

# End of Life Care Strategy

The National Council for Palliative Care  
Submission

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# End of Life Care Strategy

## Submission from the National Council for Palliative Care

### 1. Introduction

The National Council for Palliative Care welcomes the proposal of the Department of Health to prepare a comprehensive strategy to develop and progress end of life care. It notes that the intention of the strategy is to establish the means whereby the Government's commitments on palliative care outlined in its election manifesto can be delivered together with those on end of life care contained in the White Paper '*Our health, our care, our say*'.

While wholeheartedly welcoming this focus on end of life NCPC will be concerned to make sure that the strategy is placed in the context of the well established current policies for meeting supportive and palliative care needs that arise throughout the patient journey. That will mean ensuring that the new strategy takes account of and complies with the NICE Guidance on Supportive and Palliative Care for Adults with Cancer as well as the recommendations on palliative care contained in all National Service Frameworks.

### 2. Key Matters for Consideration

It is suggested that the following matters be considered during the development of the strategy:

- Definition of end of life care
- Definition and size of the client group
- Identifying the specific needs of the client group
- Identifying the processes that can identify the specific needs of individuals from the client group
- Identifying the principal areas of care where individuals may wish to exercise choice
- Identifying models of service that appear to work well in meeting identified needs in individuals in different care settings
- Development of guidance about the volumes of service that may be needed to meet the needs of populations with different epidemiological, demographic and socio-economic characteristics
- Estimation of the costs of the required level of services and their funding
- Development of guidance about coordination of services across organisational boundaries
- Development of guidance for commissioners of supportive and palliative care services

### 3. Definition of End of Life Care

It is crucial to develop an understanding about what meaning can be attached to the term 'end of life care' and to relate that meaning to the established definitions of supportive and palliative care as included in the NICE Guidance on Supportive and Palliative Care. Without such understanding it may not be possible to define either the client group or

its 'end of life care' needs in a way which is complementary to existing well-established definitions. Furthermore, it might also result in some confusion on the part of commissioners as to whether a strategy for end of life care constituted a shift of focus to the exclusion of supportive and palliative care that may be needed earlier in the patient journey.

It is suggested that it may be useful to regard 'end of life care' as simply an everyday expression that may be easily understood by the general public and in that context does not require formal definition. However, that does not lessen the need to produce a common understanding of its meaning for health and social care professionals.

There have been some suggestions that it would be useful to import a definition from abroad. There are several good examples but these do not necessarily fit well with current supportive and palliative care policy and health care system in this country.

In the light of that there remain two key questions:

- When does the phase begin that may be called 'end of life'?
- What meaning can be attributed to 'end of life care'?

### ***How can the period of end of life be defined?***

It is clear that the beginning of the phase is variable according to the following factors:

- Variation according to condition e.g. cancer, organ failure, frail elderly/dementia
- Variation according to the perspective of individual patients
- Variation according to the clinical/prognostic judgement of individual professionals

It may be that the key factor is professional judgement. There may nevertheless be criteria that are commonly used by professionals in exercising their judgement. In response to that the GSF Team has recently produced a set of prognostic indicators that may help in making decisions about when 'end of life' begins. In summary they are:

The Surprise Question – Would you be surprised if this patient were to die in the next 6-12 months?

Patient Choice/Need – The patient with advanced disease makes a choice for comfort care only (not curative treatment) or is in special need of supportive or palliative care.

Clinical Indicators – General predictors of end stage illness (multiple co-morbidities, weight loss, general physical decline, serum albumin level, reduced performance status, dependence in most activities of daily living) and condition specific indicators.

The Liverpool Care Pathway also includes guidance on when diagnosis of dying may be made. However the LCP is concerned with the last days of life rather than the last weeks or months.

In essence, the focus on end of life has the aim of ensuring that at the point of entering the last phase of life a comprehensive assessment is undertaken of the individual's supportive and palliative care needs. The search is therefore for a recognisable trigger point for that assessment. Given the variations due to condition, patient perspective and professional judgement, it is clear that there is no common trigger point. In consequence, the trigger is likely to be determined, as argued above, mainly by professional judgement.

Assessment at that point sits within a continual iterative process of assessment that should start at or around the time of diagnosis. Comprehensive assessments subsequent to that time should be triggered by major changes in diagnosis, treatment, condition or prognosis. Entry to the end of life phase constitutes such a major change and comprehensive assessment at that point should be informed by both the findings of prior comprehensive assessments and those arising from the ongoing assessment process.

In the latter part of the patient journey there may be at least three common trigger points for comprehensive assessment; the point of recognition of incurability, the point of recognition of the beginning of end of life, the point at which dying is diagnosed. It is suggested that the end of life care strategy should be concerned only with the last two points. In consequence, for most individuals, it is likely that 'end of life' does not begin earlier than one year before death and for most it may come much later than that.

#### ***What meaning can be attributed to end of life care?***

Given that the period called end of life has so many variations, it may be that the term can have no formal definition. Nevertheless it would still be important to attribute a general meaning to it that is embedded in and reflective of currently accepted definitions of supportive and palliative care.

That would suggest that the following may be acceptable:

End of life care is simply acknowledged to be the provision of supportive and palliative care in response to the assessed needs of patient and family during the last phase of life.

#### **4. Definition and size of the client group**

If it is considered, as suggested above, that in most cases end of life does not begin earlier than one year before death, then the client group at maximum is equivalent to all those who die in any one year. The average annual number of observed deaths in England for the years 2002 to 2004 was 495,212. The population of England in 2004 according to lists extracted from ADS 2004 and reconciled to ONS mid 2003 estimates for Primary Care Organisations was 49,632,436. The ratio of deaths to 100,000 population was therefore 998. However, there is a very large variation in the mortality rate for current Primary Care Trust populations. The rate varies from 1963 per 100,000 in Bexhill & Rother PCT (nearly twice the national rate) to as low as 505 per 100,000 in Kensington &

Chelsea PCT (about half the national rate). These variations have significant implications for the level of resources needed for end of life care.

The principal causes of death expressed as percentages of total deaths are as follows. The data is for the year 2003.

Neoplasms	25.9%
Diseases of the nervous system	2.9%
Diseases of the circulatory system	38.2%
Diseases of the respiratory system	13.9%
Diseases of the digestive system	4.6%
External causes of morbidity & mortality	3.1%
Other causes	11.4%

The distribution of numbers of deaths by age expressed as percentages of total deaths is as follows:

Age range	
1-4	0.1%
5-14	0.2%
15-34	1.5%
35-64	14.7%
65-74	17.5%
75 and over	66.0%

It will be important in developing the end of life care strategy to take account of the variations in supportive and palliative care needs that arise due to differences in condition that will ultimately be the principal cause of death and also the differences due to age at which death occurs.

One further important factor is the wide prevalence of symptoms of dementia in people with other conditions. **Appendix 1** to this paper provides estimates of the numbers of people with different conditions who may be expected to have such symptoms in the last year of life for different age ranges. These numbers represent significant proportions of total deaths due to cancer (8.7%), to diseases of the circulatory system (14.4%) and to diseases of the respiratory system (13.7%). It is suggested that it will be necessary to give particular consideration to the end of life needs and care of this patient group. The NCPC Older People Policy Group is paying further attention to this in its current activities.

