

The Current National Picture in Palliative Care

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The Context for Development of National Policy

- Demography and epidemiology of mortality
- Aging population
- Growing incidence and prevalence of dementia
- Current access to specialist palliative care services
- Place of care and death
- Current issues in end of life care

Underlying Causes of Death England & Wales 2005 (ONS)

Neoplasms	138,454	27.0%
Diseases of Nervous System	15,209	3.0%
Diseases of Circulatory System	183,997	35.9%
Diseases of Respiratory System	72,517	14.1%
Other causes	102,505	20.0%
All Causes	512,682	100%

Underlying Causes of Death

Points to note

- 83.1% of all deaths are of people aged 65 and over
- 32.7% of all deaths are of people aged 85 and over
- Two thirds of deaths of people aged 85 and over are of females
- 77% of all cancer deaths are of people aged 65 and over

The Aging Population

- Between 1995 and 2025 the number of those over 80 is set to increase by almost half – those over 90 will double
- More people will live alone particularly women – in the over 75s they outnumber men 62% to 38%, in the over 85s by 71% to 29%
- The longer people live the more likely it is for them to have multiple conditions particularly symptoms of dementia

Prevalence of Symptoms of Dementia

Current Estimates of People with Dementia

England	652,000
Scotland	63,700
Northern Ireland	17,100
Wales	41,800
Total	775,200

*Estimated to rise to 870,000 by 2010 and to
1.8 million by 2050*

Prevalence of Symptoms of Dementia by Age

50/60% of people in care homes have symptoms of dementia

Age Band	Prevalence
40 to 65	1/1000
65 to 70	1/50
70 to 80	1/20
80 plus	1/5

Access to Specialist Palliative Care Services by People with Non-Cancer Diagnosis

	06/07	05/06	04/05	96/97
Hospital Support	13.6%	13.1%	11%	5%
Day Care	10.1%	9.3%	7.9%	6%
Home care	7.3%	6.2%	5%	3%
In-patient	7.2%	6.1%	5.3%	5%

Patient Choice over place of death

Patient preferences from national survey

- 56% at home
- 24% in hospice
- 11% in hospital
- 4% in care home
- 5% elsewhere

Actual place of death for England & Wales for 2005

- 18.4% at home
- 4.7% in hospice
- 58.2% in NHS hospitals
- 16.1% in care homes
- 2.6% elsewhere

Place of occurrence of male & female deaths

- 6.5% of male deaths occur in care homes with nursing but 12.1% of female deaths
- 3.6% of male deaths occur in residential care homes but 9.2% of female deaths
- 21.7% of male deaths occur at home but only 15.4% of female deaths

Deaths: Place of occurrence, England & Wales 2005 ONS

Place of occurrence of death by underlying cause

Underlying Cause	Circulatory Disease	Respiratory Disease	Diseases of Nervous System	Neoplasms
NHS Hospitals	60.3%	67.9%	45.1%	49.5%
Hospice	0.2%	0.3%	1.7%	16.1%
At Home	21.4%	12.3%	12.0%	22.6%
Elsewhere	18.1%	19.5%	41.2%	11.8%

Current Issues in End of Life Care

1

- While many receive excellent care, many do not
- Death & dying often not discussed by professionals with patients
- Patients' preferences for care often not elicited
- Needs for care not adequately assessed
- Care may not be planned or reviewed

Current Issues in End of Life Care

2

- Services may be patchy and poorly coordinated especially across organisational boundaries
- Families/carers may be inadequately supported
- Patients are offered inadequate choices about the nature and location of their care

End of Life Care Strategy

Development of National Policy for End of Life Care

- In 2005 the Labour Party set out its manifesto commitment to improve choice at end of life and to increase investment in palliative care

Our health, our care, our say (2006 White Paper)
emphasised need for

- Strategic planning of local services
- Rapid response services to enable patients to stay at home
- Programmes to skill up workforce in EOL care delivery

End of Life Care Strategy

June 2006 Ministers announced that DoH would develop a EOL strategy which should:

- Encompass patients with all conditions in all care settings
- Build on the experience of specialist palliative care and hospice services
- Build on the existing EOL Care Programme (GSF, LCP, PPC)
- Build on the experience of the Marie Curie Delivering Choice Programme and other innovative services
- Review funding arrangements for specialist palliative care services
- Due to be published in July 2008

Emergent Themes for EOL Care

1. Raising the profile of EOL care
2. Strategic commissioning
3. Identifying the patient/client group
4. Care planning
5. Coordination of care
6. Rapid access to care
7. Integrated service delivery
8. Last days of life & care after death
9. Involving and supporting carers
10. Education, training, CPD

Strategic Commissioning

- Integrated approach to planning, contracting and monitoring of service delivery
- Future commissioning to be based on joint strategic needs assessments undertaken by PCTs & Local Authorities across health and social care
- Ensuring that services are in place that can meet patient and carer needs at each step of the pathway – commissioning against the pathway
- Need for service specifications
- Need for mechanisms to ensure coordination of services

Care Planning

- Needs for care often not adequately assessed
- Patients' preferences for care not always elicited
- Need for comprehensive holistic needs assessment at beginning of end of life and at all key points of major change e.g. in diagnosis, treatment, prognosis, carers' ability to cope, at diagnosis of dying
- All patients to have a care plan through which needs are met and reviewed on an iterative basis
- Patients enabled to make Advance Decisions
- Care plan to be open to access by all who need it

Coordination of care

- Need to establish mechanisms to ensure that each person receives care in accordance with the care plan, across all sectors and at all times, day and night
- Need to consider a central coordinating facility e.g. Marie Curie Delivering Choice Programme
- 'Action for London' EOL care review has suggested the creation of locality wide registers of people approaching end of life.

Funding Mechanisms for SPC Services

Review of Current Situation
And
Potential Solutions

Outstanding Questions

- Service specifications, costing and pricing
- Will PbR be introduced for palliative care?
- If so, when?
- What has happened to the 2004 commitment on full cost recovery?
- Will the EOL strategy resolve these outstanding issues?

Current Situation 1

- Scope of PbR is limited to acute services provided by or for the NHS
- Scope excludes NHS community services and independent/voluntary services
- DH response to the consultation on 'The Future of PbR' published in January 2008
- No reference to introduction of PbR in the voluntary sector

Current Situation 2

Priorities for Extension of PbR

1. Mental health
2. Community services
3. Critical care
4. Urgent and emergency care
5. Long term conditions

How PbR is to be used in future is to some extent dependent on the Darzi review

Current Situation 3

- Existing HRGs for specialist palliative care services could be introduced in 2009/10 but only for NHS acute sector
- Policy on Full Cost Recovery for voluntary services was always dependent on introduction of PbR
- Cost for PCTs of over £200 million extra for voluntary hospices probably unrealistic
- EOL strategy unlikely to resolve most issues since dependent on general policy considerations?

Current Situation 4

- Further work on service specifications dependent on identifying structure & process standards (quality standards)
- Timing and probability of that work uncertain – consequential uncertainty about when it will be possible to estimate costs of service delivery in compliance with them
- Variations in service models may arise from the SHA workstreams on EOL
- Reference cost data for current NHS services limited; for voluntary services non-existent

Options

1. Assume that new national policies will resolve outstanding issues and wait for promulgation of them
2. Take action at a local level now that will resolve some of those issues

Option 1

Considerations

- Resolution of funding issues at national level has been outstanding for 2 decades
- Clear national policies were established in 2004 for their resolution but have not been implemented
- Any new policies would need to be accompanied by an implementation plan
- There is as yet no news of that!

