care and support for the person.
5	Title: Formal carers involved in care: Professional group Description: Identification of the health and social care professionals and staff, including carers from voluntary agencies, who provide care and support for the person.	Title**:** Care workers involved in care: Professional group Description 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.
6	Title: Telephone numbers for formal carers involved in care	Title: Telephone numbers for care workers involved in care

2.2.5 Changes to data items regarding cardiopulmonary resuscitation decisions

The term DNACPR decision is to be replaced with **cardiopulmonary resuscitation decision**. The following amendments have been made to support this change:

	Current title	Revised title
1	DNACPR decision made	Cardiopulmonary resuscitation decision
2	Date of DNACPR decision	Date of cardiopulmonary resuscitation decision
3	Date for review of DNACPR decision	Date for review of cardiopulmonary resuscitation decision
4	Location of DNACPR documentation	Location of cardiopulmonary resuscitation documentation

2.2.6 To amend categories for Preferred place of death and Actual place of death

The NHS data model and dictionary categories have been amended for data items:

Preferred place of death 1st choice
Actual place of death

Current Categories	Revised Categories
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	**10 Hospital** Acute* Community** Other **20 Private residence** 21 Patient's own home 22 Other private residence (eg relatives home, carers home) **30 Hospice** (inpatient specialist palliative care)*** **40 Care Home** **50 Other** (free text eg secure and detained settings) *Acute hospitals provide a wide range of specialist care and treatment for patients. Services offered in acute hospitals include: • 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 www.nrls.npsa.nhs.uk/resources/healthcare-setting/acute-hospital **The community hospital is a service that offers integrated health and social care and is supported by community-based professionals" (Meads, G. Participate. University of Warwick, 2004). ***Hospice includes NHS and voluntary specialist palliative care inpatient beds, including those located in NHS hospitals or on NHS hospital grounds.

2.2.7 Changes to the summary table of data items

The summary table of data items has been revised to align with headings specified in the standards for the clinical structure and content of patient records published by Academy of Medical Royal Colleges (AoMRC). July 2013.

	Summary Core Data Items
1	**Consent** Consent Status*
2	**Record creation* date AND record amendment* dates**
3	**Plan and requested actions** Planned review date 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 Main carer name and contact details Availability of carer support*
5	**Special requirements** Need for interpreter Preferred spoken language Functional status Disability End of life care tools in use eg Gold Standards Framework
6	**Information and advice given** Is main carer aware of person's prognosis? Is person aware of the cardiopulmonary resuscitation clinical decision? Family member/carer informed of cardiopulmonary resuscitation clinical decision
7	**GP Practice** GP Name* GP practice details*
8	**Key worker** Name Telephone number
9	**Services and care** Names of health and social care staff and professionals involved in care Professional group Telephone number

	Summary core data items
10	**Diagnoses** Primary end of life care diagnosis* Other relevant end of life care diagnoses and clinical issues Likely prognosis
11	**Allergies or adverse reactions**
12	**Medications and medical devices** Whether a ‘just in case box’ or anticipatory medicines have been prescribed Where these medicines are kept
13	**Legal information** **Advance statement** Requests or preferences that have been stated **Advance Decision to Refuse Treatment (ADRT)** Whether a decision has been made, the decision, date of decision and the location of the documentation **Lasting Power of Attorney or similar** Name and contact details of person appointed with Lasting Power of Attorney (LPA) for personal welfare • without authority to make life-sustaining decisions • with authority to make life-sustaining decisions
14	**Person and carers’ concerns, expectations and wishes** Preferred place of death 1st and 2nd choices if made Names and contact details of others (1 and 2) that the person wants to be involved in decisions about their care Other relevant issues or preferences around provision of care?
15	**Actual place of death**
16	**Date of death**

* Completion of these items is mandatory.

2.2.8 Change the data entry status for NHS number

Entry status

Current status: Required
New status: Mandatory

Please note that this change is supported by the new data item: NHS number status indicator code.