## **5. Identifying the specific needs of the client group**

The strategy will need to include a description of the potential needs of individuals in the last phase of life. Broadly they can be described as supportive and palliative care needs. They can further be defined as falling into four principal domains of need for the patient and a further two for the family/carers:

For the patient:

- Physical functioning/disease symptoms and treatment related side effects
- Psychological well-being and cognitive
- Social and occupational
- Spiritual well-being

For the family/carers

- Family and carer support
- Bereavement support

It will be necessary to set out the specific elements within each of those domains that are particularly pertinent to the last phase of life. Current thinking would also suggest that there is a further domain the content of which may include the following:

- Preferences for care and treatment
- Preferences for place of care and death
- Assessment of the patient and carer understanding of what was happening in respect of care and prognosis
- Advance care planning, directives as to future care in potential circumstances
- Preferences around how much information and the medium for its communication

## **6. The processes for identifying the specific needs of individuals from the client group**

In section 3 above it is argued that comprehensive assessment of supportive and palliative care needs at the beginning of the last phase of life should be seen as sitting within the ongoing process of assessment that precedes and follows that point in the patient journey. Given that the process may well be undertaken in a succession of different care settings, it will be important for all those responsible for assessment to have a common understanding about what the key features are of the process. The areas on which guidance may be required are as follows:

- Purpose of assessment
- Individuals to be assessed
- Domains of assessment and their content
- When the assessment should be undertaken
- Who should undertake the assessment
- Skills/knowledge/competence of staff undertaking assessment
- Availability/communication of assessment findings
- Monitoring assessment carried out

### ***Purpose***

The purpose is to:

- Identify, record and assess individual needs across all potential domains of need

- Inform the priorities for and development/revision of a care plan for meeting identified needs, mutually agreed between the individual and professionals
- Ensure that individuals receive appropriate, effective and timely care in response to their needs

### ***Individuals to be assessed***

All those who are judged to be in the last year of their life (see section 4 above)

### ***Domains of assessment and their content***

See section 5 above.

### ***When the assessment should be undertaken***

Comprehensive assessment of supportive and palliative care needs should be undertaken at the beginning of the period of end of life and on any subsequent occasion when there is judged to be a major change in condition, prognosis or the informal carers' ability to cope. Assessment on a continual iterative basis is ongoing between those occasions.

### ***Who should undertake assessment***

There are two related questions on which guidance may be important:

- Who should be able to undertake comprehensive and ongoing assessment
- Where responsibility lies for ensuring that assessments are undertaken taking into account that the individual may move several times between different care settings

### ***Skills/knowledge/Competence of staff undertaking assessment***

Skills for Health have already defined the competence required to undertake assessment or re-assessment of a patient and have further defined a limited range of competences linked or relevant to supportive and palliative care.

It is suggested that these be reviewed with the purpose of appraising their appropriateness, user friendliness and completeness in respect of individual assessment during the last phase of life. And that these competencies are appropriate and joined up across sectors and staffing groups.

### ***Availability/communication of assessment findings***

In order to facilitate coordination of care across different care settings, the findings of assessment need to be available/ communicated to all teams who may be responsible for the patient at different times during the last phase of life



## ***Summary***

Systematic assessment of individual needs is considered crucial to the patient and family receiving care and support appropriate to their needs. Without comprehensive and iterative processes of assessment there is less chance of needs being identified and consequently more chance of them being met either too late or not at all.

### **7. Identifying the principal areas of care where individuals may wish to exercise choice**

Individuals need to be given the opportunity of exercising choice about the care they need and the setting in which it is delivered. For most individuals it may be more important to ensure that the care delivered is in accordance with their preferences than to have it delivered in the care setting of choice. In other words the first priority may be to ensure that the care is right wherever the individual happens to be.

#### ***Preferences about care***

The assessment process described above should be one of partnership between patient and professional. Asking patients how they are feeling and helping them, if they are able, to assess their own needs should be central to the process. The plan to meet assessed needs should be in accordance with the patient's priorities and options.

#### ***Preferences about place of care***

Information about preferred place of care should be collected, recorded and reviewed/revised whenever it seems appropriate to do so throughout the end of life phase. Retrospective data needs to be collected in respect of whether patient preferences were satisfied.

#### ***A collection of relevant data***

The following sets of data are provided with the aim of informing discussion about policy development on place of care and place of death.

The ONS data for 2003 on place of occurrence of death shows:

Place	% of all deaths	% of cancer deaths
Home	18.1%	22.0%
Hospital	57.7%	50.2%
Hospice	4.3%	15.7%
Elsewhere	19.9%	12.1%

**Note:** Elsewhere includes deaths in care homes both with nursing and residential and many other categories. After taking into account these other categories the proportion of care home deaths is between 16 & 17%.

The data usually quoted about people's preferences for place of death is derived from a telephone survey of a random selection of the general public. The findings do therefore have to be treated with some caution since it cannot be assumed that the preferences of those who are in the last phase of life would match those of the survey sample. The findings are nevertheless quoted below:

Preferred Place	%
Home	56%
Hospital	11%
Hospice	24%
Care Home	4%
Elsewhere	5%

Perhaps the safest conclusion to draw from this data is that substantially more people would prefer to die at home or in a hospice than actually do and consequently many fewer people would prefer not to die in a hospital or care home.

It is interesting to note that males appear to have more choice over where they die than females. This results at least in part from the fact that in general females have a longer life expectancy than males and therefore outlive their partners. Relevant data is as follows:

- 6.8% of male deaths occur in care homes with nursing but 13.0% of female deaths
- 3.8% of male deaths occur in residential homes but 10.1% of female deaths
- 21.4% of male deaths occur at home but only 15.1% of female deaths

It will also be important to consider the data about place of occurrence of death by underlying cause. The table below provides that:

Underlying Cause	Circulatory Disease	Respiratory Disease	Diseases of the Nervous System	Neoplasms
Place of death				
NHS Hospitals	60.0%	64.5%	43.7%	50.0%
Hospice	0.15%	0.2%	1.5%	15.7%
At Home	20.7%	12.9%	12.7%	22.2%
Elsewhere	19.15%	22.4%	42.1%	12.1%

This table demonstrates the different levels of choice and therefore inequities as between people with different conditions.

### ***The economics of patient choice***

It is often assumed that care at home for those who want that is less costly than institutional care. It may be but the evidence about the

precise difference is not substantial and it will be necessary for further research to be undertaken.

For example in 2004/05 2.2% of all discharge episodes from NHS Hospitals ended in death i.e. around 270,000. What was the average length of stay in respect of those episodes and what was the average cost? How does that cost compare with the total costs of supporting the patient at home?

The survey about preferences for place of death referred to above suggests that 24% of people would prefer to die in a hospice. Currently only 4% do so. To meet such a preference level would require a six fold increase in hospice beds at a probable cost of more than a billion pounds and which, economically, is totally unrealistic. This one simple example demonstrates that patient choice cannot be open-ended. Consequently it will be necessary for the strategy to set out what is meant by patient choice in palliative care. Will it include choice of provider and, if so, between what options – hospice, hospital, community hospital, care home? And how will informed choice be ensured?