Generic Models of PbR

DH paper on Future of PbR proposed 3 generic models:

1. National currencies (HRGs) & associated national tariffs
2. National currencies (HRGs) & associated local tariffs
3. Local currencies & associated local tariffs

Option 2

1. Adopt the generic models
2. Define 'local' – probably SHA wide rather than Cancer Network wide or single PCTs
3. Develop local tariffs for the approved HRGs
4. Develop local currencies and tariffs for services not covered by HRGs

Option 2

5. Develop service specifications for each core service element
6. Cost the specifications (reference or normative)
7. Identify units of cost measurement (the currencies)
8. Negotiate associated tariffs

Measurement of Structure, Process & Outcome

Current Situation 1

- Guidance on structure & process standards and outcome measurement has not yet emerged in the course of EOCLC strategy development
- Current plethora of structure & process standards – NICE Guidance, NSFs, Cancer Manual, regulatory framework
- Probability of a continuing lack of guidance on outcome measurement

Current Situation 2

- National policy on commissioning for outcomes
- Increasing need for commissioners to measure performance of services in terms of population access to services, their effectiveness, their efficiency and value for money
- Absence of measures likely to disadvantage palliative and EOLC services

Way Forward – Structure & Process

Review all current structure & process standards with a view to retaining only those for which there is evidence that they are necessary conditions for achievement of good outcomes for patients, families and carers

Way Forward – Outcome Measurement

Stimulate a national debate in order to discover whether there is any consensus about the answers to the following:

What are the principal reasons for wanting to measure?

What should be measured?

When should it be measured?

How should it be measured?

NCPC to publish a discussion paper

Why outcome measurement?

- To demonstrate the degree of equality of access
- To demonstrate the degree of effectiveness of care
- To demonstrate how far care is efficiently provided
- To reveal whether care provided is value for money i.e. cost-effectiveness
- To facilitate comparison of performance through benchmarking

The 3 levels of measurement

At three levels:

1. At an individual patient or carer level
2. In aggregate for a group of patients or carers served by a team, unit or organisation
3. At a population level

What should be measured & when at patient level

- **WHAT** - Whether the care goals agreed with the patient and/or carers have been achieved wholly, partly, not at all or whether intervention has had a negative effect
- **WHEN** - At the end of each episode of care e.g. at each transition point from the care of one team to another and/or at each comprehensive needs assessment

Patient Choice

- Dependent on the individual patient assessment process – identifying needs and eliciting patient preferences about the care that can meet those needs
- Choice is related to meeting needs and not wants
- Choice cannot be open ended – never enough resources to meet all needs of all people at all times
- Key question is about what options should always be available

NCPC to publish a discussion paper

Nursing Home Provision

- Provision has been measured in places per 100,000 population for 148 local authorities i.e. London Boroughs(32), Metropolitan County Districts(36), Unitary Authorities(46) and County Councils(34).
- Variation in provision ranges from 16 places per 100,000 in Haringey up to 761 in North Somerset.
- In NE from 359 (S Tyneside) up to 538 (Newcastle)
- Variation in provision based on the 28 former SHA populations ranges from 176 places per 100,000 in N London up to 518 in Surrey/Sussex
- In Co. Durham & Tees Valley provision is 475 per 100,000 and in Northumberland Tyne & Wear 417.

Deaths in Nursing Homes

- Annual deaths in nursing homes has been expressed as a ratio of places to deaths in each of the 28 former SHA populations
- The variation is from 0.37 deaths per place per year in Essex down to 0.12 deaths per place per year in NE London.
- In County Durham & Tees Valley it is 0.25 and in Northumberland Tyne & Wear it is 0.20
- The percentage of all deaths that occur in nursing homes varies from 3.6% in NE London up to 13.3% in Surrey/Sussex
- In County Durham & Tees Valley it is 11.4% and in Northumberland Tyne & Wear it is 7.6%

Possible effect of level of nursing home provision on place of death

- The 3 former SHA populations with the highest provision have lower than average percentages of hospital deaths (53.8%, 55.4%, 56.6%)
- The 3 former SHA populations with the lowest provision have higher than average percentages of hospital deaths (70.9%, 64.1%, 61.7%)
- 11 out of 13 with higher than average provision have lower than average hospital deaths
- 10 out of 15 with lower than average provision have higher than average hospital deaths