2.2.9 Change to data item: EoLC tool in use

Removal of SNOMED and Read terminology relating to ‘on integrated care pathway’ from the options. This includes:

818241000000105 | On integrated care pathway (finding) |
XaYpW | On integrated care pathway |
8CMR. | On integrated care pathway |

2.2.10 Person gender

The standard has been updated with the new NHS data model and dictionary terminology for Person stated gender. ‘Person gender code current’ has been replaced with ‘Person stated gender’.

DD Note
www.datadictionary.nhs.uk/data_dictionary/attributes/p/person/person_stated_gender_code_de.asp?shownav=1

Format

NHS data model and dictionary or SNOMED/Read terminology.

NHS data model and dictionary:

1	Male
2	Female
9	Indeterminate (unable to be classified as either male or female)

Description

The gender of a person.

Person stated gender code is self declared or inferred by observation for those unable to declare their person stated gender.

Note: SNOMED/Read terminology is unchanged.

2.2.11 Note added to requirements specification regarding Read Terminology

The following note has been added to the requirements specification:

SNOMED CT is specified as the single terminology to be used across the health system and Read codes will be deprecated as detailed below:

1. Read codes V2 will cease to be maintained by the Standardisation Committee for Care Information (SCCI) from April 2016 and will be withdrawn in April 2020. Further information: www.hscic.gov.uk/media/15868/1553disn/pdf/1553disn.pdf
2. Read codes CTV3 will cease to be maintained by the Standardisation Committee for Care Information (SCCI) from April 2018 and will be withdrawn in April 2020. Further information: www.hscic.gov.uk/media/15869/1552disn/pdf/1552disn.pdf

Information standard notices 1552 and 1553 confirm the schedule for the phasing out and withdrawal of the Read V2 and Read V3 clinical terminologies:

The final updated release of Read V2 is 1/4/2016.

The date of withdrawal of Read V2 is 1/4/2020.

The final updated release of Read V3 is 1/4/2018.

The date of withdrawal of Read V3 is 1/4/2020.

Service users will need to plan to migrate from the use of READ codes to SNOMED CT coding within the timescales above.

2.2.12 Change of definition for Key worker

The NHS data model and dictionary definition will replace the existing definition:

Current definition	New definition
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.	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.

2.2.13 Amendment to Section 3.1 Requirements No 38

The NHS number will be mandatory for completion. Update item number 38 from SHOULD to MUST.

38	The system MUST use the NHS number as the primary unique identifier for a person.

2.2.14 Amendment to Section 5 (previously called Maintenance)

The standard has been amended to provide clearer information about reporting implementation issues and making requests for change. Other information has been moved to the maintenance plan.

Section 5 Reporting implementation issues and making requests for change

Issues and requests for change can be made via neolcin@phe.gov.uk**.** Acknowledgement of receipt will be made within two working days. A register is maintained of issues raised and requests for change which is available on request.

All issues are logged and reviewed first by the standard's implementation manager and then, if necessary, by the Clinical and Professional Assurance Group or the Technical Advisory and Support Group and recommendations made to the Implementation and Dataset Management Group, which holds responsibility for maintenance of the standard. If required, additional guidance is sought from external experts or professional associations. The issue raiser will be kept appraised of progress through the process. Requests for change are reviewed by the Clinical and Professional Advisory Group and/or the Technical Advisory and Support Group and recommendations made to the Implementation and Dataset Management Group for decision. When required, requests for changes to the information standard will be made to SCCI, as required but generally not more frequently than two yearly.

If organisations decide to extend the core data set, local systems will be required to support maintenance of these additional items. Please refer to Palliative care co-ordination Implementation guidance for further detail.

A full review of the National Information Standard is undertaken on a three-year cycle, unless required sooner, by the group, PHE or NHS England. A post implementation review was carried out and reported to the Information Standards Board in March 2014. The first maintenance review is expected to take place in 2017 and the second review in 2020.

