National End of Life Care Intelligence Network

Palliative care co-ordination: core content

Implementation guidance

National Information Standard SCCI1580

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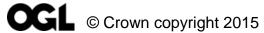www.gov.uk/phe
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SCCI Standardisation Committee for Care Information

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.

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Introduction

Palliative and end of life care is provided by many professional groups from a variety of organisations, often working across sectors. Consequently, effective co-ordination of care is crucial for safe care delivery that supports the person to achieve their preferences and choices at the end of life.

The Palliative care co-ordination core content information standard supports consistency of information held against a core data set. The standard is of relevance to all those working to improve palliative and end of life care co-ordination, and will underpin effective communication through electronic or paper-based systems. This implementation guidance is particularly focused on implementing the standard through electronic palliative care co-ordination systems (EPaCCS), previously known as locality registers.

The information standard will ensure that all IT system suppliers make available in their systems a consistent, complete core data set to support co-ordination of care at the end of life. Its use will be dependent on local decision-making around whether to implement EPaCCS (or other co-ordination systems) and, if so, the approach localities wish to take, however, where these data items are utilised, their use must comply with the standard.

The standard covers the core content required to support EPaCCS as detailed in the requirements specification. The data set may, however, be extended to meet local requirements. All IT systems are required to be compliant with the information standard.

This guidance and its associated documents should be made available to all professional groups that deliver care to people at the end of life, to provider organisations, to IT systems suppliers and to those who commission end of life care services.

This guidance incorporates the learning from the eight sites that participated in a Department of Health and National End of Life Care Programme (NEoLCP) pilot project to support and develop the local development of end of life care registers in England. The pilot project ran from October 2009 to March 2011. An independent evaluation of the project was carried out by Ipsos MORI and published in June 2011. The eight pilot sites and additional sites implementing EPaCCS were involved in the development of this guidance. Their learning has been incorporated together with evaluation, analysis and development work carried out by the national team.

This guidance should be read alongside the Palliative care co-ordination Record Keeping Guidance which provides guidance for the staff and professionals using EPaCCS to record details of people's wishes and preferences for palliative care.

Purpose

This guidance aims to provide commissioners, health and social care organisations and IT systems suppliers with the information needed to support implementation of the national information standard for palliative care co-ordination. It is particularly relevant for those developing and implementing EPaCCS, though it is still a useful resource for those planning to, or currently making use of, paper-based co-ordination systems.

The guidance includes business requirements for procuring and setting up EPaCCS and descriptions of potential technical approaches that could be used.

The guidance together with the information standard requirements specification will support local areas to develop EPaCCS (or other systems) and will ensure consistency of the information held in the record. A range of technological systems approaches can be considered and local areas will decide the best approach for their local circumstances and need. This guidance is not comprehensive and local areas need to build on this information to ensure that they develop a fully compliant safe solution.

For full details of the standard please refer to Palliative care co-ordination: core content requirements specification, SCCI1580.
Available at www.hscic.gov.uk/isce/publication/scci1580

Disclaimer

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

Every effort has been made to ensure that the guidance provides accurate and reliable information and guidance at time of publication. We do not accept responsibility for any loss, damage or expense resulting from the use of this information.

1. Background

A recommendation to develop locality registers as a means to improve communication and care co-ordination was made in the End of Life Care Strategy (2008). This followed the identification in Lord Darzi's report 'Healthcare for London: A Framework for Action' (2007) of the potential benefits of locality registers, as well as work underway in Scotland to develop an electronic palliative care summary.

The end of life care work stream focused on the early identification of people approaching the end of life and planning for their care, and identifies implementation of an Electronic Palliative Care Co-ordination System (EPaCCS) as an important mechanism to support this.

Support for EPaCCS has been expressed by the Independent Palliative Care Funding Review final report, which was commissioned by the Secretary of State for Health. The review, published in July 2011, includes a recommendation for every clinical commissioning group to maintain an end of life care locality register. The quality standard for end of life care for adults, developed by the National Institute for Health and Care Excellence (NICE), also recognised the potential of EPaCCS. Statement eight of the quality standard, which was published in November 2011, states:

'People approaching the end of life receive consistent care that is co-ordinated effectively across all relevant settings and services at any time of day or night, and delivered by practitioners who are aware of the person's current medical condition, care plan and preferences.'

The definition for this statement identifies EPaCCS (locality registers) and standardised documents as mechanisms for facilitating effective care co-ordination.

The Health and Social Care Act 2012 gives commissioning and regulatory organisations in England duties to secure or promote integrated services. The national information standard supports integration of palliative and end of life care services across health, social care, voluntary and independent sectors. The standard supports integrated working between professionals and staff working across multiple organisations and sectors including health, social care, voluntary sector, out-of-hours service providers, ambulance services and the private sector. In this way, provision of seamless, person-centred and individualised care for people and their families and carers is supported. The Care Act 2014 also promotes integration of care and support between health and social care services.

National guidance of care integration recognises the role of technology in supporting care integration and identified EPaCCS as a means of supporting care integration. Reference: Integrated Care: Our Shared Commitment, Department of Health (2013).

The NHS Information Strategy 2012, the Power of Information, requires accurate, consistent and standardised information to be held in records to improve the quality of data available for patient care and also reduce over time the need for time consuming and costly additional data collections. It aims to have clear national standards in place to ensure that locally developed IT systems can 'talk' to each other and exchange information effectively and securely. EPaCCS supports this strategy.

In 2013, Dame Fiona Caldicott published a review of information governance (IG) policy in the NHS. The review recognised the critical importance of information sharing, and re-enforced this by adding a new IG principle to those previously agreed in 1997:

> The duty to share information can be as important as the duty to protect patient confidentiality. Health and social care professionals should have the confidence to share information in the best interests of their patients within the framework set out by these principles. They should be supported by the policies of their employers, regulators and professional bodies.

This principle clearly supports the need to share information, for which EPaCCS systems, and care co-ordination systems more generally can play an important part.

The 111 service to access non-emergency NHS healthcare was launched in 2010 and is currently being rolled out nationally. The 111 service aims to improve access to urgent care services, including out-of hours care and local areas may want to consider linking implementation of EPaCCS with that for the 111 service. Some EPaCCS implementers have introduced automatic flagging systems in 111 and GP out-of-hours systems. See the case study on the NHS Improving Quality website. The National Information Board's Personalised Health and Care 2020 framework for action published in 2014 identifies EPaCCS as a way to support the vision for better use of data and technology to improve health, transforming the quality and reducing the cost of health and care services and to give patients and citizens more control over their health and wellbeing, empower carers, reduce the administrative burden for care professionals, and support the development of new medicines and treatments.

The Five Year Forward View into action planning 2015/16 highlights the importance of patients and their families being more involved in decisions about their care and support to have more choice. The House of Commons Select Committee report published March 2015 also supports the implementation of an EPaCCS system.

NHS England's 'Actions for End of Life Care: 2014-16' includes a commitment to support the continuing implementation of digital record-sharing systems to improve care co-ordination, including:

- the ability and willingness to share data across care settings
- ensuring that systems are capable of capturing and making explicit the individual's preferences and goals, and how they wish these to be achieved
- working with Public Health England to ensure that the national information standard for the content of Electronic Palliative Care Co-ordination Systems (EPaCCS) remains up to date, fit for purpose and is in alignment with the proposed Information Standard for personalised care planning

An EPaCCS, underpinned by a standardised information set, is intended to improve the service provided to people approaching the end of life, their families and carers. Such systems will record and make available people's preferences and wishes to the multidisciplinary team delivering care. This information, available 24 hours a day, facilitates co-ordination of care between the members of the team. It supports appropriate treatment decisions to allow more people to experience their preferences about palliative and end of life care, in the place that they wish and with the appropriate interventions.

The standard supports consistent recording of information that improves accuracy and avoids misinterpretation, misunderstanding and duplication of questioning across the multidisciplinary team.

2.   Data items

A summary of the data items included in the national information standard are:

No	Content heading/subheading
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
10	**Diagnoses** Primary end of life care diagnosis* Other relevant end of life care diagnoses and clinical issues Likely prognosis

No	Content heading/subheading
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.

