

The Scottish Government  
Health Delivery Directorate  
Improvement and Support Team

# Anticipatory Care Planning

## Frequently Asked Questions



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ISBN: 978-0-7559-9213-3 (web only)

The Scottish Government  
St Andrew's House  
Edinburgh  
EH1 3DG

Produced for the Scottish Government by RR Donnelley B63344 3/10

Published by the Scottish Government, March 2010

## Purpose

The purpose of this guidance is to provide practical support to local teams. Anticipatory and Advance care planning (ACP), in practical terms, are both about adopting a “thinking ahead” philosophy of care that allows practitioners and their teams to work with people and those close to them to set and achieve common goals that will ensure the right thing is being done at the right time by the right person(s) with the right outcome. Advance care planning is the term most commonly referred to in end of life care, although it does incorporate the writing of wills or “Living Wills” now known as advance directives or advance decisions which can be done by the well person early on in life to plan for what **may** happen at the end of life. Anticipatory care planning is more commonly applied to support those living with a long term condition to plan for an **expected** change in health or social status. It also incorporates health improvement and staying well. Completion of a common document called an anticipatory care plan is suggested for both long term conditions and in palliative care.

This guidance complements Long Term Conditions Collaborative guidance notes SPARRA Made Easy on risk prediction tools and Proactive, Planned and Coordinated Care Management in Scotland and the implementation of Living and Dying Well.

## Care Planning

Care planning is a process that applies at all ages, throughout the continuum of care and support and is undertaken by a variety of professionals across all care settings. It is a reflective and voluntary process that facilitates discussion with the individual, and often the people who are close to them, to identify their personal values, goals and needs. Care planning is an opportunity to think about personal wishes and preferences and to make informed choices about current and future care and support based on shared decision making. Recording and sharing these decisions with the full range of care providers improves communication and helps ensure people identify the outcomes that are important for them and receive the care of their choice.

## What is an Anticipatory Care Plan?

An Anticipatory Care Plan is a dynamic record that should be developed over time through an evolving conversation, collaborative interactions and shared decision making. It is a summary of Thinking Ahead discussions between the person, those close to them and the practitioner.

The ACP is a record of the preferred actions, interventions and responses that care providers should make following a clinical deterioration or a crisis in the person’s care or support. It should be reviewed and updated as the condition or the personal circumstances change and different things take priority.

As the condition becomes more complex it may be helpful to discuss legal and practical issues as well as care and support preferences. As the needs and dependency of the person increase, it may become appropriate to explore end of life preferences within these conversations. The Anticipatory Care Plan will then include additional information about the person's:

- concerns and goals
- their understanding about their illness and prognosis
- wishes for end of life care, including preferred place of care, as well as their views about the degrees of interventions, treatments and cardiopulmonary resuscitation welcomed.

This type of information is currently recorded as a Palliative Care Summary. This summary is a specific component of an Anticipatory Care Plan for someone who has palliative or end of life care needs.

## Why is this important?

Most people who live with a long term condition manage their own condition or do so with help from family, unpaid carers or from community and voluntary sector partners. Supported self management encourages people to take decisions and make positive choices about their health, wellbeing and health-related behaviours. It involves a holistic assessment of personal goals. A self management plan is a way of recording these personal goals and the supports people need to achieve them. It is designed to be held and used by the person at home.

Anticipatory care encourages people to make positive choices about what they should do themselves, and from whom they should seek support, in the event of a flare up or deterioration in their condition, or in the event of a carer crisis. An anticipatory care approach supports important outcomes:

- Person centred care, dignity, choice and control
- Effective co-ordination and communication between the individual, their family and the health and social care professionals involved
- Care at home where appropriate, or care which is more local and closer to home

## Are Anticipatory Care Plans the same as Shared Care and Support Plans?

Assessments, shared care and support plans and reviews are the main interfaces that health and social care staff have with people and their carers who need support or access to services. Care planning is the process of discussion in which people, their care providers and those who are close to them make, record and communicate shared decisions about health, personal and practical aspects of care and support so that people receive the right care at the right time and in the right setting with the best possible experience and outcome. Regular Reviews provide an opportunity to check that the outcomes identified in the care and support plan have improved for the individual concerned, and to adjust services or support accordingly.

