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Palliative and End of Life Care Information Standard

May 2022
(Updated July 2025)

Document Management

Revision History

Version	Date	Summary of Changes
V0.1	03/11/21	1st draft
V0.2	01/02/22	2nd draft
V0.3	04/02/22	3rd draft
V0.4	07/02/22	4th draft
V0.5	08/02/22	5th draft
V1.0	07/03/22	Final version
V1.01	22/07/25	Minor updates to correct typos

Reviewers

Reviewer name	Title / Responsibility	Date	Version
Kath Lambert	Clinical Lead and Consultant in Palliative Medicine	24/11/21-07/03/22	V0.1- 1.0
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Approved by

Name	Date	Version
EPaCCS Working Group	05/11/21	V0.1
Assurance Committee	16/02/22	V1.0

Glossary of Terms

Term / Abbreviation	What it stands for
ACP	Advance Care Plan
ADRT	Advance Decision to Refuse Treatment
CIS	Core Information Standard
CPR	Cardio-Pulmonary Resuscitation
CYP	Children and Young People

DNACPR	Do Not Attempt Cardiopulmonary Resuscitation
EPaCCS	Electronic Palliative Care Coordination System
EHR	Electronic Health Record
EoL	End of Life
FHIR	Fast Healthcare Interoperability Resources
GSF	Gold Standard Framework
ICS	Integrated Care System
LHCR	Local Health Care Record
LPA	Lasting Power of Attorney
NHSE/I	NHS England /NHS Improvement
NHSD	NHS Digital
PCN	Primary Care Network
PCSP	Personalised Care and Support Plan
PEoLC	Palliative and End of Life Care
PID	Project Initiation Document
PRSB	Professional Record Standards Body
STP	Sustainability and Transformation Programme
TEP	Treatment Escalation Plan

Planned Review Date and Route for User Feedback

The next maintenance review of this document is planned for 2025 subject to agreement with NHS England/Improvement as the commissioning body.

Please direct any comments or enquiries related to the project report and implementation of the standard to support@theprsb.org

Contents

1.1 Executive Summary

Death and dying are inevitable and the quality and accessibility of palliative and end of life care will affect all of us. The needs of people of all ages who are living with dying, death and bereavement, their families, carers and communities, must be addressed, taking into account their priorities, preferences and wishes. Personalised care at end of life will result in a better experience, tailored around what really matters to the person, and more sustainable NHS services.

PRSB has updated the SCCI 1580 standard for Palliative Care Coordination – Core Content, working with NHS England and Improvement, the Palliative and End of Life Care Electronic Palliative Care Coordinating Systems (EPaCCS) group, Lexicon working groups, professional members representing the four nations of the UK, patient representative groups and groups representing the voluntary, charitable and social enterprise sectors.

The aim has been to ensure clinicians have access to appropriate information to support decision making for those with palliative care needs and those who are approaching the end of their life. The standard supports the Universal Principles for Advance Care Planning which are outlined in section 2.1.

1.2 PRSB approach to updating the standard

Starting in 2020, PRSB undertook a review and refresh of the Palliative Care Coordination – Core Content Standard (SCCI 1580) resulting in substantial changes and improvements to the standard. This work included:

- An initial review of barriers to EPaCCS and end of life information sharing, with key stakeholders. This was carried out in June 2020 and identified key areas of focus for the project, in collaboration with the Palliative and End of Life Care EPaCCS group and Lexicon working groups.
- Mapping between local data sets and national standards, followed by a webinar on 11 December 2020 to finalise the focus of the work. This was with 62 participants, representing professionals working in palliative and end of life care, patients/carers, and system suppliers. Suppliers involved in the project included Black Pear, Graphnet, Cerner, Nourish Care, EveryLIFE technologies as well as associations CASPA and TechUK.
- An online survey with Compassion in Dying was conducted in February 2021, to understand what would give people more confidence in their palliative and end of life care information. In all 1,700 people took part.
- PRSB with Together for Short Lives interviewed five parents of children and young people with life limiting conditions, and one young person about advance care planning, and difficult discussions around palliative and end of life care.
- Early drafts of the standard and supporting materials were made available to key stakeholders for review and comment over a six-week period in May – June 2021 and

five virtual drop-in sessions were held to facilitate discussion on key areas of the draft standard over the same time period.

- The draft standard was mapped against the ReSPECT process and form, showing close alignment.
- A national survey with professionals and people/carers was conducted in July 2021 to test the standard and yielded 450 responses. Individual and group responses to the standard were also reviewed and included feedback from the Resuscitation Council, regional Children and Young People's Palliative Care Networks and the Children and Young People's Advance Care Planning network.

1.3 PRSB recommendations to update the SCCI 1580 Standard

The Palliative and End of Life Care Information Standard will help to enhance the delivery of palliative and end of life care for people, including advance care planning. PRSB recommends changes to the existing standard including the addition of items that reflect current practice and following consultation with a range of stakeholders:

1. Person-centred care: People with palliative and end of life care needs, should be able to have personalised care and support planning conversations, including advance care planning, if the person wishes. This should involve carers, loved ones and/or advocates as appropriate.

- All personalised care and support planning, including advance care planning conversations and end of life care decisions should be available for review by the person and if they wish their carer/family.
- A clear and accessible record should be kept of all involved in decision making, including professional and personal contacts, relationships to the person, date, time and review date.
- A person should be encouraged to share their preferences, wishes and fears around their care and death and dying. PRSB's About Me standard can support people to share information about their preferences, wishes and needs for palliative and end of life care including where they would prefer to be cared for, information about rituals, faith, routines or what they want to happen at death or after death, support for the family/carer at the time of death.
- This should include members of a person's care team and carers/family if that is the person's preference. Where people are unable to advocate for themselves, a carer/family member or legal representative should have access to their information to advocate on the person's behalf, if that is the person's wish.
- It is important to train clinicians, professionals and support groups for people who use services to undertake good person-centred conversations as part of personalised care and support planning and advance care planning to help implement the Palliative and End of Life Care Information Standard. This should include information that they can record and review in their advance care plans for palliative and end of life care needs.
- Mechanisms should be available for people to access their care record and local initiatives should be supported to champion people's wishes and recognise the support needed by carers /loved ones and legitimate representatives.

2. Integrated care:

The Palliative and End of Life Care Information Standard forms part of a person's shared care record and should be used in conjunction with their shared care record and their care plan, if they have one, to ensure that all involved in their care have up-to-date information with which to provide care.

- As stated above, people with palliative and end of life care needs should be supported to develop personalised care and support plans, which include the opportunity to have conversations about advance care planning. The patient and, with their permission, their advocate or legitimate representative should be fully involved in conversations on care planning and treatment preferences.
- People nearing the end of life should be offered the opportunity to create an end-of-life care plan with their healthcare professionals, regardless of whether they choose to complete a personalised care and support plan in full.

As part of the programme to implement the standard, PRSB will develop guidance and test it with users to demonstrate how the information in a person's personalised care and support plan and care record informs a person's palliative and end of life care.