It should be noted that SNOMED CT, Read CTV3 and Read V2 codes are provided in the standard. SNOMED CT is specified as the single terminology to be used across the health system in England and it should be noted that Read codes will be deprecated over the next five years. Areas using Read terminology will need to migrate to SNOMED CT within this timescale.

Where a pick-list of codes is suggested, local areas will select relevant codes to match local circumstances and information requirements.

Example:

Primary end of life care diagnosis: select code or text to describe the main contributing factor to the need for end of life care.

Additional content which could be used to supplement the core content data set is set out in Appendix 4.

For full details of the standard please refer to Palliative care co-ordination: core content requirements specification, SCCI1580.
Available at www.hscic.gov.uk/isce/publication/scci1580

Equality considerations

The Equality Act (2010) sets out nine protected characteristics, for example age, race and disability, which service providers need to take into account of in the development and delivery of services. Some of these characteristics are reflected in the core content, and others (though not all) are included in the additional data items in Appendix 4. It is important that mechanisms are established to enable reporting on these areas, whether through the EPaCCS or other systems, to assess the equitable provision and delivery of services for these groups.

3. Implementation approach

The provision of a standardised data set for palliative care supports effective, safe, reliable and co-ordinated care across a range of health and social care providers.

The data set can be used within EPaCCS, to be accessed by the multidisciplinary/inter-professional team providing palliative and end of life care to identified individuals.

This section of the guidance provides suggestions for implementation of such a system, and incorporates the learning from the eight locality register pilot sites and early implementers of EPaCCS.

In addition, organisations may want to consider using the NHS Change Model to build improvement capacity and capability. The model provides a framework for sustainable change and transformation to deliver real benefits for patients.

3.1 Local vision and commitment

Local teams need to identify all stakeholders and ensure that there is a shared understanding of the vision and task. Organisations deemed as 'successful' are those whose communities are strong, passionate and committed to delivering improvement and outcomes and who create shared purpose as a common thread. Shared purpose connects commitment and contribution to core NHS values to support delivery of outcomes that matter to local communities, beyond what is done as individuals, teams or organisations. It is important to have clarity of the problems to be solved, why it matters and a clear direction towards a worthwhile purpose. See details at NHS Change Model.

Step	Guidance on implementation	Considerations
1. Establish an executive project team	Identify leads representing key provider organisations together with senior clinical, IT and change management leads.	Identification of the benefit of EPaCCS to supporting end of life care commissioning intentions, included within business priorities, will facilitate commitment, funding and agreement for procurement. See Making the case for change Electronic Palliative Care systems. NEoLCP (2012) and Economic Evaluation of EPaCCS Early Implementer Sites. NEoLCP (2013). The development of EPaCCS needs to be considered as part of local commissioning and procurement strategies. The geographical scope

Step	Guidance on implementation	Considerations
		of the systems will have to be considered as well as the scope of provider organisations required to access EPaCCS. Plans need to align with national and local IT strategies. It is important to determine any requirement for compatibility or synchronisation with other local IT systems.
2. Establish a stakeholder group	Map the stakeholders. They should include GPs, out-of-hours service providers, ambulance services, acute hospitals, social care, community and voluntary sector service providers, people approaching the end of life and their families, technical delivery and commissioners.	Early engagement of stakeholders is important, as are efforts to ensure on-going engagement throughout the project. It is essential to include GP representation. The involvement of Health and Wellbeing boards should also be considered, especially when looking to incorporate social care services.
3. Support collaborative planning	Health and social care commissioners and providers should work together to plan an approach that will best support multidisciplinary working and care co-ordination across sectors.	
4. Obtain dedicated IT and clinical input	Care professionals and IT specialists working together from the outset will ensure that the data and process meets professional need.	
5. Confirm vision, commitment and scope	Confirm feasibility, leadership and resources. Agree the priorities for implementation.	Consider development of a critical success factors checklist for evaluation.

3.2   Preparation

Preparation is needed to achieve clarity on the solutions that will be developed. The learning from the pilot sites and early implementers will be valuable in informing this.

Step	Guidance on implementation	Considerations
1. Select groups that will access the end of life care data set	Clarify the priority of professional groups that need to access the data. Decide administration and access rights for each group: creation, editing, viewing and reporting. Map a person's illness trajectory to identify the staff that will need to access the record and the types of access that will be required.	Ownership of the record needs to be decided locally (i.e. the organisation that will act as the data controller). CCGs frequently have ownership of the pilot sites' records.
2. Establish the data (information set) requirements	The core data items are specified in the national information standard. Full details are provided in the requirements specification that accompanies this document. Localities will decide which of the core data items and any additional data items that they wish to include. The pilot sites identified additional data items which have been consulted on through development of the information standard. (See Appendix 4 of this document). The extent to which this detail is utilised and what other additional data items are collected will be for local determination.	

Step	Guidance on implementation	Considerations
3. Agree name of the (EPaCCS) system	Careful consideration should be given to the name of the system.	Some localities have avoided reference to 'end of life care' within the name of their system, as it was felt that this deterred individuals. A decision has been made for the London-wide EPaCCS, currently being developed to be called 'Coordinate my Care' to avoid any reluctance to discuss the system because of sensitivities or taboos about discussing end of life. Other names used include: 'My Wishes' in Medway.
4. Design consent process	An opt-in consent approach is to be used. Local decisions need to be made to identify the staff groups that will take consent, create a record and record the consent. Systems need to be in place to remove a record should a person change their mind and no longer wish to be on the system.	New clinical codes relating to EPaCCS consent, and the specific consent gained (either from the patient, a Lasting Power of Attorney, or via a best interests decision) have been added to the standard. These codes should be used to ensure all parties understand the basis upon which the record was created.
5. Develop a data/information sharing agreement	Establish data sharing agreements between the service providers that will be using EPaCCS.	An example of the data sharing agreement and website implemented by South West region. The HSCIC technology team has also developed guidance to support local teams in establishing such agreements (see the EPaCCS IG document link in Appendix 3).

3.3   IT readiness

Map the current information systems in place across the multiple service providers and determine functionality and compatibility requirements against the business requirements for the end of life care dataset/EPaCCS. Consider the national and regional/local IT strategies. Consider geographical boundaries and service provision.

Step	Guidance on implementation	Considerations
1. Map information systems already in place	Map the existing IT infrastructure across the range of service providers involved in delivering end of life care. Identify existence of other electronic records and consider how local systems/processes will be developed to manage multiple electronic records. Consider access for the required services.	It is likely that there will be a wide range of IT platforms being used and it is essential that the scope is fully understood. Some services may sit outside the NHS, so N3 connectivity may need to be arranged, for example hospices and specialist palliative care.
2. Determine the functionality and compatibility requirements	Clarify the functionality required to support the data set and the way in which it will be used. Clarify the IT systems and platforms and consider integration and interface. Define the non-functional requirements of the solution (eg availability, resilience, performance).	Compatibility enabling effective integration between IT platforms will facilitate ease of use for service providers. The use of Open 'Application Programming Interfaces' (APIs) is a key principle that has recently been re-enforced in the Safer Hospitals Safer Wards paper. It is also a requirement in the Government Service Design Manual. The use of Open APIs should allow greater compatibility between systems and potentially allow for automatic population of the record from existing data. When it comes to sharing EPaCCS information between systems, standard messaging interfaces should be used. Wherever possible nationally defined interfaces within the national Interoperability Toolkit (ITK) should be used.

Step	Guidance on implementation	Considerations
3. Select IT approach	Determine the best option to support the data set. Selection criteria may include: • functionality • integration with multiple providers' platforms • access for priority service providers • reporting functions • compatibility • ease of use • costs • training implications A key consideration when sharing EPaCCS records will be deciding which system will act as the 'authoritative' EPaCCS record. This is important when managing changes to records that can originate from a range of different services and systems. Without this being explicitly and overtly defined, there is a risk that clinicians may act on information that is out of date.	A key challenge is to find a platform which can be used across the different local IT platforms. Many of the pilot sites did not develop a new platform but built onto existing local or national platforms. The approach taken differs across local solutions, with some areas making use of the Summary Care Record, some implementing a dedicated EPaCCS solution, and others making use of an existing shared clinical system. See Section 11 for an overview of some possible technical approaches. An existing IT platform will reduce the training need and remove the need for double-keying, whereas a dedicated system may better facilitate sharing across services. Additional technical support is being provided, by the national team to support implementation and to support the implementation of national interoperability (ITK) specifications to enable data exchange between IT systems. To support local teams in defining their requirements, a document summarising the recommended IT system requirements for an EPaCCS has been published. (Now part of HSCIC). Organisations will need to carefully consider their reporting requirements when selecting an IT system.

