

Dear Colleague

## **THE PRIMARY MEDICAL SERVICES DIRECTED ENHANCED SERVICES (SCOTLAND) 2012 PALLIATIVE CARE**

### **Summary**

1. This guidance summarises the arrangements for the new Palliative Care Directed Enhanced Service in Scotland which will come into effect from 1 April 2012. The DES Directions setting out the legal obligation on Health Boards, were issued under cover of circular [PCA2012\(M\) 04](#) and come into force on 1 April 2012.
2. This guidance replaces the previous Palliative Care guidance which was issued in November 2008. This DES will start on 1 April 2012 and will run on a year on year basis until further notice.
3. This circular also gives Directions to Health Boards on behalf of Scottish Ministers detailing the payment arrangements which must be made under the DES, **Annex A**

### **Rationale**

Palliative and end of life care are integral aspects of the care delivered by any Health or Social care professional to those living with and dying from any advanced, progressive or incurable condition. Palliative care is not just about care in the last months, days and hours of a person's life, but about ensuring quality of life for patients, their families and carers at every stage of the disease process from diagnosis onwards.

The Scottish Government published *Living Well and Dying Well, a national action plan for palliative and end of life care in Scotland* on 2 October 2008.

In keeping with this action plan, this DES supports practices in taking a systematic approach to Palliative and

Amended  
23 April 2012

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#### **Addresses**

##### For Action

Chief Executives NHS Boards  
Director of Practitioner Services  
Division, NHS National Services  
Scotland

PC Leads

##### For Information

GP Practices

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end of life care, to ensure that they identify appropriate patients for the Palliative care register and that these patients have electronic palliative care summaries completed and available in the out of hours period. This work is expected to be carried out within the context of the wider multidisciplinary team both within and outwith the practice.

## **Eligibility**

Participating practices must achieve the QOF Palliative Care clinical indicators, PC2 and PC3 (Annex H), and QOF indicator Records 13 . Practices must also have one or more palliative care patients on their registered list in order to be eligible to participate in the DES.

## **Requirements**

Participating practices will:

### **LEVEL 1 ACTIVITY**

1. Ensure that they include patients identified with Palliative and end of life care needs irrespective of diagnosis on their QOF Palliative care register.
2. Ensure that patients on the QOF Palliative care register have been assessed and that an initial care plan has been compiled and an electronic palliative care summary completed using the standardised Electronic Palliative Care Summary (ePCS) or equivalent where practices are not yet enabled to use ePCS. See guidance notes for standard for non ePCS record. The ePCS or equivalent should be completed and made available to professionals involved in the patient's care in the out of hour's period within 4 weeks of inclusion on the register.

### **LEVEL 2 ACTIVITY**

3. Engage in a programme of reflective practice involving the wider multidisciplinary team as described below:
  - The number of patients fulfilling the criteria in Table 1 below should be entered in the Level 2 report

Table 1

Practice population at 1 Oct 2012	Number of patients who died from Long Term Condition (LTC) 1.4.2012-31.3.2013	Number who died from cancer		Number who died from LTC other than cancer	
		Number on palliative care register	Number with ePCS or equivalent	Number on palliative care register	Number with ePCS or equivalent

4. From their total patient deaths during the year 2012/13, practices will be required to carry out 1 reflective practice (as detailed in section 18 of guidance) per 1000 patients on their practice list (with a minimum of 3, maximum 15). The maximum number for list sizes >15000 is 15. If the total number of eligible deaths is less than 1 per 1000 patients, then practices will be required to carry out a reflective practice on all such deaths. In addition, and to ensure that patients from all groups including cancer, non cancer long term conditions (LTC) and with or without an ePCS or equivalent are considered, the relevant numbers in table 2 should be applied. If all patients had an ePCS the overall total number should still apply

TABLE 2

Practice population at 1 Oct 2012	Total Number of SEAs required	Number with ePCS	Of which died of cancer	Number with no ePCS (if available)	Additional LTC patients
<6,000	5	2	1	2	1
6,000-6,999	6	3	1	3	
7,000-7,999	7	3	1	3	1
8,000-8,999	8	4	2	4	
9,000-9,999	9	4	2	4	1
10,000-10,999	10	5	2	5	
11,000-11,999	11	5	2	5	1
12,000-12,999	12	6	3	6	
13,000-13,999	13	6	3	6	1
14,000-14,999	14	7	3	7	
15,000-15,999	15	7	3	7	1

Current appraisal Significant Event Analysis (SEA) format (**Annex F**) to be used to allow the GP's to present the information as part of their appraisal.