2.2.15 Updating of glossary and guidance documents

The Palliative care co-ordination Record keeping guidance and implementation guidance have been updated:

a) Glossary

The glossary has been updated with new entries for acute hospital, community hospital and hospice. Integrated care pathway and locality registers have been removed from the glossary and end of life care co-ordination has been changed to palliative care co-ordination. Changed definitions for CARER, CARE WORKER and KEY WORKER to the NHS Data Model and Dictionary definitions. Weblinks in the glossary have also been updated.

b) On consent

Removal of requirement: ‘Whenever possible, staff should seek consent each time the record is viewed’.

Revised guidance on consent when EPaCCS is part of a wider clinical record.

See Appendix A for the revised guidance in the palliative care co-ordination: core content implementation guidance and record keeping guidance.

c) Recording cardiopulmonary resuscitation decisions

Additional guidance has been added to the Palliative care co-ordination Record keeping guidance:

Patient consent is required for the professional to have a conversation regarding cardiopulmonary clinical decisions with the family.

Conversations with family/carers regarding cardiopulmonary decisions should be recorded in the care plan and on the DNACPR form.

d) Reporting functionality

The following guidance on reporting functionality has been added to the Requirements Specification and the Palliative care co-ordination Implementation guidance to better support the commissioning of appropriate EPaCCS functionality:

It is recommended that EPaCCS include reporting functionality. Localities implementing new EPaCCS systems should include reporting functionality in their procurement requirements. Localities who have implemented systems that do not have reporting functionality are advised to work to towards this.

e) Implementation risks

Risks and issues for implementation have been added to the implementation guidance:

#	Description	Recommendations
1	The name of the record/system may be a barrier for professionals to engage in conversations about recording and sharing end of life care preferences.	Local consideration should be given to the name of the record/system. For example London has decided on ‘Coordinate My Care’. Professionals responsible for seeking consent for the record to be created on the system and shared must be competent in EoLC communication skills and advance care planning.
2	Potential data security breaches including risk when sharing data with voluntary sector organisations who may not have N3 connectivity.	Systems must conform with the NHS IG Toolkit and with legal and NHS IG requirements. Implementers apply secure administration rights systems to control access and permissions. There is an audit trail of all access to the data items. Information sharing protocols are implemented. Staff using registers must receive appropriate information governance training. Note: The risk is low if this guidance is followed.
3	A shared electronic record with multiple agencies contributing raises the risk of no single organisation being responsible for who decides how and why information is processed.	One organisation should be nominated as the lead for managing the contract with the processor and for day to day management. Data controllership overall should be joint, so that new purposes or changes have to be agreed with all partner organisations. For further details see the Palliative care co-ordination Implementation guidance section 6.

#	Description	Recommendations
4	Out of date, incomplete or inaccurate information will impact on safety and the quality of care and treatment. This includes completion of data items for date and place of death.	This risk applies to all digital record systems. The risk is low if guidance is followed. Professionals and clinical governance leads must ensure that systems and process support timely updating of the record and safe decision making. All staff must be aware of their responsibility for keeping the record up-to-date. It is suggested that the key worker or GP has overall responsibility for the record. A review date is set (maximum of three months) Local systems to be put in place to ensure that records are updated on death. Localities may wish to use ONS mortality files to keep records updated when a person dies as part of routine information governance. Systems that use the national demographics services (PDS or DBS) to match patients and retrieve NHS numbers can use these to update records when a person dies. Note that the service does not provide information about the place of death. (N3 access only). Localities may wish to consider designing IT systems that support completion of the fields to be completed on death. Local audit to be considered. Further guidance is provided in this document and the Palliative care co-ordination Record keeping guidance.

#	Description	Recommendations
5	Staff might use free text fields in the care co-ordination record to add information that should be recorded elsewhere, for example, prescribed medications.	This risk will apply to all digital record systems. The risk is low if guidance is followed and is not higher than for other shared record systems. Coding is used in the standard wherever feasible Staff creating and updating the record must keep free text to a minimum and ensure it relates only to the core content heading. They should be made aware of the safety implications of recording additional information that should be recorded elsewhere. Localities to provide staff training or guidance that free text should be kept to a minimum and ensure it relates only to the core content heading. Local audit to be considered (Please refer to Palliative care co-ordination Record keeping guidance for further detail).

