Palliative Medicine

QUALITY INDICATORS FOR PALLIATIVE DAY SERVICES: A MODIFIED DELPHI STUDY

Journal:	*Palliative Medicine*
Manuscript ID	PMJ-18-0136.R1
Manuscript Type:	Original Article
Date Submitted by the Author:	11-Sep-2018
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Keywords:	Quality Indicators, Delphi technique, Day services, Quality Improvement, Palliative care
Abstract:	Background: The goal of Palliative Day Services is to provide holistic care that contributes to the quality of life of people with life threatening-illness and their families. Quality indicators provide a means by which to describe, monitor and evaluate the quality of Palliative Day Services provision, and act as a starting point for quality improvement. However, currently, there are no published quality indicators for Palliative Day Services. Aim: To develop and provide the first set of quality indicators that describe and evaluate the quality of Palliative Day Services. Design and setting: A modified Delphi technique was used to combine best available research evidence derived from a systematic scoping review with multi-disciplinary expert appraisal of the appropriateness and feasibility of candidate indicators. The resulting indicators were compiled into ‘toolkit’, and tested in five UK Palliative Day Service settings. Results: A panel of experts independently reviewed evidence summaries

	for 182 candidate indicators and provided ratings on appropriateness, followed by a panel discussion and further independent ratings of appropriateness, feasibility, and necessity. This exercise resulted in the identification of 30 indicators which were used in practice testing. The final indicator set comprised 7 structural indicators, 21 process indicators, and 2 outcome indicators. Conclusions: The indicators fulfil a previously unmet need among Palliative Day Service providers by delivering an appropriate and feasible means to assess, review, and communicate the quality of care, and to identify areas for quality improvement.

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MeSH keywords: Palliative Care; Delphi Technique; Quality Indicators, Health Care; Day Services, medical; Quality Improvement.

QUALITY INDICATORS FOR PALLIATIVE DAY SERVICES: A MODIFIED DELPHI STUDY

ABSTRACT

Background: The goal of Palliative Day Services is to provide holistic care that contributes to the quality of life of people with life threatening-illness and their families. Quality indicators provide a means by which to describe, monitor and evaluate the quality of Palliative Day Services provision, and act as a starting point for quality improvement. However, currently, there are no published quality indicators for Palliative Day Services.

Aim: To develop and provide the first set of quality indicators that describe and evaluate the quality of Palliative Day Services.

Design and setting: A modified Delphi technique was used to combine best available research evidence derived from a systematic scoping review with multi-disciplinary expert appraisal of the appropriateness and feasibility of candidate indicators. The resulting indicators were compiled into ‘toolkit’, and tested in five UK Palliative Day Service settings.

Results: A panel of experts independently reviewed evidence summaries for 182 candidate indicators and provided ratings on appropriateness, followed by a panel discussion and further independent ratings of appropriateness, feasibility, and necessity. This exercise resulted in the identification of 30 indicators which were used in practice testing. The final indicator set comprised 7 structural indicators, 21 process indicators, and 2 outcome indicators.

Conclusions: The indicators fulfil a previously unmet need among Palliative Day Service providers by delivering an appropriate and feasible means to assess, review, and communicate the quality of care, and to identify areas for quality improvement.

WHAT IS ALREADY KNOWN ABOUT THE TOPIC?

- Measurement of health care quality creates the basis for quality improvement
- Quality indicators can provide a valid and reliable means of measuring quality of care
- There are currently no published quality indicators specifically for Palliative Day Services

WHAT THIS PAPER ADDS

- This paper describes the development of the first set of quality indicators specifically for quality improvement in Palliative Day Services
- The final set comprises 7 structural indicators (e.g. ‘Service has a written standard operating procedure for development and use of multidisciplinary care plans’), 21 process indicators (e.g. ‘Proportion of service users with assessment of pain severity at screening using a valid measure’), and 2 outcome indicators (e.g. ‘Proportion of service users re-assessed at regular review who report that main care goals are met’).

IMPLICATIONS FOR PRACTICE, THEORY OR POLICY

- The quality indicator set offers day service providers with a means of describing and reviewing the quality of their care, and providing feedback to stakeholders
- Use of the indicator set in practice will allow providers to identify areas for quality improvement

INTRODUCTION

Quality indicators are statements that define explicitly and in measurable terms the quality of a given construct or phenomenon. They provide a means with which to describe, monitor and evaluate healthcare.[1] Ideally, they should be evidence-based with a theoretical foundation such as Donabedian's structure, processes and outcomes framework.[2] Quality indicators can provide service users, their families, care staff, providers, commissioners, purchasers, and inspectorates of care with data in relation to the quality of care, sometimes against benchmarks or previous quality assessments. In addition, by providing a valid and reliable means of measuring quality of care, quality indicators (although not sufficient by themselves) can act as a starting point for quality improvement.[3]

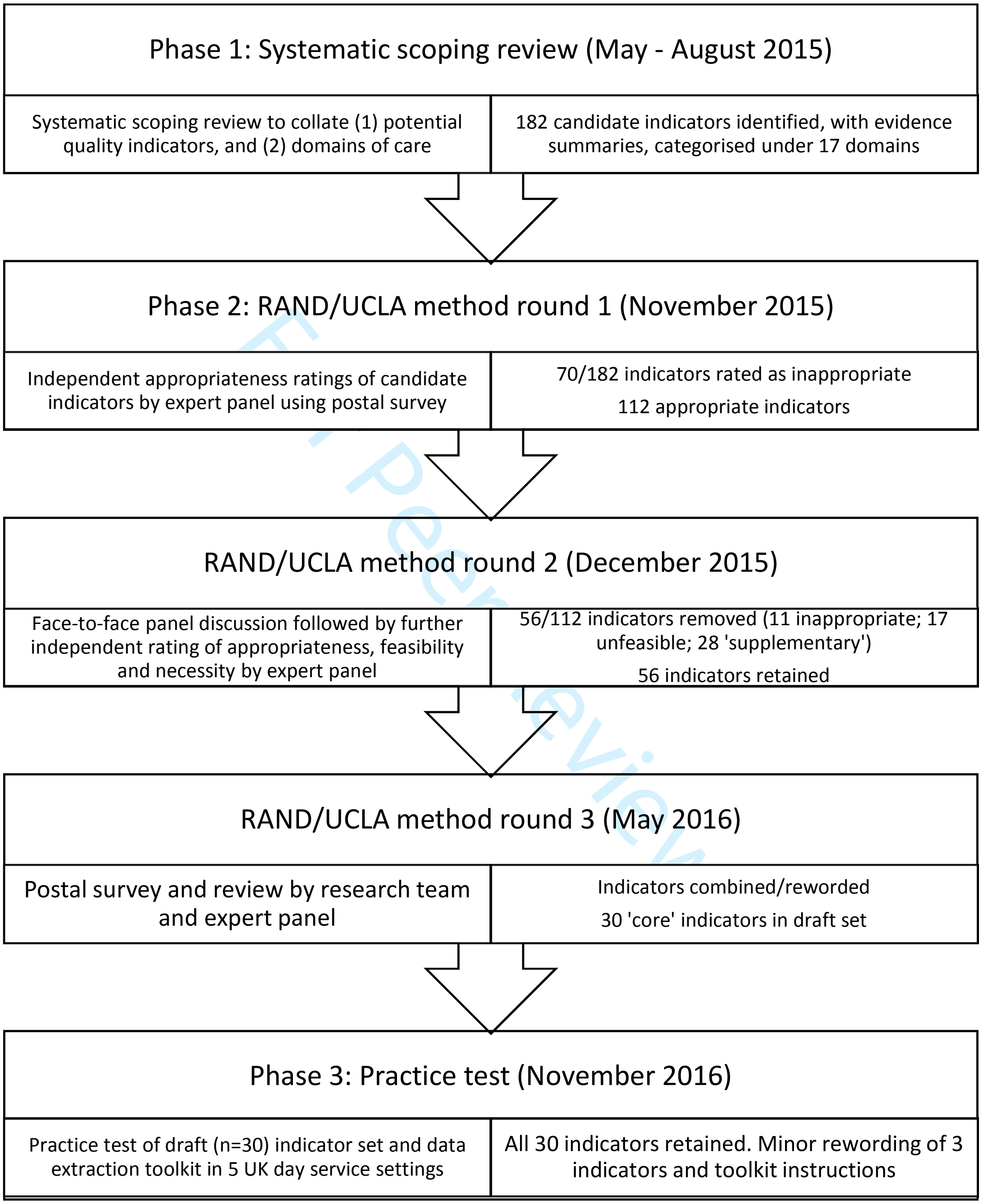
In the United Kingdom, as in many European countries, Palliative Day Services provide specialist palliative care within a group context for people with terminal or life-limiting illness, facilitated by a specialist multi-disciplinary team.[4] The goal of Palliative Day Services is to provide individualised, holistic care that promotes independence and rehabilitation, improves self-worth, and ultimately enables the best quality of life for patients and their families.[4,5] However, there is considerable variation within Palliative Day Services, and providers are under pressure to define and measure the quality of their services, identify areas for improvement and assess the impact of service development and improvement efforts. In order to address these issues, we developed the first set of quality indicators that are designed specifically for use by Palliative Day Services. We propose that our indicators be used to support services to evaluate care quality on an ongoing basis, to identify valid and appropriate goals for quality improvement.