Report of overall reflective activity to be completed using reporting template at **Annex G**

### **Reporting arrangements**

Information will be extracted or provide to the local NHS Board at the end of each year on the above criteria as described below

**LEVEL 1** ; An automatic data extraction for level 1 payment will be generated if using ePCS. A patient will be added to the palliative care register when a record is created in ePCS. Once the clinician is ready to send the care plan to out of hours the consent button must be ticked within 4 weeks of the patient being entered on the ePCS system.

If a practice decides not to use ePCS then codes will need to be entered manually into the record and searches created - SCIMP advise the following codes for entry in the patient clinical record :

- **Add a patient to the register - 9ke.** (Palliative care – enhanced services administration)
- **Record a palliative care plan is available for out of hours within 4 weeks - 9e02.** (Notification to primary care out of hours service of palliative care plan)

**LEVEL 2** activity: Reporting template including number of SEAs and summary of learning form SEAs (**Annex G**) to be submitted to relevant department in NHS Board by 31<sup>st</sup> May 2013.

### **Action.**

NHS Boards are asked to action this guidance and to bring this circular to the attention of all relevant staff and contractors.

Yours sincerely



FRANK STRANG  
Deputy Director, Primary Care Division

## Palliative Care Directed Enhanced Service: Guidance

### Rationale

1. The World Health Organisation (WHO) defined Palliative care in 2004 as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Planning for care at the end of life should be responsive to patient choice regarding their preferred place of care and place of death.
2. Palliative and end of life care are integral aspects of the care delivered by any health or social care professional to those living with and dying from any advanced, progressive or incurable condition. Palliative care is not just about care in the last months, days and hours of a person's life, but about ensuring quality of life for both patients and families at every stage of the disease process from diagnosis onwards. A Palliative care approach should be used as appropriate alongside active disease management from an early stage in the disease process. Palliative care focuses on the person, not the disease, and applies a holistic approach to meeting the physical, practical, functional, social, emotional and spiritual needs of patients and carers facing progressive illness and bereavement.
3. Patients in their last year of life have significantly higher numbers of emergency admissions and once admitted, generally stay in hospital for longer. There is evidence that by enabling patients to think ahead and anticipate some of the changes that might occur that Healthcare services can respond to meet changing needs in a safer, more effective and person centred way.
4. The Scottish Government published ***Living Well and Dying Well, a national action plan for palliative and end of life care in Scotland*** in October 2008, following their commitment in the *Better Health, Better Care* Action Plan 2007, and in line with the recommendations of *Palliative and end of life care in Scotland: the case for a cohesive approach*, the 2007 report from the Scottish Partnership for Palliative Care.
5. In keeping with this action plan and the developments that have come from its implementation, this DES supports practices to:
  - ensure that they identify appropriate patients for the Palliative Care register;
  - share assessed needs through anticipatory care plans with patients, those close to them and with Healthcare professionals who provide care both in hours and out of hours, especially when needs change;

- determine a patient's preferred place of end of life care and to seek to meet their wishes where possible; and
- To make a systematic approach to their end of life care.

This complements the guidance within the QOF and the recent guidance for doctors from the GMC on End of Life Treatment and Care. The link to the guidance is: [http://www.gmc-uk.org/guidance/ethical\\_guidance/6858.asp](http://www.gmc-uk.org/guidance/ethical_guidance/6858.asp).

6. The main causes of death in the UK (i.e. organ failure, cancer, dementia and/or frailty) are fairly evenly distributed and all can benefit from effective palliative and end of life care. However, the pattern of progression of advanced respiratory, cardiac or other organ failure will differ from that of cancer. End-stage cancer is likely to be characterised by a gradual and steady deterioration while end-stage respiratory disease may be characterised by acute exacerbations and remissions. End-stage cardiac disease may be similar but the risk of sudden death is greater. Understanding the differences between these trajectories can help in planning care more appropriately to meet patients' and carers' needs.
7. A Palliative care approach and the subsequent stepping up and stepping down to appropriate types and levels of care should be triggered at the initial diagnosis of a life-limiting condition, as well as at times of critical events and changes in disease progression. This will include:
  - holistic assessment, with the patient and carer, of their physical, social, emotional, cultural, religious and spiritual care needs and other relevant life circumstances;
  - planning, coordination and delivery of appropriate care based on the needs identified;
  - appropriate sharing and communication across all care settings of the needs, and plans identified and actions taken; and
  - Regular review and repetition of the assessment and planning cycle.

## Outline of the DES

This guidance is intended to support practices in meeting the requirements of this DES. Sections in the specification are highlighted in the boxed sections below followed by guidance notes.

