Death and dying

Understanding the data

EXECUTIVE SUMMARY

February 2013

Marie Curie Cancer Care

Executive summary

The delivery of end of life care in England is currently shared by hospitals, hospices, residential care homes, nursing services, families, carers and volunteers. This diversity enables us to meet the different needs and wants of people with terminal diagnoses, but also means that people are likely to have very different experiences of end of life care services.

To improve end of life care, we must enhance the quality of all services, in all settings. To help us do so, we must look at a range of data sources to examine patterns, experiences and outcomes in end of life care across different services and localities.

In October 2012, we launched the Marie Curie End of Life Care Atlas – http://apps.mariecurie.org.uk/atlas/flash/atlas.html. This tool helps commissioners, health and social care providers, policy makers and the public across the UK to identify gaps in end of life care in their areas.

Our new online report, *Death and dying: Understanding the data*, provides headline analysis of the key end of life care data for England – mariecurie.org.uk/deathanddying. It enables comparisons of different aspects of end of life care, different localities and different health care settings. By clicking on the various tables and charts in the full report you will be able to access the Atlas. To help you use the Atlas, we have produced a simple online guide.

Death and dying: Understanding the data provides analysis of external data sources and attempts to identify patterns of service delivery and outcomes. Much of the data used in the report has previously been published by the National End of Life Care Intelligence Network's profiles[1], Department of Health, Office of National Statistics and local NHS providers. What is new here is the policy analysis and the resulting recommendations. The report offers analysis at Primary Care Trust (PCT) and PCT cluster level, allowing us to identify local trends and variation in the provision of end of life care. The report does not set out to name and shame organisations, but rather seeks to identify variations in service delivery, expenditure and outcomes across all parts of England. It is this variation which emerges as the overarching theme of the report. It is intended to help commissioners and others to use the Atlas to address local gaps and identify where current provision is not delivering excellent quality care.

The focus here is on what Appleby and colleagues[2], call 'unwarranted' or 'bad' variation - those incidences for which there are no external explanatory factors for variations in service delivery and outcomes. In analysing the available data we are mindful of the complex factors which can lead to variation in the delivery and outcomes of health services. However, no matter whether one looks at experiences, perceptions, expenditure or outcomes, it is clear that there is significant variation in services for people at the end of life across England. It is important that we minimise 'bad' variation so that people can access the same high standards of care, regardless of where they live, or the types of services they use. Bad variation in all facets of end of life care can ultimately lead to an inefficient use of scarce resources.

1 http://www.endoflifecare-intelligence.org.uk/end_of_life_care_profiles/default.aspx
2 Appleby et al (2011) *Variations in Healthcare: The good, the bad and the inexplicable*, The Kings Fund
3 http://publications.nice.org.uk/quality-standard-for-end-of-life-care-for-adults-qs13

Chapter one

Explores the significance of demography for end of life care. Differing demographic patterns underline the importance of designing and commissioning services which reflect local populations and patterns of disease, and improve quality of care.

Recommendation: Clinical Commissioning Groups and Local Area Teams should follow NICE Quality Standard QS13[3] for end of life care. Commissioners should use the Marie Curie End of Life Care Atlas so that they can commission services and adjust targets to reflect local need.

Chapter two

Examines experiences of care, as seen through the eyes of those who had lost a loved one in the previous year. The VOICES Survey provides a fresh perspective. It is important that the survey becomes an annual occurrence and reports findings at Clinical Commissioning Group level. The clear message to emerge is that hospitals score worst for most measures of care, coordination and support, with higher ratings for hospices, home and care homes. This has been reinforced by the findings of the Francis report into care at Mid Staffordshire NHS Foundation Trust. This all supports a fundamental shift away from hospitals to home and community-based services. However, we must acknowledge that any such shift would take time and that it is important that we also improve end of life care in hospitals. Equally, we must focus on improving pain management for those who are cared for at home.

Recommendation: Marie Curie Cancer Care should work with the Royal Colleges to improve initial and continuous end of life care training for doctors and nurses and improve prescribing and pain management for patients at home.

Chapter three

Demonstrates the very clear variation in local spending on end of life care. We quickly conclude that a radical overhaul of reporting on end of life care spending in England is needed.

Recommendation: The National Commissioning Board should adopt a standardised approach to reporting spending on end of life care, such as that used for cancer spending.

Chapter four

Illustrates the divergent levels of recognition of palliative care needs and use of palliative care registers across England. It is clear that this variation is not simply explained by demographic differences, but rather reflects wider differences in local priorities. The recognition of palliative care needs should be the first step in setting in motion a series of interventions which support the person through to death. It is important that we move towards more outcomes-focused measures of performance.

Recommendation: The National Commissioning Board should develop outcomes-based Key Performance Indicators (KPIs).

Chapter five

Shows that where you live has a significant impact on where you die. It illustrates the very real differences in hospital death rates and the length of time people spend in hospital prior to death across England. The most striking differences are to be found between urban and rural areas. It is important that we explore how we can reduce the number of people who find themselves in hospital in the last few weeks and days of life, who do not want or need to be there.

Continued overleaf

Recommendation: As a first step, the coalition government should introduce free social care funding for those in the last six months of life. In the longer term, commissioners must grasp the nettle and shift the balance from hospital to community-based care. This will require a fundamental shift in thinking and ultimately in the ways services are funded. The results of the Palliative Care Funding Review Pilots will be important in moving this situation forward.

The current changes to the NHS, together with the realities of an ageing society and the current financial pressures on public spending mean that, for the foreseeable future, we will have to find ways to provide more appropriate services, for more people, with less money. The Marie Curie End of Life Care Atlas will help commissioners and those who deliver NHS services to identify gaps in the current provision of end of life care and to improve services across all parts of the country. The Atlas, alongside the recently published VOICES Survey, the Nuffield Trust's reports on social care at the end of life and its independent evaluation of the Marie Curie Nursing Service, provides a sound basis from which to fundamentally rebalance end of life care services and to improve outcomes for people at the end of life and their families and carers. The challenge over the coming years will be to achieve this goal.

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