

# The Significance of Data

Palliative & End of Life Care

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# Why do we need data?

To demonstrate to commissioners, general public and service users that services to patients, their carers and families are provided:

***Equitably***

***Efficiently***

***Effectively***

***Cost-effectively***

# What data is needed?

- About the population in need of palliative and end of life care (the client group)
- About those in need who access services and those who do not
- About the degree to which the outcomes of support and care reflect the aims of such support and care
- About the resources that are employed to produce such support and care

# Some key concepts

- **Equity:** the principle that those who are in similar need of palliative and EOL care should receive the same level of care
- **Efficiency:** the principle that for any given output, the inputs employed to produce it are minimised (cost)
- **Effectiveness:** the measurement of the degree to which the aims of care are achieved (quality)
- **Cost/effectiveness:** occurs when inputs are combined so as to minimise the cost of any set of desired outcomes (relationship between cost and quality)

# Data about the whole palliative & EOL care service

- About generic as well as specialist and other discrete palliative care services
- About social care as well as health care
- Includes providers in statutory, voluntary and independent sectors
- At home, in hospitals, in care homes, in other institutions – wherever the individual happens to be

# Never enough data

- No common data set across principal services provided by health and social care in the statutory, voluntary and independent sectors
- Very little data about the financial and other resources employed
- Very little data about the outcomes of care

**BUT**

***Less than optimal use made of data that is available***

# Equity - 1

- The client group is defined as all those individuals with advanced, progressive illness/conditions (for EOL add 'incurable')
- How large is that group in specific populations?
- How is that group made up? By age, gender, diagnosis, ethnicity, relative socio/economic deprivation
- There is a need to know in order to assess whether access to services reflects the make-up of the client group in those terms

# Equity - 2

*Populations vary in respect of palliative care need*

- Incidence of mortality ranges from a ratio of 512 per year per 100,000 population in Kensington & Chelsea PCT up to 1533 per year in Hastings & Rother PCT
- The England average is 989 per year per 100,000 population
- The client group which may consist mainly of those in the last year of life differs considerably in its proportion of specific PCT populations

# Equity – 3 Place of occurrence of death by underlying cause

Underlying cause	Circulatory disease	Respiratory disease	Diseases of nervous system	Neoplasms
NHS Hospitals	60.0%	64.5%	43.7%	50.0%
Hospices	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%

## Equity – 4 Place of occurrence of male and female deaths

- 6.7% of male deaths occur in care homes with nursing but 12.5% of female deaths
- 3.7% of male deaths occur in residential care homes but 9.7% of female deaths
- 21.6% of male deaths occur at home but only 15.3% of female deaths

*Deaths: place of occurrence, England 2004 ONS*

# Equity – 5

## Deaths in care homes

- As at March 2005 there were 4058 nursing homes in England with 177,021 beds (*data source CSCI*)
- Number of deaths occurring in nursing homes for 2004 was around 46,600 (*data source ONS*)
- Average number of deaths per bed was around 0.26 per year i.e. around 1 death per 4 beds per year.
- For any PCT population if that ratio was significantly lower than the national average then that could indicate unnecessary transfers to hospital in the dying phase.

# Equity – 6

## Place of care in last year of life

- Data generally not available
- Data could however be collected relatively easily about those dying in institutional care (in hospital, care home, hospice) in respect of:

Place from which the individual was admitted

Length of the final episode of institutional care

# Efficiency

- Data about inputs to services in financial or other terms is generally not available
- Difficulties arise from differences in service models, units of cost measurement and apportionment of costs to specific service elements
- MDS provides patient activity data but only for specialist palliative care providers – some measures of output (but not quality) are therefore available
- Only some NHS services collect and submit reference costs for NHS managed palliative care services
- In the absence of comprehensive data a benchmarking approach may be helpful

# Development of Benchmarking Techniques - 1

- Publication of Indices of Comparative Care Need for all new PCT populations (Compendium of Data for SHAs & PCTs, NCPC; 2006)
- Based on annual mortality and relative socio/economic deprivation
- Indicates a variation in resource need per head of population from 50% below average (Kensington & Chelsea) to 50% above average (Blackpool) for individual PCT populations

