

Data and the End of Life Care Strategy

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Data and the EOLC Strategy

- Who needs data?
- What data and why?
- What data do we currently have?
- What are we doing now?
- What will we need to do in the future?

Who needs data?

- Patients and carers
- Clinicians
- Commissioners
- Service providers
- Policy makers
- Researchers

Patients' questions

- How would I like to be cared for?
- What services are available locally?
- How good are they?
- Which services best meet my needs and preferences?

➔ Directory: "Good EOLC Guide"

Clinicians' questions

- What specific problems / concerns does my patient have?
 - and how severe are they?
- How are these problems changing?
 - is the treatment I am giving making a difference?
- How well does the care that my team provides to our patients compare with that provided by other teams?

➔ Patient assessment tools and clinical audit

Commissioners' questions

- What are the levels of need in the population we serve?
 - What services do we currently have?
 - How good are they (quality)?
 - How fairly distributed are they (equality)?
 - Are they meeting patients' needs and preferences (choice)?
 - What are the gaps?
 - What am I currently investing?
 - Are we getting good value for money?
- ➔ Population needs assessment; service profile; costs and outcomes

Service providers' questions

- What services are we providing?
 - How good are they (quality)?
 - Are we meeting the needs of all our patients / carers?
 - How do we compare with other service providers?
 - Are our services efficient and cost effective?
 - How does income from EOLC match expenditure?
- ➔ Benchmarking of quality and efficiency

Policy makers' questions

- Broadly similar to commissioners' questions but on a larger scale
 - Population needs?
 - Current service profile?
 - Choice, quality, equality, value for money?

What data do we currently have?

- It depends on who we mean by “we”.
 - There is much more information available locally than nationally

Nationally available data

Now

- Number of deaths; cause of death and place of death (death certification)
- Specialist palliative care services workforce
- Resource utilisation – specialist palliative care

Soon

- QOF data from primary care
- HES data linked to death data to look at hospital admissions / attendances in final year of life
- Epidemiology trends
- Resource utilisation (hospitals; care homes)

Local data / intelligence: where next?

- Baseline service review led by PCTs
- Announced in the NHS Operating Framework for 2007/8
- Purpose: to promote stronger commissioning
- PCTs were asked to work jointly with Local Authorities and with all service providers
- Scope: All adults with advanced, progressive incurable illness – and families / carers (+/- children's services)

Baseline Service Review (1)

1. Epidemiology of death and dying
 - How many? What conditions? BME groups? Where?
2. Place of care in the last year of life
3. Service mapping (specialist and generalist)
4. Workforce and training
5. Quality of care
6. Choice

Baseline Service Review (2)

7. Service coordination (strategic and individual)
8. Equity
9. Research and audit
10. Expenditure
11. Governance
12. Areas of need (priorities)
13. Strategy and proposed developments

National data: Where next?

- Two of the six End of Life Care Strategy Working Groups are considering this
 1. Analysis
 2. Measurement

EOLC Strategy: Measurement

- Key question: How will we know whether end of life care has improved both locally and nationally in five years' time?
 - choice, quality, equality, value for money
- To address this a 'measurement framework' is being developed, based on:
 - steps in the end of life care pathway
 - measures of structure, process and outcome

Measurement Framework

Care Pathway	Measures		
	Structure	Process	Outcome
Public awareness			
Initiating discussions			
Care planning			
Coordination of care			
Service delivery			
Last days of life			
Care after death			
Care for carers			

Measurement framework

Potential measures (examples only)

- Surveys of public awareness / attitudes
- Numbers of patients with care plans
- Numbers of patients on registers
- Numbers of patients accessing SPC
- Use of tools (e.g. Liverpool Care Pathway)
- Surveys of bereaved relatives

Summary

- Data / information is vital to
 - good individual patient care,
 - local service planning and monitoring
 - national strategy
- Improving data on end of life care is a high priority