METHODS AND RESULTS

We used the RAND/UCLA appropriateness method[6] which has been incorporated into a comprehensive approach for the development of quality indicators in palliative care.[7] The RAND/UCLA appropriateness method is a modified Delphi method which combines the use of evidence with the collective judgement of experts, and is particularly suited to this area of healthcare because of the dearth of evidence related to day services. Expert panellists provide two rounds of *independent* ratings and have the opportunity to discuss their judgments between the rating rounds during a face-to-face meeting. The method has been shown to have a high level of reproducibility and validity.[6] Figure 1 shows the phases in the research process.

The study protocol was approved by the School of Psychology, Queen's University Belfast Research Ethics Committee (ref: 10-2015-16) in September 2015. Expert panel members provided written informed consent to participate in the study.

Figure 1: Phases in the research process, including number of potential quality indicators identified at each stage.



Phase 1 – A systematic scoping review to identify existing quality indicators and domains

A systematic scoping review was conducted to identify existing quality indicators in all areas of palliative care, and other evidence or recommendations which might inform the development of (or translation of evidence into) a quality indicator, i.e. structural or process level variables which have been shown to be related to outcomes of care. Any domains / themes used to describe the indicators were also identified. Established frameworks were used to guide the review protocol,[8,9] which is published elsewhere.[10]

This review resulted in the identification of 182 unique candidate indicators (supplementary file 1) and 17 care domains. Evidence tables summarising the content, sources and quality of evidence (using AIRE[11] and GRADE[12] scores where appropriate) of quality indicators represented in each domain were compiled.

Phase 2 - Quality indicator selection by expert consultation following the internationally validated RAND (Research ANd Development) / UCLA (University of California, Los Angeles) Appropriateness Method (RAM)

Round 1 – Expert panel questionnaire

A multidisciplinary panel of individuals with expertise in Palliative Day Services was established. A total of 58 potential panel members were directly approached (recommended by the research team) or responded to advertisements. We selected experts based on their experience and expertise in the area of Palliative Day Services, while aiming for diversity in geographical representation and professional specialism. Panel members were asked to commit 21 hours to the project over 3 months. The resultant panel consisted of 21 individuals from across the United Kingdom, including palliative care consultants, specialist nurses, day service and hospice managers, allied health professionals, spiritual care providers, a social worker, a complementary therapist, a psychologist and a pharmacist. Several panellists had experience of more than one day service model and previous experience of consensus development methods. Panel members were sent a document pack including general information about quality indicators and their properties (including a description of Donabedian's model)[2], a series of evidence tables for candidate quality indicators, a rating booklet, and a short commentary from Marie Curie (a major UK palliative care provider) endorsing the project objectives. All materials were reviewed by the research team and two user representatives.

Panellists were asked to independently rate the *appropriateness* of each quality indicator on a 9-point scale (according to the RAND/UCLA method[6] method) where an appropriate indicator (rated 7-9) was defined as one which was acceptable and likely to represent a reasonable measure of quality in Palliative Day Services. Alternatively, an inappropriate indicator (rated 1-3) was defined as one which should rarely or never be used as a measure of quality in Palliative Day Services, and where any re-wording or reframing of the indicator would not alter this assessment. Ratings of 4-6 represented indicators which were thought to be neither appropriate nor inappropriate. Panellists were asked to base ratings on their own knowledge and experience, as well as the evidence summary tables provided, but not to rate appropriateness based on the cost implications associated with a particular indicator. It was explained to panellists that although cost consideration is an important factor in deciding whether a particular procedure or treatment is ultimately made available to patients, the RAM focuses only on the initial question of whether it is effective. Panellists were also asked to suggest additional quality indicators, and to review and provide feedback on the proposed quality domains. The indicator ratings were subsequently analysed based on their median appropriateness scores and the level of agreement between panel members using the criteria specified by the RAND/UCLA appropriateness method.[6] Indicators with a median appropriateness rating of 3 or less (inappropriate) and good agreement on this rating by the panel, were highlighted for exclusion.

Twenty panellists returned round 1 ratings. Round 1 resulted in the identification of 70 inappropriate indicators and 112 candidate appropriate or uncertain indicators.

Round 2 – Expert panel meeting

All panellists who participated in round 1 were invited to attend a one day, face-to-face meeting, where the analysis of round 1 ratings was presented. The meeting was moderated by a health psychologist (MDe) with extensive experience in facilitating group discussion, and was attended by 12 panellists. The aims of the meeting were to:

1) confirm the exclusion of indicators rated as inappropriate as a result of round 1 ratings,
2) discuss those indicators for which, following round 1, appropriateness was uncertain
3) discuss indicators for which appropriateness was acceptable but there was disagreement between panellists and
4) review the terminology used in indicator descriptions

Following the discussions, panellists were asked to independently re-rate the *appropriateness* of the 112 indicators. Panel members agreed that the indicator set should be designed and promoted as a tool to support the assessment of quality in a formative manner, and the identification of quality improvement goals, and not as a means of comparison between services or for inspection purposes - which would require more detailed consideration of risk adjustments. At this stage, panel members were also asked to independently rate the *feasibility* of measuring each indicator in the day service setting using the same 9-point scale, and to assess if each indicator was a *necessary* measure (yes/no response). A necessary measure was defined as: *appropriate; likely to benefit the patient; that the benefit is not small; and where it would be improper care not to offer the procedure under review.*[6] The same criteria as round 1 were used to remove inappropriate indicators. In addition, only quality indicators with a median feasibility rating of 4 or greater (with good agreement) were retained. The categorisation of necessity was used to produce a list of core and supplementary indicators. Indicators were defined as supplementary if less than half the panel identified the indicators as a necessary measure.

As a result of round 2 ratings, 11 indicators were agreed to be inappropriate, and 17 were unfeasible. A further 28 indicators were removed based on the assessment of necessity. Hence 56 core indicators (agreed to be appropriate, feasible and necessary) were retained following round 2. Supplementary file 1 shows the decisions during rounds 1 and 2.

Round 3 – Second panel questionnaire

The set of 56 core indicators were then reviewed by the research team and expert panel members (with a particular focus on wording and duplication) who were sent the indicator set by email.

Round 3 resulted in the rewording or combination of 41 indicators, and hence a consolidated set of 30 unique indicators. Supplementary file 2 shows the derivation of the draft indicator set from the original 182 candidate indicators. This draft indicator set included 7 structural indicators, 21 process indicators and 2 outcome indicators, categorised under 10 domains of care. There were most quality indicators (n=9) representing the domain ‘co-ordination and continuity of care’. For 24 of the indicators, the focus is on patient or staff interaction with the service (eg. *'Proportion of service users with assessment of pain severity at screening using a valid measure' (#A1))*, while 6 indicators represented service characteristics (eg. *'Service has a written care pathway for assessment and management of moderate or severe pain including appropriate onward referral routes' (#E12)*).

