Public Health England

Protecting and improving the nation's health

NHS Improving Quality

National End of Life Care Intelligence Network

Palliative care co-ordination: core content

Clinical safety report

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.

Public Health England
Wellington House
133-155 Waterloo Road
London SE1 8UG
Tel: 020 7654 8000
www.gov.uk/phe
Twitter: @PHE_uk
Facebook: www.facebook.com/PublicHealthEngland

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.
enquiries@nhsiq.nhs.uk
www.nhsiq.nhs.uk

Prepared by: National End of Life Care Intelligence Network (NEoLCIN)
For queries relating to this document, please contact neolcin@phe.gov.uk

Published September 2015
PHE publications gateway number: 2015191

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	SCCI 1580 Amd 11/2015
Sponsor	Jane Allberry
SRO	Dr Martin McShane NHS England Professor John Newton, Public Health England
Author	Katie Lindsey Public Health England

Reviewers:

Name	Organisation	Date	Version
Maggie Morgan-Cooke	NHS Improving Quality	01/06/2015	1.0

Approvals:

This document must be approved by the following:

Name	Organisation	Date	Version
Rob George	Clinical Safety Officer for SCCI 1580 and President APM	01/06/2015	1.0

References:

Ref no	Doc Reference Number	Title	Version
[1]	Gateway reference 9840	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]	-	End of Life Locality Registers evaluation Final Report. www.nhsiq.nhs.uk/resource-search/publications/eolc-locality-registers-evaluation.aspx	29 June 2011
[3]	-	NICE Quality Standard for end of life care for adults http://publications.nice.org.uk/quality-standard-for-end-of-life-care-for-adults-qs13	November 2011
[4]		Palliative care co-ordination: core content standard Implementation guidance www.hscic.gov.uk/isce/publication/scci1580	September 2015
[5]		Health and Social Care Information Centre,	2013

Ref no	Doc Reference Number	Title	Version
		Guide to logging clinical safety incidents https://nww.nhscfhservicedesk.nhs.uk/CFHSD_LIVE/NSD/cms/page_2/Guide%20to%20logging%20clinical%20safety%20incidents_v2.pdf	
[6]		Palliative care co-ordination: core content Record keeping guidance www.endoflifecare-intelligence.org.uk/resources/publications/record_keeping_guidance	September 2015
[7]		Palliative care co-ordination: core content Requirements specification www.hscic.gov.uk/isce/publication/scci1580	September 2015

Contents

1 Overview

1.1 Summary

This document identifies the clinical safety hazards associated with the palliative care co-ordination: core content information standard and the risk management plan in place.

During development of the standard, a hazard assessment identified the following potential clinical safety hazards regarding the content of the standard and/or its implementation:

‘Hazard’	Standard content	Implementation
Wrong patient, wrong treatment	✓	✓
Information out of date or wrong		✓
Unable to access information when needed		✓
Information accessed inappropriately		✓

The first step to preventing harm to patients through the use of this standard is to ensure a good development process that results in a standard that is fit for purpose – see 3.2.1.Activities that have been carried out to clarify and address this potential include:

- initial patient safety assessment (hazard identification and risk assessment)
- production of hazard log
- review of the End of Life Care Locality Registers evaluation Final Report [2] to identify safety concerns and lessons learnt
- review of issues received and logged by the national team
- drafting of safety case (approaches to mitigating the risks identified)
- incorporation of clinical safety mitigation into draft implementation guidance for the standard
- review and updating of patient safety assessment
- review of mitigation of risks as part of the development of the standard itself and the implementation guidance and professional guidance
- confirmation of risks being managed in the implementation/maintenance stages

2 The standard

2.1 Purpose

Improving the co-ordination and quality of care provided for people at the end of life is a major aim of the Department of Health End of Life Care Strategy [1]. This standard supports communication between providers (such as out of hours services) about end of life care decisions and preferences so that more people are supported to die in the place of their choosing and with their preferred care package.

Approaches to communication between providers of palliative and end of life care vary widely and depend on local service and system configuration. In some areas, this communication is being implemented through electronic palliative care co-ordination systems (EPaCCS), as recommended in the strategy and more recently supported by NHS England in their Actions for End of Life Care 2014/16. The National Information Board highlight EPaCCS as an example of meeting their vision for using data and technology to transform outcomes for patients and citizens in the Personalised health and care 2020: a framework for action (October 2014). The standard specifies the core record content required to support communication and co-ordination of palliative and end of life care so that it can be implemented consistently in electronic record systems irrespective of the local implementation approach.