Issues

#	Description	Recommendations
1	Staff see recording end of life choices as a data collection exercise and do not appreciate its importance in supporting service quality and improvement	Localities provide training and guidance for staff using PCCS and to reinforce the importance and value of the system. The following guidance is available: **Palliative care co-ordination Implementation guidance** emphasises system and change process issues, including engagement of clinical staff. **Palliative care co-ordination Record keeping guidance** emphasises staff responsibilities for supporting individual wishes and preferences and for recognition that some people may not wish to have discussions or have this information recorded but should receive equal care.

2.3 Deletions

None.

Appendix 1 – Previous and revised wording for consent

1. Palliative care co-ordination Implementation guidance

Previous wording	Revised wording
6.4 Consent Discussions with people at the end of life about their preferences and choices are extremely sensitive. Generally, they are not one-off discussions and need to take place over a number of visits. 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. The NHS Code of Practice on Confidentiality is clear that when disclosure of a person's medical record extends to non-NHS organisations, it is important that every effort is made to inform the person of the intention to disclose and that there is a secure legal basis for doing so. People also have a general right to object to the use and disclosure of their own confidential information. Lack of capacity or safeguarding issues may provide justification for disclosure of confidential information without consent where it is in the individual's best interests. When an individual provides their consent for information sharing it must be 'informed'. This means that the person giving consent needs to understand why information needs to be shared, what will be shared, who will see their information, the purpose to which it will be put and the implications of sharing that information and of non-disclosure on their care and treatment. They also need to give their consent freely. Separate explicit consent to be placed on EPaCCS and to share	**6.4 Consent** The NHS Code of Practice on Confidentiality is clear that when disclosure of a person's medical record extends to non-NHS organisations, it is important that every effort is made to inform the person of the intention to disclose and that there is a secure legal basis for doing so. People also have a general right to object to the use and disclosure of their own confidential information. Lack of capacity or safeguarding issues may provide justification for disclosure of confidential information without consent where it is in the individual's best interests. Separate explicit consent to create an EPaCCS record and to share their information is required. Explicit consent is given by a person agreeing actively, orally or in writing. The record is not initiated until consent has been given or a best interests decision made. A data field records the type of consent for creation and sharing the record. This includes whether explicit consent has been given, whether it was a best interests decision or whether the decision was made by a Lasting Power of Attorney. Withdrawal of consent is also recorded. Organisations should be aware that the recording of consent supports effective implementation, providing confirmation of the consent to share patient information and facilitating identification of people with an EPaCCS record in electronic clinical systems. They should also be aware of the importance of recording of the withholding of consent to respect individual's wishes.

Previous wording	Revised wording
their information is required. Explicit consent is given by a person agreeing actively, orally or in writing. The record is not initiated until consent has been given. A data field records the type of consent for creation and sharing the record. This includes whether explicit consent has been given, whether it was a best interests decision or whether the decision was made by a Lasting Power of Attorney. The record also records if consent for the record has been withdrawn. However, organisations should be aware that the recording of consent supports effective implementation, and the importance of recording of the withholding of consent to respect individual's wishes. Additionally, organisations should consider how they can evidence that consent has been given to their partner organisations supporting end of life care. When possible, professionals should seek consent each time the record is viewed. Consideration is needed on whether consent is required from those identified as a carer, nominated as part of advance care planning as having Lasting Power of Attorney, or as a contact for their name and contact details to be included on the system. In general, the individual at the end of life will provide the details and the information is unlikely to be confidential or sensitive in nature. There is an obligation under the Data Protection Act to provide fair processing of information, eg to tell those concerned that their personal information is included on the record. It is suggested that the individual at the end of life is asked whether the people identified by them have been informed when details are added to the record. An EPaCCS information leaflet targeted at the people could be provided and include this guidance. See example in Appendix 2. Exceptionally, the individual may not wish other people to know about the record, or not at the current	Additionally, organisations should consider how they can evidence that consent has been given to their partner organisations supporting palliative and end of life care. The purpose of the EPaCCS-specific consent codes specified in this information standard is to record that: 1. The discussion around moving to a palliative care phase has been had. 2. The patient (or representative) has been made aware that information will be recorded and shared with others involved in providing care. 3. The patient (or representative) has agreed to the information being recorded and shared for this purpose. OR 4. A clinician has made the decision in the best interests of a patient who lacks capacity to consent. EPaCCS can therefore use the existence of the specific consent codes to control whether the specific SCCI1580 data items should be shared electronically with other clinical systems. **Recording carers' contact details** Consideration is needed on whether consent is required from those identified as a carer, nominated as part of advance care planning as having Lasting Power of Attorney, or as a contact for their name and contact details to be included on the system. In general, the individual at the end of life will provide the details and the information is unlikely to be confidential or sensitive in

