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

Guidance to implementing changes (Amd 11/2015)

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

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

This information standard comprises the following documents:

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

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

The controlled versions of these documents can be found on the HSCIC website.

Date of publication 18 September 2015.

The intelligence networks

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

National End of Life Care Intelligence Network

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

National Cancer Intelligence Network

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

National Cardiovascular Intelligence Network

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

National Child and Maternal Health Intelligence Network

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

National Mental Health, Dementia and Neurology Intelligence Network

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

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Maggie Morgan-Cooke	NHS Improving Quality	1.0	10/8/2015

Related and Supporting documents:

Ref no	Document reference number	Title	Dated
[1]	Gateway reference 9840	Department of Health End of Life Care Strategy: Promoting high quality care for all adults at the end of life www.gov.uk/government/publications/end-of-life-care-strategy-promoting-high-quality-care-for-adults-at-the-end-of-their-life	July 2008
[2]		Ipsos MORI. End of Life Locality Registers evaluation Final Report. www.nhsiq.nhs.uk/resource-search/publications/eolc-locality-registers-evaluation.aspx	June 2011
[3]		SCCI1580 Palliative care co-ordination: core content Implementation Guidance www.hscic.gov.uk/isce/publication/scci1580	Sept 2015
[4]		Clinical Safety Report www.hscic.gov.uk/isce/publication/scci1580	Sept 2015
[5]		SCCI1580 Palliative care co-ordination. Record keeping guidance www.endoflifecare-intelligence.org.uk/resources/publications/record_keeping_guidance	July 2015
[6]		Common User Interface design guides http://systems.hscic.gov.uk/data/cui/uig	
[7]		ISB Information Governance baselines www.isb.nhs.uk/use/baselines/ig	

Ref no	Document reference number	Title	Dated
[8]		SCG Guidance on the Representation of Allergies and Adverse Reaction Information Using NHS Message Templates http://systems.hscic.gov.uk/data/scg/scg0001.pdf	April 2008
[9]		Electronic Palliative Care Co-ordination Systems (EPaCCS) Mid 2012 survey report www.nhsiq.nhs.uk/resource-search/publications/eolc-epaccs-mid-2012-report.aspx	February 2013
[10]		EPaCCS Information Governance Guidance http://systems.hscic.gov.uk/qipp/library/epaccsig.pdf	January 2014
[11]		Economic Evaluation of the Electronic Palliative Care Co-ordination System (EPaCCS) Early Implementer Sites www.england.nhs.uk/wp-content/uploads/2013/05/economic-eval-epaccs.pdfPage 6 - Relating	April 2013
[12]		EPaCCS Recommended IT System Requirements http://systems.hscic.gov.uk/qipp/library/epaccsreq.pdf	August 2015
[13]		EPaCCS Making the Case for Change. National End of Life Care Programme www.nhsiq.nhs.uk/resource-search/publications/eolc-epaccs-case-for-change.aspx	November 2012
[14]		Care co-ordination interoperability http://developer.nhs.uk/library/interoperability/care-co-ordination-interoperability/	Accessed Aug 2015
[15]		Information sharing patterns summary http://developer.nhs.uk/library/architecture/integration-patterns/information-sharing-patterns-summary/	Accessed Aug 2015
[16]		SCCI1580 Palliative care co-ordination: core content Change Specification www.hscic.gov.uk/isce/publication/scci1580	Sept 2015
[17{		SCCI1580 Palliative care co-ordination: core content Requirements Specification www.hscic.gov.uk/isce/publication/scci1580	Sept 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
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

<table>
<tr><th>Term</th><th>Definition</th></tr>
<tr><td></td><td>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)</td></tr>
</table>

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	**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.

Term	Definition
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.
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)

Term	Definition
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.
End of life care tools	Tools that health and social care professionals use to support provision of the best possible care for people who are nearing the end of their life.
Electronic Palliative Care Co-ordination Systems (EPaCCS)	Electronic systems linking care providers across a locality. By holding key information, centred on a core data set, for individuals who have been identified as approaching the end of life, the EPaCCS enables co-ordination of care for these people, and their families and carers.

Term	Definition
Frailty	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: 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. 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)

Term	Definition
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.

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1 Purpose of this document

This guidance aims to support existing users to implement the changes to the information standard specified in Amd11/2015. This guidance is relevant to health and social care organisations that have implemented the information standard Palliative care co-ordination: core content, previously called End of life care co-ordination: core content (SCCI1580) and IT systems suppliers that provide Electronic Palliative Care Co-ordination systems (EPaCCS).

This Implementation guidance should be read in conjunction with the Palliative care co-ordination Change specification [16] which provides full details of the changes made to the information standard. In addition organisations should refer to the Palliative care co-ordination Implementation guidance [3] for the standard.

This guidance is valid until the conformance date for the changes 1 March 2016.

2 Background

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 Electronic Palliative Care Co-ordination Systems (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.

Following feedback from implementers, national consultation, national review and phasing out of the Liverpool Care Pathway, changes to the national information standard have been made to ensure that the standard continues to meet user needs and remains fit for purpose.

The Information Standards Notice for Amd 11/2015 was published in September 2015 with a conformance date of 1 March 2016.

3 Scope

The changes in the information standard apply to:

- organisations that have implemented Electronic Palliative Care Co-ordination Systems (EPaCCS) to co-ordinate end of life care service provision and to communicate people's preferences and wishes for palliative and end of life care
- service providers providing care for adults (those aged 18 years and older) at the end of their life who use EPaCCS or other co-ordination systems
- suppliers of systems to providers and commissioners (including any systems that contribute to, or hold information that relates to care co-ordination for adults at the end of their life)

4 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)

5 Changes

The changes included in Amd11/2015 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 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

Please refer to the appendix for a summary of the data items and the changes required.

