Palliative Care Funding Pilots 2012/14

Expression of Interest: Supporting Notes

DH INFORMATION READER BOX

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HR / Workforce	Commissioning
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Description	This document invites expressions of interest from organisations wishing to apply to be Palliative Care Funding pilot sites
Cross Ref	Palliative Care Funding Review final report
Superseded Docs	N/A
Action Required	Organisations wishing to apply to be Palliative Care Funding pilot sites are invited to complete and return applications by 31 January 2012
Timing	**By 31 Jan 2012**
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For Recipient's Use	

Contents

Palliative Care Funding Pilots 2012/14

Expression of Interest: Supporting Notes.

Call for Pilots: (24 month duration)

The Department of Health is seeking to set up a number of pilot sites to gather the information needed to inform decisions on the creation of a new funding system for palliative care, for adults and children, and to consider the proposals of the independent Palliative Care Funding Review Report. A copy of the report is available here.

Deadline
The deadline for submissions of interest by completing the attached proforma is **31 January 2012.** Successful pilots will be notified in March 2012. The pilot programme will begin in April 2012.

Background
The final report of the independent Palliative Care Funding Review was published in July 2011. It set out a series of recommendations designed to create a fair and transparent funding system for palliative care, which delivers better outcomes for patients and provides better value for the NHS. It recommended that a number of pilots be set up to collect data and refine its proposals due to the lack of good quality data currently available.

The pilots are intended to:

- **Collect the data** and information needed to support the development of a new NHS per-patient tariff for palliative care, which is ready for implementation in 2015. This includes:
  - Data collected to inform the development and refinement of a **classification system** categorising palliative patients according to level of need
  - Data to **attach resource use/ costs** to each of the levels of need in the classification system, which will support the tariff development

- **Inform the creation of a funding mechanism** that is fair to all sectors, encourages the development of community based palliative care services, supports the exercise of choice by care users of provider and of location of palliative care provision and provides value for money to the state

Aim of the pilots

Our intention through the pilots is to gather sufficient data in order to form an understanding of the national picture for palliative care resource use and associated costs. Our estimate is that we will need to capture **at least 5,000 palliative care episodes*** (see definition below) for adults, with numbers split evenly across inpatient and community settings.

For children we expect to need a similar number of **palliative care episodes*** but we recognise that there will be a significant challenge in capturing these numbers in smaller local pilots so **we will work with experts and national organisations to consider how best we build on one or two pilots to create a national picture.**

We anticipate needing no more than 10 pilots in total (covering both adults and children).

Across all the pilot sites we will be looking to ensure we reach a balance between many elements, including geographical spread, urban/rural locations, diagnosis/condition, socio-economic status and ethnic mix.

***The palliative care episode** in the context of the Palliative Care Funding pilots is defined as **each period of contact between a patient and a palliative care service provider or team of providers that occurs in one setting**. This may be a stay in hospital or a hospice, or a period of care by a community provider in the patients' own home or care home. Whenever the patient moves to a different location, a new episode is initiated. A palliative care episode commences at the start of palliative care involvement with a patient and finishes when the patient moves to a different location or is discharged from palliative care. For children, our initial thinking is that a new episode may also be triggered by a change in problem severity sufficient to require significant revision of the care plan and corresponding care provision, even if this occurs in the same setting.

What information and data will the pilots be collecting?

Palliative care is an emerging field, and models for funding it are still being developed.

The Palliative Care Funding Review was asked to develop a per-patient funding mechanism for palliative care for adults and children in England. It identified that the first step in doing this is to understand patient needs by developing a patient classification system that organises patients based on characteristics of care needs and similarity in resource use.

The cost drivers in acute care (which are largely based on diagnosis and procedures, and which are the main determinants of the current Payment by Results system) do not work well for palliative care. This is why the pilots will seek to understand which criteria work best to predict needs in palliative care

The review identified the main criterion for shaping palliative care needs **as phase of illness** (stable, unstable, deteriorating and dying). **See Annex 1 for refined definitions of the phases.** The phase of illness can further be combined with other main cost drivers (provider type, problem severity, functional status and age), which would allow for further refinement of the classification system going forward. We envisage that for accuracy and ease of use, the system would need to be different for adults and children.