3. Support for implementation of the standard: An implementation plan for the Palliative and End of Life Care Information Standard is essential if we are to capture and access data for care for everyone responsible for a person's care, the person and their family.

- This should include testing and refining implementation of the information standard with key IT suppliers and promoting adoption of the standard including mandating its use through the Information Standards Notice (ISN) process in due course.
- Suppliers and frontline staff across the health and care system may require training to understand the role of standards, how to use them and what benefits should be expected from their adoption. An implementation plan should be developed with local clinical teams and system suppliers to support adoption. Local areas should be encouraged to name local clinical champions for adoption of the Palliative and End of Life Care Information Standard.
- We recommend that web-based learning materials/a toolkit would help health and care professionals adopt the standard and a community of practice should support sharing best practice around adoption, implementation and maturity. The NHS Futures Platform could support sharing the materials/a toolkit.
- The implementation programme should set out how adoption will be monitored and benefits reported locally and nationally through best-practice examples and case studies.
- The NHS should commission development or update of technical FHIR (Fast Healthcare Interoperability Resources) message specifications to ensure a complete set of materials for national implementation.
- Effective palliative and end of life care coordination requires UK-wide adoption of standards. Terminology varies across the four nations, making it difficult to ensure consistency of information across borders and boundaries. PRSB will work with colleagues across the four nations to ensure standards and accompanying implementation guidance for palliative and end of life care align, wherever possible.

4. Specific information requirements: The consultation process (which included surveys, workshops, webinars and one to one consultations) yielded support for information contained in the SCCI 1580 standard, but suggested the following enhancements and refinements:

4.1. The name of the standard: The proposed standard aims to support care for people with palliative and end of life care needs.

We therefore recommend a name change to Palliative and End of Life Care Information Standard.

4.2. Cardio-pulmonary resuscitation decision: We asked people whether recording a person's wishes about resuscitation should reflect that it is a decision made with professionals or a recommendation made by professionals.
We recommend that recording Do not attempt cardio-pulmonary resuscitation (CPR): as a 'decision' rather than a 'recommendation'. This should include involvement in CPR decision-making to reflect the wishes of the person or those important to them.

Opinion was equally divided over whether to record 'modified CPP' in the case of children and young people.
We therefore recommend CPR decisions in the case of children and young people should be reviewed as part of the further consultation needed in this area.

4.3. Carer needs: Many people who took part in the consultation felt it was important to capture information on carers' needs including information on carers' capacity to cope, and if the carer required support (e.g. access to respite care).
We recommend that a carer should be clearly identified in the patient's records, but that the carer's specific needs and further details should be addressed in the carer's record.

4.4. Primary palliative care diagnosis: Feedback from clinicians and suppliers highlighted the need to easily identify a person's primary palliative care diagnosis from a list of their recorded diagnoses. This will support clinical and other health and social care professionals to make urgent decisions about the patient's care.
We recommend adding primary palliative care diagnosis to the list of diagnoses in a person's care record.

4.5. Preferred place of death: Recording and complying with a person's preferences around place of death is important, but first preferences may not always be available so people should be able to state alternatives that would be acceptable and have them recorded in addition to their preferred place of death. .
We recommend that a preferred place of death should be recorded with any additional notes or text used, so that people may state what alternative places of death would be acceptable.

4.6. Advance care plans/Treatment escalation plans: Feedback from the consultations confirmed the need to record advance care planning conversations and processes to support such conversations including Treatment Escalation Plans Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) and other local tools that set out ceilings of treatment (limits on interventions which are likely to be futile or at odds with a person's wishes). It is key that clinicians are able to record that advance care planning conversations have been offered/declined/are inappropriate. These elements should form part of the information standard. It is important to explicitly record that these plans exist and also to know that they are specified in the Palliative and End of Life Care Information Standard.
We recommend that the Palliative and End of Life Care Information Standard is able to record the offer of an advance care planning conversation and the outcome of any clinician-led discussion about treatment preferences, where there is one, using SNOMED CT codes.

4.7 Emergency care and treatment plan: This forms part of a person's advance care plan and contains guidance on specific interventions or actions that may be required or should be avoided in specific situations in end-of-life care.

We recommend that this record entry replaces ‘anticipatory actions’ to avoid confusion with other usage/definitions of ‘anticipatory actions’. It should include information about a person’s priorities of care.

4.8. Place of residence: It was noted that collecting information on where a person lives could improve end of life care planning that is personalised and takes into account an individual’s living situation.
We recommend that the Person Demographics section of the PRSB’s Core Information Standard should include whether an individual resides in a private home, communal setting (i.e. care home) or other setting.

4.9. Person(s) responsible: Recording who is responsible for ensuring a person’s end of life care plans are met will enable care that meets a person’s wishes and needs.
The Palliative and End of Life Care Information Standard should record who is responsible for aspects of a person’s care (as a specific Professional Contact) and who completed parts of the care record to ensure that care is delivered in a way that meets a person’s needs and wishes.

4.10. Children and Young People: Many children live for years with palliative care needs and it was felt that the focus of personalised care and support planning for children and young people should be on living well and having a good quality of life, as well as conversations about advance care planning. There was an acknowledgement that further consultation to agree any adaptations of the standard for children and young people would be required.

Professionals and people involved in the consultation fed back that further work may be required to identify any additional data items specific to children and young people’s palliative and end of life care such as legal requirements regarding parental responsibility for palliative and end of life decisions.
It is recommended that the NHS consider commissioning further consultation to explore whether there are additional information requirements around advance care planning for children and young people so that the standard can be updated as required in due course.

4.11. Supporting best practice: People felt it was important to align the information standard, where possible, with widely used tools and frameworks that support patients approaching the end of their life.
PRSB recommends that the record should include whether a person is on the palliative care register (i.e. a palliative care register held within a GP practice).

PRSB recognises that people may choose, with their clinician, to complete the ReSPECT process and form or use other care delivery frameworks and tools to support conversations and planning for palliative or end of life care needs. The standard enables clinicians to identify their use, where desired.

To promote best practice PRSB will produce materials to support implementation of the Palliative and End of Life Care Information Standard by health and care professionals and people using services to improve care.

PRSB will adopt and maintain the updated standard within our portfolio of standards.

2 Introduction

2.1 Background and Context

In revising the standard for palliative and end of life care, PRSB has adhered to the vision and principles set out in ‘‘Ambitions for Palliative and End of Life Care: A national framework for local action’ and the Universal Principles for Advance Care Planning.

The National Partnership for Palliative and End of Life Care published the ‘Ambitions for Palliative and End of Life Care: A national framework for local action’ and updated it in 2021. The Ambitions Partnership is made up of a broad group of national organisations with a deep commitment to improving palliative and end of life care in England. The Partnership presents an overarching vision for palliative and end of life care and six ambitions that need to be achieved around personalisation, access to care, wellbeing, coordination and support for care by health and care professionals and communities.

The Universal Principles for Advance Care Planning have been published by a partnership of national organisations. The purpose of this document is to set out six high level principles for advance care planning to facilitate a consistent national approach. It is for the person, those important to them, practitioners and organisations involved in supporting advance care planning conversations and honouring their outcomes. All discussion with the person should convey a sense of ownership of the process. These universal principles should be used to drive improvements in inclusion, equality and diversity everywhere across the country.