### Eligibility

**Participating practices must achieve the QOF Palliative Care indicators, PC2 and PC3, and QOF indicator Records 13. Practices must also have one or more palliative care patients on their registered list in order to be eligible to participate in the DES.**

Practices should refer to the Guidance on these QOF indicators which are reproduced, in part, for convenience in **Annex H**.

8. Please note that practices with a null register at year end will be eligible for payment under PC3 if they are able to demonstrate that they had a Palliative care register during the year.

## Requirements

Participating practices are required to:

### LEVEL 1 ACTIVITY

**Ensure that they include patients identified with Palliative and end of life care needs irrespective of diagnosis on their QOF palliative care register.**

**Ensure that patients on the QOF Palliative care register have been assessed and a care plan compiled and an electronic palliative care summary (ePCS) or equivalent completed and made available to professionals involved in their care in the out of hours period within 4 weeks of inclusion on the register.**

9. The Palliative care register should include all patients with a life limiting condition, identified as having Palliative care and end of life care needs, not just those with cancer. The QOF guidance for PC3 gives guidance on how to decide whether a patient should be on the Palliative care register (**see Annex H**). In addition the tool at **Annex B** may assist identification of such patients.
10. Anticipatory care planning is at the core of good Palliative Care (Anticipatory Care Planning <http://www.scotland.gov.uk/Publications/2010/04/13104128/4> ). Pro-active care planning and management and the early management of symptoms can enhance the quality of life for patients and their carers and help to prevent crises and unscheduled hospital admissions. This should include the use of anticipatory prescribing, particularly for conditions such as advanced heart failure and COPD where sudden exacerbations are likely, and for end of life medication. Steps should be taken to ensure that patients living in care homes also have access to the benefits of this approach.
11. The information required for the patient's anticipatory care needs will be recorded in a standardised format in the electronic Palliative Care Summary (ePCS) or equivalent.
12. It is essential for high quality, coordinated care that Health professionals working in the out of hours period have information pertinent to the care of patients with Palliative and end of life care needs, with the patient's consent.
13. Some Boards have a dedicated Palliative Care Handover form and system already in place. In others some information is transferred to out of hours (OOH) services through each Board's "special notes" arrangement and the Board OOH service will ensure that the special note is then automatically and securely uploaded to NHS 24. This system has inherent weaknesses and the purpose of the level 1 activity in this DES is to maximise recording in the standardised format of the ePCS.

14. A national electronic Palliative Care Summary (ePCS) has been developed for Scotland and the roll out process began in June 2010 and all practices should have access to e PCS by 1<sup>st</sup> April 2012.
15. To recognise that the development of an anticipatory care plan may involve sensitive discussions over a period of time, this DES will be payable following the practice adding the patient to the Palliative Care Register and within four weeks of entry on the register, entering the following basic data on to ePCS
  - Relevant diagnosis
  - Indication that patient has consented to share information
  - Review date

For practices not yet enabled to use ePCS an equivalent form of communication /documentation should be used and must include as a minimum

- basic demographics (name, address, CHI number, contact telephone number)
- relevant drugs (the complete list can be accessed from ECS if necessary)
- relevant diagnoses
- indication that the patient has consented to sharing information
- review date

Evidence of non ePCS communication should be retained within the patient record for post payment verification purposes.

Details of the dataset contained in ePCS are shown in **Annex C** and a sample of an equivalent non ePCS proforma is shown at **Annex D**

16. It is recognised that further discussions, including patient and carer understanding of diagnosis and prognosis, preferred place of care, DNACPR status etc are critical aspects of the anticipatory care plan. However, these may be discussed quite appropriately later than four weeks after initially adding the patient to the Palliative Care Register. The ePCS or equivalent notes should be updated accordingly to share this, or any other new or changed information, with Out of Hours colleagues.

The ePCS can be used to create a list of patients needing review at practice Palliative care meetings etc by searching for those whose review is due. These lists can also prompt which conversations/referrals need to be considered for each patient.

## **LEVEL 2 ACTIVITY**

**Engage within wider multidisciplinary team in reflective practice**



18. Key areas recognised as delivering high quality palliative care and that should be considered in the reflective practice include

- **Identification of patients with non-malignant illness who have palliative care needs?**

Do you find this difficult? Did the attached guidance in Annex H or SPICT help (annex B)?

- **Expected or unexpected death**

If any of your patients who died from a LTC in the past year were not on your palliative care register then

- consider the reasons for this
- Could it have been predicted by using the guidance in Annex H or SPICT annex B ?

- **ePCS or equivalent**

If any of your patients who died from a LTC in the past year did not have an ePCS then

- consider the reasons for this
- Would it have been helpful?

- **Do Not Attempt Cardiopulmonary Resuscitation (DNA CPR) status**

If any of your patients who died from a LTC in the past year did not have DNACPR discussed then

- consider the reasons for this
- Would it have been helpful?

