

Introduction

5 Step
Approach

Identification

Clinical
Validation

Personalised
Care & Support
Planning

Sharing
Information

Review &
Evaluation

Health
Inequalities

National End of Life Care NHS England and Improvement

EARLY Identification and Personalised Care Planning Toolkit

The purpose of this toolkit is to support colleagues in Primary Care settings in the early identification of people who may be in their last year of life and benefit from an opportunity to discuss a Personalised Care Support Plan (PCSP) which is shared on a local Electronic Palliative Care Coordination System (EPaCCS).

The EARLY toolkit includes a clinical search tool along with a suite of resources to support implementation.

Acknowledgement to London and North-West Palliative and End of Life Care Strategic Clinical Networks, Dr Andrew Fletcher and Midlands and Lancashire Commissioning Support Unit for their development and review of the EARLY Clinical Search Tool and Toolkit

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Introduction

5 Step
Approach

Identification

Clinical
Validation

Personalised
Care & Support
Planning

Sharing
Information

Review &
Evaluation

Health
Inequalities

INTRODUCTION

EARLY is an acronym for:

- E** - Early identification
- A** - Advance care planning
- R** - Record
- L** - Look again
- Y** - You can continually improve

Following extensive clinical development, a clinical search tool (EARLY) has been developed within GP electronic patient records to help identify people who are likely to be in their last year of life. It searches Systematized Nomenclature of Medicine Clinical Terms (SNOMED CT) codes based on a range of prognostic indicator guidance including the Gold Standard Framework Proactive Identification Guidance (GSF PIG) and the Supportive and Palliative Care Indicators Tool (SPICT) resources.

It identifies people who can be offered the opportunity to have an advance care planning discussion in order to share their wishes. It supports the documentation of the personalised care and support plan on your local Electronic Palliative Care Coordination System. (EPaCCS)

The EARLY search tool and toolkit have been developed collaboratively by London Strategic Clinical Network, North-West Strategic Clinical Networks and Midlands and Lancashire Commissioning Support Unit. Currently, the tool runs on EMIS, SystmOne and Vision web GP IT system.



Why identification of patients nearing the end of life is important



National EOLC – EARLY Identification and Personalised Care Planning



Introduction

5 Step
Approach

Identification

Clinical
Validation

Personalised
Care & Support
Planning

Sharing
Information

Review &
Evaluation

Health
Inequalities

IDENTIFICATION

Run EARLY Identification Search Tool

CLINICAL VALIDATION

Clinical review of the list of patients generated

PERSONALISED CARE & SUPPORT PLANNING

Contact patient and/ or family (where appropriate) to offer discussion about personalised care planning

DECLINE

Consider support from health and social care partners

ACCEPT



SHARING INFORMATION

Begin discussion, complete documentation, ongoing referrals etc.

(A copy should be offered to the patient)

Outcomes should be coded on the GP IT System
(SNOMED CT)

REVIEW & EVALUATION

The care plan should be reviewed and updated regularly

Ongoing feedback from patients and staff should be obtained



Introduction

5 Step
Approach

Identification

Clinical
Validation

Personalised
Care & Support
Planning

Sharing
Information

Review &
Evaluation

Health
Inequalities

IDENTIFICATION

It is important to identify and support people with advanced progressive illness who might die within the next twelve months. Early identification will support them to have well-planned and coordinated care that is responsive to the patient's changing needs with the aim of improving the experience of care.

It's suggested the clinical search is run annually, but consideration given to more frequent searches depending on the registered population demographics



[EARLY– An Introduction to a clinical search tool for early identification](#)

The EARLY search tool is compatible with the following clinical systems. Click on the system logo to access the relevant EARLY search tool and guides





Introduction

5 Step
Approach

Identification

Clinical
Validation

Personalised
Care & Support
Planning

Sharing
Information

Review &
Evaluation

Health
Inequalities

CLINICAL VALIDATION

Once the EARLY tool has been run and a list of patients generated, the list requires validation by a clinician to ensure that each patient is appropriate for a personalised care and support planning discussion.

A key consideration when undertaking clinical validation of the generated list is the surprise question:

Would I be surprised if the patient would die in the next year?

The inclusion criteria outlined below are general prompts to consider that may help decide whether the patient would benefit from personalised care support planning.

This list is not exhaustive, and clinicians should ensure that each patient is individually clinically validated.