Anticipatory care planning fits well with the personal outcomes approach to care planning in community care. Through discussions at multi-disciplinary team meetings health and social care practitioners can review individual care plans, address any gaps and identify triggers for anticipatory care planning in a collaborative way as the situation or clinical condition changes.

Good care planning and communication across teams and with carers improves co-ordination of care, enables early intervention and better access to safe and effective alternatives to avoidable hospital care. Some of these shared decisions will be based on thinking ahead about preferences for future care. Anticipatory Care Plans are therefore an important component of a shared care and support plan.

*“It is very important that any document is revisited regularly as people’s views change – people report that sometimes they also change as the condition progresses – different things take priority and some things that used to matter, matter less. Small things in terms of preferences can be very important.”*

## Who should have an Anticipatory Care Plan?

Not everyone either needs or wants an Anticipatory Care Plan. The decision about when and whether it would be appropriate to support someone to initiate an Anticipatory Care Plan depends on the stage of their condition, professional judgement about their readiness to engage in the conversation and the benefits of having an Anticipatory Care Plan.

Triggers for Anticipatory Care Plans are practical opportunities that can be used to prompt conversations with people about their condition and to discuss the potential benefits from developing their own Anticipatory Care Plan. This is a voluntary process and the decision to have one rests with the individual. Having an Anticipatory Care Plan would be particularly helpful for people who:

- Live in a care home
- Are being proactively care managed
- Have complex, palliative or end of life care needs.

Useful triggers may include:

### Situation

- When the person is house bound long term
- When the person is in receipt of a complex care package
- When the person is resident in, or has been admitted to, a care home
- Following discharge from an unscheduled admission to hospital
- When the person has frequent contacts with Out of Hours services
- When the person is in receipt of respite care
- When a patient is admitted or transferred to a community hospital
- Following carer assessment or identified carer stress

## *Condition*

- Advanced long term condition e.g. COPD in receipt of domiciliary oxygen
- Patient is receiving enhanced support from a specialist nurse
- Patient referred to or attending memory clinic
- Placement on practice dementia register
- Placement on practice learning disability register
- Placement on practice mental health register
- Placement on Palliative Care register – should prompt a PCS

## *Clinical assessment*

- High SPARRA risk score (>50%) and assessment confirms instability
- Recognised as vulnerable by primary or community care services due to change in health, function, psychological state or carer situation
- Patients receiving poly-pharmacy (more than six medicines) or on certain categories of drugs, e.g. opioids
- Patients referred for falls assessment

## **Does this approach apply to people with dementia?**

The principles and purpose of anticipatory care plans apply equally to people with dementia. Dementia is the commonest cause of loss of capacity to make informed choices and decisions, followed by Learning Disability, Stroke and Head Injury. Capacity is not an all or none phenomenon. It may be temporary, indefinite, fluctuating or permanent. Significant communication problems also can render someone incapable. Every effort must therefore be made to help the individual understand the decision they are being asked to make, be able to communicate that decision, understand its consequences and retain the memory of that decision.

As most people with early dementia retain the capacity to make informed choices and decisions, an anticipatory care plan should be initiated as soon as possible after diagnosis whilst the person can still be an active participant. People should be encouraged to let staff know who they trust and would like to be involved and included in discussions and to indicate who they would like to involve if and when they no longer have the capacity to decide themselves.

Where a person is deemed incapable, any decisions that are made relating to their health and social welfare must adhere to the Principles of the Adults with Incapacity Act (2000) – any action must be of benefit to the adult, take account of the adult's previous wishes if known, take account of the views of relevant others and encourage independence.

People with dementia deemed incapable of giving informed consent to treatment should be treated under the Adults With Incapacity Act (2000), Part V Medical Treatment and Research (<http://www.opsi.gov.uk/legislation/scotland/acts2007/20070010.htm>)

A certificate can be issued for a three year period, although at least annual review is encouraged. The treatment plan attached to the completed certificate should cover all necessary interventions, including medical, nursing and dental treatments and must be discussed and agreed with any appointed proxy. It may include a plan for managing their long term conditions, what to do in the event of a deterioration and should include discussion about palliative and end of life care. It should not authorise an intervention that would normally require signed consent from the patient. A separate certificate of incapacity would be required for this type of intervention.

Any appointed attorney or guardian must be included in the process as well as members of the multidisciplinary team. Account must be taken of any formal advanced directive that exists. Decisions, including those relating to withdrawal of treatments and resuscitation, should be clearly recorded and communicated to all relevant members of the care team. Where there is dissent about the plan, assessment by a third party may be necessary.