Phase 3 - Testing the draft quality indicator set in practice

The draft indicator set was compiled into a toolkit with detailed descriptions of each quality indicator (including the numerator, denominator and definitions), and instructions to assist with the extraction of relevant data. Supplementary file 3 is an extract from the toolkit. The indicator set and toolkit was then field-tested in 5 UK Palliative Day Service settings, in England (2), Scotland (1) and Northern Ireland (2) representing 3 different palliative care providers. The toolkit instructed data abstractors to assess performance on each quality indicator using paper-based or electronic records for 15 consecutive patients discharged from the Palliative Day Service in the previous 12 months (for patient level indicators), and any relevant accessible documentation including service policies and procedures (for service level indicators). Day service managers at each site completed the data abstraction. Abstractors were asked to 'think aloud'[13] while completing the paperwork – so that challenges or misunderstandings could be readily identified by the researcher, who was available during the entire abstraction process.

In total, data were extracted from 82 patient records. Following completion of the practice test, the rate and variation in the proportion of patients/staff for whom each quality indicator was met, and the proportion of settings which satisfied the service level indicators was compiled (supplementary file 4). Overall, there was considerable variation across the 5 services in performance against the indicators, particularly for assessment of patient satisfaction, recording of care goals, and completion of care plans. The indicators that were least likely to be met were concerned with quality of life assessment, availability of a completed multidisciplinary care plan, and assessment of patient satisfaction with support for decision making, with some services not collecting any information on patient satisfaction or quality of life. The indicators that were most likely to be met were concerned with the documentation of: time from referral to first attendance date offered; informed consent to treatment or medical intervention; and communication between the service and the General Practitioner providing information on care needs and care plans. Feedback from data abstractors indicated that:

- Data abstraction was perceived as time consuming
- Abstractors had to refer to several different sources of information
- The paper-based extraction forms added to the cumbersome nature of the process
- Data abstractors were not confident about the process for *calculation* of each indicator

As a result of the practice test minor amendments were made to three of the indicators, and to the toolkit instructions. Table 1 shows the final (QualPalUK) quality indicator set.

Table 1: Final QualPalUK quality indicator set (n=30), following phase 3 of the RAND/UCLA Appropriateness Method

	Indicator description, categorised by care domain	Indicator type*
	A. Physical care and support, assessment and treatment	
A1	Proportion of service users with assessment of pain severity at screening using a valid measure	P
A2	Proportion of service users with moderate or severe pain assessed to explore possible causes of pain	P
A3	Proportion of service users with assessment of breathlessness at screening using a valid measure	P
A4	Proportion of service users with assessment of fatigue at screening using a valid measure	P
A5	Proportion of service users with assessment of functional status to identify daily activity limitations completed before a multidisciplinary care plan	P
	B. Psychological care and support, assessment and treatment	
B6	Proportion of service users screened for depression at screening using a valid measure	P
B7	Proportion of service users screened for anxiety at screening using a valid measure	P
B8	Proportion of service users with assessment of cognitive functioning	P
	C. Spiritual and emotional care and support	
C9	Proportion of service users with documentation of a ‘spiritual aspects of care discussion or assessment’ completed before a multidisciplinary care plan	P
	D. Information and Communication with Service Users	
D10	Proportion of service users who report that they are provided with sufficient, appropriately tailored information or advice on their condition and on intervention options to support decisions on agreed care planning	O
	E. Co-ordination and continuity of care	
E11	Proportion of service users with a comprehensive needs assessment completed before a multidisciplinary care plan to identify main symptoms and concerns, and their effect	P
E12	Service has a written care pathway for assessment and management of moderate or severe pain including appropriate onward referral routes	S
E13	Proportion of service users with documentation of re-assessment at regular review in line with time points agreed in the multidisciplinary care plan	P
E14	Service has written standard operating procedures defining timeframes for time to initial contact, completion of needs assessment and multidisciplinary care plan	S
E15	Proportion of service users with documentation of appropriate intervention in line with the agreed, multidisciplinary care plan	P
E16	Proportion of service users with documented communication between the service & the General Practitioner providing information on care needs and care plans	P
E17	Proportion of service users with a care plan available as specified by the service’s written standard operating	P

	procedure for development and usage of multidisciplinary care plans	
E18	Proportion of service users with documented evidence of being offered the opportunity for completion of advance care planning	P
E19	Proportion of service users with quality of life assessed using a valid measure at screening and at regular review in line with time points agreed in the multidisciplinary care plan	P
	F. Care planning, goal setting and shared decision making with service users	
F20	Service has a written standard operating procedure for development and use of multidisciplinary care plans	S
F21	Proportion of service users with documentation of main care goals in the multidisciplinary care plan	P
	G. Evidence of effectiveness, outcome assessment and measurement	
G22	Service has a written policy for reviewing and updating standard operating procedures and care pathways	S
G23	Proportion of service users re-assessed at regular review who report that main care goals are met in line with the multidisciplinary care plan	O
G24	Proportion of service users with assessment of satisfaction with overall care and support performed using a valid measure	P
G25	Proportion of service users with assessment of satisfaction with involvement in shared decision making	P
	H. Staff training and education, service and professional development	
H26	Extent to which staff have access to training around core components of care as part of continuing education and personal development	S
	I. Access to services and service environment	
I27	Proportion of service users with a record of time in days from referral date to first attendance date offered by service	P
I28	The service provides suitable equipment and settings to deliver care	S
I29	Service has a written policy for defining standards for equipment and settings which are available for delivery of care	S
	J. Societal, ethical and legal aspects of care	
J30	Proportion of service users with correctly completed documentation of informed consent to treatment or medical intervention	P

*Indicator type: S: Structure; P: Process; O: Outcome

DISCUSSION

Results of the study

We have developed the first set of quality indicators specifically for use in Palliative Day Services, using a recommended, evidence based approach[7]. The indicators were derived from a comprehensive review of the international literature. The full set of original 182 indicators are provided as a resource in supplementary material and can be used to make adjustments for jurisdictions outside the UK if necessary. The final indicator set (reflecting Donebedian's model)[2] contains 2 outcome, 21 process, and 7 structural indicators, across 10 domains of care. The limited number of outcome indicators is a result of the expert panel's preference to incorporate patient reported outcome measurement (in relation to the assessment of pain, breathlessness, fatigue, functional status, depression, anxiety, and quality of life) into relevant *process* and s*tructural* indicators, and to avoid the complex adjustment and exclusions often associated with the quality appraisal using *outcome* indicators[14-19]. For example, rather than measure absolute 'pain intensity' or 'change in pain intensity' (both outcome indicators), the panel preferred to measure the extent to which patients had their pain measured using a validated instrument (#A1 and #A2- both process indicators), and the extent to which valid pathways were in place to manage the individual patient's pain (E12 – a structural indicator). This approach still incorporates the perspective of the service user in the process of quality assessment,[20,21] but requires that staff solicit these patient reported outcomes routinely and use them effectively to meet patient needs. Clearly however, both structural and process level quality indicators are only valid assessments of quality of care if they can be shown to increase the likelihood of a good outcome,[22] and hence the evidence base should be reviewed regularly to identify these relationships. The panel did, however, endorse *outcome* indicators in relation to service users' satisfaction with information and advice received (#D10) and whether service users reported that their main care goals had been met (#G23).