Step	Guidance on implementation	Considerations
4. Administration rights	Develop a local system for issuing and controlling permissions for those using palliative care co-ordination systems: • creation • editing • viewing • reporting Map the EPaCCS and design processes to prevent duplicate records being created by separate care professionals.	Where possible national services should be used (smartcards and national role based access controls).
5. Information governance: data security and consent	See Section 6 for details.	
6. Clinical safety	Assess clinical risk and put in place a clinical risk management system and clinical governance arrangements.	

3.4   Engagement

Step	Guidance on implementation	Considerations
1. Develop a local communications plan	Involve representatives of all staff groups and service user representatives throughout the development.	
2. Promotion	Raise awareness of the new system early. Provide case studies of use of EPaCCS in other areas with the impact that it has had.	Share the benefits described in the Economic Evaluation of EPaCCS and Making a Case for Change: Electronic Palliative Care Co-ordination Systems. These include the impact on deaths in usual place of residence, potential cost efficiencies and improved co-ordination of care.
3. Engaging staff groups	Involve representatives of all staff groups throughout the development.	Staff are required to change current practice and the system will need to provide them with benefits and be easy to use.
4. Service users	Include service users in the communication plan. Options for engagement could include membership of the project implementation team, or consultation on plans. Work with local Health Watch groups and clinical network users groups to develop engagement plans.	National Voices Principles for Integrated Care (2011) provides useful guidance for policy makers and practitioners and includes users' views and suggested measures for success.

3.5   Project Planning

Dedicated project management is recommended to support implementation. Consider the following when developing project plans:

- ✓   Local commitment and vision
- ✓   Team commitment and preparations
- ✓   Mapping of IT systems across locality
- ✓   IT decisions made and IT readiness
- ✓   Interoperability requirements identified
- ✓   Business case developed and agreed
- ✓   Budget agreed and financial management plans in place
- ✓   Timescales for implementation
- ✓   IT contracts
- ✓   Engagement with local stakeholders
- ✓   Administration system
- ✓   Consent model agreed
- ✓   Privacy Impact Assessment carried out
- ✓   Data security and data sharing policies
- ✓   Assessment of clinical risk and clinical safety plans in place
- ✓   Training plans in place
- ✓   Policies to reflect new systems
- ✓   Local reporting, monitoring and evaluation plans defined

3.6   Implementation

Step	Guidance on implementation	Considerations
1. Managing the transition	The transition needs careful consideration as working with two systems is time consuming. Enrolling enough people onto the system to achieve a critical mass will support stakeholder engagement and encourage use.	
2. Collaborative approach	Clinicians and local IT leads need to work closely with the IT systems supplier throughout implementation (or developers if a solution is being developed in-house).	
3. Training	Put plans in place for any training required to support staff in using new technologies and deliver the training prior to implementation. Look for opportunities to embed the training in existing training programmes. Remember on-going training needs for new staff, which perhaps could be delivered as part of their induction. Registration of new users should be linked to the competences, knowledge and skills, such as communication skills and care planning, which underpin use of the system.	Staff need to have the appropriate competences for their role as specified in Common Core Competences and Principles for health and social care workers working with people approaching the end of life NEoLCP/DH (2009). This includes the competences for communication and advance care planning. Implementation of EPaCCS can act as a driver for training to ensure that staff have the required competences, knowledge and skills for their role in end of life care. Any required training will need to be completed prior to implementation. Additional resources are listed in Appendix 3.
4. User group	Establish a user group with representatives from the provider services to ensure that plans and systems meet the user needs and to address any concerns.	

3.7   Evaluation

Evaluation is required to feed back into service planning and review to ensure that the electronic record systems are evolving and responsive to needs and change.

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.

Step	Guidance on implementation	Considerations
1. Reporting	Reporting functions will support local decision making and can drive service improvements for quality, access and equality.	Reporting systems can be used to assess the impact of the EPaCCS system on quality of care (eg people dying in their preferred place) and cost effectiveness of services.
2. Monitoring	Establish a mechanism to capture use of the electronic record and user feedback including views on practical and technical issues and benefits.	
3. Review	Use reporting and monitoring information to direct amendments and future updates to the system.	Provide a mechanism to feedback into national learning.

3.8   Sustainability

The decision to implement EPaCCS should be made in alignment with local and national IT and organisational strategies.

Engagement and commitment from those using the systems need to be maintained. This will require evidence of success of the electronic record in improving care, improving the quality and accessibility of information available and the ease of use of the system.

Staff recording peoples' preferences and choices for end of life care require competences in communication and advance care planning. Ongoing training is required to provide and maintain these staff competences.

Identification of efficiency savings for local services through reduced emergency admissions and unnecessary medical interventions, as a result of use of an EPaCCS, will further support sustainability.

The NHS Change Model provides guidance to support sustainable and effective improvements.

Local commissioners, providers and clinicians may want to consider the development of Commissioning for Quality and Innovation (CQUIN) schemes linked to provider payment to support implementation of EPaCCS to support improved quality outcomes and care co-ordination and sustainability.

Commissioners may wish to specify EPaCCS requirements in local contracts, for example to support completion of data item: preferred place of death and data item: actual place of death.

4.   Clinical governance

The record holds the following clinical data items:

- primary and other relevant end of life diagnosis and clinical problems
- likely prognosis
- allergies/adverse drug reactions
- anticipatory medicines/just in case box completed and in person's house/hospice
- cardiopulmonary resuscitation decision
- legal advance decision to refuse treatment made (ADRT)
- Lasting Power of Attorney (LPA) appointed
- disability

From a clinical governance perspective, it is essential that the record is accurate and kept up to date. Systems need to be in place to ensure that the editing rights for these clinical items are limited to the appropriate clinicians and that discrepancies cannot occur between the record and other databases holding this information.

It is recommended that IT systems provide an automated prompt for review of 'likely prognosis', prompting monthly review for people with a likely prognosis of months, weekly review for people with a likely prognosis of weeks and daily review for those with a likely prognosis of days.

The core data items only include a record of whether a legal advance decision to refuse treatment has been made, and the location of this document. It does not hold details of the decisions made. It also includes details for any Lasting Power of Attorney appointed. In this way, it is directing professionals to the documentation and avoids the risks that result from duplicate records.

Locally, decisions can be made as to whether the original documents are uploaded into the record but clinical risk assessment needs to be carried out, for example around how to ensure those records are kept up to date, and policy and training put in place. Details of current medication have not been included in the core data items, though a data item is included in the extended data set in Appendix 4. If the local IT systems allow for automatic completion of the medication details from the Summary Care Record or GP record, inclusion of this item could be considered.

The professional bodies provide ongoing assurance of the clinical content of the core data set. The Association for Palliative Medicine is the lead organisation for this assurance role. Local arrangements are to be made to provide assurance of the clinical content of any additional data items included in the electronic records. This will include appointment of a clinical lead.

5. Maintenance arrangements

Where EPaCCS are implemented, local maintenance plans should be in place to provide assurance that the extended content of the electronic record remains fit for purpose. The arrangements should include named leads and structures for maintenance of the local record and systems for monitoring and review. Systems are also required to capture feedback from local stakeholders. Any local issues that relate to the core data items are to be reported to the national maintenance group via neolcin@phe.gov.uk.

6.   Information governance

Health records contain private and confidential information. It is essential that those setting up EPaCCS have a full understanding of information governance requirements to ensure that there are adequate data security and data protection measures in place, and that protection of personal information held about individuals is addressed.

Undertaking a Privacy Impact Assessment (PIA) is strongly recommended if the data is also to be used for secondary uses to ensure there is a secure legal basis for processing. It is recommended more generally to ensure that appropriate information governance controls, needed to mitigate identified potential risks to people's privacy, are in place. For example, clarifying which organisation has data controller responsibilities or if more than one organisation has these responsibilities, whether they are data controllers jointly or in common. This is important to ensure that there are appropriate contractual arrangements to provide information governance assurance in relation to any data processors.