2.2 Requirement

When implemented in systems the standard must support the following requirements:

i) **Identification of people's wishes and preferences**. The standard content supports staff in having structured conversations with people approaching the end of their life, wherever this is appropriate, to identify their preferences and wishes for care and place of death.

ii) **Inform** those caring for people approaching the end of life and their families and carers, of the decisions that have been made about end of life care preferences and choices and which are aligned with clinical appropriateness and safety.

iii) **Co-ordinate individual care using patient data that includes palliative and end of life care decisions and preferences.** The core information is used by the person, family, informal carers and a wide range of professional staff to guide them in delivery of appropriate care, ensuring that end of life care decisions and preferences are taken into account.

2.3 Scope

The standard applies to adults (18 years and older) with deteriorating, progressive or life limiting illness who are approaching the end of life – ie the scope of the NICE Quality Standard for end of life care for adults, published November 2011[3].

Core content to support the requirements listed in i) to iii) of section 2.2 above is defined in this standard. Additional content that may be required to support recording of full information about palliative and end of life care choices has been identified during the piloting of the locality registers [2] and during consultation on this standard. Although not part of this core content information standard, this list of additional content is available to guide system design and clinical recording practice [6].

2.4 Out of scope

- full electronic record or care plan for people receiving end of life care
- children and young people receiving end of life care – defined locally depending on service delivery models but generally those below 18 years
- electronic exchange of information about end of life care plans
- additional data elements to support reporting requirements
- recording of clinicians' decisions about end of life care – the core content is for recording and communicating the wishes and preferences of the person or their named representative

2.5 Core content

Core/minimum set of record content items to support palliative care co-ordination:

Consent status for creation and sharing of the record

Record creation date and record amendment dates

Planned review date

Person's details including: preferred name, date of birth, usual address, NHS number, telephone contact details, gender, preferred spoken language, need for interpreter, functional status and disabilities

NHS number status indicator code

Main carer including: name, contact details, is the nominated person aware of the person's prognosis and availability of informal carer support

Name of usual GP and practice details

Key worker details

Details of care workers providing care

Primary end of life diagnosis and other relevant end of life diagnoses

Likely prognosis

Availability of anticipatory medicines

Allergies/drug reactions

End of Life Care tools being used

Advance statement requests and preferences

Preferences for place of death (first and second)

Cardiopulmonary resuscitation decisions and location of documentation

Awareness of cardiopulmonary resuscitation decision

Advance decision to refuse treatment made and location of document

Lasting power of attorney (LPA) for personal welfare and authority of LPA

Date and place of death

Consent to share the information is required as part of the process of agreeing, recording and sharing end of life care information and preferences. Local areas may decide to extend the data items included in their records depending on their own circumstances and requirements.

3. Clinical safety progress update

3.1 Clinical safety infrastructure

The role of a clinical safety lead is to review the clinical safety case using his/her clinical experience to judge the appropriateness and effectiveness of the risk management strategies and mitigating actions. The clinical safety lead should monitor the execution of the clinical safety case and ensure that clinical safety obligations are being discharged.

During development of the standard, the safety lead role was fulfilled by a combination of advice from a safety accredited clinician and review by clinical experts on the information standard's expert reference group. The clinical safety lead role for implementation and maintenance, is now held by the chair of the Association for Palliative Medicine of Great Britain and Ireland (APM) or their representative. The role includes ongoing clinical assurance for the standard. The clinical safety lead is supported by clinical and professional leads nominated by the key professional bodies. These stakeholders are represented by the APM on the standard's Implementation and data set management group (IDSMG) that has been established.

3.2 Clinical safety process – implementation and maintenance

As part of the maintenance arrangements for the standard, issues related to the standard can be raised by sending an email to neolcin@phe.gov.uk.

If there is a safety implication, the person raising the issue will be referred to the Health and Social Care Information Centre to logging safety incidents [6]. Any actual or potential clinical safety incidents that are reported locally also need to be reported to the IDSMG. This will enable the IDSMG to assess any implications for the standard as a whole and action taken to mitigate risks, including referral to clinical and safety experts if necessary.