*“One day I am going to die,” he said. “All I am really scared of is losing my mind. In the meantime, I feel better now that I have talked over what I want to happen when I am unable to make any decisions with my family and my carers and written it down in my plan.”*

*Care Home resident*

## Power of Attorney (POA)

A power of attorney document should contain either continuing powers, welfare powers or a combination of both.

Continuing Powers relating to the Granter’s financial/property affairs may be given with the intention of taking effect immediately and continuing upon the Granter’s incapacity, or beginning on the incapacity of the Granter.

Welfare powers cannot be exercised until such time as the Granter has lost the capacity to make these decisions for himself. A Continuing Welfare Power of Attorney can only come into effect once the person no longer has capacity. It then grants the appointed attorney the authority to look after the welfare and financial affairs and to make health and social care decisions on the person’s behalf.

The Office of Public Guardians (Scotland) supports and promotes decision making for those who wish to plan for the future. The department provides information on:

- Making personal arrangements
- What to do if there are concerns about someone else making decisions
- Information for those allowed to make decisions

The Office of the Public Guardians can be contacted at:

[www.publicguardian-scotland.gov.uk](http://www.publicguardian-scotland.gov.uk)

## **Good practice for people with dementia**

- Encourage early discussion about future care
- Help the person and their carers to develop an anticipatory care plan
- Promote the appointment of a Welfare Power of Attorney
- Always assess capacity and, where possible, include the person in the decision making process
- Make appropriate use of Part V of the Adults with Incapacity Act (2000)
- Adhere to the principles of the Act when considering content of care plan
- Involve all relevant parties in development of the plan
- Include preferences for palliative and end of life care
- Take account of any advanced directive
- Document and share the plan

## **How can we share Anticipatory Care Plans?**

At present there is no easy way for information on Anticipatory Care Plans to be shared between different clinicians. Anticipatory Care Plans need to be shared with the full range of care providers involved, including NHS 24 and Out of Hours Services, so that all are aware and can respond to the expressed wishes. The current system relies on a confusing array of 'special notes' faxes and emails from GP practices to Out of Hours Organisations, Accident and Emergency and admissions units.

Paper documents and ad-hoc emails have many limitations, including problems with storage, delivery, version control and confidentiality. To comply with information governance standards we need an electronic Anticipatory Care Plan that is easily generated, reviewed, revised and shared.

The ehealth team have been testing the framework for the Emergency Care Summary (ECS) (Appendix 1) successfully shared across Scotland, in order to support electronic sharing of a Palliative Care summary. The ECS takes core patient details from GP systems and sends them automatically to a central ECS store so that clinicians in emergency care and out of hours settings can access these details with the permission of the patient.

It will soon be possible to enrich the core ECS data set with more detailed information required for patients with palliative care needs. The work on this Palliative Care Summary or ePCS is now being extended to support electronic sharing of Anticipatory Care Plans. Clinical leads for ECS, Palliative Care, Long Term Conditions and adults with Learning Difficulties are collaborating to reach a consensus on a common electronic Anticipatory Care Plan form that will be detailed enough to be clinically helpful, yet concise enough to be used in a variety of clinical situations.

This electronic system will allow basic information about demography, diagnoses, drugs and allergies to be uplifted from GP systems and updated weekly. Fields such as information on current situation, care and support, recommendations and alerts for use by Out of Hours services, palliative care and end of life preferences require to be completed as and when they are relevant to the person, their situation and the stage of their condition.

This electronic Anticipatory Care Plan form is in a clinical development phase. Once the content has been agreed it will progress to a more detailed specification of the technical requirements.

A draft version is reproduced below. This indicates those items which would be uploaded automatically from the GP system, and those which could be added by 'freetext' as appropriate to the individual.

