

4 ABSTRACT: How using secondary data sources can enhance our understanding of end of life care
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Bowtell N¹, Verne J¹

1 South West Public Health Observatory

Aim: 1. To understand range and complexity of data sources currently available on end of life care; 2. How to best use data sources to inform needs assessment, and service planning and evaluation; 3. Areas where existing data is limited and needs further development.

Background: The South West Public Health Observatory has recently undertaken a systematic review of available data sources on end of life care. The compendium of data sources is now available on the NEOLCIN website. This resource enables commissioners to undertake needs assessments, to plan services, and to assess aspects of the quality of local care provision. Indeed, this resource has already been used by professionals, since its launch in June 2010, with 1,679 different individuals visiting the compendium.

Methods: A systematic review of routine data sources on end of life care. Resources were reviewed for their relevance, coverage, temporality and timeliness, completeness, and representativeness. A web-based tool was launched on the NEoLCIN website.

Results: The measure, *'The percentage of all deaths that occur at home'*, has been adopted as a national indicator (N129). To date 59 unique data sources have been identified held by 15 organisations, covering 14 topics. Data sources are available on service infrastructure, demography and disease trajectories. Service infrastructure sources include: hospice care (2), palliative care in hospitals (3), primary care (2), residential and nursing homes (8), social care (19), emergency hospital care (1) prison (1), and carers (5). Nine data sources can be used for the assessment of population change in terms of size, composition, and health status. Eight data sources provide data on illness and disease progression, to further understand place and quality of death.

Conclusion

For the first time, data sources on end of life care have been assessed and are now available on one site.

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