- **Preferred place of care/death**

How often was this discussed and if so were the patients wishes honoured?

- **Use of end of life care pathways**

If any of your patients who died from a LTC at home or in a care home in the past year were not on an end of life care pathway then

- consider the reasons for this
- Would it have been helpful?

## **Use of End of Life Care Pathways**

During the last days of life, care is necessarily more intensive so implementation of an integrated care pathway such as the Liverpool Care Pathway for the Dying Patient (LCP) can facilitate effective planning and provision of appropriate care during this dying process. *Living and Dying Well* makes a recommendation that the LCP should be implemented across all care settings with the support of education and training from NES and NHS Boards.

Key Sections of the LCP are

- Initial Assessment
- Ongoing Assessment
- Care after death

The LCP provides guidance on aspects of care including:

- Symptom Control
- Comfort measures
- Anticipatory prescribing of medication
- Discontinuation of inappropriate interventions
- Psychological and spiritual care
- Care of the family (both before and after the death of the patient)

More information about the Liverpool Care Pathway is available through the link:

<http://www.liv.ac.uk/mcpcil/liverpool-care-pathway/>

19. It is recognised that not all practices will have had access to the support and training recommended for implementation of the LCP. To help practices deliver consistent and high quality care to dying patients in such circumstances an End of Life Care Check list has been compiled summarising the essential elements of good end of life care. See **Annex E**.

## Reporting arrangements

<b>Level 1 reporting will be done by automatic data extraction. Level 2 reporting will take the form of a report to their local NHS Board at year end on the above criteria. (Attached at Annex G).</b>
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20. Practices are required to collect information on patients they enter on their Palliative Care register on or after 19<sup>th</sup> March 2012 and up to and including 18<sup>th</sup> March 2013.

## References

**Living and Dying Well - a national action plan for palliative and end of life care in Scotland**, The Scottish Government, Edinburgh 2008. Available at <http://www.scotland.gov.uk/Publications/2008/10/01091608/0>

**Illness trajectories and palliative care.** Murray, S; Kendall, M; Boyd, K; Sheikh, A. BMJ 2005; 330; 1007-1011. doi:10.1136/bmj.330.7498.1007-1011

**Gold Standards Framework:** <http://www.goldstandardsframework.nhs.uk/>

## **Payment Arrangements – Directions to Health Boards**

## **Annex A**

The Scottish Ministers give the following Directions to Health Boards. Contractors and Providers who have entered into an arrangement with a Health Board in terms of Palliative Care Scheme in the Primary Medical Services (Directed Enhanced Services) (Scotland) Directions 2012 (“DES Directions 2012”) are:

GP practices will be paid for completion of the numbered criteria as follows:

Level 1 activity - £ 68 per completion of ePCS or equivalent no cap applied

Level 2 activity - £250 per practice for administration and infrastructure costs and thereafter £58 per reflective practice carried out up to a maximum total of 15 at a maximum rate of 1 per 1000 registered patients

A **Level 1** payment will follow automatic data extraction. Practices must submit a printed version of the reflective practice template/ learning report for **level 2** payment **Annex G**. No patient identifiable information should be included.

### **Duration**

This DES will be funded in the first instance for one year from 1 April 2012. Payments will be made on an arrears quarterly basis.

### **Payment Verification**

Prior to issuing payments in accordance with the above paragraph, Health Boards must require contractors and providers who have entered into an arrangement with a Health Board in terms of the Palliative Care Scheme in the DES Directions 2012 to sign a declaration to confirm that they are meeting the requirements of the DES Directions 2012.



## Identifying patients for supportive and palliative care



### Supportive & Palliative Care Indicators Tool

#### 1. Ask

Would it be a surprise if this patient died in the next 6-12 months?

No

#### 2. Look for two or more general clinical indicators

Performance status poor (limited self care; in bed or chair over 50% of the day) or deteriorating.

Progressive weight loss (>10%) over the past 6 months.

Two or more unplanned admissions in the past 6 months.

A new diagnosis of a progressive, life limiting illness.

Two or more advanced or complex conditions (multi-morbidity).

Patient is in a nursing care home or NHS continuing care unit; or needs more care at home.

#### 3. Now look for two or more disease related indicators

##### Heart disease

NYHA Class III/IV heart failure, severe valve disease or extensive coronary artery disease.

Breathless or chest pain at rest or on minimal exertion.

Persistent symptoms despite optimal tolerated therapy.

Systolic blood pressure < 100mmHg and /or pulse > 100.

Renal impairment (eGFR < 30 ml/min).

Cardiac cachexia.

Two or more acute episodes needing intravenous therapy in past 6 months.