3.3 Clinical safety activities and products

3.3.1 Safety and quality in the development process

Content that is consistent with evidence based guidelines and best practice is more likely to remain safe and fit for purpose. This has been the aim of the development approach which is summarised below:

- analysis of clinical content of the Liverpool Care Pathway for the Dying Patient, the Preferred Priorities for Care and the Gold Standards Framework and comparison of content from a number of sources including the Electronic Palliative Care Summary - Living and Dying Well Scotland
- development and piloting of the initial draft of the core content as part of the locality register pilot programme. Comparison/alignment with the draft NICE Quality Standard for End of Life Care
- comparison with relevant record keeping and data standards including the Academy of Medical Royal Colleges A Clinicians Guide to Record Standards Part 1 and 2. October 20081
- alignment with the Standards for clinical structure and content of clinical records. Academy of Medical Royal Colleges. July 2013
- alignment with Guidance from the British Medical Association, the Resuscitation Council (UK), and the Royal College of Nursing. 2014
- development and assurance of definitions of information elements so that they are clearly understood and unambiguous
- consultation with professional organisations, expert clinicians and clinical and IT staff at implementer sites
- feedback from implementers

[1] AoMRC A Clinicians Guide to Record Standards www.aomrc.org.uk/doc_details/215-a-clinicians-guide-to-record-standards-part-1
www.aomrc.org.uk/a-clinicians-guide-to-record-standards-part-2.html

3.3.2 Safety and quality activities since publication

- publication of EPaCCS Information Governance Guidance. March 2013
- mapping of core content across SNOMED CT/Read CTV3/Read V2. June 2013
- publication of EPaCCS Recommended IT System Requirements. July 2013
- comparison of standard with the Standards for the clinical structure and content of patient records. Academy of Royal Medical Colleges. July 2013
- updating of standard to align with new NHS structures that came into effect 01/04/2013 and with new policy and guidance
- review and updating of standard following review of the Liverpool Care Pathway and publication of One Chance to get it Right. Leadership Alliance for the Care of Dying People. 2014
- lessons learned: Implementing an Electronic Palliative Care Co-ordination System (EPaCCS). NHS Improving Quality. 2014
- testing of proposed new data items related to change application Amd 11/2015

3.3.3 Patient safety assessment and hazard log

The patient safety risk assessment approach that was used was:

- what could go wrong? (seriousness and likelihood)
- possible main causes (why?)
- most likely consequences (ie for patient safety)
- current controls in place to prevent or mitigate error
- recommendations to improve patient safety

The accompanying Hazard Log comprises:

- hazard name and description
- cause
- initial hazard rating (seriousness and likelihood)
- proposed mitigation
- mitigation
- revised hazard ratings
- final status

Risk assessment was undertaken using the DH Informatics Directorate (DHID) risk matrix and scoring tool (Appendix A). Note that for this standard, consequences were interpreted in terms of impact on outcomes including the person’s experience of care and bereavement outcomes for relatives.

3.3.4 Ongoing Clinical Review

The Clinical and Professional Assurance Group, chaired by the President of the Association for Palliative Medicine of Great Britain and Ireland, includes membership from ten professional bodies across health and social care. This group convenes six-monthly or more frequently, if required. The group monitors the hazard log, assess whether any additional clinical safety issues arise through implementation of the standard or though development of the standard and reviews all clinical issues that are reported through the Risk and Issues log.

3.3.5 Safe implementation of the standard

Information standards that are relevant to the safe implementation of the core content were identified as part of the standard development process and are regularly reviewed and updated. These are listed in the standard specification to draw them to the attention of the suppliers and implementing organisations. The two safety risk management standards are of particular importance, including the requirement for a clinical safety lead and ensuring that system safety is regarded as an aspect of clinical governance in the deploying organisations.

The relevant standards are listed in the table below.

Reference	Title
ISB 1500-1507	User Interface standards for entry and/or display of: patient name, address, telephone number, sex and gender, NHS number; date; time; patient banner.
ISB 0149	NHS number

4. Patient safety assessment

Seventeen hazards have been identified during development and implementation to date. Of these, five have been closed, nine have transferred to implementation and five remain open. See accompanying Hazard Log.