A PIA is intended to identify privacy issues at the beginning of a project, before design solutions are agreed or anything put in place that can't be easily changed. If a PIA indicates certain data should not be collected and used, for example, it may be difficult to make changes if they are already implemented.

6.1   Information governance management

Existing information governance frameworks, policies and structures need to be reviewed to ensure that they reflect the needs of shared records. This should align with the requirements outlined within the Information Governance Toolkit appropriate to the care setting.

6.2   Further guidance on IG for EPaCCS

A more detailed set of guidance on obtaining data sharing agreements, and on other aspects of IG such as consent, audit, security and confidentiality can be found in the EPaCCS Information Governance guidance document produced by the digital technology team within the HSCIC.

Localities may wish to use ONS mortality files to keep EPaCCS records updated when a person dies. This would form a routine part of information governance, ensuring that the information held in EPaCCS is accurate and up to date.

6.3   Data security

The principles of information security require that all reasonable care is taken to prevent inappropriate access, modification or manipulation of data. NHS and Health

and Social Care Information Centre (HSCIC) standards for information security and secure storage and transfer of information must be adhered to.

Local decisions are required around responsibility of the content and accuracy of the data held in the EPaCCS. Guidance on shared records is provided from the Shared Professional Guidance Project (RCGP and HSCIC).

Local decisions need to be made on who has rights for creation, editing, viewing and reporting of records. Account needs to be taken of the authority required to complete each field. Clinical fields (diagnoses and clinical issues, likely prognosis, details of medication, allergies and adverse drug reactions) must be completed by a clinician. A cardiopulmonary resuscitation opinion must be made by the senior responsible clinician or their delegate, in discussion with the individual wherever possible and appropriate. It is recommended that data entry and changes to the cardiopulmonary resuscitation and ADRT fields are restricted to or reviewed by one named responsible clinician, for example, a person's GP. The electronic systems should have within their specification a feature to notify this clinician automatically when the record has been modified.

The system SHOULD prompt users that cardiopulmonary resuscitation decisions should only be recorded by the senior responsible clinician. NOTE: The choice of who the senior responsible clinician is will be made by the user and there is no requirement for the system to verify this.

> Personal data shall be adequate, relevant and not excessive in relation to the purpose or purposes for which they are processed. Data Protection Act (1998).

> People expect professionals to share information with other members of the care team, who need to co-operate to provide a seamless, integrated service. Good sharing of information, when sharing is appropriate, is as important as maintaining confidentiality. Caldicott Review. Information to share or not to share? (2013).

Ideally professionals should only be able to access the records for people under their care (ie those with whom they have a 'legitimate relationship'). In primary and palliative care settings, this is likely to form part of an ongoing registration or referral, whereas in out-of-hours and emergency care, it is more likely to be a 'self-referral' relationship, however each professional is bound by employment conditions of confidentiality and by the responsibilities of their professional organisation. Staff with a legitimate relationship are defined as the professional and voluntary staff providing care for the individual. Administrative and support staff may be delegated the task to input some (non-clinical) data or to access data on behalf of professional staff, where this is deemed necessary and appropriate by the care professional, but this will be a local decision and appropriate IG controls must be put in place. Guidance on legitimate relationships (HSCIC).

Processes used must ensure security of personal information during collection, storage and transfer.

Information accuracy is an information governance issue as well as a clinical governance issue and needs to be taken into account in system design. This includes the updating of the record with the date and place of death when a person dies.

Reference should be made to the HSCIC data security information guidance.

IT systems need to be configured to make data items that record 'actual place of death' and 'date of death' viewable only to staff caring for the person. This is important to avoid the risk of causing distress to people or their families.

6.4   Confidentiality

Supporting policies are required for decisions on the permissions allocated to professional staff viewing records on the EPaCCS to ensure that legal and NHS information governance requirements are met.

Given that the end of life care record contains sensitive clinical information, it is important that Role Based Access Controls (RBAC) are applied to ensure that access to view and update the clinical information is limited to clinical professionals who have been authorised to manage clinical information. Where possible this should be driven by the specified RBAC roles and activities for updating health records. This aligns with the NHS Care Record Guarantee: 'Show only those parts of your record needed for your care'.

Where data is transferred between organisations, a secure legal basis for doing so is needed such as through consent. This should additionally be supported by data sharing agreements to ensure there are appropriate information governance safeguards in place.

The system MUST prevent further access to a patients record (except for information governance audit purposes) if the patient withdraws their consent.

6.5   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. 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 an end of life 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.

The specific consent codes can be used to identify an EPaCCS record, and 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 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 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.

6.6 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.

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.

6.7   Data for secondary uses

Any data extracted for secondary use purposes should be effectively anonymised and/or pseudonymised or explicit consent obtained where identifiable data is needed.

Systems that use the national demographics services (PDS or DBS) to match patients and retrieve NHS numbers can also get reports with death information for any patients they have traced. These could also be used to ensure records are updated, although this service does not provide information about the place of death. (N3 access only.)

7. Advance care planning

Advance care planning with people who have a terminal condition offers them the opportunity to share in decisions about the course of action to be taken at pivotal points in their lives, should their condition deteriorate rapidly and they lose mental capacity.

The process of advance care planning often involves multidisciplinary teams working across local health, social care and voluntary sector services and an ongoing dialogue with a person and those close to them about how to meet their current needs and those that can be anticipated in the future. It requires shared decision-making between care professionals and people approaching the end of their lives.

The core data items in the national information standard support advance care planning. The following data items specifically address advance care planning:

- EoLC tool in use?
- advance statement requests and preferences
- preferred place of death
- advance decision to refuse treatment
- lasting power of attorney for personal welfare
- additional people to be involved in decisions
- other relevant issues or preferences about provision of care

A full understanding of the implications of the Mental Capacity Act is essential regarding:

- consent
- advance statements and identification of others to be involved in decisions
- Preferred Priorities for Care (PPC) is an example of a tool for making an advance statement
- advance decision to refuse treatment
- Lasting Power of Attorney

Further guidance is available:

- Palliative care co-ordination: core content record keeping guidance
- Capacity, care planning and advance care planning in life limiting illness: A Guide for Health and Social Care Staff NHS Improving Quality (2014)
- General Medical Council. Treatment and care towards the end of life: good practice in decision making (2010)
- King's Fund. Making Shared Decision-Making a reality: No decision about me, without me. Angela Coulter, Alf Collins (2011)

8. Application and definitions

8.1 Application

When should the information be collected?

It is expected that, when identification is possible, people will have an EPaCCS record for around the last 12 months of life. Once a person has been identified as likely to be in the last 12 months of life, the information collection process should be initiated by a health or social care professional, having discussed this with the person and their consent gained for inclusion on the system and for their details to be shared.

Staff must exercise judgment about when or whether to initiate discussions about end of life care and creating a record on a co-ordination system. It may not be appropriate or timely for some individuals and staff must always act in the person's best interests.

How and when should the information be captured?

Recording of the information should commence once consent has been given for the person's details to be added to the EPaCCS and for this information to be shared with the health and social care professionals involved in their care. Health or social care professionals are best placed to obtain consent. Not all information may be available at that time and completion may take place over time.

Who should capture the information?

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

How often should this information be updated?

This information should be captured and updated on an on-going basis as required to ensure that it remains accurate and up to date. A maximum review date of three months should be set.

8.2   Definitions of terms used in the data set

Term	Definition
Acute hospital	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 (for 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) Advance decisions to refuse treatment, NEoLCP (2013) Mental Capacity Act 2005 Mental Capacity Act (2005) Code of Practice. Ministry of Justice 2007

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 checklist 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 new 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, inform 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	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' when they are likely to die within the next 12 months. This includes individuals whose death is imminent (expected within a few hours or days); those with advanced, progressive, incurable conditions; those with general frailty and co-existing conditions that mean they are expected, to die within 12 months; those at risk of dying from a sudden acute crisis in an existing condition; and those with life-threatening, acute conditions caused by sudden catastrophic events. **Source** Treatment and care towards the end of life: good practice in decision making. General Medical Council. (2010)

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.
Hospice	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: An LPA for property and financial affairs: This replaces the previous Enduring Power of Attorney and does not have power to make health decisions. Please note Enduring Powers of Attorney were replaced by Lasting Powers of Attorney but may still be used if made and signed before October 2007. An LPA for personal welfare: This LPA must be appointed while the individual has capacity, but only becomes active when the individual lacks capacity to make the required decision. The LPA must act according to the principles of best interests. The LPA's role can be extended to life-sustaining treatment decisions (LPA for personal welfare including health), but this must be expressly contained in the original application. A personal welfare LPA (PW-LPA) only supersedes an ADRT if the PW-LPA was appointed after the ADRT was made, and if the conditions of the PW-LPA cover the same issues as in the ADRT. **Sources** Mental Capacity Act 2005 Mental Capacity Act (2005) Code of Practice. Ministry of Justice 2007 Deciding right - a new north east initiative for making care decisions in advance. Northern England Strategic Clinical Networks. (2014)
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.
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.

