

# What outcome domains are considered core to assessing the impact of adult specialist palliative care services in Wales? A rapid review.

20/12/21

## Review Methods

**Search Strategy:** A systematic search was conducted across a wide-ranging set of databases: Ovid Medline, including In-Process & Other Non-Indexed Citations, Ovid PsychINFO, Ovid HMIC, Ebsco CINAHL & Scopus via Elsevier.

The preliminary search strategy was developed on Ovid Medline using both text words and Medical subject headings from January 2011 to February 2021 restricted to English language articles/resources and research with human participants. The search strategy was modified to capture indexing systems of the other databases. (Search strategies available upon request).

To identify additional papers, electronic tables of content for the last two years were scanned for:

- BMJ Supportive & Palliative Care
- Palliative Medicine

Furthermore a search was carried out in Google Scholar and reference lists of systematic reviews were checked for any relevant studies. The search generated 635 citations after removing duplicates and irrelevant records. Figure 1 represents the flow of information through the different phases of the review.

**Inclusion:** Adult palliative care services; OECD countries; guidelines on domains of relevance to assessment of SPC care delivery and/or tools and systems being implemented to capture that data.

**Exclusion:** Studies set in non-Organization for Economic Cooperation and Development (OECD) countries; Case series studies consisting of less than 25 patients; and non-english language studies.

### Study selection/Quality Assessment/Data Extraction

Study selection and data extraction was carried out by two independent reviewers. The full text was assessed independently using a pre-designed eligibility form according to inclusion criteria. Data extraction form was piloted to ensure ease and accuracy of data. Quality assessment was not undertaken due to the type of the topic and research question.

Using a deductive process, individual outcomes were identified from each of the nine studies and mapped across into a classification framework to help conceptualise and compare constructs. Table 2 consists of the outcomes mapped to outcome domains.

Any discrepancies between the two reviewers were resolved by consensus or by recourse to a third reviewer.

## Context

Assessment of palliative care delivery is essential for managing service performance and providing improvement in care (Donabedian, 2005). However, such assessments have tended to focus on capturing process related outcomes (service volume, response times etc.) to demonstrate service activity, rather than consistently measuring impact of services on patient and family.

There has been increasing emphasis on, and international consensus on the need for, outcomes which focus more specifically on impact, in particular on domains such as quality, effectiveness and efficiency of palliative care rather than just service activity (Davis et al., 2013, Clark et al., 2016).

Recently, there have been several initiatives to standardise approaches to this type of outcome assessment and to encourage regional approaches which will meet local needs but also allow benchmarking at national and international levels.

In Wales, the [End-of-Life Board \(EoLB\)](#) has prioritised the need to establish a standardised approach to the collection of this type of data set, by establishing a consensus on the domains of importance and to identify whether an existing approach such as the Outcome Assessment and Complexity Collaborative (OACC) (Witt et al., 2014) or Palliative Care Outcomes Collaboration (PCOC) (Eager et al., 2010), may meet 'needs' in Wales or whether the specific health and social care economy unique to Wales mandates for additional or different domains of care to be addressed. This project is a multi-stage study, with this first stage rapid review identifying from the published literature those outcomes for adult palliative care services that are considered most important to capture in order to assess service quality.

## Key Findings

In total, database and supplementary searches generated 635 citations. After removing duplicates and irrelevant records 254 records were screened for eligibility. **Figure 1** represents the flow of information through the different phases of the review. We assessed 30 full-text articles for eligibility to identify domains for quality of palliative care. However, twenty-one articles were excluded with primary reasons being no mention of important outcomes or no assessment of important domains. To prepare a preliminary long list of outcomes for the first Expert Consensus Workshop (the consensus workshop would be the second/next step in the multi-step project this rapid review is a part of we generated an outcomes domain framework using the categories (**Table 1**) as proposed by the National Consensus Project Clinical Practice Guidelines for Quality Palliative Care (Ferrell et al., 2018). These domains include physical aspects of care; psychological aspects of care; social aspects of care; spiritual aspects of care; cultural aspects of care; care for the dying; ethical aspects of care; and structure and processes of care. This framework allowed outcomes to be classified within recognized domains of care to support conceptualization and allow for subsequent collective discussion on similarities and the ability to deduplicate. We also added two other domains relating to overall wellbeing and information and preferences (**Table 2**). A mapping process was used, whereby two reviewers cross checked and discussed the outcomes extracted for each paper and mapped them across to the framework. It was possible to add new domains to the framework if an individual outcome was thought not to fit within one of the pre-specified care domains (**Figure 2**).

**Outcomes:** We defined an 'Outcome' as a measurable variable, in this case 'what' is being measured such as a change in health status, quality of life or a symptom. Outcome measurement tools are 'how' these outcomes are assessed and can include any number of instruments (Bausewein et al. 2011). This study focuses on outcomes and 'what' needs to be measured.