##### Kidney disease

Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min).

Conservative kidney management due to multi-morbidity.

Deteriorating on renal replacement therapy with persistent symptoms and/or increasing dependency.

Not starting dialysis following failure of a renal transplant.

New life limiting condition or kidney failure as a complication of another condition or treatment.

##### Respiratory disease

Severe airways obstruction (FEV1 < 30%) or restrictive deficit (vital capacity < 60%, transfer factor < 40%).

Meets criteria for long term oxygen therapy (PaO2 < 7.3 kPa).

Breathless at rest or on minimal exertion between exacerbations.

Persistent severe symptoms despite optimal tolerated therapy.

Symptomatic right heart failure.

Low body mass index (< 21).

More emergency admissions (> 3) for infective exacerbations or respiratory failure in past year.

##### Liver disease

Advanced cirrhosis with one or more complications:

- intractable ascites
- hepatic encephalopathy
- hepatorenal syndrome
- bacterial peritonitis
- recurrent variceal bleeds

Serum albumin < 25g/l and prothrombin time raised or INR prolonged (INR > 2).

Hepatocellular carcinoma.

Not fit for liver transplant.

##### Cancer

Performance status deteriorating due to metastatic cancer and/ or co-morbidities.

Persistent symptoms despite optimal palliative oncology treatment or too frail for oncology treatment.

##### Neurological disease

Progressive deterioration in physical and/or cognitive function despite optimal therapy.

Symptoms which are complex and difficult to control.

Speech problems with increasing difficulty communicating and/or progressive dysphagia.

Recurrent aspiration pneumonia; breathless or respiratory failure.

##### Dementia

Unable to dress, walk or eat without assistance; unable to communicate meaningfully.

Worsening eating problems (dysphagia or dementia related) - now needing pureed/ soft diet or supplements.

Recurrent febrile episodes or infections; aspiration pneumonia.

Urinary and faecal incontinence.

#### 4. Assess patient & family for supportive & palliative care needs. Review treatment/ medication. Plan care. Consider patient for general practice palliative care register.

SPiCT Version 12, December 2010

## Electronic Palliative Care Summary

Patient & Carer Details	Section 1	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 Info/potential issues		
Next of kin details		
<b>Section 2 Patient medical Condition</b>		
Main diagnoses		
Other relevant issues		
Allergies/Drug reactions		
Current drugs and doses		
Additional drugs available at home		
<b>Section 3 Current Care Arrangements</b>		
Care arrangements		
Syringe driver at home		
Catheter continence prods at home		
Move & Hand equip at home		
<b>Section 4 Patient's and Carer's Awareness of Condition</b>		
Patient's understanding of Diagnosis		
Patient's understanding of Prognosis		
Carer's understanding of Diagnosis		
Carer's understanding of Prognosis		
<b>Section 5 Advice for Out Of Hours Care</b>		
Care Plan agreed		
Preferred place of care		
Should GP be contacted OOH?		
GP Home tel/mobile/pager		
Resuscitation status agreed		
Actual resuscitation status		
GP sign death cert in normal circumstances		
Additional useful OOH information		