Previous wording	Revised wording
time. In this instance, there should be a means of recording this dissent to inform relatives, friends or carers, so that staff are aware, and can revisit the discussion with the individual to highlight the importance of family and friends knowing so that they do not inadvertently breach a person's trust or, if it becomes necessary, can do so knowingly in the best interests of the person if they lose capacity. If identifiable information is to be used for secondary uses (eg for data linkages or for research) it is essential that fully informed explicit consent is sought. This should be separate to the consent sought for inclusion on the register and for sharing of information. As a minimum, the person should be offered a copy of their record. Local decisions are to be made about any data fields not to be reproduced on the person's copy and any fields to be filtered out depending on how they have been answered. This should be in line with the principles established under Section 7 of the Data Protection Act which gives individuals a right of access to personal data about them. IT systems must support this. Consideration can be given for people to access their own record and to have editing rights for specific fields, for example to record relevant issues and preferences for care or names of people to be involved in decision-making. This helps people to take greater control of their care and supports the aim of the Department of Health's information strategy the 'Power of Information' to give people better access to their care records. Adequate data security measures would be required to ensure controlled access.	nature. There is an obligation under the Data Protection Act to provide fair processing of information, eg to tell those concerned that their personal information is included on the record. It is suggested that the individual receiving palliative or end of life care is asked whether the people identified by them have been informed when details are added to the record. An EPaCCS information leaflet targeted at the people could be provided and include this guidance. See example in Appendix 2. Exceptionally, the individual may not wish other people to know about the record, or not at the current time. In this instance, there should be a means of recording this dissent to inform relatives, friends or carers, so that staff are aware, and can revisit the discussion with the individual to highlight the importance of family and friends knowing so that they do not inadvertently breach a person's trust or, if it becomes necessary, can do so knowingly in the best interests of the person if they lose capacity. **Consent for secondary use of the data** If identifiable information is to be used for secondary uses (eg for data linkages or for research) it is essential that fully informed explicit consent is sought. This should be separate to the consent sought for creating an EPaCCS record and for sharing of information. **Sharing record with individuals** As a minimum, the person should be offered a copy of their record. Local decisions are to be made about any data fields not to be reproduced on the person's copy and any fields to be filtered out depending on how they have been answered. This should be in line with the principles established under Section 7 of the Data Protection Act which gives individuals a right of

Previous wording	**Revised wording**
	access to personal data about them. IT systems must support this. Consideration can be given for people to access their own record and to have editing rights for specific fields, for example to record relevant issues and preferences for care or names of people to be involved in decision-making. This helps people to take greater control of their care and supports the aim of the Department of Health's information strategy the 'Power of Information' to give people better access to their care records. Adequate data security measures would be required to ensure controlled access.
6.5 EPaCCS as a subset 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. Terminology is available to record consent for sharing of electronic records across organisations (425691002: Consent given for electronic record sharing, and potentially: 417528008: Consent given for upload to local shared electronic record). This may be appropriate for recording consent for sharing general information recorded in the LTC record. However, as the information standard requires separate explicit informed consent for creating and sharing the end of life care co-ordination record, this consent is not adequate on its own for the EPaCCS section of the record and specific informed consent needs to be given for creating and sharing of the EPaCCS record.	**6.5 EPaCCS as a subset 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. In this situation there may be general sharing consent codes within the record. (For example, consent given for electronic record sharing (425691002), and potentially: consent given for upload to local shared electronic record (417528008). These indicate that the patient has agreed to share their record, but cannot be used to infer the specific points outlined above relating to palliative and end of life care. It is possible that some existing clinical record systems may be unable to apply sharing controls for just the EPaCCS information within the record. If they cannot use the EPaCCS consent codes to control sharing, other local system controls may need to be used to ensure the patient's wishes are respected.