**Description of included studies:** The nine included papers on assessment of domains were mainly based in United States (Dy et al., 2015; Hanson et al., 2012; Schenck et al., 2014; Zheng et al., 2018), the United Kingdom (de Wolf-Linder et al., 2019; McCorry et al., 2019), Canada (Mistry et al., 2015) and other European countries (Leemans et al., 2017; Woitha et al., 2014). Our search was limited to studies conducted in high-income countries (as defined by the World Bank; "High-Income OECD Countries") due to the nature of the healthcare system. Of the 9 included studies, all included outcomes relating to the domains of physical aspects of care and spiritual/religious/existential aspects of care. Eight studies included outcomes relating to structure and process of care and psychological/psychiatric aspects of care. Seven studies included outcomes relating to information and preferences. Five studies included outcomes relating to ethical/legal aspects of care and care nearing end of life. Four studies included outcomes relating to social aspects of care and two studies included outcomes relating to cultural aspects of care.

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## Evidence Implications:

### Clinical & Policy

The long list of domains and outcomes generated from the table, will be taken forward to a palliative care expert group, where a consensus process will take place and a final outcome set for measuring the quality of palliative care across Wales will be generated.

### Strengths & Limitations

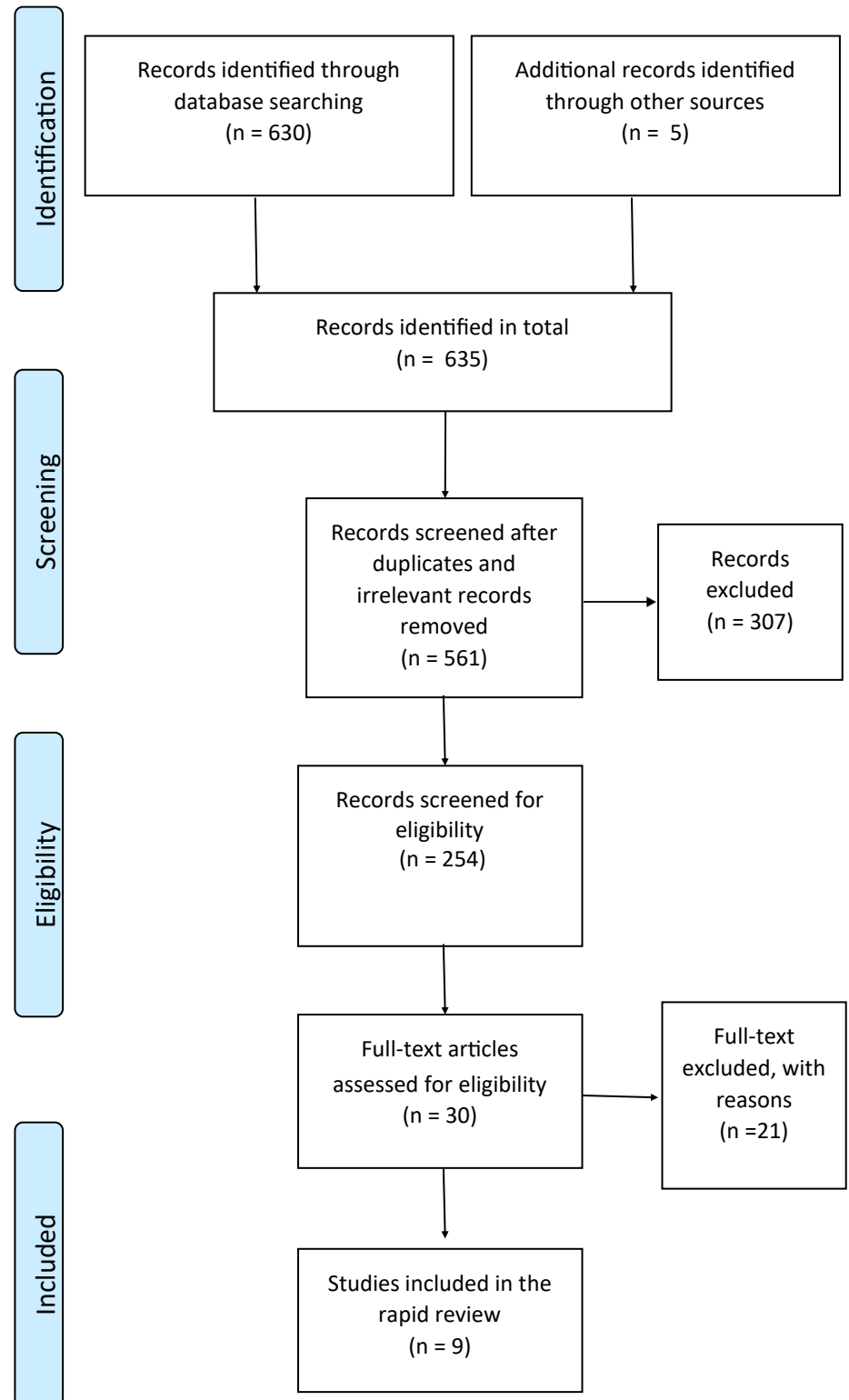
A strength of this review is that a deductive, consensus approach was taken when mapping outcomes into domains. This allowed for flexibility and movement of outcomes between domains in order to reach a finalized agreed longlist to take forward to an expert workshop group.