Advance Care Planning

Through the voluntary process of advance care planning a person can ensure that their wishes and preferences are discussed and inform their future care, and the information is captured in their care record and shared consistently so that anyone involved in their care can act upon it. The outputs of an advance care planning conversation may include the following:

- An **Advance Statement** – of wishes, preferences and priorities. An advance statement is not legally binding but it is useful to inform and guide decision making in the future if the person subsequently loses their capacity to make decisions about their care
- An **Advance Decision to Refuse Treatment** (ADRT) – legally binding if valid and applicable
- Nomination of a **Lasting Power of Attorney for Health and Welfare** (LPA) who is legally empowered to make decisions including on life sustaining treatment on behalf of the person if they do not have mental capacity at the time, depending on the level of authority granted by the person.
- Context-specific treatment recommendations such as emergency care and treatment plans, treatment escalation plans, cardiopulmonary decisions, etc. These are intended to guide future practitioners when they need to make decisions, at the relevant time in a specific situation, if the person is unable to participate in decision making – these are not legally binding except where a specific decision is included in a valid and applicable ADRT.

PRSB has developed the Palliative and End of Life Care Information Standard to support advance care planning and the information requirements for people needing palliative or end of life care.

The standard sets out what should be included for palliative and end of life care within a person's care record. It should be used in conjunction with other parts of a person's care record. For example, much of the information needed at or near end of life would be included in a person's shared care record and would include a person's demographic information (name, date of birth) GP details, medications and so forth (this is set out in the PRSB Core Information Standard that underpins shared care records). Where a person has a personalised care and support plan, the end of life information should be a section within their care plan so that they only have one care plan. If a person doesn't have a care plan we recommend that one is created using the PRSB's Personalised Care and Support Plan Standard in conjunction with the Palliative and End of Life Care Information Standard.

Section 2.2 sets out what information is contained in a person's shared care record, and care plan and how that information might inform a person's palliative and end of life plan. It illustrates how PRSB standards define the information needed for care planning in general and advance care planning for end of life in particular.

2.2 The Palliative and End of Life Care Information Model

PRSB standards include information models that define what information should be recorded for sharing. Here we describe the information that is contained within the Palliative and End of Life Care Information Standard and explain what information from other PRSB standards should be drawn on to support people's health and care.

Information in the Information Standard
Information that is specific to the Palliative and End of Life Care Information Standard includes the following elements:

- End of Life Plan(s)
    - *Advance Care Plan (exists, offered declined, inappropriate, etc.)*
    - *Treatment Escalation plan (ceilings of treatment) (if exists)*
    - *Emergency Care and Treatment Plan for End of Life/Palliative Care (includes a record of a patient's priorities of care and any anticipatory actions identified and/or completion of a ReSPECT form)*
- Cardio-pulmonary resuscitation (CPR) decision
    - Involvement in CPR decision
- Estimated Prognosis
- Person is on the Palliative Care register
- Anticipatory medicines/equipment
- Preferred Place of Death (this can be expanded to include alternative preferences and other issues around place of death)
- Documents (including correspondence, audio and images)

Other palliative and end of life information which is necessary to collect:

- Date of Death
- Place of Death

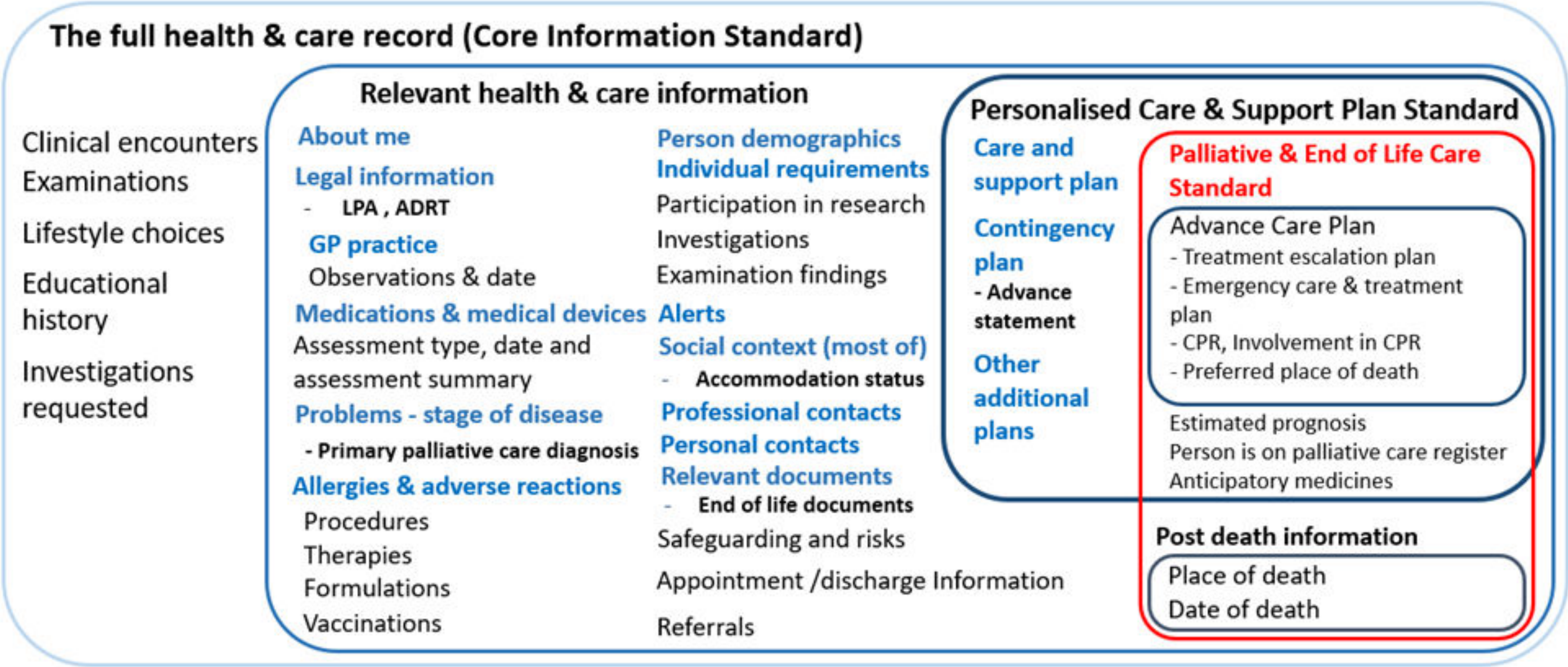
There is information in the shared care record (based on the PRSB Core Information Standard) that health and social care professionals may need to access and edit about a person to enable them (and other professionals) to provide care and support to people with palliative and end of life care needs, including to support current care and advance care planning conversations. This information includes:

- About Me – Contains guidance to include the person's preferences, wishes or requirements around their palliative and end of life care, including their Preferred Place of Care and discussion about who and what are important to the person, significant routines, rituals, faith and other matters that are precious to them, including what rituals, spiritual input etc they want to happen at and after death
- Legal Information
    - Advance Decision to Refuse Treatment,
    - Lasting Power of Attorney for Health and Welfare
    - Lasting Power of Attorney for Property and Finance
- Social Context
    - Accommodation Status
- Problem list
    - Primary Palliative Care Diagnosis
- Care and Support Plan

- Contingency Plans
    - Advance Statement
- Additional Support Plans
- Person Demographics
- GP Practice
- Personal Contacts
- Professional Contacts
- Individual Requirements
- Medication and Medical Devices
- Allergies and Adverse Reactions
- Alerts
- Those important to the person

PRSB recommends that everyone with palliative and end of life care needs should have the opportunity to have documented personalised care and support planning conversations which focus on their needs and what matters most to them, both now and in the future. These plans must be reviewed regularly and in line with a person's changing needs, to ensure that they are still relevant and reflective of what matters to the person. An advance care planning conversation should be part of the personalised care and support planning process and the following sections of the Personalised Care and Support Plan may be used to support this conversation:

- Care and support plan
- Contingency plans
- Additional support plans



The diagram above shows how the Palliative & End of Life Care Standard relates to other PRSB standards.

The full health & care record, defined by the core information standard, includes information that may be relevant to personalised care and support planning, including advance care planning for people with palliative and end of life care needs.

Relevant health & care information is essential information to support personalised care and support planning, including advance care planning, for people with palliative and end of life care needs. A care plan can’t be created/updated without being aware of this information. This information may be used for non-care planning purposes.

Personalised care and support information is essential to personalised care and support planning and elements can be used to inform advance care planning conversations for people with palliative and end of life care needs.

Information that is **unique/specific to palliative and end of life care plans:** The Palliative and End of Life Care Information Standard sets out what information is needed to support the care of people who are approaching the end of life.

3 Methodology and Consultation Approach

3.1 Project Objectives and Scope

3.1.1 Objectives

In 2015 Public Health England and partners developed and published a palliative and end of life core information standard named, “Palliative Care Coordination - Core Content” (also referred to as SCCI1580)

“This information standard specifies the core content to be held in electronic palliative care co-ordination systems (EPaCCS) and supports NHS England's objective to increase the use of technology to help people manage their health and care. All Electronic Palliative Care Co-ordination Systems (EPaCCS) must comply with this information standard”

PRSB has reviewed the Palliative Care Coordination - Core Content standard in order to adopt it as a PRSB standard and agree any new data elements required for palliative and end of life care provision. This included:

- To refresh the SCCI 1580 information standard, supporting the sharing of patient information across geographical and organisational boundaries.
- To promote interoperability, through aligning with the Core Information Standard, and incorporation of standards, SNOMED CT, and agreed terminology value sets.
- To align with other PEoLC workstreams, referencing and incorporating their outputs into the information standard.
- To clarify the position of the SCCI 1580 standard against the landscape of locally developed data sets.
- To support direct care as the primary driver for recording information, with information for secondary uses derived from it where possible.
- To keep the patient at the centre of PEoLC and support them to act as owners of their data.
- To publicise and promote the revised information standard through PRSB networks, raising awareness of the standard.

3.1.2 In scope

The project scope included:

- Development or modification of a national information standard (Palliative and End of Life Care) using tested methods and endorsement of the standard by agreed key stakeholders
- Development of a supporting safety case and implementation guidance.
- Promotion of the standard through PRSB’s networks
- Clinical assurance of FHIR profiles developed by the NHS to support this standard when they are available.

3.1.3 Exclusions from scope

- PRSB has been commissioned to provide the data items and guidance for implementation of the data items. This does not include the design and implementation of software solutions, including:
    - User interface definition for digital systems.
    - FHIR profiles or APIs technical solutions – this could be commissioned separately by the NHS as required.
- Support for piloting and implementation – this could be commissioned as a subsequent phase
- Development of any additional supporting plan standards

3.2 Consultation Approach

A working group was established to steer the project in four phases:

- Identification and agreement of the areas of focus for the work
- National consultation on the standards with multi-disciplinary professionals and staff across different settings within health and social care and people using services
- Development and finalisation of the standard and supporting materials and final draft publication (prior to endorsement)
- Endorsement by professional and patient bodies and final publication.

3.2.1 Methods and rationale

The project was conducted according to the PRSB process and assurance criteria. This included a phased approach adopted by PRSB in other information standard development projects.

Discovery Phase (June 2020 – December 2020): During this phase, the project worked to identify the landscape of EPaCCS provision, information requirements and any gaps in information between requirements and the existing information standard. This phase also included developing an initial information standard for consultation and approval.

Review Phase (December 2020 – October 2021) This phase involved both qualitative and quantitative research and involved a series of workshops, surveys, one to one consultations with palliative and end of life care experts, patients, carers (including parents) and a range of health, social and voluntary care sector stakeholders.

Publication Phase (November 2021 – February 2022) This phase includes finalisation of the standard, supporting material and publication.

Endorsement, implementation phase (February 2022 onwards) This phase includes endorsement by PRSB members identified as key endorsers of the standard (see Appendix 7.2), ongoing enhancement and review of the standard. PRSB will take the standard through the Information Standards Notice process, develop implementation materials and case studies based on pilot testing/implementation of the standard.

The following principles were agreed in providing support for the development of the national standard:

- The existing standard is widely used, this work will reuse the standard content wherever possible rather than seeking to replace it.
- Much work has already been achieved locally, this work seeks to build on it and gain national consensus

Discovery Phase

During this phase, PRSB set up the project management framework and established a key stakeholder working group to provide governance around the development of the information standard (see Appendix 8.1 for details). This group met regularly to provide subject matter expertise, policy and clinical insight:

- An initial review of barriers to EPaCCS and end of life information sharing with key stakeholders was carried out in June 2020.
- Following the invitation to join the PEoLC EPaCCS and Lexicon working groups, early discussions with group members enabled the identification of areas of focus for the project.
- Preliminary mapping between local data set specifications and existing national standards to understand level of similarity.
- A webinar took place on 11th December 2020 where mapping between local data sets and national standards was undertaken,
- This was followed by a webinar on 11 December 2020, to finalise the focus of the work with 62 participants representing professionals working in palliative and end of life care, patients/carers, and system suppliers. Suppliers involved in the project included Black Pear, Graphnet, Cerner, Nourish Care, EveryLIFE technologies as well as associations CASPA and TechUK.
- PRSB worked with NHS Digital terminologists to identify and incorporate SNOMED codes for data items and to identify and highlight gaps in coding.

Review Phase

This phase involved reviewing the draft standard, but also discussing key requirements with a diverse range of stakeholders to ensure the views and requirements of all were listened to and incorporated into the project output:

- In February 2021, PRSB conducted a patients and carers survey (in conjunction with Compassion in Dying). This survey asked people about their experiences and concerns with sharing their end of life and palliative care records. The key aim of the survey was to understand how end-of-life care records and barriers to sharing data could be improved.
- PRSB worked with Together for Short Lives and conducted a children and young people's survey which was a series of interviews with five parents of children and young people with life limiting conditions, and one young person. These interviews focused on concerns of parents, children and young people around palliative and end of life care information.
- A draft standard was initially developed for consultation and review.