One characteristic of a 'good quality indicator' is the extent to which the quality indicator refers to an aspect of care which can be influenced by the players being evaluated[23]. Many quality indicators developed more recently[7,24,25,26] have been proposed to be relevant to a range of different palliative care services. It is inevitable though that some of the indicators within these sets will not be within the control of those care personnel associated with the service being evaluated. Several authors have commented on this 'fit' between the indicator set and the service being evaluated[27,28] and have recommended that indicators be amended or removed as appropriate. We believe that the specificity of our indicator set is a significant advantage as it means the indicator set is immediately accessible to UK Palliative Day Services, without modification. There is considerable scope for international collaboration in the development of quality indicators,[29,30] and hence with appropriate modifications to account for contextual and cultural differences, our indicator set will be valuable in other PDS services, internationally. The original set of 182 unique PDS quality indicators (supplementary file 2) derived from a comprehensive review of the *international* literature is a valuable reference for other providers wishing to develop PDS quality indicators.

Implementation in practice

The value of quality indicators is fully realised when they are implemented in routine practice, and used as a basis for quality improvement. Fifteen years after the Council of Europe first encouraged the definition and adoption of quality indicators of good palliative care, there is still little evidence of widespread implementation in practice.[16,31,32] Some of the barriers to successful implementation of quality indicators in palliative care settings include the attitudes towards quality improvement within the organisation[27] and among staff,[28] the perceived value of quality indicators,[27,28] and ‘top-down’ engagement[27]. Drawing upon this evidence and the improvement science literature,[33] we have incorporated features in our research design which are intended to improve the likelihood of uptake and implementation by Palliative Day Services. Use of the rigorous RAND/UCLA method results in a set of indicators with high face and content validity.[34-36] We have enhanced the perceived acceptability and credibility of the indicator set by promoting stakeholder awareness and involvement in the development of the indicators, and by ensuring representation on our expert panel from services where we wish the indicators to be utilised. We have communicated widely (via newsletters, presentations, the QualPalUK website, and site visits) about the development process, and have provided opportunities for stakeholder feedback. However, for successful implementation we will also need to be attuned to variations in current practice, the range of measures already in place in care settings, the diversity of systems (including IT systems), and staff training.[28,37]

Assessment of care quality is agreed to be an essential element of service provision, and the quality indicator set is a comprehensive and evidence based tool that enables this process. This comprehensive assessment requires time investment by services that are often time-poor, on an annual or bi-annual basis. Implementation will be facilitated where: services are able to organise their routinely collected data in a manner that is easily accessible for data extractors; service personnel recognise the direct impact of quality assessment on service improvements; data extractors become more familiar with use of the tool; and where efficiency of data extraction is enhanced via electronic capture. We are now developing an electronic version of the quality indicator toolkit which will help to reduce the time required for data extraction and calculation of the quality indicators by allowing abstractors to input the required (prompted) fields, with calculations completed by the programme in the background. We will supplement the quality indicator toolkit with a quality improvement module which will support Palliative Day Services to first identify areas for quality improvement, and subsequently to use Plan-Do-Study-Act cycles[38] to work towards improvement.

Although there were only five practice sites, the practice test indicated that the assessment of satisfaction and quality of life, and the production (and communication of) comprehensive care plans and needs assessments are areas which may require attention within Palliative Day Services. This finding is consistent with existing literature which has demonstrated that, despite initiatives promoting the routine measurement of patient reported outcomes,[39-42], and strong evidence of a positive effect on a multitude of care outcomes (including patient-clinician communication, patient satisfaction, and identification of unrecognized symptoms),[43] they are not yet widely measured in palliative care practice. Failure to implement patient reported outcome measurement in palliative care has been attributed to barriers including fear of change, time management/ constraints, lack of education on use of tools, burden of tools for staff and service users, illness severity, concerns about criticism, and cost constraints.[44] The assessment of patient reported outcomes is therefore one area where quality improvement projects may be particularly productive and valued by the Palliative Day Services community. In contrast, indicators which utilise administrative data that maps onto the requirements of national[45] or internal organisational audits were more likely to be met, such as ‘time from referral to first attendance’, or ‘consent to treatment’.

Strengths and weaknesses

The RAND/UCLA method has been shown to produce indicators with high content[34,46] and predictive validity.[32,47,48] However, these characteristics and others (including sensitivity to change and reliability) should be field tested in a larger representative sample of Palliative Day Services, using the electronic toolkit for data extraction. In addition, the time commitment required from Delphi panellists often results in a panel that is atypical with respect to their interest and commitment to the topic being investigated. Generating interest in the value and implementation of PDS quality indicators more widely is likely to be challenging.

What this study adds

Our quality indicator set fulfils a need within the Palliative Day Services community, by providing a means of assessing and reviewing quality of care and identifying areas for improvement.

REFERENCES

1 Farquhar M. AHRQ Quality Indicators. In: Hughes RG, ed. Patient Safety and Quality: An Evidence-Based Handbook for Nurses. Rockville (MD): Agency for Healthcare Research and Quality (US) 2008: Chapter 45.

2 Donabedian A. The Quality of Care. How Can It Be Assessed? *JAMA* 1988;260:1743–1748. doi:10.1001/jama.260.12.1743

3 Donabedian A. Explorations in quality assessment and monitoring. Volume 1: The definition of quality and approaches to its assessment. Ann Arbor, Michigan: Health Administration Press, 1980.

4 Association of Palliative Day Services. https://apds.org.uk/what-are-palliative-day-services (accessed: January 2018)

5 National Institute for Clinical Excellence. Improving Supportive and Palliative Care for Adults with Cancer 2004. https://www.nice.org.uk/guidance/csg4/resources/improving-supportive-and-palliative-care-for-adults-with-cancer-pdf-773375005 (accessed January 2018)

6 Fitch K, Bernstein SJ, Aguilar MD, et al. The RAND/UCLA Appropriateness Method User's Manual. Santa Monica, CA: RAND Corporation, 2001. http://www.rand.org/pubs/monograph_reports/MR1269.

7 Leemans K, Cohen J, Francke AL, et al. Towards a standardized method of developing quality indicators for palliative care: protocol of the Quality indicators for Palliative Care (Q-PAC) study. *BMC Palliat Care* 2013;12:6. https://doi.org/10.1186/1472-684X-12-6

8 Colquhoun HL, Levac D, O'Brien KK, et al. Scoping reviews: time for clarity in definition, methods, and reporting. *J Clin Epidemiol* 2014;67:1291-4. http://dx.doi.org/10.1016/j.jclinepi.2014.03.013

9 Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology. *Implement Sci* 2010;5:69. https://doi.org/10.1186/1748-5908-5-69

10 O'Connor S, Dempster M & McCorry NK. Identifying models of delivery, care domains and quality indicators relevant to Palliative Day Services: a scoping review protocol. *Systematic Reviews*, *2017*; 6:100. DOI: 10.1186/s13643-017-0489-4

11 De Koning J. Development and validation of a measurement tool for appraising indicator quality: appraisal of indicators through research and evaluation (AIRE) instrument [abstract] 2007. www.egms.de/static/en/meetings/gmds2007/07gmds798.shtml

12 GRADE Working Group. Grading quality of evidence and strength of recommendations. *BMJ* 2004;328:1490. doi: https://doi.org/10.1136/bmj.328.7454.1490 (Published 17 June 2004).

13 van Someren MW, Barnard YF, and Sandberg JAC. The think aloud method: a practical approach to modelling cognitive processes. (Knowledge-based systems). London: Academic Press 1994.

14 Blumenthal D and Jena AB. Hospital value-based purchasing. *J Hosp Med* 2013;8:271–7. http://dx.doi.org/10.1002/jhm.2045

15 Lilford RJ, Brown CA, Nicholl J. Use of process measures to monitor the quality of clinical practice. *BMJ* 2007;335:648–50. http://dx.doi.org/10.1136/bmj.39317.641296.AD

16 Brook RH, McGlynn EA, and Shekelle PG. Defining and measuring quality of care: a perspective from US researchers. *Int J Qual Health Care* 2000;12:281–295. http://dx.doi.org/10.1093/intqhc/12.4.281

17 Bruckel J, Liu X, Hohmann SF, et al. The denominator problem: national hospital quality measures for acute myocardial infarction. *BMJ Qual Saf* 2017;26:189-199. doi: 10.1136/bmjqs-2015-004888. Epub 2016 Mar 3.