# Development of Benchmarking Techniques - 2

- Further work being undertaken on benchmarking resource availability and resource use against the Indices of Comparative Need
- Techniques demand service mapping and patient activity data
- Required data currently available for only a sample of PCTs (22 out of 152)

# Sample PCTs for Benchmarking - 1

<b>PCT</b>	<b>Index Rank</b>	<b>PCT</b>	<b>Index Rank</b>
Liverpool	2	Portsmouth	60
Knowsley	5	Dorset	64
Torbay	6	West Cheshire	86
Wirral	15	Warrington	90
Isle of Wight	16	Southampton	91
Sefton	18	Hampshire	124
Halton & St Helens	27	Oxfordshire	139
Bournemouth	30	Buckinghamshire	143
Cornwall	36	Berkshire East	146
Plymouth	56	Milton Keynes	148
Devon	57	Berkshire West	151

# Sample PCTs for Benchmarking - 2

- Combined population of 8.161 million
- Total specialist palliative care beds accessed by the population – 412 beds
- Average number of beds accessed per 100,000 population – 5.05
- Range of numbers of beds accessed by each PCT – from 3.06 to 8.96 per 100,000
- Total number of first time admissions – 6922
- Average number of admissions to beds – 16.8
- Range of numbers of admissions per bed for each PCT – from 12.7 to 23.6

# Sample PCTs for Benchmarking - 3

*Does the variation in access to beds reflect differential population resource need?*

1. The PCT with the lowest ratio of beds to population has average need and has a 40% deficiency as against need.
2. The PCT with the highest ratio of beds to need has very low need and has a 200% excess as compared with need.
3. Only one third of the PCTs have a ratio that roughly reflects differential need.

# Sample of PCTs for Benchmarking

- 4

*Are there any significant variations in use of beds?*

1. Those PCTs with a higher level of access to beds than would be indicated by the index of differential need tend to have a low ratio of new admissions per bed (9 out of 12 PCTs in the sample)
2. This may indicate less pressure on beds and may lead to longer LOS and/or more re-admissions
3. Those PCTs with a lower level of access to beds than would be indicated by the index of differential need tend to have a high ratio of new admissions to bed (7 out of 10 PCTs in the sample)
4. This may indicate more pressure on beds and may lead to shorter LOS and/or fewer re-admissions

# Sample of PCTs for Benchmarking

## 5

- Total number of Community CNS: 194
- Average number per 100,000 population: 2.5
- The average number per 100,000 for each PCT varies from 1.36 up to 3.87.
- It may have been expected that higher than average provision of CNSs would be associated with lower than average bed provision and vice versa but in there are only 8 such instances in the sample.
- In the remainder 8 had higher then average bed and CNS provision and 6 lower than average bed provision coupled with lower than average CNS provision

# Effectiveness

*Attempts to measure effectiveness usually fall into one of the following:*

1. Measuring compliance with structure and process measures (standards)
2. Measuring outputs in terms of quantity (patient activity data)
3. Assessment and re-assessment of individuals' needs
4. Patient and carer surveys

*None of these attempts appear to measure change in an individual's health status that can be attributed to preceding health care*

# Value for Money (cost/effectiveness)

*In order to assess value for money we need data about both inputs and outputs*

*Very little data is available about inputs*

*Some data is available about outputs e.g. MDS patient activity data*

*Very little data is available about outcomes that can be related directly to palliative care intervention*

## **Conclusion**

**Not possible currently to assess value for money**

# Payment by Results

## Additional Data Requirements 1

*As and when PbR may be introduced for palliative/EOL care the following data additional to the new MDS may be required:*

- LOS at an individual patient level i.e. number of in-patient stays of each length from 1 day upwards
- Similar LOS data for respite care

# Payment by Results

## Additional Data Requirements 2

- Professional composition of the SPC Hospital Support, Community support and combined Out-patient/Day Therapy teams
- Current cost data in respect of all services that are subject to national currencies i.e. subject to HRGs:

Clinical team costs

Other clinical costs

Support service costs

General management and other overheads

# Summary

- There is a need to make better use of the data that is available
- Benchmarking may be a useful approach but its development will be dependent on a new collection of some workforce and financial data
- It will also be necessary to make the revised MDS into a mandatory collection
- It will be necessary, as and when the EOL strategy is fully developed to identify the additional data requirements that will enable its implementation to be monitored
- If PbR is introduced there may be additional data requirements