Term	Definition
Preferred priorities for care (PPC)	The PPC is an end of life care tool that essentially serves three purposes. It facilitates discussion(s) around end of life care wishes and preferences. The PPC can enable communication for care planning and decisions across care providers. And, thirdly, should the person lose capacity to make a decision about issues discussed, a previously completed PPC acts as an advance statement. This means that the information included within the PPC can be used as part of an assessment of a person's best interests when making decisions about their care. Source: Preferred Priorities for Care NEoLCP (2011).
Prognosis (end of life)	A judgement about the likely outcome of a health condition or situation. Note: regarding end of life care, awareness of the prognosis is taken to mean awareness that the life span is limited.

9.   Important technical considerations

There are a number of technical aspects of delivering an EPaCCS that are not outlined in this information standard, but which will need to be considered by local teams implementing EPaCCS solutions. All the areas below should be considered by local teams, and an approach agreed.

9.1   Managing multiple local 'hubs'

If a number of different end of life care hubs exist within a locality, there needs to be some way of identifying which holds the records for a specific person. The geographical coverage of care services differs, so it is possible that services that cover a wide area (eg ambulance trusts) may have to access a number of different local EPaCCS. The process for identifying and directing professionals to the relevant location to retrieve the EPaCCS record needs careful consideration.

Thought should be given to agreeing a standard format for the list of people with an EPaCCS record. A standardised format across a locality (or even nationally – perhaps as an Interoperability Toolkit standard), which contains a pointer to direct the user to the appropriate local hub could be considered. This would potentially allow for creation of a combined listing covering a wide area. Services using this listing could then look up the individual, and identify which hub system to use to access their EPaCCS record. Technically, this may take the form of a 'registry' that can be queried to find out where information about a patient is held – which would include pointers to their EPaCCS record where one exists.

Where multiple hub systems exist within a locality, the need for a 'single sign-on' solution also becomes more important. A national solution (ie smartcards) exists which should be used wherever possible to avoid users having to remember multiple passwords for multiple hub systems.

9.2   People moving between localities

If a person has a record in a local EPaCCS and then moves to live in a different locality, there may be a need to transfer their record between local systems. In many cases this may be a manual process, but an approach needs to be agreed for handling this. As more local systems are created, there may be a need to make use of Interoperability Toolkit (ITK) standards to allow for the electronic transfer of EPaCCS records.

9.3   People's access to their EPaCCS record

Involving the person in decisions about their care—'No decision about me without me'— is an important principle in the government white paper, Equity and Excellence: Liberating the NHS, so consideration needs to be given to how the details held in the EPaCCS record will be shared with them. Conversation about end of life care will need to take place for consent to be taken.

As a minimum, there should be a way of printing a copy of the record to share with the person, but many organisations may want to develop 'portals' to allow people to access their record over the internet, and potentially also contribute to them directly. Such a portal would provide great potential benefits to the individual, but serious consideration needs to be given to information governance and security for any such portal solution (eg registration, authentication, secure transmission, controlling the level of detail shown, providing simple explanations and context for the information shown, etc.)

9.4   Reports and extracts

It is very important that any NHS organisation that uses an electronic system to hold individual records is able to extract and report on the data held in that system.

The organisations using these electronic services have a number of local and national reporting requirements which they need to be able to meet (including data to support future commissioning and outcome tracking). Many will have local data warehouses and other data analytic capabilities which require data feeds from their IT solutions. Any EPaCCS should provide full data extracts to support local organisations in meeting these and future reporting needs.

9.5   Links with other care planning solutions

The need to co-ordinate multidisciplinary teams is not unique to end of life care planning, but is very similar to the need in other areas – especially for long term condition care planning.

Careful consideration should be given to co-ordinating or combining the solutions and approaches taken in these areas. For example, if work is ongoing to create a central hub for storing long term conditions care and support plans, it may make more sense to extend that existing solution to cover palliative care co-ordination. Thought would obviously need to go into ensuring that appropriate information governance controls were in place to stop information being accessed inappropriately where a shared solution is used.

10. Technical guidance

The pilot sites explored a range of IT systems and approaches to implementing EPaCCS. The learning from the pilot projects' experiences is presented in the End of Life Care Locality Registers Evaluation Final Report (Ipsos Mori, 2011). Selection of a suitable technology platform was challenging and the pilots did not find an 'ideal' IT solution. All sites chose to 'piggyback' onto pre-existing platforms. The majority of pilots chose to use one IT platform. Ensuring access across relevant organisations is a major challenge.

Integration of data from multiple platforms could ensure full functionality with access to the EPaCCS for more health and social care service providers. Local areas will decide an approach that best meets their requirements.

IT systems used must be compliant with NHS and legal requirements for information governance, ensuring that information is processed securely and with proper regard for its confidentiality, integrity, end to end security and availability. Please refer to the Health and Social Care Information Centre website for details.

To help support organisations in framing their technical requirements for assessing or procuring EPaCCS solutions, the digital technology team within HSCIC drafted a suggested set of system requirements - a link to this document can be found in Appendix 3. This document summarises the various system requirements outlined in the SCCI Requirements specification, this implementation guidance document, and the associated record keeping guidance document.

10.1   Concept of operation

Information about a person's end of life care and preferences should appear as a single record that is updated whenever/if ever the person wishes to change it and the current up to date record is available to those who have a need and right to access it.

Data about people is often stored on multiple IT platforms with separate networks used by primary care, community care, acute care, hospices, social care, ambulance and out-of-hours services. Implementation of the information standard will be determined by local service providers. The EPaCCS may be hosted on a variety of IT platforms. It may sit on existing IT infrastructures and be accessed via separate networks or it may be a bespoke system that integrates data from multiple providers' platforms.

Local requirements for compatibility with other systems will need to be determined. Integration of systems to allow automatic population of data from existing data bases would be preferable.

A range of professional groups will need to access the data. Clear governance for the data is essential and a data controller appointed with responsibility for security and accuracy of the data and for the decisions made for administration rights. The administration rights will identify the staff groups and grades that have rights for creating, viewing and editing the record. The data needs to be available 24/7. With due consideration to information governance and data protection, it is recommended that a hard copy of the record is also available in the person's home, at the bedside or where it can be easily accessed by relevant carers.

There are likely to be a wide range of IT systems in use in local care communities. An integrated solution with full interoperability is desirable, however, it is recognised that local areas may need to take a phased approach to this, starting with a more basic solution and developing more integrated models over time.

10.2   Solution components

It is expected that detailed care plans will remain in the appropriate acute, primary and social care systems. The focus of this guidance is on two specific areas:

- identification of individuals who have a record on EPaCCS
- access to the core content on EPaCCS for relevant staff caring for the person

The exact composition of the solution in the local implementation would need to be determined, but the identification of those on EPaCCS may be by provision of a simple list of people with a record to multiple care services or by flagging in other databases. Once this has been established, the 'core' end of life care record could then be accessed/retrieved from whatever system is hosting it.

As an example, the list may be provided as a daily file to ambulance services and out-of-hours services, so that they can check whenever they start an encounter with a person. If the person is on the list, they can then open the EPaCCS record to ensure they are handling the encounter in accordance with the person's preferences. A more mature solution to this might be to use the national Interoperability Toolkit (ITK) specification for notifications.
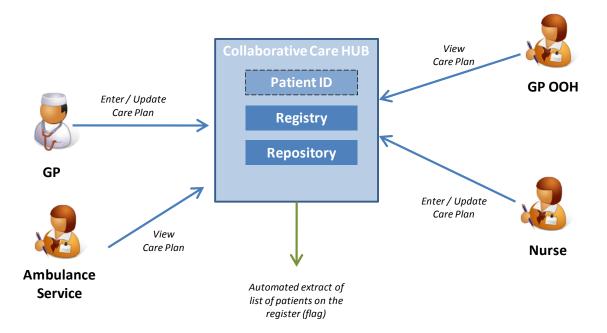
10.3   Integration with national services

The national Personal Demographics Service (PDS) provides a national authoritative source of demographic information and NHS numbers for individuals and service users. It is important that PDS is used wherever possible to ensure that the end of life care record contains accurate and up-to-date information.