- Increasingly frequent attendance at GP Surgery?
- Does this patient already have a personalised care plan? If yes, has the pre-existing care plan been reviewed within the last 3 months?
- Has the patient had 3 or more admissions into hospital in the last 6 months?
- Has the patient had 3 or more encounters with emergency and out of hours services?
- Does the patient have pre-existing, long-term condition(s) which means that s/he is likely to deteriorate?
- Does the patient receive 24-hour care?
- Does the patient have a frailty index of moderate or severe?
- Is the person known to palliative care or end of life services?
- Has the person had recurrent falls?
- Does the patient have cancer that has progressed despite anti-cancer treatment, or cancer where there are limited treatments to save or prolong life? Has any specialist team or other professional involved in the patient's care identified that this patient may be in their last 12 months of life?
- Has the patient been considered for organ transplantation? *

**Consider liaison with specialist teams regarding whether discussion around personalised care plans would be appropriate.*



Introduction

5 Step
Approach

Identification

Clinical
Validation

Personalised
Care & Support
Planning

Sharing
Information

Review &
Evaluation

Health
Inequalities

PERSONALISED CARE & SUPPORT PLANNING

There are many different approaches to care planning and conversations around end of life can be challenging. It is important that people do not feel pressurised into such conversations and decisions before they are ready. It is an opportunity to discuss the patient's current conditions and future care, wishes and preferences and a plan of care for emergency situations including, if appropriate, cardiopulmonary resuscitation (CPR).

Personalised care and support planning is an umbrella term and one of the areas which sits underneath it is Advance Care Planning (ACP). There are **6 universal principles** around ACP which we should all be familiar with prior to any communication with patients or those important to them once the person has been identified as being in the last year of life.

Personalised care means people have choice and control over the way their care is planned and delivered, based on 'what matters' to them and their individual strengths and needs. This happens within a system that supports people to stay well for longer and makes the most of the expertise, capacity and potential of people, families and communities in delivering better outcomes and experiences when unwell.

The **Comprehensive Personalised Care Model** sets out how to achieve this, through six, evidence-based standard components:

- Shared decision making
- Personalised care and support planning
- Enabling choice, including legal rights to choice
- Social prescribing and community-based support
- Supported self-management
- Personal health budgets.

NHS England seek to enhance personalised palliative and end of life care by using the Comprehensive Personalised Care Model to view the improvements needed to support increased choice and control at the end of life, and better experience of care. This includes earlier identification of people who are likely to die within the next 12 months; better conversations for people to identify their needs and preferences, and to share this information with those involved in their care; and integrated services which wrap around people.



Introduction

5 Step
Approach

Identification

Clinical
Validation

Personalised
Care & Support
Planning

Sharing
Information

Review &
Evaluation

Health
Inequalities

SHARING INFORMATION

To ensure continuity of care it is important to share information across services and organisations involved in the individual's care. Information sharing must always be with the persons consent, or in their best interests where they lack capacity.

The below resource list is not exhaustive and can be used to support the development of local policy and guidance:

- **Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026** outlines the need for electronic sharing.
- **Systematized Nomenclature of Medicine Clinical Terms** (SNOMED CT) is a clinical vocabulary readable by computers. SNOMED CT gives clinical IT systems a single shared language, which makes exchanging information between systems easier, safer and more accurate. Using standard codes to record EPaCCS supports digital sharing of clinical information
- **Professional Records Standard Body** (PRSB 2022) includes relevant Palliative & End of life Care SNOMED CT codes and defines the information that should form part of a person's shared care record for use to ensure that professionals and individuals have access to appropriate information to support decision making. The standard supports the **Universal Principles for Advance Care Planning**.
- **Personalised Care Plans** supports the recording of discussions regarding people's future care, including any changes to their preferences and wishes. This information can be coded and digitally shared via **Electronic Palliative Care Coordination Systems**, or EPaCCS. The aim of this is to ensure that any professional involved in that person's care has access to the most up to date information,

The core record is currently kept by the General Practitioner in their electronic system and allows relevant professionals involved in the person's care to view and therefore be aware of the individual's palliative and end of life personalised care plan. Information sharing must always be in line with local information sharing governance arrangements.