Previous wording	Revised wording
New terminology has been developed to provide clarity of the type of consent that has been granted (ie whether explicit, best interest decision, Lasting Power of Attorney consent) and where consent has been withdrawn. These codes have been added to the standard and will be mandatory for completion by 1 June 2014. • consent given for sharing end of life care co-ordination record (finding) • withdrawal of consent for sharing end of life care co-ordination record (finding) • best interest decision taken (Mental Capacity Act 2005) for sharing end of life care co-ordination record (finding) • 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 (finding) Where an electronic system shares the specific end of life care items outlined in the standard, checking for the existence of one of the above codes provides a means to confirm that consent has been given for sharing the end of life care preference.	For example, if a patient refuses consent for sharing EPaCCS information, the system would record the EPaCCS dissent code as per SCCI1580, but could also apply privacy markings against the EPaCCS fields to ensure those fields are not shared. Such local controls would need to be applied consistently alongside the EPaCCS consent codes - this will ensure that the EPaCCS system is sharing in accordance with EPaCCS consent preferences, but also that any other systems that receive and process the data (which may not be aware of the local system-specific controls) can do so in accordance with the recorded consent preferences. Such local mechanisms would need to be assessed by local IG and clinical safety teams to ensure they are consistent and in-line with the requirements for EPaCCS consent.

2. Palliative care co-ordination Record keeping guidance

Previous wording	Revised wording
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	**6.9 Consent** Discussions with people at the end of life about their preferences and choices are extremely sensitive. Generally, they are not one-off discussions and need to take place over a number of

Previous wording	Revised wording
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	visits. Not all people will want to have an EPaCCS record 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 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

Previous wording	**Revised wording**
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.	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	**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

Previous wording	Revised wording
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 1 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.	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 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.

Previous wording	Revised wording
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.	

Appendix 2 – Summary of changes to data items

A summary of changes which have been made to each of the data items. This includes two new data items.

Previous	New
Title of information standard	
End of life care co-ordination	Palliative care co-ordination: core content
Consent	
Consent status	No change (Note changes made to consent model- refer to record keeping guidance 6.9 and 6.10 and implementation guidance 6.4 and 6.5)
Record creation date AND record amendment dates	
Record creation date	No change
Date and time of last amendment	No change
Plan and requested actions	
Planned review date	No change
DNACPR decision made	Changed title: Cardiopulmonary resuscitation decision Remove SNOMED CT/Read CTV3/Read V2 coding: Not aware of do not attempt cardiopulmonary resuscitation clinical decision
Date of DNACPR decision	Changed title: Date of cardiopulmonary resuscitation decision
Date for review of DNACPR decision	Changed title: Date for review of cardiopulmonary resuscitation documentation
Location of DNACPR documentation	Changed title: Location of cardiopulmonary resuscitation decision
Person demographics	
Person family name	No change
Person forename	No change
Person preferred name	No change
Person birth date	No change
NHS number	Changed data entry status from required to MANDATORY
	New data item: NHS number status indicator code
Person Gender	Updated with new data dictionary definition for