<b>SPECIAL NOTES OOH Summary</b>	
<b>Patient consent</b>  <b>Patient aware</b>  <b>Date of review</b>	<b>Free Text Box (500 characters)</b>
<b>Specific support needs or anticipated problems</b>	<b>Alerts – (drop down list)</b> Medical conditions requiring specific care Visual or hearing impairment Communication difficulties Need for interpreter First language if not English Anaesthetic alerts e.g. difficult airway
<b>Risk status e.g. suicide risk or risk of violence to staff</b> Free text 250 characters	

<b>Patient and Carer Details</b>		<b>Key Professional Contacts</b>	
<b>Patient Surname</b>	From system	<b>Usual GP name</b>	From system
<b>Patient Forenames</b>	From system	<b>Practice name</b>	From system
<b>CHI Number</b>	From system	<b>Nurse</b>  <b>Care Manager</b>  <b>Specialist Nurse</b>  <b>SW contact</b>  <b>Other Agencies involved</b>	Free text 250 characters
<b>Patient Address</b>	From system		
<b>Patient Tel number</b>	From system		
<b>Patient mobile number</b>			
<b>Carer Details</b>	Free text 100		
<b>Access information – including key code</b>	Free text 100		
<b>Next of kin details:</b> Emergency contact phone numbers	Free text 250		
<b>Current Situation</b>			
<b>Main Diagnoses</b>	From system High priority codes		
<b>Current problems</b>	Free text 200		
<b>Understanding of diagnosis and situation, including goals and expectations</b>	Free text 200		
<b>Patient and family wishes</b>	Free text 200		
<b>Self management plan</b>	<b>Yes</b>	<b>No (tick boxes)</b>	
<b>Anticipatory care plan</b>	<b>Yes</b>	<b>No (tick boxes)</b>	
<b>Shared Assessment</b>	<b>Yes</b>	<b>No (tick boxes)</b>	
<b>Normal Oxygen saturation</b>	<b>Please enter</b>	<b>%</b>	
<b>Home Oxygen</b>	<b>Yes</b>	<b>No (tick boxes)</b>	
<b>Usual BP</b>			
<b>'Just in case'/anticipatory medicines available</b>	<b>Details...</b> <b>N/a</b>		

Care and Support details		
<b>Guardianship with welfare decision making powers?</b>	<b>Yes</b>	<b>No (tick boxes)</b>
<b>Power of attorney in place?</b>	<b>Yes</b>	<b>No (tick boxes)</b>
<b>Adults with Incapacity form completed?</b>	<b>Yes</b>	<b>No (tick boxes)</b>
<b>Compulsory treatment order in the community in place?</b>	<b>Yes</b>	<b>No (tick boxes)</b>
<b>Mental Health Act detention</b>	<b>Yes</b>	<b>No (tick boxes)</b>
<b>Homecare support in place?</b>	<b>Free text 200</b>	
<b>Moving and handling information and equipment in place</b>	<b>Yes</b>	<b>No</b> <b>Not needed</b>
<b>Agreed actions</b>	<b>Free text</b>	
Information and Recommended Action for OOH Clinicians		
<b>Current place of care</b>	<b>Free text</b>	
<b>Preferred Place of Care</b>	<b>Free text</b>	
<b>Special instructions for OOHs</b>	<b>250</b>	
<b>DNA CPR form in place</b>	<b>(import from system or ePCS)</b>	

## What support will staff need to develop Anticipatory Care Plans?

Staff learning and support needs will include:

- general awareness raising about the principles of ACPs
- communication, consultation and assessment skills
- recognising triggers for conversations about anticipatory care plans
- developing confidence to initiate these conversations
- recognising when to defer or discontinue the discussion

The level of required competence will vary across practitioner roles and care settings. Education should be tiered and tailored to match the practitioner's role and responsibilities. Educational support can be provided through a wide range of learning opportunities including face to face, blended, cascade training and online approaches. Training can be cascaded by inclusion in induction programmes, protected learning time sessions, or spread through a 'Champions' approach.

Training needs to extend beyond health and social care staff to reach independent home care providers and staff working in care homes. Partner organisations should collaborate to support whole system practitioner development.

Staff nurse. "Great communication tool, got all of us talking about sensitive issues that we do not think or talk about enough to each other"

## How will we know Anticipatory Care Plans are making a difference?

**Measuring success:** Food for Thought for developing local improvement measures. Measuring and evaluating impact requires a blended approach of Activity/Process, Outcome and Experience measures. For example:

<p><b>ACTIVITY/PROCESS/OUTPUT</b></p> <ul style="list-style-type: none"> <li>• Proportion of people on palliative care register who have anticipatory care plan (includes &lt; 65 years and &gt; 65 years)</li> <li>• Proportion of people who are being actively care managed who have anticipatory care plan</li> <li>• Condition specific – proportion on disease register with anticipatory care plans (e.g. COPD/ dementia)</li> <li>• Number of anticipatory care plans shared with Out of Hours             <ul style="list-style-type: none"> <li>• Number available</li> <li>• Number accessed by Out of Hours</li> </ul> </li> <li>• Review of anticipatory care plans through serial sampling to ascertain completion e.g. review date/updated</li> </ul>
<p><b>OUTCOME</b></p> <ul style="list-style-type: none"> <li>• Proportion of people admitted as emergency from a care home             <ul style="list-style-type: none"> <li>• Critical event analysis for appropriateness of admission</li> </ul> </li> <li>• Proportion of people with complex care needs cared for at home who are admitted as an emergency</li> <li>• Proportion of people on palliative care register admitted to hospital</li> </ul>
<p><b>EXPERIENCE:</b> Capturing the person’s and team’s experience consider a range of methods, e.g. digital stories, case studies, qualitative interviews</p> <ul style="list-style-type: none"> <li>• Capture experience of patients/carers/health/social care and voluntary sector though a variety of mediums</li> <li>• Utilise the CARE Measure</li> <li>• Review of case notes and updating of anticipatory care plan:             <ul style="list-style-type: none"> <li>• What was the breadth of sharing of the information/wishes within the ACP across all those involved in the continuum of care?</li> <li>• Critical event analysis involving those involved in care (health, social care and voluntary sector) to capture reflections and learning</li> </ul> </li> <li>• Identify the facilitators and/or barriers to owning their own plan             <ul style="list-style-type: none"> <li>• Who did the person share and discuss the plan with?</li> <li>• Who would you like to talk about your plan with? Explore why it did or did not happen</li> </ul> </li> </ul>

## Spread of Anticipatory Care Plans

Improvements which have been developed, adapted and tested by local teams are more likely to be successfully spread and embedded in day to day practice with demonstrable benefits for all. Effective spread planning is intrinsic to successfully widening the scope of ACPs to people across different care settings.

There are five key dimensions to effective spread, these being:

1. Organisational readiness
  - Assessing its readiness to spread
  - Executive sponsorship aligned with organisational priorities
  - Clear role and responsibilities
  - Identify successful sites and use these to develop the case
2. Developing a spread plan
  - Vision = Agreed ACP + target population for spread + time frame + target levels of performance
  - Tailor it locally
3. Develop a communication plan
  - Consider what the benefits are for different groups?
  - Has comparative data been shared?
  - What mechanisms are you going to use to reach the target audience?
  - Who are the influential people within the adopters and are they willing to be involved?
  - How are the success sites going to help the adopters?
4. Develop a plan for measurement
  - You need to consider how outcomes will be measured, how will the rate of spread be measured and who will collect, analyse and summarise the data
5. Executing and refining the plan
  - Spread agent (day to day manager) is the driver for this work by monitoring, coaching and refining as required
  - Dissemination of information and refining the plan as required
  - They will also take responsibility for monitoring any transition issues eg. barriers to implementation and identify ways to overcome them

## Some examples of where this is happening?

**NHS HIGHLAND:** The Nairn Anticipatory Care Project provides anticipatory and immediate health and social care support and information to vulnerable or 'at risk' Lodgehill Clinic patients within Nairn. The service provides person centred care and support and an opportunity for people to be involved in the creation of their Anticipatory Care Plan. This provides people with reassurance about their future care and support and records their wishes for care and resuscitation in the event of future health deterioration. Through systematic completion by a proactive multi-disciplinary team that delivers community based support and rehabilitation, people are assisted to remain at home or return home from hospital as quickly as possible.

**NHS Forth Valley:** Practices select five people with a SPARRA risk score of 40 – 60%. Each person has a quarterly multi-disciplinary/multi-agency review and discussion of current and future care needs with patient/family/carer. A management plan is agreed, Anticipatory Care Plans completed and the management plan shared with out of hours service.

**NHS Lothian's** enhanced service for anticipatory care has a focus on care homes. The service bundle requires systematic planned attendance at the care home, completion of an Anticipatory Care Plan, record of resuscitation status, assessment prior to urgent referral to hospital and a level 3 medication review.

**NHS Ayrshire and Arran** introduced an enhanced service for COPD that includes self management and anticipatory care plans that are notified to out of hours service.