Limitations of this review include an absence of quality appraisal of included studies. However, for the purpose of this study, outcome data was not synthesized as such and therefore quality appraisal of included studies was not deemed necessary. Most studies included were from the United States, where the health care system differs to that in the UK. This may have effects on the generalisability of the reported outcomes and subdomains.

### Glossary:

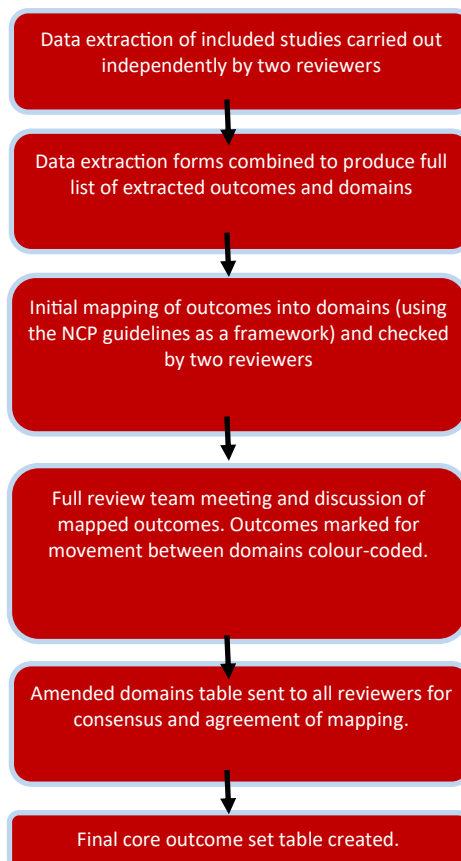
- National Consensus Project (NCP)
- Outcome Assessment and Complexity Collaborative (OACC)
- Organisation for Economic Co-operation and Development (OECD)
- Palliative Care Outcomes Collaboration (PCOC)

Figure 1 - Flow Diagram:



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**Figure 2—Consensus Mapping Process**




**Table 1—Outcome Domains**

Table 1. Outcome Domains
1. Structure and process of care
2. Physical Aspects of care
3. Psychological/Psychiatric aspects of care
4. Social aspects of care
5. Spiritual/religious/existential aspects of care
6. Cultural Aspects of care
7. Care nearing end of life
8. Ethical and legal aspects of care
9. Overall wellbeing
10. Information and preferences

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**Table 2— Outcomes mapped to outcome domains**

Domain	Outcomes (From extracted studies)
<b>Structure and process of care</b>	<ul style="list-style-type: none"> <li>Comprehensive assessment</li> <li>Adverse events and staff distress</li> <li>Medication adherence in institutional setting</li> <li>Length of unstable phase</li> <li>Timing and duration of distress </li> <li>Screening for symptoms</li> <li>Nature of care delivery, accessible, timely and knowledgeable.</li> <li>Continuity of care</li> <li>Culture of supporting palliative care</li> <li>Accessibility to service</li> <li>Timing of assessment</li> <li>Skill mix of multi-disciplinary team</li> <li>Proportion of service users assessed (per time period)</li> <li>Breathlessness management</li> <li>Pain treatment</li> <li>Treatments of psychological symptoms</li> </ul>
<b>Physical Aspects of care</b>	<ul style="list-style-type: none"> <li>Screening for physical symptoms</li> <li>Pain assessment</li> <li>Fatigue</li> <li>Nausea &amp; Vomiting</li> <li>General physical symptoms</li> <li>Comfort</li> <li>Physical symptom improvement</li> <li>Breathlessness assessment</li> </ul>
<b>Psychological/Psychiatric aspects of care</b>	<ul style="list-style-type: none"> <li>Discussion of emotional needs</li> <li>Feeling safe in institution</li> <li>Depression/psychological care</li> <li>Overall emotions including loneliness</li> <li>Psychological needs addressed</li> <li>Cognitive dysfunction</li> </ul>
<b>Social aspects of care</b>	<ul style="list-style-type: none"> <li>Family anxiety</li> <li>Family wellbeing</li> <li>Family carer burden</li> <li>Social Care</li> <li>Family Relationships</li> <li>Relationship with carer</li> <li>Family Support</li> <li>Family involvement</li> <li>Family experience</li> <li>Accessibility to family</li> </ul>