## **8. Identifying models of service that appear to work well in meeting identified needs in different care settings**

In respect of people with cancer there is a general consensus about what the palliative care service model should be and what its core components should be as set out in the NICE Supportive and Palliative Care Guidance. As far as other conditions are concerned there is as yet no equally firm consensus. The work of NCPC's policy groups has revealed innovative models of service for other conditions in a variety of settings, but this is often as a result of initiatives taken by individual clinicians or teams on an ad hoc basis, rather than planned and sustainable practice change.

Surveys carried out by our policy unit of heart failure, rehabilitation and neurology services have shown the importance each speciality places on specialist and general palliative care and how services can work effectively to meet the palliative and end of life care needs of patients if they have formalised links with dedicated models of service. For example, consensus is emerging on the key coordinating role of the heart failure nurse in any shared care model for people with advanced heart failure and palliative care needs.

The work of our Older People policy group on dementia has also shown the need for shared models of care which transcend health and social care as well as the importance of specialities working together to educate and act as resources for each other. However apart from our scoping work on service models little is understood about how these services and formalised links should operate, or what the cost implications are.

To address these issues it is important to collect the evidence on a systematic and comprehensive basis so that service models can be costed and national guidance developed to ensure individual services are not 'recreating the wheel' or floundering on their own but have practical

information about how to develop their services in realistic and sustainable ways that will improve the care of all people who need palliative and end of life care.

It is of paramount importance to involve service users and carers in identifying service models which meet individual needs across the range of conditions. This will need to include services designed to meet the needs of Black and Minority Ethnic groups and people with specific needs such as those with learning disabilities or sensory needs. It will be important to take account of the particular care and support problems occurring in areas of social disadvantage. Services will need to be multi-agency and sector, crossing organisational boundaries to encompass all areas of need and to take into account both the place of choice of the patient and the service differences this might require.

Service models for any population should have the following elements:

- A range of specialist services with access according to need e.g. palliative care, psychology etc
- A supplementary range of community services (non-specialist but discrete) to support people at home e.g. hospice/hospital at home
- A health and social care workforce able to provide general supportive and palliative care
- An expert palliative and supportive care resource that is able to facilitate the introduction of generic tools such as LCP, GSF, PPC and to provide education and training for the health and social care workforce as a whole

***A range of specialist services with access according to need e.g. palliative care, psychology etc***

Palliative care needs assessment across all conditions is vital to inform this work and is discussed in section 9.

Creative solutions are required to ensure specialist palliative care services are accessible for telephone advice 24 hours a day in line with the NICE Supportive and Palliative Care Guidance. This will include the pooling of staff and funding. It is also important that the end of life care strategy dovetails with urgent and rapid care strategies and services e.g. ambulance services, NHS Direct, Out of Hours (OOH) GP schemes.

A telephone survey of an out of hours service in London showed that 132 visits were carried out in a three month period but this would have been reduced to 16 if there had been access to drugs, syringe drivers and catheters and a twenty four hour District Nursing Service.

An innovative way to coordinate OOH care could be rolling out schemes, such as COMPASS in South London which is an out of hours palliative care telephone advice line – the low number of calls to this probably reflect the reassurance people feel from merely knowing the service is available.

***A supplementary range of community services (non-specialist but discrete) to support people at home e.g. hospice/hospital at home***

Work is needed on services designed to enable patients to remain at home or closer to home, for example, support in the home and community-based services. It needs to include Care Homes, which are the permanent home for many people (approximately 17% of people die in a care home, ONS 2003) and the emerging role of Community Hospitals in this.

Examples of potential service models include:-

Hospice at Home – there is a need to build consensus about common definitions of Hospice at Home; gather evidence about its effectiveness at meeting the needs of different groups of people regardless of diagnosis, geography, setting, marginalisation or ethnicity; identify the costs of the model thereby informing potential associated community health resource groups.

Models using a co-ordinator or key worker – if the role is seen as part of the community matron role then there needs to be a clear scoping of the training and skills they have in meeting this part of their competences; Integrated models transcending traditional boundaries.

***An expert palliative and supportive care resource that is able to facilitate the introduction of generic tools such as LCP, GSF, PPC and to provide education and training for the health and social care workforce as a whole***

*NICE (2004) states 'Staff providing general palliative care should be trained in identifying needs of patients and carers and in general principles and practice of palliative care'. NCPC in our Palliative Care Manifesto (2005) states that 'On a continuing basis a national training programme in palliative care for all health and social care professionals needs to be established'. Ensuring this happens urgently is now vital to ensure an end of life care strategy is successful in influencing choice over place of care and death.*

It is already recognised that to achieve the objectives of developing palliative care for all patients regardless of diagnosis and of enabling patients to receive care in their place of choice that tools and training are required. It is essential that local expertise and resource is utilised to produce local network and national solutions. The Specialist Palliative Care (SPC) workforce can form this resource as they work across local health communities, and by so doing sit outside the traditional organisational boundaries. Therefore they are not restricted by some of the inherent barriers, so can support and train 'usual' professional carers so that they can provide general palliative care. Mapping and disseminating effectively who the SPC resource are locally in both the voluntary and NHS sectors will enable policy makers, commissioners and providers to plan the deployment of the SPC workforce more effectively both to deliver SPC and to support and train their colleagues.

If SPC was then to offer this advice, support and education role both in and out of hours then services would need to be commissioned and could be done so across all sectors including community hospitals, care homes therefore funding the SPC resource.

### **Summary**

There needs to be a consensus on what should form the service models required to meet the needs of people with a variety of conditions. Service specifications for each service model are required and this includes hospice at home, bereavement support and institutional care in community hospitals and care homes. NCPC is well placed to develop this further.

### **9. Population-based needs assessment and service volumes**

Population-based palliative care needs assessment consists of five principal steps. They are:

- An assessment of the palliative care needs of the population
- An assessment of the core service components required to meet those needs
- A mapping of the services currently available to meet those needs
- A comparison of what services are needed with what is already available in order to identify service gaps
- An assessment of the priorities for filling the service gaps

Guidance on how to assess population needs for people with cancer has been set out in a joint publication in 2004 by the Cancer Action Team and the National Council for Palliative Care, *Population-Based Needs Assessment for Palliative Care – A Manual for Cancer Networks*. This guidance has since been employed by nearly all cancer networks in England and Wales.

The guidance acknowledges that needs assessment is not an exact science and that the techniques currently available do not lead to absolute measurements of need. They involve analysis of the principal factors that influence need. Consequently, they can at best provide data that enables the needs of one population to be compared with another. That is nevertheless valuable since population need (and consequently resource need per head of population) may vary by more than 100% between different populations. These variations are due to differences in epidemiological, demographic and socio-economic characteristics.