- An online survey was conducted from 13 July 2021 to 30 July 2021. This survey asked stakeholders for their views on the proposed palliative and end of life care standard, including specifying further requirements if necessary and providing feedback on what stakeholder thought was most important and what would give them more confidence in their end of life care information.
- We conducted interviews with eight adults on their experience of palliative and end of life care, for themselves or a loved one.
- We held five virtual drop-in sessions to facilitate discussion on key areas of the standard over the same time period.
- Reviews with the project working group and other one to one discussions with key organisation leaders were ongoing throughout this phase, ensuring a broad church of opinions were sought and included in the development of the standard.
- In parallel to this project, the Lexicon Working Group have been reviewing SNOMED reference sets used for palliative and end of life care with the aim of deprecating codes that are no longer used and identifying where new codes as required.
- A Clinical Safety Case was developed in parallel with the national consultation.

Publication Phase

- In September 2021, PRSB began sharing the draft standard for further refinement and evaluation with lead clinicians and key personnel.
- Further work was conducted on alignment of standard information with other end of life tools, including the ReSPECT form.
- Further discussions were scheduled in late 2021 to determine whether there were any specific requirements for children and young people that may not be covered by the proposed standard.

Endorsement and Implementation Phase

- At the outset of the project PRSB identified organisations with a key role in palliative and end of life care to endorse the standard and support its implementation. These organisations are identified in Appendix 8.B. The published standard and supporting documents will be shared with endorsing organisations and their endorsement will be published on the Palliative and End of Life Care Information Standard page in due course.

4 Consultation Findings

4.1.1 Overview

This section of the final report draws together and syntheses feedback from webinars and surveys carried out by PRSB, in collaboration with partners, during the development of the Palliative and End of Life Care Information Standard. We draw on feedback from a webinar conducted in December 2020 and from three main surveys conducted between February 2021 and July 2021 (Palliative Care and End of Life Survey; Patients and Carers survey in conjunction with Compassion in Dying; Children and Young People's Survey a series of interviews with parents and young people with Together for Short Lives).

A more detailed report on the Palliative Care and End of Life Survey is published along with the Palliative and End of Life Care Information Standard.

Details of webinar participants are available at Appendix C and feedback from webinar workshops on Appendix D.

Details of the Patients and Carers survey in conjunction with Compassion in Dying are available in Appendix E.

Details of the Children and Young People's interviews are available in Appendix F.

Following are the key themes from the analysis of surveys and workshop consultation. Significant weight was given to what people want to see in the information standard. Patient and carers feedback was strongly represented in surveys and the following details reflect their input, while many one to one discussions and workshops reflect the views of subject experts (including clinicians working in paediatric and adult palliative and end of life care).

4.1.2 What information is important?

Patients, carers, NHS and social care staff and other professionals' who took part in the surveys and webinars pointed to the importance of recording and maintaining information that focused on the holistic needs of the person with palliative or end of life care needs.

Together with recording their clinical care needs such as the presence of an advance statement, do not resuscitate orders and legal information (e.g. lasting power of attorney), people felt it was also important for a palliative and end of life record to include information on what was important to the person and their loved ones. For some this included religious or spiritual needs, for others it included cultural preferences that may help to support the person's emotional and mental wellbeing, especially at the end of their life.

"We should report anything that is important to the person and maybe that should be the question. 'What is important to you. What would you want us to know?"

4.1.3 Personalised Care Planning and Advance Care Planning

Survey respondents felt personalised care and support planning, including advance care planning conversations were important to help support the person, their carer and loved ones. It was important to proactively capture what was specific to the individual's needs and wishes in advance. 91% of service users and informal carers surveyed agreed that having a personal care and support plan enhanced advance care planning. This included contingency planning that adapted to a person's changing needs; advance statements and advance decisions to refuse treatment that identified the person’s wishes on what treatments they did and did not want. It was seen as important that plans were reviewed and kept up to date.

“A personalised care plan provides detailed information to help understand the individual's cultural and spiritual needs and those of their family”.

4.1.4 Shared Decision Making

Survey respondents felt that it was key to involve the person and their carer (if appropriate) in all discussions and decisions. All decisions reached should be available for review by the person and if they wish their carer/family. A clear and accessible record should be kept of all involved in decision making, including professional and personal contacts, relationships to the person, date, time and review date.

“I want the option to change my mind on refusing treatments etc as I go along and to have this updated information available to those who should be aware of it. I like the idea of an online system where I can make updates easily.”

4.1.5 Ownership

Feedback pointed to the need for end of life information to be accessible at point of care delivery e.g. emergency department, ambulance, hospital and hospice. The patient should not have to repeat themselves and have to give the same details again. This was seen as a very important requirement for information standards. It was envisaged that the patient would be the ultimate owner of the information standard.

“This will need to be accessible to ALL health care staff who become involved with the patient - currently there are different recording systems for GPs, hospitals, community services and social services - maybe need a key place where everyone knows they can access the plan, e.g. GP or patient held record?”

4.1.6 Communication

Surveys highlighted the need for good communication between professionals, the person receiving care and their loved ones. This included enabling open discussions on issues such as preferences, wishes and fears around care and death. Many emphasised the need to ensure communication and relationship details for all involved in the care of the person were recorded, easily accessible and understood.

“My Dad's care plan was never discussed with him nor with myself, his carer. I just read it after the community nurse left it in a box. It wasn't the document that it should have been, potentially because of time constraints and the sheer volume of care that each individual nurse was having to deliver (pre-pandemic). However, the failure to focus on the holistic role of the document in ensuring a 'good' death meant that opportunities to make this happen were missed.”

4.1.7 Carer Needs

Many respondent to the surveys on the palliative and end of life information standard felt it was important to capture information on carers needs including information on carers capacity to cope, the impact of caring on the carer and if the carer required support (e.g. access to respite care). Also, the relationship of the carer to the person and their communications details were considered important to capture. Some felt that this information would help support the dying person’s loved one.

“Anything relevant to their ability to provide care which they consent to being recorded like link to carers needs assessment e.g. CSNAT (in a) free text box for comments to say carers needs assessed…”

4.1.8 Preference on place of death

Those who responded felt it was important to record and meet with a person’s preference on place of death. However, many conceded first preferences may not always be available for various reason, so people should be offered choice and more should be done to ensure capacity existed to fulfil that choice when clinically appropriate.

“1st and 2nd choice ‘gives greater likelihood that their wishes are fulfilled.”

“This is not always possible, for example someone may ask to die at a hospice but the hospice has no beds. So alternatives may be helpful for the next of kin when grieving so as not to feel like they failed the individual.”

4.1.9 Advance Care Planning

During consultations many people confirmed that it was important to capture the outcomes of advance care planning discussions, while others pointed to the need to record if there was a treatment escalation plan (including ceilings of treatment) and these elements should form part of the information standard.