The Department, in collaboration with the Cicely Saunders Institute at Kings College London (KCL), is developing a draft classification system and defined dataset for collection by the pilots based on the work of the review, which will be further evolved through the pilots in order to deliver the tariff. **A draft example dataset is provided in Annex 2.**

The data which will be collected in the pilots can be divided into three main categories:

- **Demographic and diagnostic data**
- **Needs and complexity data**
- **Resource use data**

The detailed proposals for how these items will be collected in practice are set out below.

Demographic and diagnostic data
The demographic and diagnostic information for each patient, (for example age, diagnosis and referral date), will be collected once at the start of the palliative care episode, with a few additional items collected at the end of the episode. This information is likely to be already collected by services, but will need to be effectively accessed and extracted for the purposes of the pilot.

Needs and complexity data
The needs and complexity data for each patient (phase of illness, problem severity, functional level) is collected at the start and end of an episode, as well as at any change in phase of illness. This information will be collected by the clinician seeing the patient.

Resource use data
The resource use/ cost data is collected at the end of an episode, as well as at any phase change. This data is of a different nature to the demographic, diagnostic and needs and complexity data, and will be collected using a different methodology. A brief measure will be provided to pilot sites, and for a smaller number of episodes providers will need to work with the Department of Health and KCL staff to provide more detailed costing information.

In addition, a time tracker tool will need to be filled in on a daily basis, capturing the phase of illness which the patient is in. This will ensure that any change in phase of illness is captured and recorded. This tool acts as a sense

check for the use and definitions of the phases of illness, as well as a prompt to the pilot sites to fill in the required data at each of the phase changes. **A copy of the proposed time tracker developed by the KCL team is included in Annex 3.**

Based on this breakdown, the process for collection of these different types of data is illustrated in the figure below:
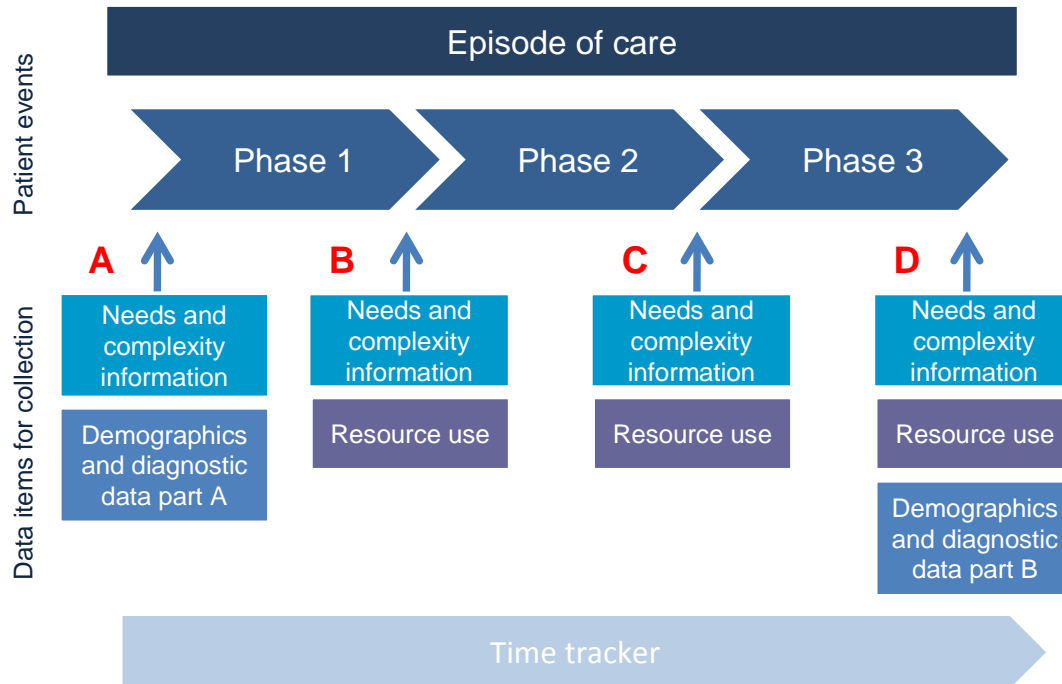
We are currently working on developing a solution for capturing the data. This may be software based or it may be a paper and scan solution. The system will be designed to minimise the work of data handling and entry, yet to be flexible enough to accommodate all services and settings.