6 Timescales

The ISN was published September 2015 with a conformance date of 1 March 2016. All organisations specified within the scope MUST comply with the changes detailed in Amd 11/2015 by this date.

7 Implementation guidance

For full guidance on implementation of EPaCCS please refer to Palliative care co-ordination Implementation guidance [3].

7.1 EPaCCS leads

The following guidance is relevant for organisations with an existing electronic palliative care co-ordination system (EPaCCS)

#	Step	Guidance on implementation
1	Review change specification	Local steering/stakeholder group to review the changes made to the information standard in Amd 11/2015. Identify all changes that are required for your system and any new risks (clinical and organisational) To be aware that the conformance date is 1 March 2016.

	Step	Guidance on implementation	
2	Develop local implementation plan	Dissemination and communication	Identify all stakeholders that need to be aware of the changes. Develop a communication plan. Disseminate through existing and specific channels. Consider use of social media, blogs, newsletters etc.
		IT system changes	Identify IT changes required (see appendix 1 for summary of data set changes). Agree changes and timescales with IT system provider.
		Information governance regarding changes in the consent model	Review patient information leaflets regarding EPaCCS and update if required to align with the revised consent model. Existing users should note the following changes have been made to the IG toolkit for version 13 in the requirements statement or attainment levels. Detailed information about all changes is available in the IGT V13 change notice published on the IG toolkit 'News' page see the article titled 'IG toolkit version 13 is now live - 29/05/2015'.
		Staff training	Ensure that all staff using EPaCCS fully understand the changes and the implications for practice and application and have the competences required. Consideration will include: • changes to the consent model • new data items • recording likely prognosis
3	Risk management	To update the risk and clinical risk log with any new risks and ensure that a lead is assigned for each risk, mitigations are agreed and that a timetable for review and monitoring is in place.	

7.1.2 Conformance Criteria

This section describes the tests that can be measured to indicate that Amd 11/2015 has been implemented correctly by an organisation. These may be different depending upon the type of organisation, eg supplier, Trust, GP practice.

Organisation Type	Criteria
Commissioners	All contracts for EPaCCS issued after the publication of this document MUST include the requirement for the system to contain the core content defined in SCCI1580 Amd 11/2015
Service providers	Audit of IT systems MUST indicate full conformance with Amd11/2015 by 1 March 2016 for all data items specified in SCCI1580.
Service providers	There MUST be documented evidence, by 1 March 2016, that Amd 11/2015 has been reviewed and assessed for additional clinical or organisational risk and that adequate clinical assurance and risk management is in place.
Service providers	From 1 March 2016, quality assurance systems MUST demonstrate that the data recorded complies with Amd 11/2015 and that this information is accessible for relevant professionals.
Service providers	Staff competence/training records MUST show that professionals using EPaCCS have been notified of the changes to the information standard and that relevant training has been delivered.

7.2 IT system suppliers

#	Step	Guidance on implementation
1	**Review change specification**	Identify changes required to the IT systems to comply with Amd 11/2015. These include: **Coding updates** new code numbers for the following data items: • disability • functional status • is main carer aware of person's prognosis **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

#	Step	Guidance on implementation
		Amendment to current data items The following changes have been made to existing 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 • 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 SNOMED terminology where required **Reporting** Recommendation that EPaCCS systems include reporting functionality.
2	**System update**	Agree implementation and timeframe with provider services using EPaCCS.
3	**Implementation and testing**	System updates and testing to be completed by 1 March 2016.

7.2.1 Conformance criteria

This section describes the tests that can be measured to indicate that the information standard is being used correctly by an IT system supplier.

Criteria
IT systems suppliers MUST demonstrate full conformance with the requirements specified in Amd 11/2015 by 1 March 2016
The system MUST use the NHS number as the primary unique identifier for a person
The IT system SHOULD have reporting functionality

7.2.2 Risks regarding implementation Amd11/2015

#	Description	Recommendations
1	Users not aware of changes to standard	Important that the change notice is adequately communicated to ensure that users are using the updated versions of documentation. Local communication plan to be put in place

#	Description	Recommendations
2	Breach of the 1 March 2016 conformance date	Implementers to review change specification and Amd11/2015 implementation guidance to identify local requirements for conformance and to put local implementation plan in place.
3	Mandatory status of NHS number may result in difficulty in creating a record for some patients.	Automated population of the NHS number where possible. Organisations creating the record can access the NHS number from person's GP, if necessary. Refer to guidance included in implementation guidance. Local areas to identify any users that create EPaCCS records that do not have access to automated population of NHS number and put alternative processes in place to ensure that records can be created for all when required.
4	New data item 'Likely prognosis' field not completed.	Local clinical lead for EPaCCS to consider any support or training required to ensure that relevant clinical staff have the confidence and competence to record.

Appendix 1

Amd 11/2014: Summary of changes to 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 person stated gender code
Person address	No change

Previous	New
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, 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) | Replace with: 473301001 | Caregiver aware of prognosis (situation) |

Previous	New
	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 Last months of life
Allergies or adverse reactions	
Allergies/adverse drug reactions	No change
Medications and medical devices	
Anticipatory medicines/Just in Case Box	No change

Previous	New
issued	
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
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

Previous	New
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

Please refer to Change specification or Requirements specification for full details of all changes.