4.1 Hazards related to the core content

Nine hazards identified relate to the core content. Five have been closed or transferred to implementers. Coding has been reopened as new coding numbers will be published in October 2015. Four remain open. Mitigations have been put in place and will be reviewed in December 2016 which will include consideration of any feedback received from implementers.

Hazard	Rating post mitigations	Status
Identification	Moderate	Transferred-users
Medications	Significant	Closed
Meaning	Moderate	Transferred-implementers
Misleading information	Moderate	Transferred-both
DNACPR codes	Low	Closed
Coding	Moderate	Open
Carer/care worker terminology	Low	Open
Prognosis	Moderate	Open
NHS number - mandatory	Low	Open

4.2 Hazards related to implementation

The remaining hazards relate to implementation of the standard in the diverse system and organisational contexts. Only one remains open regarding communication of the changes made to the information standard.

Hazard	Rating post mitigations	Status
Accuracy	Significant	Transferred-users
Completeness	Moderate	Transferred-users
Change process	Moderate	Transferred-implementers
Person and carer concerns	Moderate	Transferred-both
Access	Significant	Transferred-implementers
Staff concerns X2	Moderate	Closed
Communication	Low	Re-open for Amd 11/2015

5. Mitigation and transfer of risks

The updated hazard log summarises the actions that were undertaken to reduce the identified hazards. Note that the expert group decided that the hazard posed by inaccurate or out of date ‘current medications’ in this context was too high for it to be included in the core content, particularly given that this information would be available from other primary sources such as the summary care record or the medications list in the person’s home. ‘Current medications’ was removed from the final core content.

5.1 Open hazards

The five open hazards are:

- coding issues where code numbers are not available for new data items
- inaccurate information on prognosis as record not updated
- confusion over new terms for carer and care worker
- unable to create a record as NHS number is mandatory
- communication of changes to the standard

These all relate to the changes being implemented in Amd 11/2015.

From a terminology coding point of view, SNOMED and Read codes have been specified in the standard for every data item that needs to be coded in accordance with UKTC recommendations. So the coding interoperability risk has been eliminated, as long as implementers apply the codes and guidance provided.

Although new coding was published and available for all data items included in Amd 16/2013, additional coding is required to support Amd 11/2015. UKTC has approved and published the majority of these codes. New coding to support the following codes for will not be published until October 2015. Requests for the required new SNOMED and Read codes have been made and the terminology agreed with UKTC.

- last months of life
- family member informed of cardiopulmonary resuscitation clinical decision
- carer informed of cardiopulmonary resuscitation clinical decision

This hazard has, therefore, been re-opened.

The proposed changes to the standard (Amd 11/2015) are expected to be published in September 2015. A hazard regarding communication of the change has been identified and mitigations put in place with a communications plan for dissemination of the information.

5.2 Hazards transferred to implementers

Learning from EPaCCS implementers has found evidence of improved quality of care and cost savings. Achieving these outcomes now sits with local implementers to address the hazard that that implementation of the standard does not improve palliative and end of life care.

Person and carer concerns about the standard have been transferred to both implementers and users. Implementers need to ensure that users have the competences specified in the professional guidance and the requirements of the standard regarding seeking consent.

Meaning with misunderstanding of the information recorded in the standard is a hazard that has been transferred to implementers. The data items included in the standard have been standardised and defined and approved by the Clinical and Professional Advisory Group, the UKTC and SCCI. The Implementation and Record Keeping Guidance provides clarity on the definitions and completion. It is the responsibility of implementers to ensure that definitions, guidance on completion and training is provided to users to mitigate this hazard.

Misleading information about formal carers involved in care has been transferred to both implementers and users. Guidance is provided on keeping this data item up to date. The data item records the formal carers that the individual is ‘under the care of’. IT systems need to be structured to support the display of this data item to ensure that there is clarity of the formal carers that the person has been ‘under the care of’ and which formal carers the person is currently ‘under the care of’.

Access to the record for all relevant staff involved in care has been transferred to implementers. It is for local organisations to ensure that systems and processes are in place to enable access.

5.3 Hazards transferred to users

Patient identification is a risk for all clinical records. The standard includes multiple identifiers including family name*, forename*, preferred name, birth date*, NHS number*, gender, address*. Those data items marked with * are mandatory for completion and NHS number is required. The likelihood of this hazard is rare. The responsibility is for users to complete and check these data items each time they use the record.