**NHS Lanarkshire** Long Term Conditions Complex Care work stream produced an Anticipatory Care Plan to support and direct the care of people with complex needs who were currently being cared for within a nursing home or care home environment. An expert multi-agency working group was convened to review the literature, consult widely and identify the key deliverables which included an anticipatory care plan, guidance notes for health and social care professionals, patient and carer information leaflet and a teaching resource to support the implementation and ongoing use of the ACPs.

It was felt that the introduction of the new anticipatory care plan within GP aligned nursing homes may be a good place to test the content, design and usability of the draft plan. Eight care homes were invited to test the ACP, guidance notes and information leaflets. The Anticipatory Care Plan Facilitator attended the care home staff meetings, residents meetings and met with individual families to discuss the purpose of the ACP. ACPs were introduced however 100 residents were monitored to establish the impact. Participating care homes were asked to capture information over the month of July.

Of the 100 plans in use, care homes reported:

- 17 Residents used their ACPs to influence the length of their hospital stay by being discharged within 24 hours.
- 12 Residents used their ACPs to influence their preferred place of care and avoid hospital admission using the Red Flags (anticipatory) section. In these cases the GP and care home staff admitted to being more proactive in avoiding admission.
- five patients died in their preferred place of care.

Comments captured from residents and their families suggest that the introduction of ACPs has improved communication, acknowledged the expressed wishes of residents and provided the opportunity for families and care home staff to discuss difficult and sensitive issues.

## Long Term Condition Collaborative Programme Managers

To explore further implementation of ACPs in different areas, contact the respective local Programme Manager or LTCC Regional Manager:

<b>Health Board</b>	<b>E-mail Address</b>
NHS Ayrshire & Arran	<a href="mailto:Kathleen.McGuire@aapct.scot.nhs.uk">Kathleen.McGuire@aapct.scot.nhs.uk</a>
NHS Borders	<a href="mailto:Sandra.pratt@borders.scot.nhs.uk">Sandra.pratt@borders.scot.nhs.uk</a>
NHS Dumfries & Galloway	<a href="mailto:mari-anne.syme@nhs.net">mari-anne.syme@nhs.net</a>
NHS Fife	<a href="mailto:ingridhale@nhs.net">ingridhale@nhs.net</a>
NHS Forth Valley	<a href="mailto:david.arundel@nhs.net">david.arundel@nhs.net</a>
NHS Grampian	<a href="mailto:pamelagowans@nhs.net">pamelagowans@nhs.net</a>
NHS Greater Glasgow & Clyde	<a href="mailto:Karen.ross@ggc.scot.nhs.uk">Karen.ross@ggc.scot.nhs.uk</a>
NHS Highland	<a href="mailto:alexa.pilch@nhs.net">alexa.pilch@nhs.net</a>
NHS Lanarkshire	<a href="mailto:Marjorie.McGinty@lanarkshire.scot.nhs.uk">Marjorie.McGinty@lanarkshire.scot.nhs.uk</a>
NHS Lothian	<a href="mailto:Carol.Lumsden@nhslothian.scot.nhs.uk">Carol.Lumsden@nhslothian.scot.nhs.uk</a>
NHS Orkney	<a href="mailto:keith.farrer@nhs.net">keith.farrer@nhs.net</a>
NHS Shetland	<a href="mailto:elai@nhs.net">elai@nhs.net</a>
NHS Tayside	<a href="mailto:Rosie.cameron@nhs.net">Rosie.cameron@nhs.net</a>
NHS Western Isles	<a href="mailto:patwelsh@nhs.net">patwelsh@nhs.net</a>
North	<a href="mailto:Mandy.andrew@scotland.gsi.gov.uk">Mandy.andrew@scotland.gsi.gov.uk</a>
East	<a href="mailto:lona.philp@scotland.gsi.gov.uk">lona.philp@scotland.gsi.gov.uk</a>
West	<a href="mailto:Nigel.pacitti@scotland.gsi.gov.uk">Nigel.pacitti@scotland.gsi.gov.uk</a>

## **Appendix 1: The electronic Palliative Care Summary**

### **The electronic Palliative Care Summary (ePCS) – Update November 2009**

ePCS is a significant development which allows GPs and District Nurses to record information on the palliative and end of life needs of their patients onto their GP software system, and for this to be available to those providing care in the Out of Hours period

#### **What is ePCS?**

The ePCS builds on the Emergency Care Summary (ECS) and the Gold Standards Framework Scotland (GSFS) projects. The ePCS will, with patient/carer consent, allow automatic twice-daily updates of information from GP records to a central store, from where they will be available to Out of Hours (OOH) document, plan and review care. A paper Palliative Care Summary can be printed off and sent to OOH. Ultimately, ePCS will replace information currently faxed/emailed to OOH providers for palliative patients. Once your practice is “switched on” for ePCS, and patient consent is obtained and recorded on the GP system, all information will be available) services, NHS 24, Acute Receiving Units, Accident and Emergency Departments and, shortly, to the Scottish Ambulance Service. This will allow vital, structured information to support these patients and their families to be available in hours and OOH.