“It is long and detailed. My concern is that there is reference to many different types of care plan and this is incredibly confusing to understand what information to place in the different sections. But I am not sure there is a place to record specific information related to the wishes and preferences and the end of life – an advance care plan.”

4.1.10 Primary Palliative Care Diagnosis

Clinicians and suppliers highlighted the need to easily identify a person’s primary palliative care diagnosis from the list of their recorded diagnoses. (The PRSB Core Information Standard lists diagnoses, symptoms, disabilities and social or behavioural issues, and comprise the ‘Problem list’ in the standard.) This will enable clinical and other health and care professionals to make urgent decisions about the patient’s care.

“Someone like an ambulance paramedic needs to able to see a person’s primary problem without having to wade through several pieces of information.”

4.1.11 Clear understanding of actions required and by whom

Many respondents felt that the proposed information standard should record who was responsible for aspects of a person’s care and who completed parts of the information standard in order to clarify actions required to deliver care that aligned with a person’s needs and wishes.

“It should be clear but again the tool is only as good as the person using it. Therefore, the standard needs to include something which requires the health and care staff to understand the document and what their roles and responsibilities are within it.”

4.1.12 Children and Young People

For children and their families, many felt the focus of personalised care and support planning should be on living well, having a good quality life, as well as conversations about advance care planning. There was an acknowledgement that further consultation to agree any adaptations of the standard for children and young people would be required.

“I also mentioned that it may be that you look at concentrating on the adult dataset first and getting things sorted with that before concentrating on paediatrics. Alternatively, it may be that we need to ensure paediatrics is really looked into a bit more before finalising the data needed for paediatrics as it was clear from our discussions that there really were significant differences to the adult dataset.”

“For children, it is absolutely essential that the standard includes information about who has parental responsibility, as this will influence the legality of decision making. This is not currently included.”

4.1.13 Supporting best practice

Many people who responded to the survey felt that the information standard should align with the Resuscitation Council’s ReSPECT form and enable compliance with the Gold Standard Framework for the delivery of end-of-life care.

“We are also encouraging more conversations around end of life care in the emergency department and promoting the Resuscitation council ‘ReSPECT’ documentation.”

4.1.14 Quality of care

Respondents commented on the requirement for the information standard to ensure equity and quality of access to care. For instance, ensuring people who live in communal settings receive comparative high-quality care to those in other settings or using the information from the standard to ensure that a patient’s wishes of preferred place of death are met.

4.1.15 Information Quality

Respondents commented that the information collected as part of the information standard needs to be explicit and comprehensive and allowances made for how information can change over time. Some felt the documentation and terminology used while collecting the information was important and should be clear and unambiguous.

4.1.16 Fit for purpose IT Systems

People expressed concerns in each of our surveys that there are systems in place that meet the requirements of the standard. Some responders expressed concerns that the information is coded correctly thus ensuring interoperability between systems. Many felt the data was only as good as the ability of the key workers to capture it and emphasised the need for adequate training on the information standard

“This will need to be accessible to ALL health care staff who become involved with the patient - currently there are different recording systems for GPs, hospitals, community services and social services - maybe need a key place where everyone knows they can access the plan, e.g. GP or patient held record?”

4.1.17 Urgent/Emergency Care

Respondents emphasised the need for the information standard to align with urgent/emergency care provision, processes and systems. Comment from an Emergency Medicine Consultant:

"Easy access to this information would help a lot in the Emergency Department and with paramedic or medical crews attending patients at home to make good decisions."

"One of our main stumbling blocks in the Emergency Department is when a patient is unable to tell us this information e.g. found unconscious and we end up over-treating them."

4.1.18 Information Sharing

Most respondents in all three surveys acknowledged the importance of sharing data across all care settings and how important it was for health and social care professionals to be able to locate information recorded as part of the standard as and when they require it to help them provide holistic and personalised care. Of the 299 respondents to a question on data sharing, as part of the parent and carer survey, 69% were happy for clinical data to be shared with professionals needing to view the data and 73% were happy with their wishes and preferences around dying to be shared with everyone involved in their care.

"I cared for my terminally ill husband until his death. I often felt there was a gap as to the information available to GP, palliative care and other healthcare professionals especially when out of hours care was needed. It was distressing to have to constantly be checking and checking again that the information was correct. It has not given me much confidence for my own end-of-life care. I'm a Stage IV cancer patient and this is a constant worry."

4.1.19 Implementing the patient's wishes and desires

People using services, carers and citizens expressed concerns in the surveys about whether information about a person's preferences and wishes is known by health and social care professionals providing care, or information about who the person wants involved in decision making. Even if the standard were adequately completed, respondents were not confident that clinical and other professionals would act on their wishes.

"I have a DNAR in place and always carry documentation with me and even have a tattoo across my chest as a belt and braces action in the hope people would see it and look in my bag. Before every surgery or test I have, I need to tell the consultant this and show my documentation. I wish with permission it could just stay on my records so everyone treating me now and in the future can know just by looking at my records. I have a Lasting Power of Attorney but what if something happens to me and they can't get hold of my attorneys and do actions I don't want? It really worries me."

"My father was in a care home and (sic) nearly sent to hospital but they saw that was against our wishes in the care plan and kept him at the home - thank goodness."

4.1.20 Patient Advocacy

Many people consulted as part of the development of the information standard felt that for many patients their end of life advance statements, preferences and wishes were only guaranteed if they had a strong advocate.

"When my father died, his wishes, and the wishes of the family, were ignored by hospital staff. I was a lecturer in palliative and end-of-life care at the time and was able to successfully challenge this. Had I not been able to, he would have had interventions to prolong his life against his express wishes. I am personally worried that my preferred priorities and Advance Decision (to Refuse Treatment) will not be considered if I lose capacity. I have a Lasting Power of Attorney for health and welfare but I am aware of how healthcare teams can, if not managed well, fail to seek information that is recorded."

5 Evidenced Recommendations

Themes	Findings	Recommendations	Evidence / Comments
Key themes identified in consultation	Output of all consultation methods summarised	Summary of recommendations	Evidence for Consultation
Person-centred care	Feedback from consultations emphasised the need to put the patients and their loved ones at the centre of their care. Many people felt this involved not only capturing and sharing a person's clinical information, but also what is important to the person and their loved ones. This included active participation in all decision making, patient advocacy and access to their own care record. Many respondents surveyed expressed concerns that their wishes around their care and death though known may not be acted upon	People with palliative and end of life care needs, should be able to have personalised care and support planning conversations, including advance care planning, if the person wishes. This should include carers, loved ones and/or advocates as appropriate. • All personalised care and support planning, including advance care planning conversations and end of life care decisions should be available for review by the person and if they wish their carer/family. • A clear and accessible record should be kept of all involved in decision making, including professional and personal contacts, relationships to the person, date, time and review date. • A person's preferences, wishes and fears around their care, death and dying should be shared with those important to the person, if that is what they would like. They should also be shared with professionals responsible for the delivery of their care. Where people are unable to advocate for themselves, a carer/family member or legal representative should have access to their information to	Those interviewed for the Children and Young People's survey shared their concerns that the team caring for their child/themselves often did not understand their child's individual needs, and did not recognise what quality of life means to a child with a life-limiting or life-threatening condition "…Needs to be in-depth discussions around care – e.g. not just about CPR yes or no but the level of resuscitation required. …Need to include the details of life, how far parents want to go, optimise time at home, keep out of hospital, all the options that are available for parents" Feedback from the webinar on 11th December 2020 emphasised how important it is that what matters most to the patient should be at the front of the information record and thus help clinicians make appropriate decisions. "We need to move away from needs/wants to what really matters to me conversations and documentation of those conversations. Knowing what really matters and understanding this can help