## PALLIATIVE ANTICIPATORY CARE PLAN

<b>Patient's Name:</b>  <b>Address:</b>  <b>Date of Birth/CHI:</b>  <b>Tel No:</b>  <b>Access issues? Yes <input type="checkbox"/> No <input type="checkbox"/></b> <b>Details:</b>	<b>Main Carer:</b> <b>Relationship:</b> <b>Carer Tel No:</b> <b>District Nurse:</b> <b>Care Manager: DN <input type="checkbox"/> Other <input type="checkbox"/></b> <b>Clinical Nurse Specialist:</b> <b>General Practitioner:</b> <b>Practice:</b>  <b>Contact GP OOH? Yes <input type="checkbox"/> No <input type="checkbox"/></b> <b>GP Home Tel/Mobile/Pager:</b>
<b>SITUATION – current situation</b> <b>Main Diagnosis &amp; Date of onset:</b> <b>What is the patient's understanding of</b> <ul style="list-style-type: none"> <li>Diagnosis?</li> <li>Prognosis?</li> </ul> <b>What is the carer's understanding of</b> <ul style="list-style-type: none"> <li>Diagnosis?</li> <li>Prognosis?</li> </ul>	
<b>BACKGROUND – other relevant issues including social care and significant medical history</b> <b>Care package in place? Yes <input type="checkbox"/> No <input type="checkbox"/> Details:</b> <b>DS1500 completed? Yes <input type="checkbox"/> No <input type="checkbox"/></b> <b>Carer issues (capability, age, medical problems)?:</b> <b>Relevant past medical history:</b>	
<b>ASSESSMENT – current problems and their management</b> <b>Relevant problems and management:</b> <b>End of Life Care Pathway? Yes <input type="checkbox"/> (Date commenced ) No <input type="checkbox"/></b> <b>Relevant drugs (eg analgesics, anti-emetics, breakthrough analgesia), doses and allergies:</b> <b>Yes – <input type="checkbox"/> (please specify)      None <input type="checkbox"/></b> <b>If oral medication: Manage own <input type="checkbox"/> Dosset/compliance aid <input type="checkbox"/> Reliant on carers <input type="checkbox"/></b> <b>Palliative Care Kardex completed? Yes <input type="checkbox"/> No <input type="checkbox"/></b> <b>Syringe driver in use? Yes <input type="checkbox"/> No <input type="checkbox"/></b>	
<b>RECOMMENDATIONS – anticipated problems/deterioration and planned management</b> <b>Anticipated problems and planned management:</b> <b>Patient has self management plan: COPD <input type="checkbox"/> Crisis medication <input type="checkbox"/> Other (specify)</b> <b>OOH Palliative care phone number and leaflet given to patient? (appropriate if patient's condition changing and OOH help likely to be required) Yes <input type="checkbox"/> No <input type="checkbox"/></b> <b>PRN Chart completed? Yes <input type="checkbox"/> No <input type="checkbox"/></b> <b>Palliative care drug box in home? Yes <input type="checkbox"/> No <input type="checkbox"/></b> <b>Catheter/continence products in home? Yes <input type="checkbox"/> No <input type="checkbox"/></b> <b>Moving and handling equipment in home? Yes <input type="checkbox"/> No <input type="checkbox"/></b> <b>Patient's preferred place of end of life or crisis care:</b> Home <input type="checkbox"/> Nursing Home <input type="checkbox"/> Community Hospital <input type="checkbox"/> Hospital <input type="checkbox"/> <b>If admission necessary, please admit to</b> <b>Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) form completed?</b> Yes <input type="checkbox"/> (Location ) No <input type="checkbox"/> N/A <input type="checkbox"/> <b>Adults with Incapacity (Scotland) Act form completed? Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/></b>	
<b>AGREEMENT – with patient / family / carer</b> <b>Summary of discussion</b> <b>Patient agrees with plan and gives consent to share it with relevant others: Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/></b> <b>Family/carers agree with plan and gives consent to share it with relevant others: Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/></b>	
<b>Form completed by</b> <b>Name:</b> <b>Date:</b>	<b>Job title: District Nurse</b> <b>Revision due:</b>

**1. ESTABLISH THAT THE PATIENT IS DYING**

- All possible reversible causes for the current condition of the patient have been considered and
- the multi professional team has agreed that the patient is dying

**2. INITIAL ASSESSMENT****(a) Communication with patient**

- Assess communication barriers and patient's capacity
- Assess patient's wishes, feelings, faith, belief values
- Confirm patient is aware he or she is dying

**(b) Communication with relatives**

- Assess barriers
- Ensure relative is aware patient is dying
- Record contact information
- Assess relative's wishes, feelings, faith, belief values

**(c) Anticipatory prescribing/medication for 5 key symptoms**

- Pain
- Agitation
- Respiratory tract secretions
- Nausea/vomiting
- Breathlessness

**(d) Syringe driver, drugs and equipment available****(e) Interventions no longer appropriate are stopped**

- Medication, vital signs monitoring, investigations
- DNACPR form completed
- Implantable defibrillator deactivated

**(f) Hydration and nutrition**

- The need for clinically assisted (artificial) hydration and nutrition is reviewed by the team

**(g) Explanation of current care plan**

- Patient
- Relative or carer

**3. REGULAR ASSESSMENT****(a) Patient**

- Symptoms: pain, agitation, respiratory tract secretions, nausea/vomiting, breathlessness
- Physical care needs: urinary and bowel problems, skin care, mouth care, personal hygiene, fluids to support individual needs
- Psychological wellbeing including spiritual, religious and cultural needs

**(b) Carer**

- Psychological wellbeing including spiritual, religious and cultural needs



#### **4. AFTER DEATH**

- Relative or carer is given information and understands what to do next
- Patient's death communicated to appropriate services

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## Sample Report Form: Significant Event Analysis

Date of significant event meeting:

Date report compiled:

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### 1.1 What happened?

1.1.1 (Describe what actually happened in detail. Consider, for instance, how it happened, where it happened, who was involved and what the impact or potential impact was on the patient, the team, organisation and/or others).