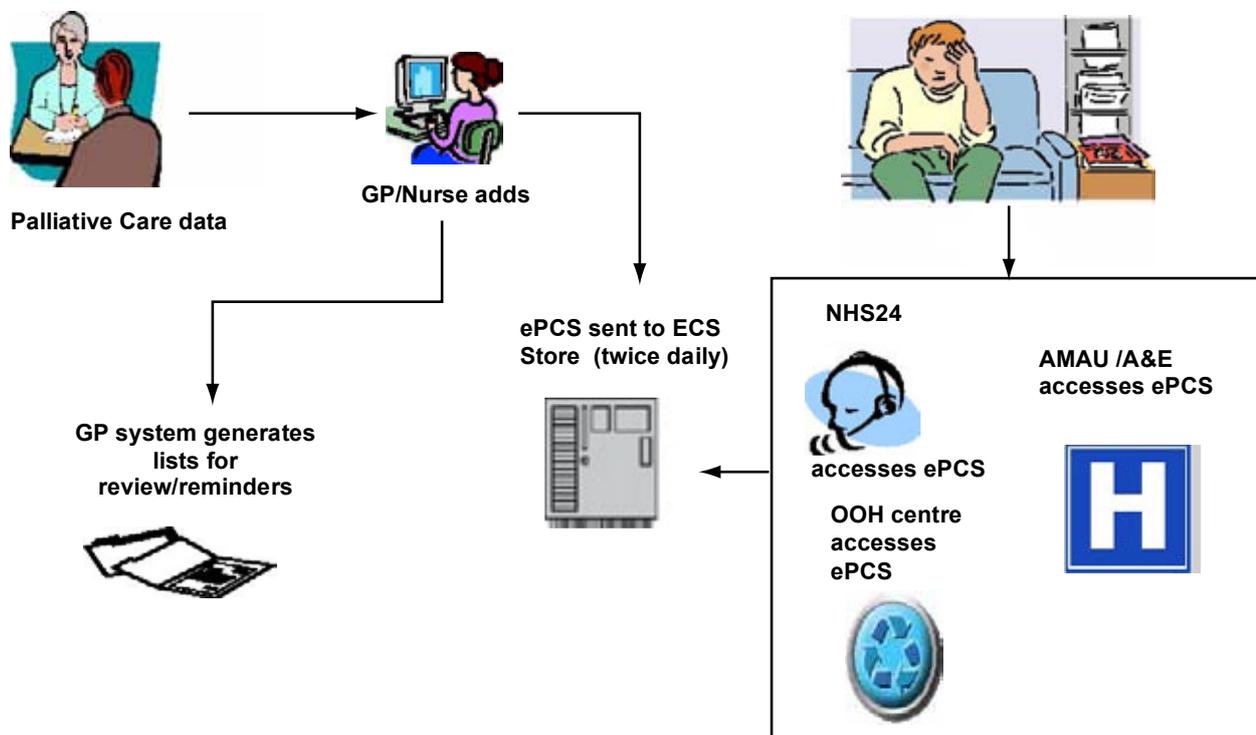
#### **Pilot phase complete – now starting rollout**

Following positive pilots in NHS Grampian, Lothian and Ayrshire & Arran, the ePCS is being rolled out Board-wide in Lothian starting September 2009 and will be rolled out nationally from late 2009 on a Board by Board basis.

#### **Using ePCS in the practice**

Practices will notice new software on their GP system which allows information on patients with palliative care needs to be recorded in one place, prompts to record patient’s wishes, prompts for Anticipatory Care and review dates. The system also produces patient lists for team meetings and helps fulfil the Palliative Care DES. Prior to Board-wide roll out, practices can use the ePCS locally i.e. without transmitting to ECS, as it gives prompts and helps to end users in OOH, NHS24 and A+E Departments.