It is suggested that the development of needs assessment methodology which is tailored to each of the principal disease groups may be particularly useful in understanding the differences in population need for supportive and palliative care and consequently for end of life care. Some preliminary work has already been undertaken and more is planned e.g. for those with heart disease. NCPC's Circulatory and Respiratory Policy Group will be working with the British Heart Foundation and other partners to further this work.

One of the products of needs assessment is an index of comparative need. This can be produced for any category of populations e.g. clinical networks, PCTs, local authorities, health authorities. Attached at **Appendix 2 and 3** are example indexes for cancer network populations. These were originally included in the Manual referred to above and have recently been updated. Similar indexes could be produced for other disease or patient groups.

It will be noted that one of the essential steps in the needs assessment process (see above) is an assessment of the core service components required to meet assessed needs. In respect of people with cancer there is a general consensus about what the palliative care service model should be and what its core components should be as set out in the NICE Supportive and Palliative Care Guidance. As far as other conditions are concerned there is as yet no equally firm consensus although that is emerging for some conditions e.g. for heart failure (as reflected in Section 8).

It is clear that until such a consensus emerges for all the principal conditions, the usefulness of needs assessment will be limited. Subsequent to that it will also be necessary to develop some understandings about the volume of each service component that may be required to meet the varying levels of need uncovered by population-based assessments. It will therefore be enormously useful to the needs assessment process if the end of life care strategy can help to generate some consensus around models of service and volumes that are related to population need.

#### **10. Estimation of the costs of the required level of services and their funding**

It is apparent that until a view can be taken about what the appropriate model of service looks like, no estimate can be made of its cost. However, that will need to be undertaken as part of the strategy development.

##### ***Information about current costs***

Some work has already been undertaken in 2006 by the Department of Health in respect of the current costs of specialist palliative care services and their sources of funding. This showed that the estimated total costs of services for adults was between £418 and £440 million of which £326 million was expended by the voluntary hospices and the remainder by NHS managed services. It was also estimated that the NHS contributed £119 million to the costs of voluntary hospices. The remaining £208 million was funded from charitable sources.

It is however important to note that:

- Many current services may not be NICE compliant in respect of their multi-professional teams
- Volumes of service may be less than or in excess of estimates of service need derived from population-based needs assessment

- Current service activity is 90 to 95% in respect of people with cancer

### ***Government Policy on the Introduction of PbR and Full Cost Recovery***

In its response to the House of Commons Health Committee Inquiry into Palliative Care in 2004, the Government made the following commitments:

'We remain on course to implement Payment by Results (the national tariff) with respect to palliative care in both the NHS and the voluntary sector by 2008/09.'

'In palliative care the national tariff will, in effect, provide the full cost recovery recommended by HM Treasury's *Cross Cutting Review on Voluntary and Community Sector in Public Service Delivery*'

'However, it is likely that full cost recovery will take time to implement, with contracts being renewed on a case by case basis over the five years from the publication of the Cross Cutting Review recommendation up to 2008. Within the context of healthcare provision it is important to remember that these contracts will be determined by Primary Care Trusts, as commissioners, and local service providers'

### ***Progress in Implementing Government Policy***

An Expert Working Group (EWG) was set up by the NHS to develop Health Resource Groups (HRGs) for specialist palliative care services. The EWG completed its work in January 2006 and its recommendations have been accepted as part of the HRG Version 4 development programme. In May 2006 the EWG was advised by the NHS Information Centre that:

'HRG version 4 is now approved for use by the Department of Health Payment by Results Team. It will be used for reference costing for year 2006/07 and for reimbursement against tariff from April 2008.'

The National Partnership Group for Palliative Care (NPG) has recommended to the PbR Team an approach to costing the HRGs, to the collection of reference costs and to developing minimum NHS service specifications that would underpin them. No response has yet been received from the PbR Team.

### ***Current Government Policy***

The delay in obtaining a response from the PbR team together with other indications of possible changes in Government thinking has led to an exchange of letters between the National Council and the responsible Minister, Rosie Winterton MP. These are attached as **Appendices 4 and 5**. The following issues arise:

- Further work on developing arrangements for the introduction of PbR for specialist palliative care services appears to be put in abeyance until the Department publishes a publication in the



autumn on the Future of PbR. This puts at risk achievement of PbR in 2008. It also delays the production of guidance for providers and commissioners on service specifications unit costs (let alone national tariffs). This will result in the meantime in more ad hoc local decisions on these matters by commissioners and providers.

- Primary Care Trusts are apparently being instructed that the funding of full cost recovery is a problem for them and not the Department. However, it is clear that most PCTs will not have the financial flexibility to provide full cost recovery unless it is in respect of a minority of patients currently referred by the NHS to voluntary hospices. That would mean that the NHS would need to restrict its referrals to the current level of NHS funding available. If the NHS nevertheless continued to refer patients that would incur costs above that level, then the voluntary hospices could be expected to take action to recover their costs through whatever means they may think appropriate.

### ***Summary***

The scope of the end of life care strategy includes funding issues for hospices and specialist palliative care services. The National Council strongly urges that:

- The work on the introduction of PbR continues and that the target date of April 2008 is adhered to
- Further consideration be given as to how the Government's commitment to full cost recovery can be realistically funded
- As the model of service for end of life care emerges together with service specifications for each service component within the model, HRGs are developed with a view to the introduction of PbR for all such components in addition to those for specialist palliative care services.

### **11. Development of Guidance about Coordination of Services across Organisational Boundaries**

The White Paper envisages the establishment of end of life care networks. This recommendation has arisen in the light of often poor coordination of care of individual patients who pass through several health care settings in the last year of life and may also require support from social services. It is suggested that in considering how best to respond to the recommendation, the following is taken into account:

- a) End of life care is pertinent to the care of most disease/patient groups
- b) End of life care is the responsibility of very large numbers of health and social care professionals working within each healthcare specialty and providing more generic health and social care in the community
- c) Cancer has developed supportive and palliative care networks, initially for people with cancer, but progressively and gradually for people with other conditions. Such progress varies across the country and there are also differences in how far the networks embrace general palliative care, particularly in the community

- d) How can this essentially pioneering work of the supportive and palliative care networks contribute to a new end of life care strategy?
- e) How practicable is it to bring all groups together in an end of life network?
- f) What is the critical mass of population for establishing such a network?
- g) What would be the role and responsibilities of such networks?
- h) Who would provide the leadership required?
- i) What managerial or other support would be required and where would it come from?
- j) Could some of the existing supportive and palliative care networks take on the role? If so would they need to break free their structural association with cancer networks and would that be detrimental to the care of cancer patients?

## **12. Development of Guidance for Commissioners of Supportive and Palliative Care**

The NHS End of Life Care programme in association with the Care Services Improvement Partnership has produced an initial draft of a service specification for end of life care for commissioners. It is suggested that there are some limitations in its current version that require further consideration in this strategy. The principal limitation is that there is no description of the model of service and its standard service components. Also it does not show how the process for assessment of supportive and palliative care needs should sit within the ongoing assessment that precedes and follows the beginning of the end of life phase. These limitations can only be addressed as and when the development of the new end of life strategy is developed.