18 Bilimoria KY. Facilitating quality improvement: pushing the pendulum back toward process measures. *JAMA* 2015;314:1333-4. doi: 10.1001/jama.2015.12470.

19 Gross PA. Editorial process versus outcome measures: the end of the debate. *Med Care* 2012;50:200-2. doi: 10.1097/MLR.0b013e31824a59fb.

20 Claessen SJ, Francke AL, Belarbi HE, et al. A new set of quality indicators for palliative care: Process and results of the development trajectory. *J Pain Symptom Manage* 2011;42:169-182. http://dx.doi.org/10.1016/j.jpainsymman.2010.10.267

21 Seow H, Snyder CF, Mularski RA, et al. A framework for assessing quality indicators for cancer care at the end of life. *J Pain Symptom Manage* 2009;38:903-912. http://dx.doi.org/10.1016/j.jpainsymman.2009.04.024

22 Shahian DM, Meyer GS, Mort E, et al. Association of National Hospital Quality Measure adherence with long-term mortality and readmissions. *BMJ Qual Saf* 2012;21:325-36. doi: 10.1136/bmjqs-2011-000615. Epub 2012 Mar 2.

23 Reiter A, Fischer B, Kötting J, et al. QUALIFY: instrument for the assessment of quality indicators. Version 1.0 (English). https://www.researchgate.net/publication/267256474_QUALIFY_Instrument_for_the_Assessment_of_Quality_Indicators

24 Woitha K, Van Beek K, Ahmed N, et al. Validation of quality indicators for the organization of palliative care: A modified RAND Delphi study in seven European countries (the Europall project). *Palliat Med* 2013;28:121-129. https://doi.org/10.1177/0269216313493952

25 Dy SM, Kiley KB, Ast K, et al. Measuring What Matters: Top-Ranked Quality Indicators for Hospice and Palliative Care From the American Academy of Hospice and Palliative

Medicine and Hospice and Palliative Nurses Association. *J Pain Symptom Manage* 2015;49:773-781. https://doi.org/10.1016/j.jpainsymman.2015.01.012

26 van Riet Paap J, Vernooij-Dassen M, Dröes R-M, Radbruch L, Vissers K, Engels Y. Consensus on quality indicators to assess the organisation of palliative cancer and dementia care applicable across national healthcare systems and selected by international experts. *BMC Health Services Research* 2014;14:396. doi=10.1186/1472-6963-14-396

27 Iliffe S, Davies N, Manthorpe J et al. Improving palliative care in selected settings in England using quality indicators: a realist evaluation. *BMC Palliat Care* 2016;15:69. doi: 10.1186/s12904-016-0144-1.

28 Leemans K, van den Block L, Vander R, et al. How to implement quality indicators successfully in palliative care services: perceptions of team members about facilitators of and barriers to implementation. *Support Care Cancer, 2015*;23:3503–3511. doi: 10.1007/s00520-015-2687-8

29 Marshall NM, Shekelle PG, McGlynn EA, Campbell S, Brook RH, Roland MO. Can health care quality indicators be transferred between countries? Qual Saf Health Care 2003;12:8–12. doi: 10.1136/qhc.12.1.8

30 Thomson RG, McElroy H, Kazandjian VA. Maryland hospital quality indicator project in the United Kingdom: an approach for promoting continuous quality improvement. Qual Health Care 1997;6:49–55.

31 Pasman HR, Brandt HE, Deliens L, et al. Quality indicators for palliative care: a systematic review. *J Pain Symptom Manage* 2009;38:145-56. doi: 10.1016/j.jpainsymman.2008.07.008.

32 DeRoo ML, Leemans K, Claessen SJJ et al. Quality indicators for palliative care: update of a systematic review. *J Pain Symptom Manage* 2013;46:556-572. doi: 10.1016/j.jpainsymman.2012.09.013. Epub 2013 Jun 26.

33 Grol R, Baker R, Moss F, eds. Quality Improvement Research: Understanding the Science of Change in Health Care. London: BMJ Books 2004.

34 Campbell SM, Braspenning J, Hutchinson A, et al. Research methods used in developing and applying quality indicators in primary care. *Qual Saf Health Care* 2002;11:358-364.

35 Shekelle PG, Kahan JP, Bernstein SJ, et al. The reproducibility of a method to identify the overuse and underuse of procedures. *N Engl J Med* 1998;338:1888–95.

36 Selby JV, Fireman BH, Lundstrom RJ. Variation among hospitals in coronary-angiography practices and outcomes after myocardial infarction in a large health maintenance organisation. N Engl J Med 1996;335:1888–96

37 Palliative Care Outcomes Collaboration. *Palliative Care Outcomes Collaboration: Three years of progress (2010 to 2013)*. Australian Health Services Research Institute, University of Wollongong, Wollongong 2013. https://ahsri.uow.edu.au/content/groups/public/@web/@chsd/documents/doc/uow154319.pdf

38 Langley G, Nolan K, Nolan T et al. The Improvement Guide. Jossey-Bass, San Francisco 1996.

39 Council of Europe. Recommendation Rec (2003) 24 of the Committee of Ministers to member states on the organisation of palliative care. CM 2002:130. https://www.coe.int/t/dg3/health/Source/Rec(2003)24_en.pdf

40 Radbruch L, Payne S, and the Board of Directors of the EAPC. White Paper on standards and norms for hospice and palliative care in Europe: Part 1 Recommendations from the

European Association for Palliative Care. *European Journal of Palliative Care* 2010;17:1. www.eapcnet.eu/Themes/Resources/Organisation/EAPCStandardsNorms.aspx

41 Bausewein C, Daveson BA, Currow DC et al. EAPC White Paper on outcome measurement in palliative care: Improving practice, attaining outcomes and delivering quality services – Recommendations from the European Association of Palliative Care (EAPC) taskforce on outcome measurement. *Palliat Med* 2016;30:6-22. DOI: 10.1177/0269216315589898

42 Simon S, Higginson I, Harding R, et al. Enhancing patient reported outcome measurement in research and practice of palliative care and end-of-life care. *Support Care Cancer* 2012;20:1573-1578. doi: 10.1007/s00520-012-1436-5. Epub 2012 Mar 7.

43 Dudgeon D. The Impact of Measuring Patient-Reported Outcome Measures on Quality of and Access to Palliative Care. *J Palliat Med* 2017;20:S76-80. doi: 10.1089/jpm.2017.0447

44 Antunes B, Harding R, Higginson J, on behalf of EUROIMPACT. Implementing patient-reported outcome measures in palliative care clinical practice: A systematic review of facilitators and barriers. *Pall Med* 2014;28:158-175.

45 The National Council for Palliative Care Minimum Data Set [online]. Available at: http://www.ncpc.org.uk/minimum-data-set [Accessed 28 Aug. 2018].

46 Merrick NJ, Fink A, Park RE, Brook RH, Kosecoff J, Chassin MR, et al. Derivation of clinical indications for carotid endarterectomy by an expert panel. *Am J Pub Health* 1987;77:187-90. doi: 10.2105/AJPH.77.2.187.

47 Salzer MS, Nixon CT, Schut LJA, Karver MS, Bickman L. Validating quality indicators: quality as relationship between structure, process and outcome. *Evaluation Review* 1997;21:292-309. doi: 10.1177/0193841X9702100302.

48 Kravitz RL, Laouri M, Kahan JP, Guzy P, Sherman T, Hilborne L, et al. Validity of criteria used for detecting underuse of coronary revascularization. *JAMA* 1995;274:632-8. doi: 10.1001/jama.274.8.632.

DECLARATIONS

Authorship

All authors made a substantial contribution to the concept or design of the work or acquisition of data, revised the article for important intellectual content, approved the submitted version, and participated sufficiently in the work to take public responsibility for appropriate portions of the content. McCorry, Dempster and O'Connor drafted the article.