## Patient consents to share How does ePCS work? electronic Palliative Care Summary (ePCS) Patient/Carer calls NHS24



## How will ePCS be seen in OOH?

Out of Hours access will be via NHS24 and for most boards will be via the Adastral OOH system. Adastral has also been adapted to include access to ePCS in cars to enable access for staff in remote areas or on call. For Out of Hours access in boards where Taycare is used, developments are underway and a timescale will be confirmed by NHS Tayside as soon as possible.

## What information is recorded and sent in ePCS?

Information will be recorded in the GP system to form an Anticipatory Care Plan which will be available OOH and includes:

- Prescribed Medication (all Repeat & last 30 days Acute) & Allergies as per ECS
- Medical Diagnoses – as agreed between GP and patient
- Patients and Carers' understanding of diagnosis and prognosis
- Patient wishes – e.g. Preferred Place of Care & resuscitation (DNA CPR)
- Information on medication/equipment left in patients' home, "Just In Case"

ePCS – Full Information sent from GP systems	
Date – Updated when sent to ECS	Date – Patient review Date
Patient & Carer Details	Patient's Own GP and Nurse
Review date	Usual GP name
Patient Surname	Nurse
Patient Forenames	Practice details
CHI Number	
Patient Address & Tel Number	
Carer Details	
Access Information / potential issues	
Next of kin details	
Patient Medical Condition	Current Care Arrangements
Main diagnoses	Care arrangements
Other relevant issues	Syringe driver at home
Allergies/Drug reactions	Catheter continence products at home
Current drugs and doses	Moving and Handling equipment at home
Additional drugs available at home	
Patient's and Carer's Awareness of Condition	Advice for Out Of Hours Care
Patient's understanding of Diagnosis	Care Plan agreed
Patient's understanding of Prognosis	Preferred place of care
Carer's understanding of Diagnosis	Should GP be contacted out of hours?
Carer's understanding of Prognosis	GP Home telephone/mobile/pager
	Resuscitation status agreed?
	Actual resuscitation status

For more information, including ePCS Patient Information Leaflets, and training materials see <http://www.ecs.scot.nhs.uk/epcs.html> and for more information on the national programme Living and Dying Well; see [www.scotland.gov.uk/livinganddyingwell](http://www.scotland.gov.uk/livinganddyingwell)

**Dr Peter Kiehlmann**, GP, Aberdeen and National Clinical Lead Palliative Care eHealth SGHD  
Email [peter.kiehlmann@scotland.gsi.gov.uk](mailto:peter.kiehlmann@scotland.gsi.gov.uk)

**Marysia Williamson** ePCS Project Manager, NSS, Edinburgh  
Email: [Marysia.williamson@nhs.net](mailto:Marysia.williamson@nhs.net)

## Appendix 2: Additional resources

- LTCC Community of Practice
- LTCC Shared Space
- Improvement and Support Team, Scottish Government
- LTCC/JIT – Improving Complex Care
- SPARRA Made Easy
- Proactive, Planned & Coordinated: Care Management in Scotland
- National Minimum Information Standards
  - Talking Points Personalised Outcomes approach
  - Community Care Outcomes Framework
- Living and Dying Well
  - Developments from Living and Dying Well Short Life Working Group 3
- CARE Measure
- GMC – Withholding and withdrawal of life-prolonging treatments ; Good practice in decision making
- Mental Welfare Commission – Legal and practical guidance on Covert Medication

### **A range of useful competencies can be found within existing frameworks:**

National Training Framework for Care Management (Circular CCD2/2006):

<http://www.scotland.gov.uk/Topics/Health/care/JointFuture/Publications/CCD0206>

Capable, Integrated and Fit for the Future

A Multiagency Capability Framework for Intermediate Care

[www.nes.scot.nhs.uk](http://www.nes.scot.nhs.uk)

[www.skillsforhealth.org.uk](http://www.skillsforhealth.org.uk)

- Spread and Sustainability
  - Spreading Improvement Across Your Health Care Organization Authors: Schall MW & Nolan KM (eds.) - Pub: Oakbrook Terrace, Illinois: Joint Commission Resources and the Institute for Healthcare Improvement; 2007
  - A Framework for Spread: From Local Improvements to System-Wide Change Pub: IHI, 2006



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ISBN: 978-0-7559-9213-3 (web only)

RR Donnelley B63344 3/10

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