There also needs to be a realistic appraisal of what commissioners are able to achieve through the commissioning process. Whatever the ultimate shape of the service model for cancer and other conditions, there will be a range of discrete services that can be commissioned and there will be other elements of the model over which commissioners will merely have influence. It is suggested that it is important to be able to distinguish between those two categories.

Some evidence of the potential service models have been described in Section 8. Commissioners should receive guidance on what discrete services should be available for any population. The guidance should include service specifications for each core component and indicative volumes related to population size and its characteristics. This can be obtained from guidance on population-based needs assessment. It is already known that each service model will include the following discrete services:

- Specialist palliative care in-patient, hospital support teams, community teams, day therapy/out-patients
- Non-specialist community services supplementary to the specialist services e.g. hospice at home, bereavement support, institutional care in community hospitals and care homes

Other specialist and non-specialist services remain to be defined.

The areas that are subject to commissioner influence include the following:

- Design of patient pathways
- Introduction of mechanisms such as LCP, GSF, PPC
- Continuous professional development of the health and social care workforce in supportive and palliative care
- The inclusion of such requirements in service specifications for each health care activity – the real costs of that should be reflected in the national tariffs for such activity

***Summary and general conclusion***

Commissioners can determine the structure of the service by commissioning discrete services in appropriate volumes for their populations. They can influence the process of end of life care in the ways suggested above. They can as a result influence outcomes but they cannot guarantee any particular set of outcomes. That will be largely dependent on the quality of professional practice.

### **Possible Approaches to Population-based Palliative Care Needs Assessment for people with dementia**

One of the assumptions built into the methodology for assessment of the palliative care needs of people with cancer is that a good proxy measure of need is the annual incidence of deaths where cancer is the underlying cause. This is considered to be a reasonable assumption to make since most palliative care for people with cancer may be needed in the last year of life.

In the case of dementia there are relatively few deaths where the underlying cause of death is one that has caused the dementia (Vascular & Unspecified Dementia – 12,500 deaths; Alzheimers – 4,700 deaths). This means that dementia, given its very wide prevalence (over 650,000), is much more likely to be present in people whose deaths are due to other principal causes. If that can be considered to be a valid conclusion, then one approach to needs assessment for people with dementia would be to estimate the prevalence of dementia in the last year of life of those who are subject to the most common underlying causes of death i.e. cancer, diseases of the circulatory system, diseases of the respiratory system.

The Table overleaf provides such estimates. It shows that it can be expected that around 12% of people aged 45 and over will have symptoms of dementia in the last year of life. That would suggest that those who are providing the principal healthcare for those people e.g. cancer specialists, cardiologists, specialists in respiratory medicine, will need knowledge and skills relating to care of people with dementia, to know when to refer for specialist advice and to assess in what care setting the total care needed by the patient can best be delivered.

It is suggested that the Table below reveals a scale of the problem that would justify specific action to improve both individual patient and carer needs assessment as well as to provide education and training in the care of people with dementia for all those who have responsibility for end of life care.

**Peter Tebbit**  
**6 January 2006**

**Estimates of the Number of People with dementia in England in the last year of life where the underlying cause of death is cancer or diseases of the circulatory system or diseases of the respiratory system**

<b>Age Bands</b>	45 to 54	55 to 64	65 to 74	75 to 84	85+	<b>45+</b>
<b>Cancer</b>						
Number of deaths	7496	18982	33305	43330	20474	<b>123588</b>
Number with dementia	7	19	977	3800	5951	<b>10754</b>
% with dementia	0.1%	0.1%	2.9%	8.8%	29.1%	<b>8.7%</b>
<b>Circulatory</b>						
Number of deaths	5211	12822	31548	71469	67962	<b>189012</b>
Number with dementia	5	13	941	6319	19992	<b>27270</b>
% with dementia	0.1%	0.1%	3.0%	8.8%	29.4%	<b>14.4%</b>
<b>Respiratory</b>						
Number of deaths	1068	3475	9615	21019	18239	<b>53415</b>
Number with dementia	2	4	283	1817	5224	<b>7328</b>
% with dementia	0.1%	0.1%	2.9%	8.6%	28.6%	<b>13.7%</b>

**Notes to the Table:**

1. Numbers of deaths: These have been derived from ONS Population Series DH1 no.36 (Table 2: Estimated resident population as at June 2003: sex and age-group by area) and ONS Age Sex and Marital Status Series DH1 no. 36 (Table 7: Death rates per million population; age-group and sex, infant mortality rates and SMR ratios for selected underlying causes, 2003)

2. Numbers with dementia: These have been derived by use of the estimated prevalence of people with dementia contained in Table 2 of the article entitled 'Dementia in People aged 65 years and older: a growing problem?' in Population Trends (Summer 1998). This Table makes use of the findings of the EURODEM study published in 1991 in the International Journal of Epidemiology.

3. The estimate of the numbers with dementia is based on an assumption that the prevalence of dementia among those in the last year of life is similar to the prevalence of dementia in the population as a whole.

**Index of Palliative Care Need for Cancer Network Populations**

**Cancer Diagnosis**

<b>Rank</b>	<b>Cancer Network</b>	<b>Deaths per 100,000 population</b>	<b>Index Value</b>	<b>Deprivation Score</b>	<b>Deprivation Modifier</b>	<b>Modified Index Value</b>
<b>1</b>	Merseyside & Cheshire	292.8	93.3	32.74	1.52	<b>141</b>
<b>2</b>	Northern	302.5	96.4	28.60	1.44	<b>139</b>
<b>3</b>	Teeside, N Durham & N Yorks	298.5	95.1	28.65	1.44	<b>137</b>
<b>4</b>	North Trent	292.8	93.3	27.96	1.43	<b>133</b>
<b>5</b>	Peninsula	312.2	99.5	21.07	1.30	<b>129</b>
<b>6</b>	Humber & Yorks Coast	289.4	92.2	26.06	1.39	<b>128</b>
<b>7</b>	Greater Manchester & Cheshire	262.8	83.7	29.10	1.45	<b>121</b>
<b>8</b>	Lancs & S Cumbria	279.3	89.0	23.71	1.35	<b>120</b>
<b>8</b>	Dorset	313.9	100.0	16.07	1.20	<b>120</b>
<b>10</b>	Black Country	275.4	87.7	23.75	1.35	<b>118</b>
<b>10</b>	Pan Birmingham	245.6	78.2	32.33	1.51	<b>118</b>
<b>12</b>	Sussex	301.7	96.1	16.69	1.22	<b>117</b>
<b>12</b>	Mid Trent	273.6	87.2	23.24	1.34	<b>117</b>
<b>14</b>	Norfolk & Waveney	287.2	91.5	18.52	1.25	<b>114</b>
<b>15</b>	Yorkshire	255.7	81.4	25.55	1.38	<b>113</b>
<b>16</b>	North West Midlands	274.8	87.6	19.97	1.28	<b>112</b>
<b>17</b>	Kent & Medway	279.3	89.0	16.55	1.21	<b>108</b>
<b>18</b>	South Essex	268.3	85.5	17.49	1.23	<b>105</b>
<b>18</b>	Derby/Burton	247.9	79.0	22.87	1.33	<b>105</b>
<b>20</b>	Mid Anglia	275.9	87.9	14.67	1.18	<b>104</b>
<b>21</b>	Avon, Somerset & Wilts	258.6	82.4	15.73	1.20	<b>99</b>
<b>21</b>	Central South Coast	267.2	85.1	13.95	1.17	<b>99</b>
<b>23</b>	Arden	245.7	78.3	18.44	1.25	<b>98</b>
<b>24</b>	3 Counties	261.3	83.2	13.97	1.17	<b>97</b>
<b>25</b>	North East London	201.0	64.0	31.98	1.50	<b>96</b>
<b>26</b>	South East London	209.6	66.8	26.21	1.39	<b>93</b>
<b>27</b>	Leics, Northants & Rutland	234.9	74.8	17.53	1.23	<b>92</b>
<b>28</b>	West Anglia	244.0	77.7	13.43	1.16	<b>90</b>
<b>29</b>	North London	189.1	60.2	29.04	1.45	<b>87</b>
<b>30</b>	Mount Vernon	225.6	71.9	12.09	1.13	<b>81</b>
<b>31</b>	West London	179.0	57.0	23.20	1.34	<b>76</b>
<b>32</b>	Surrey, W Hants & Sussex	224.6	71.5	8.03	1.05	<b>75</b>
<b>33</b>	Thames Valley	210.6	67.1	10.94	1.11	<b>74</b>
<b>33</b>	South West London	196.1	62.5	15.18	1.19	<b>74</b>