Funding

This work was supported by the Marie Curie Research Grants Scheme, grant [C10667/A17151].

Conflicts of interest

There are no conflicts of interest.

Ethics

The study protocol was approved by the School of Psychology, Queen's University Belfast Research Ethics Committee (ref: 10-2015-16).

Data management and sharing

The final QualPalUK indicator set is available for use in the main document. The most recent version of the QualPalUK data extraction toolkit can be obtained by contacting the corresponding author. Supplementary files 1 and 2 provide a detailed account of the derivation of the final indicator set.

Acknowledgements

We are grateful to the members of the QualPalUK expert panel for providing their time and expertise in the development of the indicator set, including representatives of: Marie Curie Hospice West Midlands; Rowcroft Hospice, Torquay; Brunel University; LOROS Hospice, Leicester; Marie Curie Hospice Hampstead, Sobell House, Oxford; St Joseph’s Hospice, London; Sue Ryder Leckhampton Court Hospice, Cheltenham; Bournemouth University; St Catherine’s Hospice, Crawley; Northern Ireland Hospice; University of East Anglia; St Michael’s Hospice, Hereford; University of the West of Scotland; Willen Hospice, Milton Keynes; St Barnabas Lincolnshire Hospice, Lincoln; St Benedict’s Hospice and Centre for Specialist Palliative Care, Sunderland; and St Clare Hospice, Essex.

We thank our colleagues who performed data abstraction at each participating site, including Gail Watson and Susan Buchanan.

Supplementary file 1: Original 182 candidate indicators, and panel ratings during round one and two of the RAND/UCLA Appropriateness Method (RAM)

#	**Potential quality indicator descriptions**	**Round 1**		**Round 2**			
	Care Domains	**Median Appropriateness Score/9 (Range)***	**Agreement between panel Y/N†**	**Median Appropriateness Score/9 (Range) ‡**	**Median Feasibility Score/9§**	**Rated as necessary by panel Y/N (% yes)¶**	**Core or supplementary indicator**
	Physical care and support, assessment and treatment						
DQI#01	Number of patients screened for pain using a validated measure	8 (5)	Y	8.5 (3)	8	Y (100)	Core
DQI#02	Number of patients with a score >x/10 on a NRS/VAS (average pain on a typical day over the last week)	3 (8)	N	-	-	-	-
DQI#03	Number of patients with moderate to severe pain	7 (8)	Y	7 (5)	5.5	Y (55)	Core
DQI#04	For patients who screen positive for pain, the number with any treatment within [x] week[s]	7 (4)	Y	8 (3)	7.5	N (36)	Supplementary
DQI#05	For patients who screen positive for pain, the number with significant improvement after [x] week[s]	5.5 (7)	N	4.5 (4)	2	N (45)	-
DQI#06	Number of patients assessed to identify likely cause of pain based on site and radiation (e.g. using a body diagram)	7 (3)	Y	8 (3)	8	N (27)	Supplementary
DQI#07	Number of patients assessed to identify likely cause of pain based on character (e.g. using a list of descriptors)	9 (3)	Y	7.5 (3)	7.5	N (27)	Supplementary
DQI#08	Number of patients assessed to identify likely cause of pain based on exacerbating/relieving factors including analgesics	8.5 (3)	Y	8 (3)	8	N (27)	Supplementary
DQI#09	Number of patients assessed to identify likely cause of pain based on timing and duration	7.5 (3)	Y	7 (4)	7.5	N (27)	Supplementary
DQI#10	Number of patients assessed to identify likely cause of pain based on effect on function, sleep and mood	9 (2)	Y	7.5 (2)	8	Y (55)	Core
DQI#11	Documentation of other factors (e.g. emotional, psychological or spiritual) with possible effect on pain perception	4 (5)	Y	4.5 (3)	4.5	Y (55)	Core
DQI#12	Number of patients screened for SOB using a validated measure	7 (3)	Y	8 (4)	5.5	N (57)	Core
DQI#13	For patients who screen positive for SOB, the number with any treatment within [x] week[s]	5 (4)	Y	3.5 (4)	7	N (36)	Supplementary
DQI#14	For patients who screen positive for SOB, the number with significant improvement after [x] week[s]	3.5 (4)	Y	7 (3)	8	N (64)	Core
DQI#15	Number of patients screened for upper GI (stomach) problems (nausea/vomiting) using a validated measure	6 (5)	Y	4 (2)	5.5	N (18)	Supplementary
DQI#16	For patients who screen positive for upper GI problems, the number with any treatment within [x] week[s]	8 (3)	Y	8 (3)	8	N (45)	Supplementary
DQI#17	For patients who screen positive for upper GI problems, the number with significant improvement after [x] week[s]	7 (5)	N	4.5 (3)	3	N (9)	-
DQI#18	Number of patients screened for lower GI (abdominal) problems (constipation) using a validated measure	7 (4)	Y	7.5 (3)	6	Y (55)	Core
DQI#19	For patients who screen positive for lower GI problems, the number with any treatment within [x] week[s]	7 (3)	Y	5.5 (2)	7.5	Y (55)	Core
DQI#20	For patients who screen positive for lower GI problems, the number with significant improvement after [x] week[s]	9 (2)	Y	5 (5)	2	N (27)	-
DQI#21	Number of patients screened for poor mobility using a validated measure	6.5 (2)	Y	3.5 (2)	7.5	N (45)	Supplementary
DQI#22	For patients who screen positive for poor mobility, the number with any treatment within [x] week[s]	6 (8)	N	5.5 (3)	1.5	N (27)	-

DQI#23	For patients who screen positive for poor mobility, the number with significant improvement after [x] week[s]	3 (5)	N	4.5 (3)	2	N (27)	-
DQI#24	Number of patients screened for tiredness/weakness	8 (3)	Y	8 (3)	8	Y (55)	Core
DQI#25	For patients who screen positive for tiredness/weakness, the number with any treatment within [x] week[s]	4 (5)	N	5.5 (3)	3	N (36)	-
DQI#26	For patients who screen positive for tiredness/weakness, the number with significant improvement after [x] week[s]	5.5 (3)	Y	3.5 (4)	5.5	Y (73)	Core
DQI#27	Number of patients screened for insomnia using a validated measure	3 (6)	N	-	-	-	-
DQI#28	For patients who screen positive for insomnia, the number with any treatment within [x] week[s]	3 (4)	Y	-	-	-	-
DQI#29	For patients who screen positive for insomnia, the number with significant improvement after [x] week[s]	3 (4)	Y	4	5	Y (55)	Core
DQI#30	Number of patients with an assessment of functional status made using a validated measure reviewed within a [x] month period	9 (3)	Y	7 (3)	5.5	Y (64)	Core
DQI#31	Number of patients screened for general symptom assessment using a validated measure and reviewed within a [x] month period	9 (3)	Y	8 (4)	8	Y (91)	Core
DQI#32	Number of patients with a symptom management plan, including goals, agreed in conjunction with the patient and family	9 (3)	Y	7.5 (4)	7.5	Y (100)	Core
DQI#33	Number of patients with agreed arrangements for regular review of symptoms	9 (3)	Y	7 (5)	7.5	Y (73)	Core
DQI#34	Number of patients provided with written advice on physical symptom management	5 (5)	Y	4 (5)	2	N (27)	-
DQI#35	Number of patients who receive an individualized assessment of physical activity levels	3 (7)	Y	-	-	-	-
DQI#36	Number of patients with an assessment made of satisfaction with overall physical care and support	8 (2)	Y	7.5 (3)	8	Y (55)	Core
DQI#37	Number of patients satisfied with overall physical care and support assessed using a standardized measure	3 (8)	Y	-	-	-	-
	Psychological care and support, assessment and treatment						
DQI#38	Number of patients screened for depression using a validated measure within a [x] month period	9 (2)	Y	7.5 (3)	8	Y (55)	Core
DQI#39	Number of patients who screen positive for depression, the number with any treatment within [x] week[s]	5 (6)	N	6.5 (3)	4	Y (55)	Core
DQI#40	Number of patients who screen positive for depression, the number with significant improvement after [x] week[s]	7 (4)	Y	8 (4)	5.5	Y (55)	Core
DQI#41	Number of patients screened for anxiety using a validated measure within a [x] month period	9 (1)	Y	8 (3)	7.5	Y (91)	Core
DQI#42	Number of patients who screen positive for anxiety, the number with any treatment within [x] week[s]	5 (4)	Y	5.5 (2)	6	N (27)	Supplementary
DQI#43	Number of patients who screen positive for anxiety, the number with significant improvement after [x] week[s]	7 (3)	Y	7 (3)	2	Y (55)	-
DQI#44	Number of patients who receive support when they feel anxious or feel depressed	3 (7)	N	-	-	-	-
DQI#45	Number of patients diagnosed with depression with a documented treatment plan	8.5 (2)	Y	6 (3)	8.5	Y (64)	Core
DQI#46	Number of patients diagnosed with depression with response to therapy documented within [x] week[s]	3 (7)	N	-	-	-	-
DQI#47	Number of patients who receive adequate attention from their	1 (8)	N	-	-	-	-