NHS number is mandatory for completion. Whenever possible, a verified NHS number, where the patient's identity has been cross-checked using demographic details on the Personal Demographics Service (PDS) should be used. The standard records the NHS number status indicator code, proving information on the verification status of the NHS number recorded. Guidance to support use of NHS number is available from the Health and Social Care Information Centre. In addition, staff holding an NHS smart card can access NHS numbers through the Summary Care Record (SCR) application.

Also, the national NHS SCR contains a core data set of medications, allergies and adverse reactions. This information comes from the GP record and 99% of GP practices have an IT system that enables them to participate in SCR– extending to 100% during 2015. As of June 2015, 96% of the English population have a core SCR. With patient consent, further additional information can be added to the SCR by their GP practice such as significant past medical history and procedures, anticipatory care information, patient preferences and other relevant information including all data items specified in the Palliative care co-ordination Requirements specification (SCCI1580). The SCR is updated automatically as and when changes are made in the GP record and is available to all clinicians across the NHS in England either through the web based SCR application or suitably enabled clinical applications. For more information, visit: www.systems.hscic.gov.uk/scr
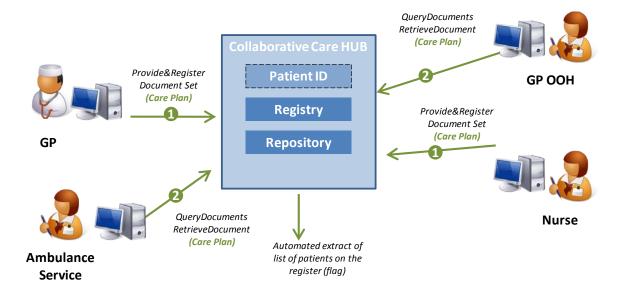
10.4   Integration methods

There are many ways that information can be populated into EPaCCS. Although not desirable, the simplest is for the information to be manually re-keyed, which may be faster to implement, but may dissuade users from contributing to the EPaCCS record (evidence from pilot sites found that this did indeed present a barrier to implementation), and could potentially lead to keying errors. This would require that authorised users log into a 'hub' website and use the system directly to add/update the content of the EPaCCS record.

It is very likely that some systems will already hold some of the information required to populate the EPaCCS record. For example, many systems will hold demographic information (linked to PDS in many cases), and also some of the care management aspects of the EPaCCS record (medications, allergies, adverse reactions, diagnoses, etc.).

Many systems have generic data capture form capabilities that could be used to also capture any additional fields required for the EPaCCS record, and may either host the record and make it available to other services (ie act as the 'hub'), or feed the information into a separate 'hub' system for wider sharing. These data capture forms should constrain the data capture values/coding to ensure it is consistent with other systems, and with the end of life care data standard.

A better solution, therefore, is to provide electronic feeds from the systems that are already collecting relevant information – either in the form of extracts or direct electronic messaging between systems.

It is possible that a combination of approaches may be required, depending on the software solutions in use within the local estate. For example, core data from various existing systems could be fed into the EPaCCS record, and then manual entry used to add the additional information required where it does not exist in the source systems.

Over time, the solution could be enhanced to progressively remove the need for manual keying, as the various source systems are updated to incorporate the end of life care data set and message it electronically to the central 'hub'.

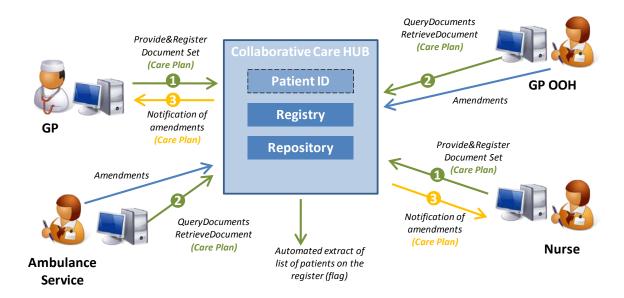## 10.5   Handling updates to palliative care records

Wherever a local end of life care record allows for electronic updates from other systems, the approach for version control needs to be considered.

One potential approach is to treat the record in the central 'hub' as a read-only view, and rely on updates to flow down from the various source systems as required. The problem with this approach is that it could cause significant delays in updating information, especially when updates need to be made out-of-hours.

Another approach is to allow updates to be made directly in the central 'hub' record. This would allow for the greatest level of flexibility in allowing updates to be made from any care setting, and being reflected in the record immediately. The risk, however, is that any updates that are made could subsequently be overwritten by information flowing down from other systems as they feed through updates.

A possible way around this would be to provide a feedback mechanism, whereby any updates made to information in the central 'hub' could be notified to the source systems to allow the relevant updates to be reflected as appropriate.

This has the added advantage of helping to ensure these other systems are kept up to date as people progress through their end of life care plans, and their circumstances or preferences change. Again, these updates could be done through an electronic messaging interface, or through direct editing of the information on the 'hub' website (or both).

10.6   Messaging standards

Where there is an intention to use electronic messaging, it is important that this messaging is standardised wherever possible. The Health and Social Care Information Centre is working with NHS organisations and suppliers to develop and maintain a set of interoperability standards through the Interoperability Toolkit (ITK) programme, and can provide support in the development of standards for messaging of EPaCCS record content between local systems.

A number of new ITK specifications were developed by the digital technology and ITK team within HSCIC. These include the following electronic messages which could support an integrated EPaCCS solution:

I.   **End of life care preferences**: this is a clinical document using the international Clinical Document Architecture (CDA) standards from HL7 to allow the sending of end of life care preferences as defined in this national information standard.

II.   **Notifications**: to notify others caring for the patient when key events occur such as changes to their care plan, or an unscheduled care encounter.

III.   **Document Retrieval**: to allow systems to retrieve documents held in remote systems or repositories (eg an EPaCCS system) when they are required – potentially as a result of being notified about events or changes to key patient information.

Further details, examples, and links to the specifications can be found on the NHS Developer network.

Where applicable ITK standards already exist for the transfer of information, these should be used to avoid a proliferation of incompatible interfaces being developed. Where applicable interoperability standards do not exist, local organisations should consider working with the ITK team to propose and develop new standards.
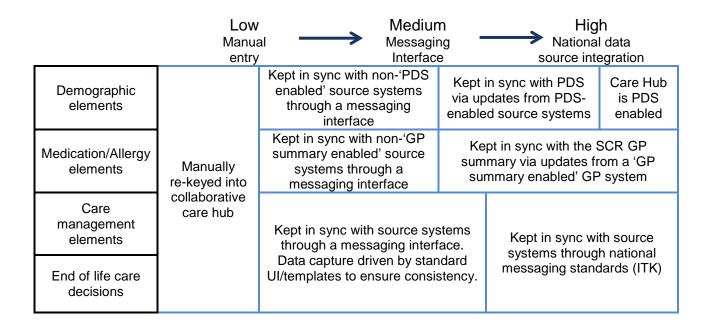
The 'trust operating model' for ITK (available in the Core ITK specifications on TRUD contains some sample text that should be included in contracts with suppliers to require that ITK interfaces are used where they are available.

There are also potential opportunities to leverage some of the solutions already developed under the ITK accreditation process to provide simple interfaces into PDS (referred to as 'Spine Mini-Services'). More details can be found on the HSCIC website, including contact details for the ITK team.

10.7   Maturity model for integration

Given the wide range of IT systems in use in local care communities, a high level of variation exists in the potential level of technical integration achievable via an EPaCCS. Whilst a fully integrated solution, linked with national services is obviously desirable, it may not be realistic in many cases. It may be preferable to start with a more basic solution, and potentially develop a longer term roadmap to enhance the solution over time. This should allow for immediate benefits to be realised, whilst establishing a route to delivering further efficiencies moving forward through tighter integration.