**Notes:**

- a) The first column records the average annual numbers of observed deaths per 100,000 population for which cancer is the underlying cause for the years 2002 to 2004. The data source is the Compendium of Clinical Indicators produced by the Health and Social care Information Centre
- b) The second column translates the data into an index. The index values are calculated relative to the Network with the highest ratio of cancer deaths to 100,000 population i.e. to that for Dorset Cancer Network.
- c) The third column records the average deprivation score for Super Output Areas across each Cancer Network. This has been calculated from the average SOA scores for each PCT population within each Cancer Network. The original data source is the Index of Multiple Deprivation 2004.
- d) The fourth column translates the deprivation score into a deprivation modifier for each Network. The calculation of the modifier is based on the assumption that a PCT population with the highest level of deprivation may need twice the palliative care resources per head of population compared with the PCT with the lowest level of deprivation. The calculation for the Network modifier contains two steps. The first consists of the calculation of the modifier for each PCT within the Network. The modifier represents the relative position of each PCT population between the highest level of deprivation of any PCT (this would be represented by a modifier of 2) and the lowest level of deprivation of any PCT (this would be represented by a modifier of 1). The second step consists of population weighting each PCT modifier within the network and deriving an average network modifier.
- e) The final column is the product of the modifier and the Index Value in the second column.

**Interpretation of the Network Index**

- a) The Cancer Network ranked 1 has the population with the greatest palliative care resource need per head of population and that ranked 34 has the lowest need.
- b) A Network with an index value of around 108 could be considered to have a population with average need
- c) A Network with an index value of around 118 could be considered to have a population with about 10% above average need; that with an index value of around 129 about 20% above; that with an index value of around 140 about 30% above.
- d) A Network with an index value of around 97 could be considered to have a population with about 10% below average need; that with an index value of around 86 about 20% below average need; that with an index value of around 75 about 30% below average need.

August 2006

**Index of Palliative Care Need for Cancer Network Populations**

**All Diagnoses**

<b>Rank</b>	<b>Cancer Network</b>	<b>Deaths per 100,000 population</b>	<b>Index Value</b>	<b>Deprivation Score</b>	<b>Deprivation Modifier</b>	<b>Modified Index Value</b>
<b>1</b>	Merseyside & Cheshire	1094.4	87.2	32.74	1.52	<b>132</b>
<b>2</b>	Northern	1135.0	90.5	28.60	1.44	<b>130</b>
<b>3</b>	Teeside, N Durham & N Yorks	1115.0	88.9	28.65	1.44	<b>128</b>
<b>4</b>	Humber & Yorks Coast	1117.6	89.1	26.06	1.39	<b>124</b>
<b>4</b>	Peninsula	1193.9	95.2	21.07	1.30	<b>124</b>
<b>4</b>	North Trent	1094.2	87.2	27.96	1.43	<b>124</b>
<b>7</b>	Lancs & S Cumbria	1140.1	90.9	23.71	1.35	<b>122</b>
<b>8</b>	Greater Manchester & Cheshire	1043.8	83.2	29.10	1.45	<b>120</b>
<b>8</b>	Dorset	1254.6	100.0	16.07	1.20	<b>120</b>
<b>10</b>	Sussex	1231.7	98.2	16.69	1.22	<b>119</b>
<b>11</b>	Pan Birmingham	976.0	77.8	32.33	1.51	<b>117</b>
<b>12</b>	Black Country	1069.9	85.3	23.75	1.35	<b>115</b>
<b>12</b>	Norfolk & Waveney	1152.5	91.9	18.52	1.25	<b>115</b>
<b>14</b>	Mid Trent	1062.9	84.7	23.24	1.34	<b>113</b>
<b>15</b>	Yorkshire	997.3	79.5	25.55	1.38	<b>110</b>
<b>16</b>	North West Midlands	1057.1	84.3	19.97	1.28	<b>108</b>
<b>17</b>	Derby/Burton	989.6	78.9	22.87	1.33	<b>105</b>
<b>18</b>	Kent & Medway	1072.1	85.5	16.55	1.21	<b>104</b>
<b>19</b>	Mid Anglia	1068.5	85.2	14.67	1.18	<b>100</b>
<b>20</b>	South Essex	1003.2	80.0	17.49	1.23	<b>98</b>
<b>20</b>	3 Counties	1055.0	84.1	13.97	1.17	<b>98</b>
<b>22</b>	Arden	977.0	77.9	18.44	1.25	<b>97</b>
<b>22</b>	Central South Coast	1046.7	83.4	13.95	1.17	<b>97</b>
<b>24</b>	Avon, Somerset & Wilts	997.6	79.5	15.73	1.20	<b>95</b>
<b>25</b>	North East London	787.7	62.8	31.98	1.50	<b>94</b>
<b>26</b>	Leics, Northants & Rutland	943.1	75.2	17.53	1.23	<b>93</b>
<b>27</b>	South East London	814.1	64.9	26.21	1.39	<b>90</b>
<b>28</b>	North London	753.7	60.1	29.04	1.45	<b>87</b>
<b>29</b>	West Anglia	922.4	73.5	13.43	1.16	<b>85</b>
<b>30</b>	Mount Vernon	864.6	68.9	12.09	1.13	<b>78</b>
<b>31</b>	South West London	792.9	63.2	15.18	1.19	<b>75</b>
<b>32</b>	Surrey, W Hants & Sussex	885.9	70.6	8.03	1.05	<b>75</b>
<b>33</b>	West London	693.2	55.2	23.20	1.34	<b>74</b>
<b>34</b>	Thames Valley	802.2	63.9	10.94	1.11	<b>71</b>