Case study A – Hospital inpatient episode

Mr A is admitted to hospital due to complications from his lung cancer. During his stay, the lung cancer specialist identifies that Mr A has palliative care needs, and he is therefore referred to the hospital specialist palliative care team. The specialist palliative care consultant visits Mr A in the cancer ward, triggering the start of the palliative care episode. At this point, the specialist palliative care team collect Mr A's personal details (name, address, age etc), his diagnostic information (diagnosis, co-morbidities etc), as well as his needs and complexity data (phase of illness, problem severity, functional status etc). **Point A on the diagram.**

At the time of the first contact, Mr A is identified as being in a stable phase. The team draw up a palliative care plan. Using the time tracker, the staff monitor his phase status each day.

As Mr A's symptoms are under control, the decision is made to discharge him to his own home, triggering the end of that episode of care. Around discharge, the specialist palliative care team record any change in Mr A's demographic and diagnostic information, details of the episode end, as well as his needs and complexity data and his resource use during the phase and episode **Point D on the diagram.** Mr A is discharged into the care of a palliative care community nursing team, triggering the start of a new episode of care.

Case study B – Hospice inpatient episode

Mrs B is identified by her GP as having a palliative care need, and is referred to her local hospice. Mrs B is admitted to the hospice, triggering the start of the palliative care episode. At this point, the hospice staff collect Mrs B's personal details (name, address, age etc) her diagnostic information (diagnosis, co-morbidities etc), as well as her needs and complexity data (phase of illness, problem severity, functional status etc). **Point A on the diagram.**

At admission, Mrs B is identified as being in an unstable phase. The hospice draws up a palliative care plan. Using the time tracker, the staff monitor her phase status each day. After a week, the staff identify that Mrs B is no longer unstable but is now in a stable phase, triggering the end of one phase of care and the start of another. The hospice staff record her needs and complexity data again at the time of the phase change, and record Mrs B's resource use so far in relation to the finished unstable phase (using the brief measure of resource use provided). **Point B on the diagram.**

As Mrs B's symptoms are now under control, the decision is made to discharge her to her own home, triggering the end of that episode of care. The specialist palliative care team record any change in Mrs B's demographics and diagnostic information, details of the episode end, as well as her needs and complexity data and her resource use during the new stable phase as well as the finished episode of care. **Point D on the diagram.** Mrs B is discharged into the care of a palliative care community nursing team, triggering the start of a new episode of care.

Case study C – Community care episode

Mrs C is identified by her GP as having palliative care needs, and is referred to the local palliative care community nursing team. A specialist palliative care nurse visits Mrs C's in her home, triggering the start of a palliative care episode in the community. At this point, the nursing staff collect Mrs C's personal details (name, address, age etc) her diagnostic information (diagnosis, co-morbidities etc), as well as her needs and complexity data (phase of illness, problem severity, functional status etc). **Point A on the diagram.**

At the first contact, Mrs C is identified as being in a deteriorating phase. The community team draw up a palliative care plan. Using the time tracker, the staff monitor her phase status each day. After three weeks, the staff identify that Mrs C is no longer deteriorating, but has entered the dying phase, triggering the end of one phase of care and the start of another. The community staff record her needs and complexity data again at the time of the phase change, and record her resource use so far for the finished deteriorating phase. **Point B on the diagram.**

After a few days, Mrs C's passes away, leading to the end of the episode of care. The community palliative care team record details of the episode end, as well as her needs and complexity data and her resource use during the dying phase as well as the finished episode of care. **Point D on the diagram.**

What are we looking for from pilot site applications?

Whilst the aim is to create NHS tariffs for palliative care, which are applicable to people of all ages, we anticipate that we will need separate pilot sites for adults and children.

Applications to be a pilot site will be measured on the following criteria;

For adult sites –
- Pilots will collect data on all palliative care patients over 18yrs old
- We are aiming for pilot sites to collect around 1,000 palliative care episodes* over an 18 month period across both acute and community settings. As an absolute minimum pilot sites need to be able to collect 500 palliative care episodes* in this timeframe. The split between settings does not need to be 50/50 but you should specify how many episodes of care you anticipate collecting over this time period within each organisation involved in your bid