	caregivers						
DQI#48	Number of patients are satisfied with the counselling aspects of “politeness” and “being taken seriously”	1 (7)	N	-	-	-	-
DQI#49	Number of patients who experience respect for their autonomy	2.5 (8)	N	-	-	-	-
DQI#50	Number of patients who experience respect for their privacy	2 (4)	Y	-	-	-	-
DQI#51	Number of patients who receive overall quality of life assessment using a validated measure	9 (3)	Y	8 (2)	7.5	Y (100)	Core
DQI#52	Number of patients who receive condition specific psychological assessment using a validated measure	1 (8)	N	-	-	-	-
DQI#53	Number of patients referred to / receiving stress management program or intervention	1.5 (8)	N	-	-	-	-
DQI#54	Number of patients who receive treatment for psychological symptoms in a timely, safe and effective manner	5 (6)	N	6 (4)	6.5	N (27)	Supplementary
DQI#55	Number of patients with an assessment of cognition performed and results reviewed at least [x] times within [x] months	9 (2)	Y	4.5 (3)	7.5	Y (64)	Core
DQI#56	Number of patients with neuropsychiatric symptoms receiving or recommended to receive intervention within a [x] month period	1 (8)	N	-	-	-	-
	Social care, assessment and management						
DQI#57	Number of patients with a comprehensive social care plan addressing social, practical, and legal needs of patient and caregivers	1.5 (6)	N	-	-	-	-
DQI#58	Number of patients with equity of access to support for social care needs including counselling services	1.5 (8)	N	-	-	-	-
DQI#59	Number of patients with a comprehensive interdisciplinary assessment identifying social needs of patients and families	9 (2)	Y	8 (3)	8	Y (82)	Core
DQI#60	Number of patients with an assigned professional who maintains contact to ensure co-ordinated delivery of services	6 (5)	N	5.5 (4)	4	N (18)	Supplementary
	Spiritual and emotional care and support						
DQI#61	Number of patients who indicate that caregivers respect their life stance	1 (8)	N	-	-	-	-
DQI#62	Number of patients who indicate that they have access to a counsellor for spiritual problems	3 (7)	N	-	-	-	-
DQI#63	Number of relatives who indicate that the patient had access to a counsellor for spiritual problems	1 (8)	N	-	-	-	-
DQI#64	Number of relatives who indicate that the patient had accepted her/his approaching death	1 (8)	N	-	-	-	-
DQI#65	Number of relatives who indicate that there was attention and respect for the spiritual well-being of the patient	5 (4)	Y	2 (3)	1.5	N (9)	-
DQI#66	Number of relatives who indicate that the patient had access to a counsellor for spiritual problems	1 (8)	N	-	-	-	-
DQI#67	Number of patients who indicate that they feel that life is worthwhile	1 (8)	N	-	-	-	-
DQI#68	Number of patients with documentation of discussion of spiritual/religious concerns or that the patient did not want to discuss	9 (3)	Y	6 (2)	8	Y (82)	Core
DQI#69	Number of patients with a plan based on an assessment of religious, spiritual, and existential concerns using a structured instrument	9 (4)	Y	4 (3)	8	Y (64)	Core
DQI#70	Number of patients with information about the availability of spiritual care services	8 (4)	Y	6 (4)	8	Y (91)	Core

DQI#71	Number of patients assessed to identify important spiritual and emotional aspects of care using a validated measure	6 (4)	Y	4 (2)	6.5	Y (73)	Core
	Cultural aspects of care						
DQI#72	Number of patients with a non-English native language who have baseline screening performed in their native language	4.5 (5)	N	5 (4)	2	N (9)	-
DQI#73	Number of patients with access to translators where caregivers and patient / family members do not speak the same language	8.5 (2)	Y	7 (3)	2.5	Y (64)	-
DQI#74	Number of patients with a cultural assessment including preferences regarding disclosure of information and desire for support measures	3 (7)	N	-	-	-	-
DQI#75	Number of patients provided with culturally sensitive materials in the patient's and family's preferred language	9 (2)	Y	5 (6)	2	Y (55)	-
	Generic aspects of care and health promotion						
DQI#76	Extent to which staff assess and manage symptoms and side effects in a timely, safe, and effective manner	8 (1)	Y	8 (3)	7.5	Y (64)	Core
DQI#77	Number of patients with documented communication between Day Service and General Practitioner	9 (2)	Y	8 (4)	8	Y (100)	Core
DQI#78	Extent to which patients receive information about the expected course of the illness	1 (8)	N	-	-	-	-
DQI#79	Extent to which patients receive information about the advantages and disadvantages of various types of treatments	2.5 (8)	N	-	-	-	-
DQI#80	Extent to which the distinct care needs of patients with different conditions are recognised and addressed	2 (8)	N	-	-	-	-
DQI#81	Number of patients who receive individual or group patient self-management	2 (8)	N	-	-	-	-
DQI#82	Number of exercise / rehabilitation sessions attended by patient	1 (8)	N	-	-	-	-
DQI#83	Number of patients or their caregiver(s) referred for counselling regarding safety concerns within an [x] month period	1 (8)	N	-	-	-	-
DQI#84	Number of patients provided with education on disease management or referred to additional resources of support	1 (8)	N	-	-	-	-
DQI#85	Number of patients with assessment and appropriate management of sexual dysfunction	8 (6)	N	7 (2)	8	Y (52)	Core
DQI#86	Extent to which patients experience respect for their autonomy / privacy	6 (3)	Y	4 (4)	7	N (36)	Supplementary
DQI#87	Number of patients assessed screened at least once to detect whether they use tobacco regularly	1 (8)	N	-	-	-	-
DQI#88	Number of patients with an inventory of complaints and problems	1 (8)	N	-	-	-	-
DQI#89	Number of patients assessed to detect problem drinking by taking a history of alcohol use or using standardized screening questionnaires	1 (8)	N	-	-	-	-
DQI#90	Extent to which commissioners work to meet needs of patients for complementary therapies where there is evidence to support their use. As a minimum, high quality information should be made available to patients about complementary therapies and services	9 (2)	Y	4 (3)	8	Y (82)	Core
DQI#91	Extent to which providers ensure practitioners delivering complementary therapies conforms to policies designed to ensure best practice	9 (2)	Y	8 (2)	7.5	Y (82)	Core
DQI#92	Extent to which commissioners institute mechanisms to ensure patient needs for rehabilitation are met and that services and	8.5 (2)	Y	8.5 (3)	8.5	Y (91)	Core