**Notes:**

- a) The first column records the average annual number of observed deaths per 100,000 population for all underlying causes for the years 2002 to 2004. The data source is the Compendium of Clinical Indicators produced by the Health and Social Care Information Centre
- b) The second column translates the data into an index. The index values are calculated relative to the Network with the highest ratio of deaths to 100,000 population i.e. Dorset Cancer Network.
- c) The third column records the average deprivation score for Super Output Areas across each Cancer Network. This has been calculated from the average SOA scores for each PCT population within each Cancer Network. The original data source is the Index of Multiple Deprivation 2004.
- d) The fourth column translates the deprivation score into a deprivation modifier for each Network. The calculation of the modifier is based on the assumption that a PCT population with the highest level of deprivation may need twice the palliative care resources per head of population compared with the PCT with the lowest level of deprivation. The calculation of the modifier contains two steps. The first consists of the calculation of the modifier for each PCT within the Network. The modifier represents the relative position of each PCT population between the highest level of deprivation of any PCT (this would be represented by a modifier of 2) and the lowest level of deprivation of any PCT (this would be represented by a modifier of 1). The second step consists of population weighting each PCT modifier within the Network and deriving an average network modifier.
- e) The final column is the product of the modifier and the Index Value in the second column.

**Interpretation of the Network Index**

- a) The Cancer Network ranked 1 has the population with the greatest palliative care resource need per head of population and that ranked 34 has the lowest need.
- b) A Network with an index value of around 101 could be considered to have a population with average need
- c) A Network with an index value of around 112 could be considered to have a population with about 10% above average need; that with an index value of around 122 about 20% above; that with an index value of around 132 about 30% above.
- d) A network with an index value of around 91 could be considered to have a population with about 10% below average need; that with an index value of around 81 about 20% below; that with an index value of around 71 about 30% below.

August 2006

Rosie Winterton MP  
Minister of State for Health Services  
House of Commons  
Westminster  
London  
SW1A 0AA

3<sup>rd</sup> July 2006

Dear Rosie,

Thank you for attending the All Party Hospice and Palliative Care Group on 27<sup>th</sup> June and we were pleased that you were able to hear first hand the issues and challenges around current and future funding for palliative care, as well as the opportunities to work together to deliver more responsive services in line with the White Paper 'Our health, our care, our say'.

We really welcome your announcement that you intend to set up a strategic review of end of life care and we look forward to working with Mike Richards and Ian Philp in developing this strategy. It was very reassuring to receive Mike's helpful letter the next day setting out further details and timescale for the strategy and we were pleased to see that funding issues for hospices and specialist palliative care are included in this important work and that it will establish the means whereby the government's manifesto commitment to palliative care and its White Paper proposals can be delivered. As we all stressed at the meeting the NCPC and its voluntary sector partners are really committed to working with Mike and Ian on all the issues to be addressed within the strategy. If we could only make progress on the funding issues then the voluntary sector could focus its expertise on developing creative solutions to wider choice and access for people who need palliative care.

In summary, there are two areas of concern. The first is about current funding levels. As you have heard in many parts of the country there is erosion of baseline NHS funding of both NHS and voluntary services and we are also seeing some erosion of the extra £50 million.. As a result, the optimism generated by the £50 million, the NICE Guidance and the EOL initiative is gradually giving way to frustration at seeing how hard won gains are now being lost. There is also a sense of powerlessness in seeking to prevent that and not knowing what to do next except to draw attention to erosions of funding and services when these occur.

The second area of concern that we raised is about future funding. It was made clear that there is general support for the Government's commitment to the introduction of PbR. There is also widespread support for the commitment to full cost recovery in respect of voluntary hospices services provided for NHS patients that would otherwise have to be provided by the NHS itself. We want to know how Government proposes to do that. Delay in doing that breeds scepticism about whether full cost recovery will ever happen.

We acknowledge that some progress has been made to fulfil these commitments. HRGs have been developed and endorsed by the NPG and approved for use. The NHS has put forward proposals for how they should be costed and developed service specifications that would underpin them. A response is awaited by the DH PbR team to these proposals. However a view now seems to be emerging from the PbR team that the current model of PbR may not work for

services provided by the voluntary sector. We would dispute that. The proposals that the NPG has put to the PbR team demonstrate that the current model can work. The major problem is not with PbR, It is with funding services currently provided by voluntary hospices for NHS patients.

The funding gap between what the NHS contributes and what voluntary hospices spend on care for NHS patients is probably around £150 million. The government through its policy of full cost recovery is publicly committed to bridging that gap. It is hard to escape the conclusion that more money is needed through a central budget.

To help to address these issues the NCPC is now enclosing some proposals agreed by its Board and partner organisations that it would welcome your views on. We look forward to working with you on resolving these important issues

Yours sincerely,



Eve Richardson  
Chief Executive  
The National Council for Palliative Care



David Prall  
Chief Executive  
Help The Hospices



Tom Hughes Hallet  
Chief Executive  
Marie Curie Cancer Care



Iain Henderson  
Chief Executive  
Sue Ryder Care

CC: Sue Hawsett, Professor Mike Richards & Ian Philp (Department of Health) and Ed Milliband MP

## Arrangements for Future Funding of Specialist Palliative Care Services

### A Position Statement

#### Background

1. In the Government's Response (Command 6327) to House of Commons Health Committee Report on Palliative Care Fourth Report of Session 2003-04 it was stated as follows:

'We remain on course to implement Payment by Results (the national tariff) with respect to palliative care in both the NHS and voluntary sector by 2008/9. In the run up to this milestone the Department of Health proposes to work up a national strategy to achieve and deliver the national tariff in consultation with the National Partnership Group for Palliative Care.

In palliative care the national tariff will, in effect, provide the full cost recovery recommended by HM Treasury's *Cross Cutting Review on Voluntary and Community Sector in Public Service Delivery*.

However, it is likely that full cost recovery will take time to implement, with contracts being renewed on a case by case basis over the five years from the publication of the Cross Cutting Review recommendation up to 2008. Within the context of healthcare provision it is important to remember that these contracts will be determined by Primary Care Trusts, as commissioners, and local service providers.'

2. There is therefore a clear commitment by Government:
  - To implement Payment by Results for both the NHS and the voluntary sector by April 2008.
  - To develop a strategy to achieve that in consultation with the National Partnership Group
  - To see the national tariff as a means towards the provision of full cost recovery for the voluntary sector
  - To achieve full cost recovery by April 2008 (but recognising that commissioning of palliative care services is for determination locally by Primary Care Trusts)
3. The National Council for Palliative Care welcomed these commitments and now seeks to ensure that they are fulfilled.