For children and young people sites –
- Pilots will collect data on all palliative care patients from 0-24yrs (in order to capture transition)
- It is anticipated that we will need to capture nationally a minimum of 5,000 episodes of care* for children, 2,500 in a hospital setting, 2,500 in the community (incl. hospice). We recognise that it will be challenging to collect this amount of episodes through a few pilot areas. We therefore anticipate establishing one or two pilot areas as

front-runners, with a view to working with the sector to roll out to a much wider geographical area in order to capture sufficient information to create a robust tariff. These front-runners will need to demonstrate the ability to collect 300-500 episodes of care over 12 months. Providers may need to work together to deliver this number of episodes

For all sites -
- Ability to be ready to start collecting data by June 2012
- Demonstration of involvement in related national/local projects, which have aimed to develop palliative care funding or classification models and data collection systems, including, but not limited to, collaboration with the King's College London C-Change team, work on Electronic Palliative Care Co-ordination and Locality Register systems, or the National Council for Palliative Care Minimum Dataset Pilots
- Pilot sites will need to demonstrate that they are working in partnership with all the key providers of palliative care (NHS, voluntary sector and social care) in an area. We are particularly interested in pilots, which cover multiple settings (e.g. hospital, home, care home and hospice), and we would welcome consortia bids
- Delivery of a clear project plan including governance, timescales and resources required
- Demonstration of senior commitment (at Director level or above) of all organisations involved
- Enthusiasm and dedicated leadership for the project

How will the selection process be undertaken?

The Department has established the 'Palliative Care Funding Pilots Working Group', which will oversee the appointment of the pilot sites and monitor the progress of the pilots once established; ensuring lessons are learned and shared as quickly as possible. The group comprises:

Name	Job Title and Organisation
Professor Sir Mike Richards (chair)	National Clinical Director for End of Life Care, DH
Dr Teresa Tate	Deputy National Clinical Director for End of Life Care, DH
Tom Hughes-Hallett	Chair, National End of Life Care Strategy Implementation Advisory Board.
Professor Sir Alan Craft	Paediatric expert
Dr Fliss Murtagh	Consultant and Clinical Senior Lecturer in Palliative Care, Kings College London
Catherine Davies	Programme Lead PCF Pilots, DH
Tilde Nielsson	Specialist Support to PCF programme, DH
Martin Campbell	Deputy Director NHS Finance, Payment by Results Development, DH
Karen Turner	Deputy Director, Children, Families and Maternity, DH
Sally Warren	Deputy Director, Social Care Strategic Policy and Finance, DH

The group will further receive specialist support and advice from the National End of Life Care Programme.

The group will consider the expressions of interest in February and following consultation with ministers will select pilot sites in March 2012.

What support will be provided by DH to the pilots?

- Financial support to each pilot site of a total of up to £200k, over the entire two year period

- Training and support on how to record and collate the data

- Strategic guidance and central coordination and analysis of data

- Leadership through the palliative care funding pilots working group and monthly meetings to facilitate progress and enable shared learning

- Support for detailed costing information work to inform the brief resource allocation measure.

Submitting an Expression of Interest

Completed 'Expression of Interest' forms should be submitted via the Department of Health website.

If you have any questions please e-mail palliativecarefunding@dh.gsi.gov.uk or contact Catherine Davies on 0207 972 3208.

The closing date for expressions of interest is **31 January 2012**. The pilot programme will begin in April 2012.

Annex 1 – Definitions of 'Phase of Illness'

Start of phase	End of phase		For example
Stable: • Patient problems and symptoms are adequately controlled by established plan of care **and** • Further interventions planned to maintain symptom control and quality of life **and** • Family/carer situation is relatively stable and no new issues are apparent	**Stable:** • The needs of the patient and or family/carer increase, requiring changes to the existing care plan (ie the patient is now unstable, deteriorating or terminal)		Symptoms and other concerns are well controlled and stable. Family carers are aware of how to access support in the event of change.
Unstable: An urgent change in the plan of care or emergency treatment is required <u>because</u> • Patient experiences a new problem that was not anticipated in the existing plan of care, **and/or** • Patient experiences a rapid increase in the severity of a current problem; **and/or** • Family/ carers' experience changes which impact on patient care	**Unstable:** • The new care plan is in place, it has been reviewed and no further changes to the care plan are required (ie the patient is now reverting to the stable or deteriorating phase) **and/or** • Death is likely within days (ie patient is now terminal)		Symptoms and overall condition need regular review because they are unpredictable and at risk of worsening quickly. Informal carers need additional support as condition is unpredictable.
Deteriorating: The care plan is addressing anticipated needs but requires periodic review <u>because</u> • Patient experiences an anticipated and gradual worsening of existing problem **and/or** • Patient experiences a new but anticipated problem **and/or** • Family/carers experience gradual worsening distress that is anticipated but impacts on the patient care	**Deteriorating:** • Patient condition plateaus (ie patient is now stable) **or** • An urgent change in the care plan or emergency treatment is required **and/or** family/ carers experience a sudden change in their situation that impacts on patient care, and requires urgent intervention (ie patient is now unstable) **or** • Death is likely within days (ie patient is now terminal)		Symptoms and overall condition are gradually worsening, but in an anticipated way. Informal carers may need pre-emptive support to facilitate on-going care