GP Education Masterclass 2 - Capacity and Information Sharing



Introduction

5 Step
Approach

Identification

Clinical
Validation

Personalised
Care & Support
Planning

Sharing
Information

Review &
Evaluation

Health
Inequalities

REVIEW & EVALUATION

REVIEW

It's suggested the clinical search be run annually, but consideration given to more frequent searches depending on the registered population demographics

It is important for individuals to be provided with ongoing opportunity and support to review their future care plans, ensuring they remain relevant and up to date. For many reasons there are times when people change their minds about the care they want to receive and where want to receive that care. When this happens, it is necessary to update the persons EPaCCS record using the correct SNOMED CT codes to allow sharing of information across services.

Regular palliative care meetings are the ideal opportunity to revisit, review and share information about a patient's care plan and to consider the needs of those important to the person.

Regular auditing of the care provided can support service development which can lead to improvement in care



How to undertake a retrospective death audit and interpret an initial baseline audit (RCGP)

EVALUATION

Patient Experience Questionnaire Capturing case studies and feedback from the patient, those important to the person and staff feedback is strongly recommended to improve patient experience.

Workforce Skills & Training It is necessary to understand the needs of staff with regards to their skills, knowledge and confidence in having ACP discussions to ensure the right level of training is provided to them depending on their role.

Practice Evaluation Questionnaire Feedback is needed from those involved in using the clinical search tool and toolkit to support continuous improvement and ongoing development of the toolkit resource.



Introduction

5 Step
Approach

Identification

Clinical
Validation

Personalised
Care & Support
Planning

Sharing
Information

Review &
Evaluation

Health
Inequalities

HEALTH INEQUALITIES

“Dying well wherever you are and whatever your background or circumstances are fundamental aspects of human dignity. As part of a compassionate humane society, we need to do everything we can to make sure that people who are facing their last months, weeks and days of life receive the best possible palliative and end of life care. Those who care for them, including their families, others important to them and staff around them, equally deserve this consideration and support”. (NHS England 2022)

Everyone deserves high quality and compassionate care that meets their individual needs and responds to their wishes and choices in the last years, months and days of life. In order to address inequity, it is not enough to improve quality of care for the majority. Those living with health inequalities have unique needs and considerations which must be identified and addressed during personalised care planning.

A report by the Care Quality Commission, ‘**A different ending: Addressing inequalities in end-of-life care**’, 2016, details people’s experience of end-of-life care and brings together examples of good practice.

There are **10 briefings** in the series:

- People with conditions other than cancer
- Older people
- People with dementia
- People from Black and minority ethnic (BAME) groups
- Lesbian, gay, bisexual or transgender people
- People with a learning disability
- People with a mental health condition
- People who are homeless
- People who are in secure or detained settings
- Gypsies and Travellers

A separate report by the **Care Quality Commission**, ‘**Protect, respect, connect – decisions about living and dying well during COVID-19, 2021**’, considered how DNACPR decisions were made in the context of advance care planning across all types of health and care sectors, including care homes, primary care and hospitals.



National EOLC – EARLY Identification and Personalised Care Planning



Introduction

5 Step Approach

Identification

Clinical Validation

Personalised Care & Support Planning

Sharing Information

Review & Evaluation

Health Inequalities

RESOURCES

Ambitions – National Framework	NHS England » Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026
EARLY Toolkit & Guides – Cheshire ePaige	EARLY Tool (cheshire-epaige.nhs.uk)
EPaCCS (Electronic Palliative Care Co-ordination Systems)	NHS England — North West » Electronic Palliative Care Coordinating Systems (EPaCCS) Standard
GSF PIG (Gold Standards Framework – Proactive Identification Guidance)	Gold Framework - Proactive Identification Guidance (PIG) (goldstandardsframework.org.uk)
Health Inequalities	Care Quality Commission, ‘A different ending: Addressing inequalities in end-of-life care’ ,
	Care Quality Commission Protect, respect, connect – decisions about living and dying well during COVID-19 - Care Quality Commission (cqc.org.uk)
	Equality in Hospice and End of Life Care: Challenges and change Hospice UK
National Confidential Enquiry into Patient Outcome and Death Report (2024)	NCEPOD - End of Life Care: (2024)
Personalised Care	NHS England » Personalised care
	NHS England » Comprehensive model of personalised care
Professional Records Standards Body, PRSB, 2022	Palliative and End of Life Care – PRSB (theprsb.org)
SNOMED CT	SNOMED CT - NHS Digital
SPICT (Supportive and Palliative Care Indicators Tool)	SPICT – Supportive and Palliative Care Indicators Tool
Universal Principles for Advance Care Planning	NHS England » Universal Principles for Advance Care Planning (ACP)