## **Progress in Fulfilling Government Commitments**

4. In 2005 the NHS Health and Social Care Information Centre established an Expert Working Group to develop Health Resource Groups (HRGs) for Specialist Palliative Care Services
5. The EWG has completed its work and the recommended HRGs have been approved for use by the Department of Health Payment by Results Team. They will be used for costing during 2006/7 and for reimbursement against tariff from April 2008.
6. The NHS Information Centre has published the HRGs with a view to obtaining feedback that will enable the Centre to help focus its implementation effort.
7. A working group of the NPG has set out a recommended approach to the costing of the HRGs and to the development of NHS minimum service specifications which underpin the HRGs. This approach applies equally to both NHS and voluntary managed services.
8. The NPG has endorsed both the HRGs and the recommendations from its working group on costing and service specifications.
9. The NPG working group has identified the data requirements which in its view will be essential to the costing process which should take place in 2006/7. The PbR team has been asked to approve these so that arrangements can be put in hand for data collection from a representative sample of NHS and voluntary sector providers of specialist palliative care services.
10. The Department of Health has initiated an economic review of the implications of PbR and full cost recovery. The result of that review is awaited.

## **Outstanding work and issues**

11. Further work on costing and service specifications cannot usefully proceed unless and until the Department of Health PbR team responds to the NPG recommendations on the approach to costing the HRGs, to development of service specifications and on the data requirements for the costing process.
12. Further work is also required to develop HRGs for community services supplementary to the specialist palliative care services which are not currently included in the approved set of HRGs e.g. hospice at home type services, bereavement support services.
13. It is recognised that the introduction of PbR for specialist palliative care services does not in itself increase the amount of cash in the system for funding contracts between local NHS commissioners and service providers.

Given that the current NHS funding contribution to the costs of voluntary hospices is, on average across England, around one third of their annual running costs and that most of their activity is in respect of NHS patients, there is clearly a significant shortfall in the amount of NHS funding that would be required to meet the Government's commitments. The measurement of the funding gap is likely to be somewhere between £150 and £200 million. A more precise estimate is anticipated from the economic review referred to above.

14. In recognition of this funding problem it has been suggested by the Head of the PbR team that consideration should be given to the introduction of differential tariffs between the NHS and the voluntary sector that reflect the currently available NHS cash in the system for each sector i.e. a 100% tariff for the NHS and one third of the tariff for the voluntary sector. The NPG is totally opposed to such an arrangement. It believes that any tariff should reflect 100% of the costs of treating NHS patients and should be applied equally to both NHS and voluntary sector services.

It should also be recognised that the introduction of differential tariffs would not enable the Government's commitment on full cost recovery to be realised. Nor would it be realised if the currently available cash in the system was to be used to fund the full tariff for one third of activity. If referrals of NHS patients to voluntary hospices continued at current levels, the consequence of that would be that over half of all voluntary sector activity for NHS patients would attract zero cost recovery from the NHS.

15. There is considerable variation in the volume of services currently provided in relation to assessed need. Some service provision is in excess of assessed need and some is much less than assessed need would indicate.

There is also considerable variation in the current NHS funding contribution to individual hospices expressed as a percentage of their total annual running costs.

In consequence of these factors the funding gap is likely to vary considerably at local level (even when deficits in service provision against assessed need are not taken into account). Further variation may result as a consequence of decisions by individual NHS commissioners in respect of the volumes of services they consider to be necessary for their populations in the context of overall budget constraints and priorities.

## **Conclusions**

16. It is clear that the Government's commitment on full cost recovery cannot be met in respect of the current level of patient activity undertaken by voluntary hospices without additional funding for that activity.

17. Such funding would need to be provided either from existing commissioning budgets or from a new central budget or from a mix of the two.
18. Given the current and likely future pressure on PCT budgets and that commissioning priorities are a matter for local decision it is unlikely that in the majority of cases that the first possibility is realistic.
19. The only way forward would therefore appear to be for the creation of a central budget. (In this connection it is noted that the Government has recently established a central budget of £27 million for distribution to children's hospices).
20. The fair distribution of such a budget would have its difficulties taking into account that the funding gaps when measured locally would vary considerably.

### **Recommendations**

21. That the Government should re-state its commitments as set out in Command Paper 6327
22. That the current timetable for the introduction of PbR in 2008 be adhered to.
23. That the current model of PbR should continue to be seen as the appropriate vehicle for the introduction of PbR for both NHS and voluntary sector specialist palliative care services.
24. That the Department of Health PbR team be asked to resolve in consultation with the NPG, without any further delay, the outstanding issues relating to costing of the HRGs and the development of service specifications.
25. That the Government should set out how it proposes to meet those commitments and its timetable for so doing.
26. That as a means of achieving its commitments consideration should be given to establishing a central budget of a size that would help to deliver full cost recovery for NHS patients referred for care to specialist palliative care services provided in compliance with the proposed service specifications.
27. That the NPG be invited to undertake work to measure the funding gaps at local level and to consider, in the light of that, how a central budget might best be allocated.

June 2006

From the Rt Hon Rosie Winterton MP  
Minister of State for Health Services



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26 JUL 2006

*De Gov,*

*20 July 2006*

Thank you for your letter of 3<sup>rd</sup> July about the future funding of palliative care. I was pleased to meet you and your colleagues at the All Party Parliamentary Group on Hospices and Palliative Care on 27<sup>th</sup> June 2006 and do appreciate the opportunity that meeting gave me to hear first-hand the concerns of the palliative care voluntary sector regarding funding and other issues.

Payment by Results (PbR) increases transparency in the way NHS services are funded by paying providers according to volume and complexity of cases and on the basis of a national tariff. We have started with acute services commissioned from NHS Trusts and Foundation Trusts, and we intend to increase the range of coverage. We will set out further details in our *Future of PbR* publication this autumn.

However, we are doing this in a managed way by introducing the tariff incrementally over four years and limiting the financial impact. An important principle governing the introduction of PbR in England is to ensure a 'zero sum game'. For example, we have introduced PbR for NHS Trusts and Foundation Trusts by setting tariffs that reflect historical commissioning patterns and average levels of baseline funding. In this way, the roll-out of PbR involves reducing payments to hospitals that have been funded above the national average so that payments can be increased for hospitals that have been funded below the national average.

In line with this principle, any extension of PbR into other sectors must be cost neutral for baseline activity (i.e. before growth). An extension of PbR to Specialist Palliative Care would not increase funding for voluntary sector hospices and therefore would not, of itself, provide a basis for full NHS funding. Moreover, future pricing policy (e.g. PbR) and baseline funding levels are separate issues as you have helpfully distinguished in your letter.

In general, the Department is not prescriptive about the level of funding that PCTs must provide for particular services. However, following HM Treasury's



cross-cutting review the Department notified PCTs of their obligation to ensure Full Cost Recovery in respect of activity commissioned from the voluntary sector. This means that the level of funding agreed locally must include a provision for overheads as appropriate for the volume of activity commissioned by the PCT.

Finally, as you know I have charged Mike Richards, with support from Ian Philp, to prepare an end of life care strategy. As well as addressing the commitments in the manifesto and *'Our health, our care, our say'*, this will take account of a number of other important issues, including funding issues for hospices and specialist palliative care issues. I understand that the National Council has been invited to put forward suggestions and ideas for this work. Mike and Ian are to report to me in the autumn. I look forward to receiving their report then.

Yours etc,  
Rosie Winterton

**ROSIE WINTERTON**

## End of Life Care Strategy The National Council for Palliative Care Submission

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