Professional guidance in the Record Keeping Guidance addresses the hazard of accuracy of the record. Guidance is provided on completion of the data items and emphasises professional responsibility for keeping records accurate and updated. A

maximum review date of one month is specified in the standard. The responsibility for this hazard is transferred to users.

Free text fields are available for relevant data items to support users to provide Completeness of the record. In addition data item (Other relevant issues or preferences about provision of care) has free text provision for additional information. This hazard is transferred to users.

Person and carer concerns about the standard have been transferred to both implementers and users. Users need to ensure that they have the specified competences to inform people and their carers about the shared record and to take consent. This includes an understanding of the Mental Capacity Act 2005.

Misleading information about formal carers involved in care has been transferred to both implementers and users. Users have professional responsibility for ensuring that the data item is kept up to date.

6. Glossary of terms

Term	Definition
Clinical risk	Combination of the severity of harm to a patient and the likelihood of occurrence of that harm.
Clinical risk management	Systematic application of management policies, procedures and practices to the tasks of analysing, evaluating and controlling clinical risk.
Clinical safety	Freedom from unacceptable clinical risk to patients.
Clinical safety case	Accumulation and organisation of product and business process documentation and supporting evidence, through the lifecycle of a Health IT System.
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.
End of life care (EoLC)	End of life care is care that helps all those with advanced, progressive and incurable conditions to live as well as possible until they die. It enables the supportive and palliative care needs of both patient 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, spiritual and practical support.

Term	Definition
Harm	Death, physical injury, psychological trauma and/or damage to the health or well-being of a patient.
Hazard	Potential source of harm to a patient.
Hazard log	A mechanism for recording and communicating the on-going identification and resolution of hazards associated with a Health IT System.
Health and Social Care Information Centre (HSCIC)	An executive non departmental public body that provides national information and information technology (IT) systems to health and social care organisations
Implementation and Data set management group (IDSMG)	Stakeholder group established by NHS Improving Quality and Public Health England to oversee maintenance of the standard.
Locality register	Locality registers are electronic systems where important details are recorded about people in an area that have been identified as approaching the end of life. By enabling relevant organisations/professionals to access these records, the registers provide a means to improve co-ordination of care for these people, and their families and carers. Locality registers will be known in future as *Electronic Palliative Care Co-ordination Systems.*
Patient safety assessment (PSA**)**	End to end, continuous, iterative assessment to establish the safety integrity of a deliverable. It consists of two main processes: hazard identification and risk assessment; and hazard analysis and risk management. Various safety specific activities (eg risk assessment workshop), methods (eg structured what if technique, hierarchical task analysis) and tools (eg hazard checklists, cause and effect (fishbone diagrams) can be used during a PSA.
Severity	Measure of the possible consequences of a hazard.

˜ CUI CAPS – Demographics – Clinical Safety Case and Closure Report Dec 2009

Appendix A. DHID risk matrix

LIKELIHOOD	Certain	5	5 (Moderate)	10 (Significant)	15 (High)	20 (High)	25 (High)
	Likely	4	4 (Moderate)	8 (Significant)	12 (Significant)	16 (High)	20 (High)
	Moderate	3	3 (Low)	6 (Moderate)	9 (Significant)	12 (Significant)	15 (High)
	Unlikely	2	2 (Low)	4 (Moderate)	6 (Moderate)	8 (Significant)	10 (Significant)
	Rare	1	1 (Low)	2 (Low)	3 (Low)	4 (Moderate)	5 (Moderate)
Department for Health Informatics Directorate			1	2	3	4	5
			Minor	Moderate	Serious	Major	Critical
RISK MATRIX			**CONSEQUENCE**				

Status		**Hazard Rating**	
Open		**Likelihood**	
Closed		Definition	**Score**
Transferred		Rare	1
		Unlikely	2
Hazard Rating		Moderate	3
Consequence		Likely	4
Definition	**Score**	Certain	5
Minor	1	**Rating**	**SIL**
Moderate	2	Low	1 – 3
Serious	3	Moderate	4 – 6
Major	4	Significant	8 – 12
Critical	5	High	15 – 25