The content of the EPaCCS record can be considered across a few dimensions, and a maturity level can be assessed for each dimension. An example of such a maturity model is shown below. Local teams may want to consider adopting this model, or developing a local maturity model to drive local development roadmaps.

		Low Manual entry	Medium Messaging Interface		High National data source integration
Demographic elements	Manually re-keyed into collaborative care hub	Kept in sync with non-'PDS enabled' source systems through a messaging interface	Kept in sync with PDS via updates from PDS-enabled source systems		Care Hub is PDS enabled
Medication/Allergy elements		Kept in sync with non-'GP summary enabled' source systems through a messaging interface	Kept in sync with the SCR GP summary via updates from a 'GP summary enabled' GP system		
Care management elements		Kept in sync with source systems through a messaging interface. Data capture driven by standard UI/templates to ensure consistency.		Kept in sync with source systems through national messaging standards (ITK)	
End of life care decisions					

10.8   Summary care record (SCR) supporting EPaCCS

Another aspect that should be considered by local implementation teams is the extent to which the SCR could be used to reflect and share the palliative and end of life care information recorded in the patient's GP record.

The SCR contains key medical information that is available to authorised healthcare staff providing care in an urgent or emergency care situation. A person can choose whether to have an SCR or not. As of June 2015, 96% of the English population have an SCR and these are being used in a wide number of care settings to support care, including palliative and end of life care.

It is possible to include additional information, beyond the core data set of medications, allergies and adverse reactions, in a person's SCR. This can only be done with the explicit consent of the individual. Any coded data item and its associated free text can be included in this manner. An example of end of life care plan information in an SCR can be seen in Appendix 1.

It should be possible to store most or all of the data items described in this standard in the SCR. There is specific guidance on including additional information in the SCR and obtaining explicit consent.

The SCR can be viewed on a number of IT systems—including an N3 portal which can be deployed to any N3 networked computer—and a variety of integrated systems that are used in urgent and emergency care, including Adastra, TPP SystmOne, Cleo, Emis Web, Lorenzo and Ascribe. Other SCR integrated IT systems will be introduced over the next few years. There are also messaging interfaces available on the national

Spine which could be used to retrieve the information from the SCR directly. Implementers should note that the new Health and Social Care Network will replace N3 when the N3 contract ends in 2017.

There are a number of limitations that would need to be considered with this approach however:

- there are no reporting services provided as part of the SCR, so reporting will be done through the source GP system. SCR will not automatically reflect all the EPaCCS dataset as some elements are not relevant to direct care of the patient eg actual place of death. Recording and reporting of such information can be done in the source GP system if required
- only the registered GP practice is able to update the SCR, via the source GP system, which may cause a delay in updating the record if changes need to be made out of hours, and have to wait for the information to be passed back to the GP (eg in a discharge summary) before it is updated
- currently, not all patients have an SCR, but it is expected that most of the remaining 4% of the population will have an SCR created during 2015. By summer 2015, over 99% of GP practices will have the capability of adding further additional information for patients including end of life care information

10.9   Using the SCR to 'signpost' users to EPaCCS

Another potential way that the SCR could be used to support end of life care, is to include 'signpost' information in the SCR, which indicates that an individual has an end of life care plan, and directs the user to where this is held. This could be achieved by adding a coded item to the SCR, adding some textual information as a note against the item (ie explaining where the full care plan can be found), and then including this coded item as an additional item in the person's SCR.

For example:

Code and term	Free text
9Ng7. On end of life care register	Patient has been identified as receiving end of life care. Please contact District Nursing team on 0113 xxxxxxx to discuss this person's care.

The SCR can also be used to 'signpost' where information can change frequently or be particularly sensitive. For example, many localities operate a standard DNACPR form, but that form has to be kept as a paper version, particularly to support ambulance staff. The SCR could 'signpost' in these situations.

For example:

Code and term	Free text
1R1.. Not for resuscitation	DNACPR paper form in purple multidisciplinary team folder in lounge.

11. EPaCCS technical approach examples

A range of EPaCCS solutions are already in place across the country. Some of these were originally developed as part of the locality register pilot that was funded by the National End of Life Care Programme, but there are also a range of other solutions which have been created as local teams recognise the benefits of having an EPaCCS in their locality.
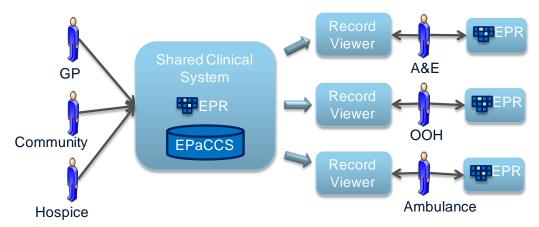
Generally, the approach taken by a locality will be driven by the IT landscape within the area. Some common approaches that the digital technology team came across when discussing EPaCCS with local teams across the country are outlined below.

In reality, most solutions will not fall neatly into one of these four approaches. Some may incorporate aspects of more than one approach for different care settings and participants, but in general most solutions can be categorised into one of the following four high-level approaches.

A broader set of integration patterns for sharing records between systems (wider than just EPaCCS) can also be found on the NHS Developer Network.

11.1   Shared clinical system:

In some localities, an existing centrally hosted clinical system is already in place and is used across a number of care settings. In this case, it is logical to incorporate EPaCCS records into the existing system. This is typically achieved by developing data-entry templates for capturing the EPaCCS information, and providing views of that information across the various care settings using the shared clinical system.

Benefits:
- reusing existing shared system may be quicker and cheaper initially
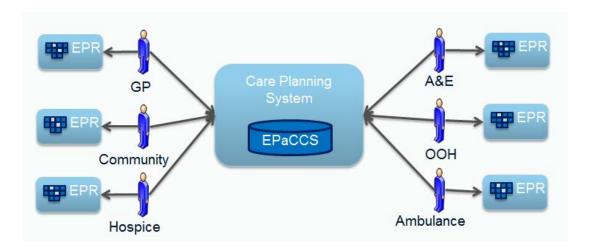- IG controls and agreements may already be in place
- familiarity for users

Concerns:
- unlikely to ever be used by all care settings
- granting access outside services using the system may be difficult or costly
- getting EPaCCS-specific changes challenging if small part of a bigger system
- could lock services into a single supplier

11.2   Dedicated EPaCCS/care planning system

In some cases, local teams have procured a new shared solution specifically for holding EPaCCS records. This may be limited to EPaCCS records, or in some cases it may be a more general care planning/co-ordination system that can also support the sharing of other care plans (eg LTC care plans).

This system is generally made available to all care settings using a web-based interface, with appropriate controls over who can view/update as per their role in the care planning process. A separate process is often used to 'flag' within the various clinical systems that a care plan exists in the care planning system, so clinicians know to look there for EPaCCS/care plan details.
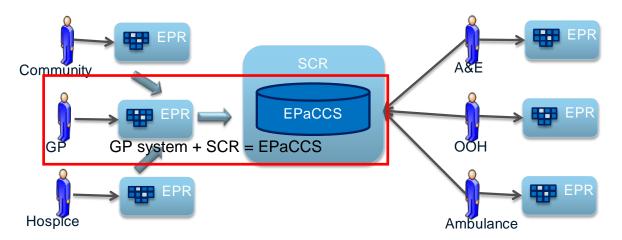

Benefits:
- can provide access to any clinician over N3
- does not require any changes to existing clinical systems

Concerns:
- information duplicated from clinical systems – requiring re-keying
- more logins and passwords to remember
- processes needed to 'flag' in other systems so that clinicians know an EPaCCS record exists

11.3   Summary care record supporting EPaCCS

With the consent of the patient, GPs can add end of life care information into the national summary care record. Local teams who have a good uptake of SCR have used this to support their EPaCCS solution.
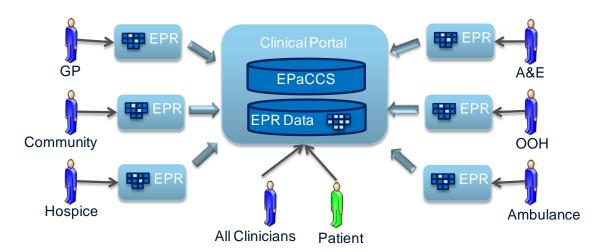
Benefits:

- once information is recorded in SCR it is available to any clinician in England

- SCR is already used in a variety of urgent and emergency care settings, including hospital pharmacies, acute hospital admissions, A&E departments, NHS 111 services, GP Out of Hours, ambulance services, community and mental health services, where EPaCCS information would be very valuable

Concerns:

- the current policy to only allow GPs to update SCR introduces a human bottleneck for all updates

- SCR cannot provide reporting, however the source GP system can provide the reporting

11.4   Clinical portal

A clinical portal can allow clinicians to view information extracted from a variety of systems via a single, consistent interface, thus allowing clinicians to share information across specialities and care settings. This does not in itself provide an EPaCCS solution, but often forms part of a wider information strategy within organisations, so is included here for completeness.

