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# How do we measure the quality of specialist palliative care? An Editorial

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## Abstract

A legal obligation to commission palliative care was established in England in 2022, however commissioners may struggle with what needs to be provided, how this should be funded, how effective services are, and care quality. This is compounded by differing intersections between specialist and generalist palliative care across England. Challenges to be addressed include service specification, integration of healthcare IT systems, and funding for the implementation of an agreed national dataset of outcomes for specialist palliative care. Funding is also required to build connectivity, coordination and digital infrastructure. Engaged political and clinical leadership, supported by research capacity is vital.

1231 words

Nearly four decades after Specialist Palliative Medicine was recognised as a medical specialty in the UK, a legal obligation to commission palliative care was established in England in 2022 (1). Effective commissioning builds upon a number of components: health-needs assessment for a population; clinical optimisation of patient pathways; service specification; contract negotiation and procurement, and quality assessment including equity of service access and provision (1). Commissioners could reasonably expect to see service specifications including optimal workforce numbers and skill mix, and quality assessments based upon benchmarking of nationally agreed patient related outcomes, with supporting process measures. Whilst progress has been made with some elements of commissioning, others remain less developed, including service specification (2), and national benchmarking of quality (3). If any country were able to meet this expectation it would surely be one with a nationally provided healthcare system. So why does England fall short? And are there other jurisdictions that might show the way?

Palliative care service configurations across the England are highly variable. Early hospices evolved where passion, opportunism, and fundraising potential aligned, and have evolved alongside statutory services depending on local factors. Thus, the intersections and boundaries between specialist and general palliative care services, and between NHS and charitably funded components, differ widely. Specialist palliative care services may also differ significantly in what their educational, leadership and strategy offer. There are national frameworks and standards on what good care looks like (4,5,6,7,8,9), however without agreed measures individual services, and localities, cannot be benchmarked and variation understood. There is also no clear evidence in support of what constitutes optimal palliative care service delivery, and the service specification for specialist palliative care services is not prescriptive on how it should be configured (2).

Validated outcome measures, including the Integrated Palliative care Outcome Scale (IPOS)(10), and patient and carer reported experience surveys (11,12) are available but not mandated. Efforts to develop and implement an agreed national dataset of outcomes for specialist palliative care services in England have been developed and piloted only to flounder due to lack of national funding (3). The capacity and capability of the digital infrastructure across health and social care also continues to be problematic, with multiple system suppliers, and variable development of IT capacity across palliative care providers (3).

‘Mortality follow-back’ or ‘post-bereavement’ surveys represent an internationally valid way to evaluate care (13). They provide a means of accountability and assurance about quality of care as well as identifying specific areas for improvement. In turn, these areas can inform priorities for service development and policy initiatives (14). Where national funding is available, meaningful quality assessment has been possible using this method. Between 2011-2015, a nationally representative survey of bereaved relatives, 'Views of Informal Carers-Evaluation of Services (VOICES), was commissioned by the NHS in England (15). The direct voices of bereaved individuals enabled feedback to help drive improvements in care as well as inform the commissioning landscape. Since then, the largest study of this kind within England and Wales has been the Marie Curie funded 'Better end of life report 2024 (16)'. This post-bereavement survey highlighted insufficient workforce capacity, inadequate coordination and gaps in care, especially within the community setting. Issues with representation and bias are recognised - greater response rates tend to come from specific populations e.g. those who are White British, female, and representing older individuals (17). Hence, inclusive approaches are required to reach underserved communities, especially those living within deprived and/or ethnically diverse areas. Additionally, sufficient time is required before evaluations are repeated to ensure bereaved individual feedback can be implemented into meaningful action, recommendations and policy development. Granularity of benchmarked national datasets to permit interpretation at local level of the findings, informing subsequent quality improvement, is also vital. The need for better evidence has been recognised with funding available for a body of research (26).

National audits of care of the dying in hospitals have informed national strategy and driven local quality improvement; they highlight what can be achieved with national funding (18). These have been integrally linked with post-bereavement surveys. The first was conducted in 2014 (led by the Royal College of Physicians), and the internationally validated, 'Care Of the Dying Evaluation' (CODE$^{TM}$) was the user-representative measure (19). Subsequently, a bespoke 'Quality Survey' was developed, reflecting principles from the national framework 'Ambitions for Palliative and End of Life Care' (4). However, whilst these audits reflect specialist palliative care leadership, education, and quality improvement, they do not provide direct specialist palliative care outcomes, and are limited to specific care settings.

Since 2013, the Association for Palliative Medicine (APM) has conducted an annual bereaved relative survey of specialist palliative care services, and the wealth of information gathered, the emerging themes, and lessons learned are explored in a feature in this edition of BJSPC (20).

Looking to other nations, Australia has a long established national Palliative Care Outcomes Collaborative (PCOC) that aims to embed nationally standardised clinical assessments into daily practice to improve quality and outcomes of care (21). A nationally funded partnership between universities and service providers, participation by services is voluntary and currently runs across 200 service settings (21). Point of care data collection is reported routinely to PCOC, with national benchmarking and structured feedback to teams provided. PCOC further supports services with celebrations of success via the media, networking opportunities through conferences, and with academic work continuously underpinning development. With this complete package, significant improvements in patient outcomes are demonstrable, along with a reduction in variation in service level outcomes (22).

With a lack of progress with benchmarking of palliative care at national level, and a shift to commissioning at integrated care board (ICB) level, NHS England are now focusing on locality/ICB-based palliative and end of life care dashboards (23) to enable ICBs to address and track the improvement of health disparities. Such dashboards could draw on data from electronic palliative care coordination systems (24) where they exist, public health profiles on palliative and end of life care (25), locality bereaved family surveys, and process measures including contribution to education and training; governance arrangements including review of complaints; quality improvement programmes, and staff support measures. However, whilst this approach provides an overview of palliative and end of life care, it does not differentiate between the specialist and generalist palliative care components.

## Conclusion

A substantial amount of work needs to be done to ensure that SPC services are consistently good, accessible and equitable. Within the current context of assisted dying potentially being introduced within the UK, it has never been more important to provide robust palliative care services and quality assurance about the care delivered. Currently commissioners in England may struggle with defining the population to be served, be less familiar with mixed economy funding models, and find it hard to define how good local services are and how much they should cost. To address this, funding to support national benchmarking of the quality of palliative care has been shown to be effective and feasible at scale in a not too dissimilar healthcare system and is strongly recommended. This could be complemented at local level by the collaboration of networks of palliative care providers across health and social care, supported by information analysts, in compiling and interpreting local data, clinical outcomes, and service user feedback. For this, funding is also required to build connectivity, coordination and digital infrastructure. Engaged political and clinical leadership, underpinned by research and evidence, is vital to lead development, and to listen, explain and negotiate how palliative care services fit within elective service commissioning templates. To be effective, dedicated leadership, research and quality improvement time must be recognised in job plans.

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