In particular for Palliative Care DES purposes consider the following information

- Diagnosis
- Sudden /unexpected death
- ePCS or equivalent
- DNA CPR Recorded
- Preferred place of care /death
- ICP end of life pathway used

### 1.2 Why did it happen?

1.2.1 (Describe the main and underlying reasons – positive and negative – contributing to why the event happened. Consider, for instance, the professionalism of the team, the lack of a system or a failing in a system, lack of knowledge or the complexity and uncertainty associated with the event).

### 1.3 What have you learned?

1.3.1 (Demonstrate that reflection and learning have taken place on an individual or team basis and that relevant team members have been involved in the analysis of the event. Consider, for instance: a lack of education & training; the need to follow systems or procedures; the vital importance of team working or effective communication).

### 1.4 What have you changed?

1.4.1 (Outline the action(s) agreed and implemented, where this is relevant or feasible. Consider, for instance: if a protocol has been amended, updated or introduced; how was this done and who was involved; how will this change be monitored. It is also good practice to attach any documentary evidence of change e.g. a letter of apology to a patient or a new protocol).

**Palliative Care: Reporting Template 2012-13 for level 2 activity****PALLIATIVE CARE DES LEVEL 2 ACTIVITY – PRACTICE REPORT****Practice Name and Code:****Date of reflective practice meeting:****Attendees:****Please enter the appropriate numbers of patients in the boxes below**

Practice population at 1 Oct 2012	Number who died from cancer 1.4.2012-31.3.2013		Number who died from LTC other than cancer 1.4.2012-31.3.2013	
Number of SEAs completed	Number on palliative care register	Number with ePCS or equivalent	Number on palliative care register	Number with ePCS or equivalent

**1. Examining the care of the patients who died, under the following headings, are there emerging themes of note under any of the headings**

- Identification of patients with non-malignant illness who have palliative care needs?**

Do you find this difficult? Did the attached guidance in Annex B or SPICT help?

- Expected or unexpected death**

If any of your patients who died from a LTC in the past year were not on your palliative care register then

- consider the reasons for this
- Could it have been predicted by using the guidance in Annex B or SPICT?

- ePCS or equivalent**

If any of your patients who died from a LTC in the past year did not have an ePCS then

- consider the reasons for this

- Would it have been helpful?
  
- **Do Not Attempt Cardiopulmonary Resuscitation (DNA CPR) status**  
 If any of your patients who died from a LTC in the past year did not have DNACPR discussed then
  - consider the reasons for this
  - Would it have been helpful?
  
- **Preferred place of care/death**  
 How often was this discussed and if so were the patients wishes honoured?
  
- **Use of end of life care pathways**  
 If any of your patients who died from a LTC at home or in a care home in the past year were not on an end of life care pathway then
  - consider the reasons for this
  - Would it have been helpful?

**2. List 3 (or more) Learning Points for the Practice as a whole or individuals**

**3. What does the Practice intend to do to implement these learning points?**

**4. What needs to happen within your NHS Board area to support and improve the care of patients with palliative care needs? E.g. communication with secondary care, additional access to other services, guidelines, training, IT etc.**

# Palliative care (PC)

## Annex H

Indicator	Points	Payment stages
<b>Records</b>		
PC3. The practice has a complete register available of all patients in need of palliative care/support irrespective of age	3	
<b>Ongoing management</b>		
PC2. The practice has regular (at least 3 monthly) multidisciplinary case review meetings where all patients on the palliative care register are discussed	3	

## Palliative care – rationale for inclusion of indicator set

Palliative care is the active total care of patients with life-limiting disease and their families by a multi-professional team. The first National End of Life Care (EOLC) Strategy was published in July 2008. It builds on work such as the NHS cancer plan 2000, NICE guidance 2004 and NHS EOLC programme 2005.

In Scotland, “Living and Dying Well, a national action plan for palliative and end of life care in Scotland”<sup>1</sup> places great emphasis on the role of primary care in providing palliative care for all patients with such needs, regardless of diagnosis. The action plan uses the concepts of planning and delivery of care, and of communication and information sharing as a framework to support a person centred approach to delivering consistent palliative and end of life care in Scotland.

The way primary care teams provide palliative care in the last months of life has changed and developed extensively in recent years with:

- over 99 per cent of practices now using a palliative care register since the introduction of this indicator set
- specific emphasis on the inclusion of patients with non-malignant disease and of all ages since April 2008
- patients and carers being offered more choice regarding their priorities and preferences for care including their preferred place of care in the last days of life (evidence shows that more patients achieve a home death if they have expressed a wish to do so)

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<sup>1</sup> Living and Dying Well, a national action plan for palliative and end of life care in Scotland (2008). <http://www.scotland.gov.uk/Publications/2008/10/01091608/0>

- increasing use of anticipatory prescribing to enable rapid control of symptoms if needed and a protocol or integrated care pathway for the final days of life
- identification of areas needing improvement by the NAO e.g. unnecessary hospital admissions during the last months of life

The National EOLC Strategy and “Living and Dying Well” suggest that all practices should adopt a systematic approach to end of life care and work to develop measures and markers of good care. They recommend the Gold Standards Framework (GSF) and the associated After Death Analysis (ADA) as examples of good practice. Evidence suggests that over 60 per cent of practices across the UK now use GSF to some degree to improve provision of palliative care by their primary care team.

