

Using Data Sources to Better Understand Quality of End of Life Care

The National End of Life Care Intelligence Network Compendium

Nicola Bowtell (nicola.bowtell@swpho.nhs.uk) and Julia Verne
South West Public Health Observatory

1. Background

'The percentage of all deaths that occur at home' was adopted as a national indicator to assess the quality of end of life care (EOLC). However, a wide range of factors influence the end of life experience. There is also growing opinion that the indicator should be interpreted using a wider range of data sources.

Until recently, a thorough systematic review of data sources on EOLC had not been undertaken. The South West Public Health Observatory undertook a review in 2010, and the results are on the National End of Life Care Intelligence Network Compendium of Data Sources: www.endoflifecare-intelligence.org.uk

2. Method

A systematic review of data sources on EOLC: resources were reviewed for relevance, coverage, temporality and timeliness, completeness and representativeness.

3. Results

At the time of the review, 59 unique data sources were identified. Data sources are available on demography (Figure 1), service infrastructure (Figure 2) and disease trajectories (Figure 3). These are currently being reviewed and new data sources added.

4. Conclusions and recommendation

- The EOL compendium is a unique resource giving users access to EOL data in one place, for the first time.
- Commissioners and intelligence staff can improve their understanding of the delivery of end of life care services and more accurately profile their population needs.
- Ultimately, these data sources could be used to develop a suite of statistics (currently under consideration by SWPHO and the NEOFICIN).
- A guide to enable Clinical Community Groups and Local Authorities to make the most of this data could also be developed.

Figure 1: Demography

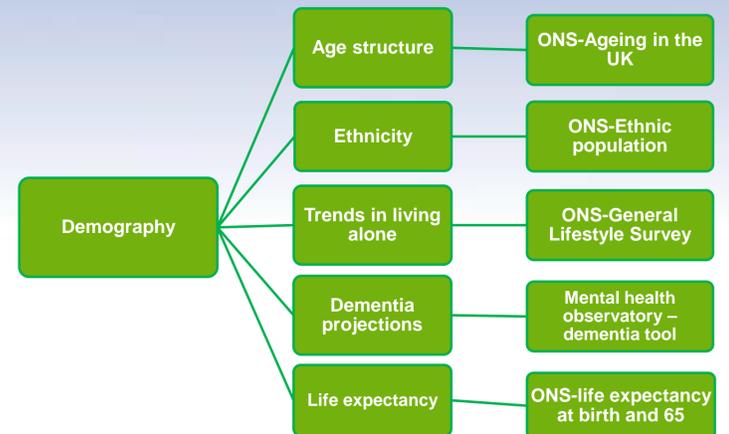
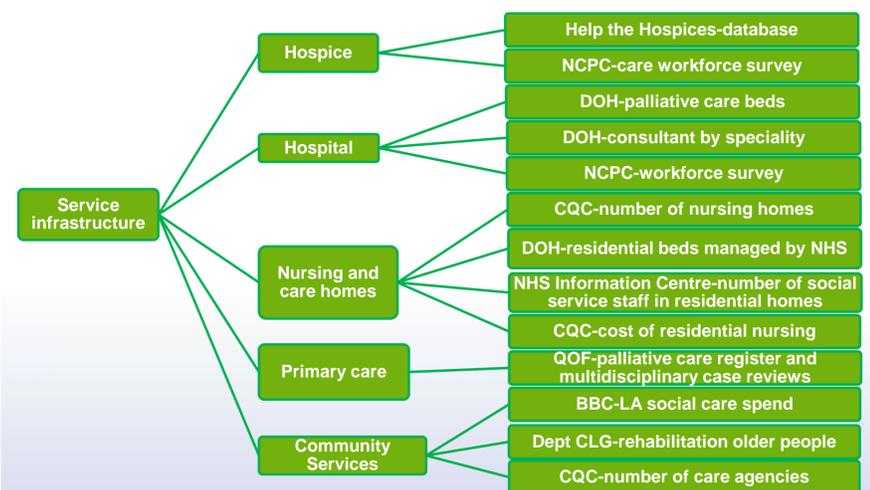


Figure 2: Service infrastructure



An interactive tool: the compendium

The screenshot shows the website interface with a search bar and navigation menu. The 'Data sources' section is highlighted, showing a table of data sources for primary care. The table has columns for 'Area of interest' and 'Location of data'.

Area of interest	Location of data
Practice has a complete register available of all patients in need of palliative care	Quality and Outcomes Frameworks
Practice has regular multidisciplinary case review meetings where all patients on the palliative care register are discussed	Quality and Outcomes Frameworks

Key to abbreviations

- BBC British Broadcasting Company
- CLG Department for Community and Local Government
- CQC Care Quality of Commission
- HES Hospital Episodes Statistics
- NCPC The National Council for Palliative Care
- QOF Quality and Outcomes Framework

Figure 3: Disease/illness progression