		advocate on the person's behalf, if that is the person's wish. • It is important to train both professional and support groups for people who use services to undertake good person-centred conversations as part of personalised care and support planning and advance care planning to help implement the Palliative and End of Life Care Information Standard. This should include information that they can record and review in their advanced care plans for palliative and end of life care needs. • Mechanisms should be available for people to access their care record and local initiatives should be supported to champion people's wishes. and recognise the support carers, loved ones and legitimate representatives have	the person make the right decisions for them." 73% of those who took part in the PRSB/Compassion in Dying survey said they wanted their personal wishes and preferences to be available to health care professionals supporting them without having to give permission to share the information The online adult survey also highlighted this issue: "We need a holistic assessment for the patient, including cultural and spiritual needs. …Often missed and misunderstood" "Sometimes the patient isn't fully involved, a GP or others think they know what's best." 88 people who took part in the adult online survey left comments on enhancing an advance care plan. 24 % felt that personal care and support plans enhance advance care planning with a further 47% citing that religious and spiritual issues should be included in care planning. While 21% felt personal care and support plans would improve the holistic care of the people at end of life.
Provide holistic integrated care for people	Many respondents acknowledged how advance care planning, including personal care and support	The Palliative and End of Life Care Information Standard forms part of a person's shared care record and should be used in conjunction with their shared care record and their care plan, if they have one, to ensure that all involved in their	Comments from the online adult survey "A personalised care plan provides detailed information to help understand the individual's cultural and spiritual needs and those of their family."

	plans could enhance a person's end of life care.	care have up-to-date information with which to provide care. - People with palliative and end of life care needs should be supported to develop personalised care and support plans, which include the opportunity to have conversations about advance care planning. - The patient, and with their permission, their advocate or legitimate representative should be fully involved in conversations on care planning and treatment preferences. - PRSB recommends that as part of the programme to implement the standard that guidance is developed and tested with users that demonstrates how the information in a person's personalised care and support plan and care record informs a person's palliative and end of life care and advance care plans.	Another person included the comment "The personalised care and support plan should be holistic and include physical, psychological, social, spiritual and information/insight needs." 310 people responded to a question on personalised care and support planning in the adult online survey of which 97% (301) favoured a patient having a personalised care and support plan. Comments from the patient and carer survey with Compassion in Dying included: "I have RLS (Willis-Ekbom Syndrome) which can make life almost unbearable at times. I'm concerned that, if I couldn't talk about it for any reason, it would not be noticed and cared for. I am also worried that my very specific sleep needs would go unnoticed or unmet if I was unable to discuss my problems because it is not recorded in an accessible way."
Support implementation of the standard	The standard incorporates information requirements that set out the direction of travel for person-centred palliative and end of life care. However, there is wide variation in the digital maturity of palliative and end of life care services across the country, and additional support will be needed by the more fragmented services. Effective palliative and end of life care coordination requires	An implementation plan for the Palliative and End of Life Care Information Standard is essential if we are to capture and access data for care for all those responsible for a person's care, the individual and their family. - This should include testing and refining implementation of the information standard with key IT suppliers and incentivising adoption of the standard including mandating its use through the Information Standards Notice (ISN) process. Suppliers and frontline staff across the health and care system may require training to understand the role of	Feedback from the webinar on 11th December 2020 included the following "The information needs to be accessible at the point of care delivery e.g. A&E, ambulance, hospital and hospice. The patient should not have to repeat themselves giving the same details over and over. It needs to be front and centre." Feedback from the children and young people's survey included: "…Electronic document needs to be accessed and owned by parents – QR

	national adoption of standards that ensures validity and consistency in information across the four nations of the UK. Key professionals need to access palliative and end of life care based on their specific needs. It is important that IT systems can configure information to meet specific use cases	standards, how to use them and what benefits should be expected from their adoption. • An implementation plan should be developed with local clinical teams and system suppliers to support adoption. Local areas should be encouraged to name local clinical champions for Palliative and End of Life Care information standards adoption. • Web-based learning materials/a toolkit would help health and care professionals adopt the standard and a community of practice should support sharing best practice around adoption, implementation and maturity. The NHS Futures Platform could support sharing the materials/a toolkit. • The implementation programme should set out how adoption will be monitored and benefits reported locally and nationally through best-practice examples and case studies. • The NHS should commission development or update of technical FHIR (Fast Healthcare Interoperability Resources) message specifications to ensure a complete set of materials for national implementation. • Effective palliative and end of life care coordination, requires national adoption of standards. Terminology varies across the four nations, making it difficult to ensure consistency of information across borders and boundaries. It is essential to establish and maintain links across the four nations, to support cross border information sharing and PRSB will work	code to access document to protect access to certain groups. Parents need to understand choices available to them to be able to populate plans.” Comments from the patient and carer survey with Compassion in Dying include: “I reviewed my end-of-life plan with my GP two years ago, he was happy for my wife to be involved in the process & was supportive & reassuring that a) My wishes were important; and b) That he would abide by them… My concern is that I do not have much faith in the NHS when it comes to sharing information digitally, so if I was in an emergency situation, I’m not confident my wishes would be known or adhered to. On two occasions I was in a situation where records had been misplaced, lost & the professionals involved with me at that time had great difficulty admitting this.” 88% of those who took part in the RSB/Compassion in Dying survey said it was important that the healthcare team supporting or treating them could see which treatments they did or did not want

