

25 HOW USING SECONDARY DATA SOURCES CAN ENHANCE OUR UNDERSTANDING OF END-OF-LIFE CARE

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The National End of Life Care Strategy outlined the reforms necessary to improve the quality of life and dying in England. Information is power to those who want to improve care, and a compendium was commissioned to bring together available data sources on end of life, in one unique place.

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). However, the complexity of death and the broad range of factors influencing decision making, mean this measure should be interpreted using a much wider range of data.

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.