Previous	New
	person stated gender code
Person address	No change
Person telephone numbers	No change
Main informal carer name	Changed title to: Main carer name Changed definition Replaced coding for ‘has informal carer’ and ‘Does not have a carer’ with ‘has a carer’ and ‘does not have a carer’
Main informal carer telephone numbers	Changed title: main carer telephone numbers
Special requirements	
Need for an interpreter	No change
Preferred spoken language	No change
Functional status	Removal of words ‘IP35,COM 32’ New SNOMED CT, Read CTV3 and Read V2 coding: • Australia-modified Karnofsky Performance Status Scale • Assessment using Australia-modified Karnofsky Performance Status Scale • Australia-modified Karnofsky Performance Status Scale Score
Disability	Code numbers added: SNOMED CT impaired ability to recognise safety risks (finding) Read CTV3 Unable to summon help in an emergency Impaired ability to recognise safety risks Read V2 Visual impairment Difficulty communicating Cognitive impairment Unable to summon help in an emergency Impaired ability to recognise safety risks
End of life care tools in use? (eg GSF, IPC, PPC, other)	Changed title: End of life care tools in use? (eg GSF, PPC, other) Removal of coding ‘on integrated care pathway)
Information and advice given	
Is main informal carer aware of person’s prognosis?	Changed title: Is main carer aware of person’s prognosis? Change of SNOMED CT coding: Remove: 751941000000100 | Carer aware of prognosis (situation) |

Previous	New
	Replace with: 473301001 | Caregiver aware of prognosis (situation) | Preferred synonym | Carer aware of prognosis | (description ID 2956650010)*
	New data item: Awareness of cardiopulmonary resuscitation decision SNOMED CT/Read CTV3/ Read V2 coding: - Not aware of do not attempt cardiopulmonary resuscitation clinical decision - Family member informed of cardiopulmonary resuscitation clinical decision - Carer informed of cardiopulmonary resuscitation clinical decision
GP Practice	
Usual GP name	No change
Practice details including phone and fax numbers	No change
Key worker	
Key worker name if not GP	The NHS data model and dictionary definition of key worker has been changed
Key worker telephone number	No change
Services and care	
Formal carers involved in care: name	Changed title: Care workers involved in care: name
Formal carers involved in care: professional group	Changed title: Care workers involved in care: professional group
Telephone numbers for formal carers involved in care	Changed title: Telephone numbers for care workers involved in care
Diagnoses	
Primary end of life care diagnosis	No change
Other relevant end of life care diagnoses and clinical issues	No change
	New data item: Likely prognosis SNOMED CT/ Read CTV3/ Read V2 coding: Last days of life Last weeks of life

Previous	New
	Last months of life
Allergies or adverse reactions	
Allergies/adverse drug reactions	No change
Medications and medical devices	
Anticipatory medicines/just in case box issued	No change
Location of anticipatory medicines/just in case box	No change
Legal information	
Advance statement requests and preferences	No change
Person has made an advance decision to refuse treatment	No change
Location of advance decision to refuse treatment documentation	No change
Lasting Power of Attorney for Personal Welfare	No change
Authority of LPA	No change
Telephone number(s) concerning Lasting Power of Attorney	No change
Person and carers' concerns, expectations and wishes	
Preferred place of death 1st choice: Hospital NHS hospice/specialist palliative care unit Person's own home Care home Other plus free text	New NHS data model and dictionary options: Hospital: • acute • community • other Private residence: • patient's own home • other private residence Hospice (inpatient specialist palliative care unit): • care home • other
Preferred place of death organisation name (1st choice)	No change
Preferred place of death address (1st choice	No change
Preferred place of death (1st choice) is usual place of residence	No change
Preferred place of death 2nd choice	No change
Preferred place of death organisation name (2nd choice)	No change
Preferred place of death address (2nd choice)	No change

Previous	New
Preferred place of death (2nd choice) is usual place of residence	No change
Name of additional person to be involved in decisions (1)	No change
Telephone number of person (1) to be involved in decisions	No change
Name of additional person to be involved in decisions (2)	No change
Telephone number of person (2) to be involved in decisions	No change
Other relevant issues or preferences about provision of care?	No change
Date of death	No change
Actual place of death Hospital NHS hospice/specialist palliative care unit Person's own home Care home Other plus free text	New NHS Data Model and Dictionary options: Hospital: • acute • community • other Private residence: • patient's own home • other private residence Hospice (inpatient specialist palliative care unit): • care home • other