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Table 2 Continued — Outcomes mapped to outcome domains

Domain	Outcomes (From extracted studies)
<b>Spiritual/religious/existential aspects of care</b>	Discussion of religious/spiritual/existential concerns Feeling at peace Religious beliefs Beliefs and values
<b>Cultural Aspects of care</b>	Cultural Beliefs
<b>Care nearing end of life</b>	Last week of life care Palliative care options End-of-life care decisions Place of death End of life preferences
<b>Ethical and legal aspects of care</b>	Documentation of surrogate Treatment preferences Care consistency Documented care preferences/documentation Advanced directive documentation
<b>Overall wellbeing</b>	Quality of life
<b>Information and Preferences</b>	Communication of clear information Discussion of preferences of Place of care Information needs of family and patient Patient treatment preferences Involvement in decision making Exchange of clinical information across caregivers, disciplines, and settings.

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## Included Studies:

- de Wolf-Linder S, Dawkins M, Wicks F, Pask S, Eagar K, Evans CJ, et al. Which outcome domains are important in palliative care and when? An international expert consensus workshop, using the nominal group technique. *Palliative Medicine*. 2019;33(8):1058-68.
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- Hanson LC, Rowe C, Wessell K, Caprio A, Winzelberg G, Beyea A, et al. Measuring Palliative Care Quality for Seriously Ill Hospitalized Patients. *Journal of Palliative Medicine*. 2012;15(7):798-804. doi: 10.1089/jpm.2011.0471
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- McCorry NK, O'Connor S, Leemans K, Coast J, Donnelly M, Finucane A, et al. Quality indicators for Palliative Day Services: A modified Delphi study. *Palliative Medicine*. 2019;33(2):197-205. doi: 10.1177/0269216318810601
- Mistry B, Bainbridge D, Bryant D, Toyofuku ST, Seow H. What matters most for end-of-life care? Perspectives from community-based palliative care providers and administrators. *BMJ Open*. 2015;5(6) doi: 10.1136/bmjopen-2014-007492
- Schenck AP, Rokoske FS, Durham D, Cagle JG, Hanson LC. Quality measures for hospice and palliative care: piloting the PEACE measures. *Journal of Palliative Medicine*. 2014;17(7):769-75.
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## Additional references

- Bausewein C, Daveson B, Benalia H, Simon ST, Higginson IJ. *Outcome Measurement In Palliative Care—The essentials*. Kings College London. 2011.
- Clark K, Eagar K and Currow DC. Embedding objective measurements of quality into routine practice in hospice/palliative care. *J Pain Symptom Manage* 2016; 52: e5–e7.
- Davis P, Milne B, Parker K et al. Efficiency, effectiveness, equity (E3). Evaluating hospital performance in three dimensions. *Health Policy* 2013; 112:19-27
- Donabedian A. Evaluating the Quality of Medical Care, *The Milbank Quarterly* 2005; 83(4):691-729.
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- Ferrell BR, Twaddle ML, Melnick A, Meier DE. National Consensus Project Clinical Practice Guidelines for Quality Palliative Care Guidelines, 4th Edition. *J Palliat Med*. 2018 Dec;21(12):1684-1689. doi: 10.1089/jpm.2018.0431. Epub 2018 Sep 4. PMID: 30179523.
- Implementation Groups 2022, *End of Life Care - NHS Wales Health Collaborative*, Collaborative.nhs.wales, <https://collaborative.nhs.wales/implementation-groups/end-of-life-care/> [Accessed 11 January 2022].
- Witt J, Murtagh F, de Wolf-Linder S, Higginson I, Daveson B. *Introducing the Outcome Assessment and Complexity Collaborative (OACC) Suite of Measures-A Brief Introduction*. Kings College London. 2014

## Additional materials available upon request:

- Data extraction forms
- Search strategies
- List of excluded studies

**This report should be cited as follows:** Palliative Care Evidence Review Service. What outcome domains are considered core to assessing the impact of adult specialist palliative care services in Wales? A rapid review. Cardiff: Palliative Care Evidence Review Service (PaCERS); 2021 December.

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**Disclaimer:** Palliative Care Evidence Review Service (PaCERS) is an information service for those involved in planning and providing palliative care in Wales. Rapid reviews are based on a limited literature search and are not comprehensive, systematic reviews. This review is current as of the date of the literature search specified in the Review Methods section. PaCERS makes no representation that the literature search captured every publication that was or could be applicable to the subject matter of the report. The aim is to provide an overview of the best available evidence on a specified topic using our documented methodological framework within the agreed timeframe.