Terminal:
Death is likely within days
	Terminal:
	   Patient dies **or**
	   Patient condition changes and death is no longer likely within days (ie patient is now stable, unstable or deteriorating)
			Prognosis is assessed to be hours or days Review and re-assessment is frequent (daily or more than daily contact)

Note 1: The key distinction between 'Unstable' and 'Deteriorating' is whether the phase is *unpredictable (and so in the 'unstable' phase)* or *anticipated (and so in the 'deteriorating' phase).*

Note 2: If the patient is 'stable' but family needs are unpredictable or family distress is worsening, then categorise according to family needs.

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Annex 2 – Example Draft Data set

1A Demographic and diagnostic data part A (Collect at the start of an episode of care)

	Item	Reason for collection	Answer format
1.1	NHS Number	Identification of patient	Number
1.2	Patient ID	Identification of patient	Number
1.3	Surname	Identification of patient	
1.4	First name	Identification of patient	
1.5	Date of birth	Identification of patient; casemix criteria	dd/mm/yyyy
1.6	Date of death	Identification of patient	dd/mm/yyyy
1.7	Usual post code	Identification of geographical area; possible cost driver	6 or 7 digit postcode
1.8	Gender	Identification of patient	male, female, unknown, not specified
1.9	Age	Casemix criteria	
1.1	Ethnicity	Possible cost driver	
1.11	Marital status	Possible cost driver	Married/ unmarried/
1.12	Language spoken at home	Possible cost driver	
1.13	Need for interpreter	Possible cost driver	Needs interpreter/ does not need interpreter
1.14	Primary diagnosis	Possible cost driver	ICD 10 codes
1.15	Secondary diagnoses	Possible cost driver	ICD 10 codes
1.16	Comorbidities	Possible cost driver	ICD 10 codes
1.17	Referral date	Establish time between referral and first contact	dd/mm/yyyy
1.18	Referral source	Transitions	Community nurse, GP, hospice or palliative care service, hospital, local authority services, relative or friend, self referral, other
1.19	Decision date	Establish time between referral and first contact	dd/mm/yyyy
1.20	Episode start date	Transitions	dd/mm/yyyy
1.21	Episode care aim	Possible cost driver	Symptom management, respite care, rehabilitation, terminal care,

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	Item		Answer format
	psychosocial support		
1.22	Accommodation before episode start	Transitions	Patient's own home, temporary place of residence, NHS hospital, NHS nursing/ residential home, local authority residential care, non-NHS nursing home, hospice/ specialist palliative care unit, other, not known
1.23	Level of support before episode start	Social care information	Lives alone (no support/ care provided), lives with others (no support/ care provided), lives alone with external support (informal or professional), lives with others (who provide informal care/ support), lives with others with external support (informal or professional), other arrangements, not stated
1.24	Social care package before episode	Social care information	Existence as well as size of a social care package
1.25	Funding of social care package before episode	Social care information	Local Authority/ self funded
1.26	Continuing Healthcare Package before episode	Continuing Healthcare Information	Existence as well as size of a Continuing Healthcare package

1B Demographic and diagnostic data part B (capture at end of an episode of care)

	Item	Reason for collection	Answer format
3.1	Episode end date	Establish time between referral and first contact	dd/mm/yyyy
3.2	Discharge destination	Transitions	Patient's own home, temporary place of residence, NHS hospital, NHS nursing/ residential home, local authority residential care, non-NHS nursing home, hospice/ specialist palliative care unit, other, not known
3.3	Level of support after episode ends	Social care information	Lives alone (no support/ care provided), lives with others (no support/ care provided), lives alone with external support (informal or professional), lives with others (who provide informal care/ support), lives with others with external support (informal or professional), other arrangements, not stated
3.4	Social care package after episode	Social care information	Existence as well as size of a social care package
3.5	Funding of social care package after episode	Social care information	Local Authority/ self funded