Benefits:

- EPaCCS information can be collated from a range of systems and presented in a single 'view'

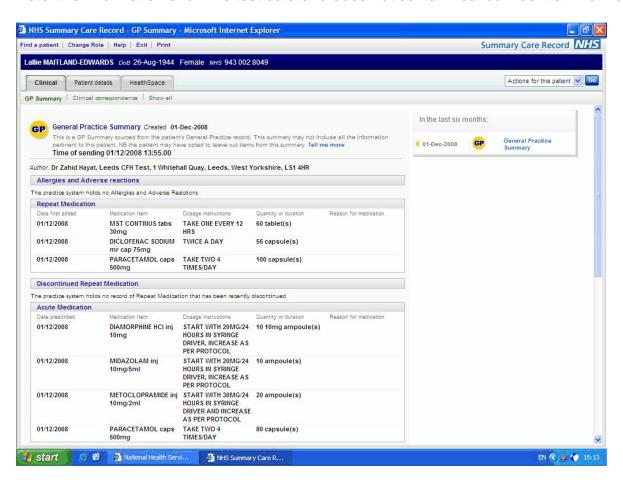- could be extended to provide a patient portal

Concerns:

- not an actual 'EPaCCS' per-se, rather a way of presenting information

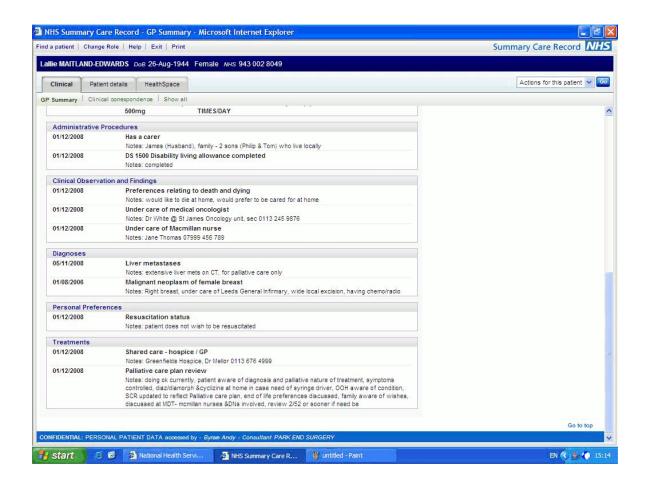- doesn't address the issues of managing changes to this information

Appendix 1: example end of life care information in an SCR

The screenshots below show how some of the information in this standard can be captured and displayed within the summary care record.

Note: the information shown is test data and does not contain real confidential information.

Appendix 1: example end of life care information in an SCR (continued)

Appendix 2: information leaflet

What will my data be used for?

The recording and sharing of your information is crucial to ensuring good co-ordination of your care, which is the objective of this system.

It is a communication tool allowing multiple agencies to share your wishes and information.

Your data may also be used to ensure that NHS plans and services meet people's needs. If your information is used for this purpose, it will be anonymised to protect your confidentially.

What if I change my mind on any decisions?

The clinician looking after you will discuss this with you and make any changes to the information held.

Where can I get more information?

If you require more information, you should contact the clinician looking after your care.

What are the benefits of the system?

The electronic end of life care information system records some key information about your decisions. Your decisions and any needs you have will be shared to give you the best care possible.

The system will enable your preferences and needs to be communicated among staff and organisations who are responsible for your care, either now, or in the future.

Access to this information will help the staff caring for you to make every effort to follow your wishes about your care at this stage of your life.

What sort of information will be shared?

The system will share information which supports your decisions, including:

- where you want to be cared for

- where you have expressed a preference on where you would prefer to die wherever circumstances make this possible

- decisions you have made for your future care

- information for professionals delivering or co-ordinating your care, for example contact details for your main carer or contact, the key health worker, resuscitation wishes etc

The information recorded is used to support your decisions and wishes, and to help staff and organisations to respect these.

Who will have access to your information?

Computers allow us to share information between staff in different areas, but with strict controls. All information is stored securely.

Your information will only be accessed by staff responsible for delivering your care. This may include, for example, your GP, ambulance services or community nursing service.

No one without good reason to review your information will be allowed access to it.

Who should I tell?

If you have included the names and contact details of people that you wish to be involved in decisions about your care, please let them know.

Appendix 3: useful resources

1. Training and competences in communication and advance care planning

Common core competences and principles for health and social care workers working with adults at the end of life.

Resources and information on raising awareness and promoting conversations about death, dying and bereavement on the Dying Matters website.

e-Learning for Healthcare (e-LFH) contains a range of online self-learning programmes, including several relating to end of life care (e-ELCA). Registration is required but is free.

Hospice UK

Finding the Words training DVD and workbook to support staff in end of life conversations.

2. Mental Capacity Act

Mental Capacity Act 2005.

Mental Capacity Act Code of Practice 2007.

ADRT NHS website with downloads of important documentation, training modules, advice and further links.

Independent Mental Capacity Advocate (IMCA) service.

Making decisions: A guide for people who work in health and social care.

3. Information governance

Electronic Palliative Care Co-Ordination Systems: Information Governance Guidance.

Information governance toolkit version 13, HSCIC.

Caldicott review: information governance in the health and care system. (2013)

Informing Shared Clinical Care. Final Report of the Shared Record Professional Guidance Project. RCGP Health Informatics Group (2009)

Example Information exchange agreement.

NHS Care Record Guarantee.

Relevant laws, policy, standards and guidelines:

- access to Medical Reports Act (1988)
- access to Health Records Act (1990)
- NHS Act 2006 (Section 25) (previously Section 60 of the Health and Social Care Act 2001)
- Data Protection Act (1998)
- NHS Data model and dictionary records management - NHS Code of Practice (DH)
- guidelines on use of encryption to protect person identifiable and sensitive information, Department of Health Digital Information Policy, (2008)
- confidentiality and security requirements set out in HSCIC Information Governance Training Tool

4. NHS Interoperability Toolkit:

Terminology Reference Data Update Distribution service (TRUD).

Safer Hospitals Safer Wards paper.

Government Service Design Manual.

NHS Developer Network: Care Co-Ordination Interoperability.

Recommended IT System Requirements.

Appendix 4: additional content for the end of life care record

The core content in the national information standard identifies key data items to ensure effective, safe, reliable co-ordination of end of life care. The core data set can be supplemented with additional information and may be expanded to the extent that it covers all key aspects of a person's advance care planning.

Some of the pilot sites adopted additional data items which have also been consulted on as part of the development of the information standard. These items can be considered for inclusion locally taking into account the potential benefit of holding the information, the additional time required to complete the EPaCCS record, and the challenges in ensuring that any additional information, in particular clinical information, is kept up to date.

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

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

Content heading/subheading	Definition/illustrative description of the type of clinical information to be recorded under each heading
	03 Individual changed their mind 99 Not known
Should person's GP be contacted out-of-hours? Telephone numbers	
Whether the person/family has been given a copy of the record	As a minimum, the individual should be offered a copy of the record or access to it.
Ethnicity	This could be considered to support equality monitoring.
Whether GP will sign death certificate in normal circumstances	
Date person added to Gold Standard Framework register	Please refer to Glossary for definition.
Date of last discharge from hospital/hospice	The date of discharge from the most recent admission to hospital or hospice.
Implanted devices	Details of any implanted devices that may require management (includes implantable cardiac defibrillators).

Appendix 5: risk and Issues

a)   **Risks**

#	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 electronic co-ordination systems 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 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 [5] for further detail).

b)   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.