		across the four nations to seek alignment of the Palliative and End of Life Care Information Standard with related standards UK-wide.	
Specific Information Requirements	One of the key objectives in developing the Palliative and End of Life Information Standard was to review, amend (where necessary) and provide an evidence base for the SCCI 1580 information standard. During consultation, many people pointed to the need for specific changes to EPaCCS information. These included the addition of specific data items, change to existing data items or changes in terminology. In other instances people supported data items already included in the SCCI 1580 information standard.	• The name of the information standard should be the Palliative and End of Life Care Information Standard." • Feedback from clinicians and suppliers highlighted the need to easily identify a person's primary palliative care diagnosis from the list of their recorded diagnoses. (This is also referred to clinically as a problem list. Problems may include diagnoses, symptoms, disabilities and social or behavioural issues, and comprise the 'Problem list' in the PRSB's Core Information Standard). This will support clinical and other health and social care professionals to make urgent decisions about the patient's care. • Record " Do not attempt cardio-pulmonary resuscitation (CPR)": as a 'decision' which remains unchanged from the SCCI 1580 standard. • Where a person has been identified as having a carer, the needs of the carer should be addressed as part of the carer's care plan • Preference around place of death should be recorded to monitor if a person's preference is met. Free text box available in the standard to indicate an acceptable alternative.	34% of 365 survey responders said the name of the standard should be the 'Palliative and End of Life Care' Information Standard. 41 % said the standard favored the name "Urgent, Palliative and End of Care Information Standard." However, the Personalised Care and Support Plan includes urgent/emergency care for people who face life-threatening situations, rather than people with palliative and end of life care needs. Comments from the adult online survey on CPR decision include: "Decision is reasonable as professionals reading it in future should appreciate any decision is time-specific and subject to change/review. Recommendation seems less 'decisive' and perhaps too 'burdensome' to the emergency responder - faced with a cardiac arrest and only a recommendation, then who decides whether to start CPR...?" Of the service users and carers only, who responded to the adult online survey 62% opted for "CPR decision" 34% opted for "CPR recommendation" 4% opted for "Don't Know "

		• Ensure the Patient Demographic section of a shared care record can identify whether an individual resides in a private home or communal setting (i.e. care home) in order to ensure equity of care and a high standard of quality regardless of where an individual lives. • Record who is responsible for aspects of persons care and who completed parts of the care record to ensure that care is delivered in a way that meets a person’s needs and wishes. • Record (using SNOMED codes) that the person has an advance care plan and also a treatment escalation plan.	Comments from the adult online survey on recording advance care planning include: “Patient conversations about ACP and escalation plans should be prevalent so they don't have to cover the same ground every time they speak to a professional. Although there should be a check-in about that information as their ideas on ACP or escalation may have changed.” Comments from the adult online survey on recording preferred place of death include: “To document if preferred place of death is met requires someone to make that assessment. It is better to record the actual place of death, because then this assessment can be an automated process, reducing staff time to "close" a care plan/record.” 79% (295) of those who answered the question on expressing a preference about their place of death in the adult online survey said they support listing a 1st and 2nd choice on preferred place of death. Comments from the adult online survey on recording a person’s residential setting include: “It is helpful to know the person's circumstances and the baseline level of support available (e.g. whether they have waking night support). It is concerning, though, that sometimes people in care homes get less specialist palliative care input due to the expectation that e.g. a

			care home will offer this. Staff may or may not be trained to a sufficient level, (sic) staff shortages." 95% of those who answered the question on recording a person's residential setting (349) from the adult online survey said 'we should record if a person lives in a communal setting'.

6 Palliative and End of Life Care Information Standard – Information Model

The information model can be found in the PRSB standards viewer on the PRSB website.

6.1 Implementation Guidance

The implementation guidance was developed through the consultation process and expert group discussions to provide additional information to use the standard.

PRSB standards include implementation guidance intended for the following audiences:

- Technical messaging specification developers
- System suppliers incorporating the standards into systems and implementation teams at provider organisations
- Users of standards in their roles as health and care professionals, service users, patients, carers and citizens.

The implementation guidance is published along with the Palliative and End of Life Care Information Standard.

6.2 Clinical safety case and hazard log

The PRSB is producing a clinical safety case and hazard log which ensure that the data items within a standard are safe to be implemented in care systems. The approach follows the standard approach to clinical safety for the NHS and complies with DCB 0129 (for IT suppliers). Further information can be found at Clinical risk management standards.

The approach PRSB takes to developing the clinical safety case and hazard log include:

1. Identifying risks and hazards from the consultation outputs:
   - Hazard workshop
   - Workshop and webinar outputs
   - Clinical and other expert reviewer meetings
   - Survey consultation findings
   - Review hazards from other relevant PRSB standards
2. Developing the hazard log
3. Developing clinical safety case from hazard log
4. Assuring and approving hazards log and clinical safety case
   - NHS Digital clinical safety team approval
   - PRSB Assurance Committee approval
   - Clinical safety officer hands over clinical safety care to PRSB clinical director (owner)
5. Hand over ownership of clinical safety case and residual risks to NHS Digital.

7 Conclusions and Next Steps

The Palliative and End of Life Care Information Standard, which updates the SCCI 1580 standard, will help to enhance the delivery of palliative and end of life care for people, including advance care planning. PRSB recommends changes to the existing standard including the additions of items that reflect current practice and following consultation with a range of stakeholders.

The standard will capture a person’s background and clinical data, including person demographics, clinical history, problems, medicines, allergies, and personal and professional contacts. It also includes information that is important to a person and their loved ones, including what matters most to a person about their care, their preferences, wishes and fears about dying, legal information (e.g., Lasting Power of Attorney), CPR decisions, and advance statements about their care, preferred place of death and care.

This project sought to identify the specific requirements of children and young people with palliative and end of life care needs. PRSB recommends that further consultation with clinical and professional groups is undertaken to ensure that the standard fully meets the needs of children and young people.

Equally important is the recommendation that a person who is identified as having palliative and end of life care needs, should be offered the opportunity to develop a personalised care and support plan, including advance care planning, in collaboration with the relevant clinician or professional. This should include About Me information and prioritise a person’s end of life wishes, preferences, and needs as described throughout this document. Sharing this information, as appropriate, with all health and social care professionals, and loved ones as appropriate, involved in a person’s care, will help ensure that people live well for as long as possible and die with dignity.

Examples of good practice already exist and tools such as the ReSPECT process and Gold Standards Framework and accompanying forms are widely used to improve care at times of extreme need. PRSB has sought to align these processes with the standard to promote greater awareness of best practice information sharing and build support for improving care.

Clarity about what information should be shared when someone is approaching the end of their life to provide high quality care is fundamental to improving their care, particularly when people move between health and social care settings. But it is not enough. We know from the evidence review and consultation feedback for this project that far greater focus needs to be given to supporting adoption of the standard. This ranges from supporting suppliers to ensure their systems are conformant with the standard, to educating clinicians and professionals to confidently engage in advance care planning discussions and helping organisations drive the culture change needed to adopt standards and realise the benefits of digital information exchange. Addressing the cultural changes that are needed is vital if we truly are to put people at the centre of their care. This depends on clinicians and professionals being able to identify people’s care needs earlier and work with the person, their families and loved ones to ensure treatment and care, now and in the future, are in line with what matters most to the person.

There are important technical next steps necessary to support adoption and implementation of the standard. It is critical that information systems are able to share data to ensure that the standard works as it is intended. PRSB will work with the NHS to ensure the standard is awarded Information Standards Notice status which will support adoption by system suppliers. PRSB will continue to work with the Lexicon Working Group on SNOMED CT reference sets used by palliative and end of life care to identify where new codes are required and deprecate any codes, as needed.

When implemented, the Palliative and End of Life Care Information Standard will support professionals, people with palliative and end of life care needs and carers to develop, record and share care plans that are tailored to an individual’s needs and wishes. This project provides an important contribution to ensuring people have a greater say in their care and are able to exercise more choice in having their needs met.