The introduction of the GSF to primary care and its associated audit tool, the ADA, are associated with a considerable degree of research and evaluation. The GSF provides ideas and tools that help practices to focus on implementing high quality patient-centred care. <http://www.goldstandardsframework.org.uk/>

## Palliative care (PC) indicator 3

The practice has a complete register available of all patients in need of palliative care/support irrespective of age.

### Palliative care 3.1 Rationale

About one per cent of the population in the UK die each year (over half a million), with an average of 20 deaths per GP per year. A quarter of all deaths are due to cancer, a third from organ failure, a third from frailty or dementia, and only one twelfth of patients have a sudden death. It should be possible therefore to predict the majority of deaths, however, this is difficult and errors occur 30 per cent of the time. Two-thirds of errors are based on over optimism and one third on over pessimism. However, the considerable benefits of identifying these patients include providing the best health and social care to both patients and families and avoiding crises, by prioritising them and anticipating need.

**Identifying** patients in need of palliative care, **assessing** their needs and preferences and proactively **planning** their care, are the key steps in the provision of high quality care at the end of life in general practice. This indicator set is focused on the maintenance of a register (identifying the patients) and on regular multidisciplinary meetings where the team can ensure that all aspects of a patient's care have been assessed and future care can be co-ordinated and planned proactively<sup>2</sup>.

A patient should be included on the register if any of the following apply:

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<sup>2</sup> NAO End of Life Care report (November 2008). ‘In one PCT 40 per cent of patients who died in hospital in October 2007 did not have medical needs which required them to be treated in hospital, and nearly a quarter of these had been in hospital for over a month’

1. Their death in the next 12 months can be reasonably predicted (rather than trying to predict, clinicians often find it easier to ask themselves ‘the surprise question’ – ‘Would I be surprised if this patient were still alive in 12 months?’)
2. They have advanced or irreversible disease and clinical indicators of progressive deterioration and thereby a need for palliative care e.g. they have one core and one disease specific indicator in accordance with the GSF Prognostic Indicators Guidance (see QOF section of GSF website<sup>3</sup>).
3. They are entitled to a DS 1500 form (the DS 1500 form is designed to speed up the payment of financial benefits and can be issued when a patient is considered to be approaching the terminal stage of their illness. For these purposes, a patient is considered as terminally ill if they are suffering from a progressive disease and are not expected to live longer than six months)

The register applies to all patients fulfilling the criteria regardless of age or diagnosis. The creation of a register will not in itself improve care but it enables the wider practice team to provide more appropriate and patient focussed care.

### **Palliative care 3.2 Reporting and verification**

The practice reports the number of patients on its palliative care register.

Verification – in the rare case of a nil register at year end, if a practice can demonstrate that it had a register in year then it will be eligible for payment.

## **Palliative care indicator 2**

The practice has regular (at least 3 monthly) multidisciplinary case review meetings where all patients on the palliative care register are discussed.

### **Palliative care 2.1 Rationale**

The QOF monitors occurrence of the multi-disciplinary meetings but it is up to the practice to ensure the meetings are effective. The aims of the meetings are to:

- ensure all aspects of the patients care have been considered (this should then be documented in the patients notes)
- improve communication within the team and with other organisations (e.g. care home, hospital, community nurse specialist) and particularly improve handover of information to out of hours services
- co-ordinate each patient’s management plan ensuring the most appropriate member of the team takes any action, avoiding duplication
- ensure patients are sensitively enabled to express their preferences and priorities for care, including preferred place of care
- ensure that the information and support needs of carers are discussed, anticipated and addressed where ever reasonably possible.

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<sup>3</sup> <http://www.goldstandardsframework.org.uk/>

Many practices find use of a checklist during the meeting helpful, as it helps to ensure all aspects of care are covered e.g. supportive care register (SCR) templates SCR1 and 2 and the assessment tools on the GSF website.

Scottish practices have access to the Electronic Palliative Care Summary (or equivalent as described in annex D of the Palliative Care DES) that can be used as a template for this indicator.

### **Palliative care 2.2 Reporting and verification**

The practice should submit written evidence to the PCO describing the system for initiating and recording meetings.