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3.6	Continuing Healthcare Package after episode	Continuing Healthcare Information	Existence as well as size of a Continuing Healthcare package
3.7	End of life care tools	Possible cost driver	EoLC locality register, GSF, LCP, PPC, other

3 Resource use (capture at end of spell, as well as any phase changes)

	Item	**Reason for collection**	**Answer format**
5.1	Resource use	Matching needs and resource use	Palliative Resource Use Score

Annex 3 – Time tracker tool

Appendix 18: Time tracker tool

Service ID	
Study ID	

Month		Year	
Episode start date		Episode end date	

Please assess the phase a patient is in every day. Each change of phase triggers a full assessment of function and problem severity.

Day	\- Phase \- stable	unstable	deteriorating	terminal	Assessment for phase change
1	☐	☐	☐	☐	
2	☐	☐	☐	☐	
3	☐	☐	☐	☐	
4	☐	☐	☐	☐	
5	☐	☐	☐	☐	
6	☐	☐	☐	☐	
7	☐	☐	☐	☐	
8	☐	☐	☐	☐	
9	☐	☐	☐	☐	
10	☐	☐	☐	☐	
11	☐	☐	☐	☐	
12	☐	☐	☐	☐	
13	☐	☐	☐	☐	
14	☐	☐	☐	☐	
15	☐	☐	☐	☐	
16	☐	☐	☐	☐	
17	☐	☐	☐	☐	
18	☐	☐	☐	☐	
19	☐	☐	☐	☐	
20	☐	☐	☐	☐	
21	☐	☐	☐	☐	
22	☐	☐	☐	☐	
23	☐	☐	☐	☐	
24	☐	☐	☐	☐	
25	☐	☐	☐	☐	
26	☐	☐	☐	☐	
27	☐	☐	☐	☐	
28	☐	☐	☐	☐	
29	☐	☐	☐	☐	
30	☐	☐	☐	☐	
31	☐	☐	☐	☐	

Each episode of care is started on a new sheet. When an episode continues into to the next month, a new sheet must be used.

Expression of Interest Form
To be submitted by 31 January 2012

Completed 'Expression of Interest' forms should be submitted via the Department of Health website.

Please read the supporting notes before completing the form.

Name	
Lead Organisation	
Department	
Position	
Telephone and email contacts	
If you are not going to be the Palliative Care Pilot Lead, please give their name and contact details	

Organisational commitment : Please provide the name of the CEO or Director who will sponsor the project / application and ask them to briefly state their support and why they are interested in participating as a pilot site

Sponsor (name / position)	
Sponsor's contact details	
Sponsor's statement of commitment	

Partner Organisations commitment : Please provide the name of the CEO or Director from each of the partner organisations for the project and ask them to briefly state their support and why they are interested in participating as a pilot site

Partner (name / position/organisation)	
Partner contact details	
Partner statement of commitment	

Briefly describe how you would propose to take forward this project including your desired outcomes and measures for evaluation

(please do not exceed 2 page A4)

Briefly describe the palliative care provision in your area; incl. how population served by each participating service, described by diagnosis, age, ethnicity, rural/urban location, and any socio-economic or deprivation indicators. Please indicate the number of people seen in each service, both incident (new cases per month or per annum) and prevalent data (existing cases per annum)

(please do not exceed 1 page A4)

Briefly describe any current or already planned activity, which will support the capability of your proposal to collect the information needed by the Palliative Care Funding pilots.

How will you ensure you have the capability to start collecting data by June 2012 at the latest?

How will you capture the data needed?

(please do not exceed 1 page A4)

What other local/national projects are you involved in that link to this work?

(please do not exceed ½ page A4)

What resources and support are required to undertake this project?

Please describe your project plan including governance, resources, risks and timescales

(please do not exceed 1 page A4)

Please state whether you are applying to be a pilot site for adults, children and young people or both. Please also include any comments on how you might capture data for transition groups (young people up to 25 years old).

(please do not exceed ½ page A4)

Thank you for your interest
We will be in touch once your Expression of Interest has been reviewed.