	suitable equipment are available to patients in all care locations						
	Information and communication with patients, carers and family						
DQI#93	Number of patients who indicate that they receive understandable explanations	9 (1)	Y	4.5 (6)	7.5	N (45)	Supplementary
DQI#94	Number of patients with documentation concerning the desired care and treatment	8.5 (4)	Y	5 (3)	8	Y (73)	Core
DQI#95	Extent to which patients feel able to communicate their needs in the best possible way, whether verbally or non-verbally	5 (4)	Y	3 (3)	3	N (45)	-
DQI#96	Extent to which patients feel they are provided with enough information to understand their illness and treatment	9 (2)	Y	3 (2)	7.5	Y (64)	-
DQI#97	Extent to which patients feel they are given bad news in a sensitive way	5 (4)	Y	4.5 (5)	4	N (36)	Supplementary
DQI#98	Number of patients with a holistic assessment of palliative care needs of patients and their family caregivers (e.g. SPARC)	9 (2)	Y	4 (4)	8.5	N (36)	Supplementary
DQI#99	Extent to which, according to the direct relatives, attention was paid to their own psychosocial and spiritual well-being	1 (8)	N	-	-	-	-
DQI#100	Extent to which the direct relatives felt that they were treated well in all respects by the caregivers	2 (8)	N	-	-	-	-
DQI#101	Extent to which direct relatives received information that was understandable and unambiguous	1.5 (8)	N	-	-	-	-
DQI#102	Extent to which direct relatives received information about the advantages and disadvantages of various types of treatment	1 (8)	N	-	-	-	-
DQI#103	Extent to which patients feel that specialists show an interest in you as a person	1.5 (8)	N	-	-	-	-
DQI#104	Extent to which family and friends had opportunities to ask questions	4 (5)	N	3.5 (4)	2	N (36)	-
DQI#105	Extent to which patients feel they have the knowledge and support to make decisions	8 (2)	Y	3 (2)	8.5	Y (73)	-
DQI#106	Extent to which patients feel that they have opportunities to ask questions	8 (1)	Y	5.5 (2)	4.5	Y (64)	Core
DQI#107	Number of patients and family/caregivers that understand and are satisfied with provider communication about prognosis	2 (8)	N	-	-	-	-
DQI#108	Extent to which patients are satisfied with their involvement in decision making	9 (2)	Y	8 (3)	8	Y (73)	Core
	Care planning, goal setting and shared decision making with patients, carers and family						
DQI#109	Number of patients with documentation of initial assessment completed within [x] week[s] from referral	8.5 (4)	Y	7.5 (3)	8.5	Y (64)	Core
DQI#110	Number of patients with regular patient and family care conferences with interdisciplinary team to discuss goals of care and care planning	2 (8)	N	-	-	-	-
DQI#111	Number of patients with documentation of converted treatment goals into medical orders transferable across settings, for example, through Physician Orders for Life-Sustaining Treatment (POLST) program)	1 (8)	N	-	-	-	-
DQI#112	Number of patients with advance directives and surrogacy designations available across settings using Internet-based registries or electronic personal health records	8 (4)	Y	7 (2)	8	Y (55)	Core
DQI#113	Number of patients with documentation of patient/surrogate	9 (3)	Y	8 (2)	8	Y (91)	Core

	preferences for goals of care and treatment options at first assessment and at frequent intervals as conditions change						
DQI#114	Number of patients with documentation of involvement in decision-making over the past [x] months	9 (3)	Y	4.5 (6)	7.5	N (45)	Supplementary
DQI#115	Number of patients or caregiver(s) who received 1) comprehensive counselling regarding palliation and symptom management and end of life decisions 2) have advance care plan or surrogate decision maker in the medical record or documentation that patient did not wish or was not able to name a surrogate	1 (8)	N	-	-	-	-
DQI#116	Number of patients and family/caregivers that understand and are satisfied with their participation in the development of treatment goals	9 (3)	Y	5 (4)	7.5	Y (55)	Core
	End of life care and decisions						
DQI#117	Number of patients with documentation of patient and family wishes about the care setting for the site of death, and fulfil patient and family preferences when possible	1 (8)	N	-	-	-	-
DQI#118	Number of patients with adequate dosage of analgesics and sedatives as appropriate to achieve comfort during the active dying phase, and with addressed concerns and fears about using narcotics and of analgesics hastening death	3 (6)	N	-	-	-	-
	Pre and post-bereavement support						
DQI#119	Number of patients with an assessment of psychological reactions of patients and families (including stress, anticipatory grief, and coping) in a regular, ongoing fashion in order to address emotional and functional impairment and loss	3 (6)	N	-	-	-	-
DQI#120	Number of patients with a grief and bereavement care plan to provide services to patients and families prior to and for at least [x] months after the death of the patient	3 (6)	N	-	-	-	-
DQI#121	Number of relatives offered counselling for survivors	3 (6)	N	-	-	-	-
DQI#122	Extent to which the hospice team kept family members informed about the patient's condition (e.g. always/usually/sometimes/never)	3 (6)	N	-	-	-	-
DQI#123	Number of relatives who received information from the team about the medicines that were used to manage the patient's pain	1.5 (8)	N	-	-	-	-
DQI#124	Number of relatives who received information from the team about what was being done to manage the patient's trouble with breathing	3 (8)	N	-	-	-	-
DQI#125	Number of patients where an immediate bereavement plan is activated post-death	4 (8)	N	3 (5)	1	N (0)	-
DQI#126	Number of relatives who indicate that the patient received support with preparations for saying goodbye	2.5 (8)	N	-	-	-	-
	Co-ordination and continuity of care						
DQI#127	Number of patients with a professional caregiver nominated as the responsible 'key worker' who coordinates care	6 (4)	Y	2.5 (4)	2.5	N (36)	-
DQI#128	Number of patients with a regular review of the care plan based on a comprehensive interdisciplinary assessment of the values, preferences, goals, and needs of the patient and family	9 (1)	Y	7.5 (2)	8	Y (91)	Core
DQI#129	The extent to which care plans are broadly disseminated to all professionals involved in the patient's care	9 (2)	Y	7 (4)	8	Y (64)	Core

DQI#130	The extent to which treatments that are no longer helpful are stopped	4 (5)	N	1 (4)	2	N (9)	-
DQI#131	The extent to which palliative care services are integrated into the local area health authority and operate at the specific request of the GP and in association with him/her	1 (8)	N	-	-	-	-
DQI#132	While under the care of hospice, was there always one nurse who was identified as being in charge of the patient's overall care? (yes/no)	3 (8)	N	-	-	-	-
DQI#133	Was there any problem with hospice doctors or nurses not knowing enough about the patient's medical history to provide the best possible care? (yes/no)	1 (8)	N	-	-	-	-
DQI#134	Time from referral to first contact [calculated as the time in days between the referral date and the date of first contact or episode start date (whichever occurs first)] calculated for all episodes of care and across all settings of care	7 (3)	Y	8.5 (4)	7	Y (91)	Core
DQI#135	Number of patients with documentation of letter to the referring physician contains the following components: diagnosis; conclusions concerning the care needs of the patient and caregiver(s); medical treatment plan; non-medical treatment plan; advice concerning driving aptitude; care advice for the patent and the caregiver(s)	9 (5)	N	7.5 (3)	8	Y (100)	Core
DQI#136	Number of patients with a care plan that is revisited with patient and family on a regular basis and following any significant change in health condition	9 (2)	Y	8 (4)	8	Y (64)	Core
	Structure and process of care						
DQI#137	Number of patients with documentation of a regular interdisciplinary/multi-professional meeting to discuss management	9 (2)	Y	7 (3)	8	Y (100)	Core
DQI#138	Number of patients provided with documentation on important complaints that can occur after primary treatment and can be a sign of disease progression	1 (8)	N	-	-	-	-
DQI#139	Number of patients provided with sufficient time and attention during appointments and after primary treatment has finished	2 (8)	N	-	-	-	-
DQI#140	Number of patients with a palliative care clinical record containing evidence of: Ethical, legal aspects of care	1.5 (7)	N	-	-	-	-
DQI#141	Number of patients with a palliative care clinical record containing evidence of: Clinical summary	9 (2)	Y	8 (2)	8	Y (91)	Core
DQI#142	Number of patients with a palliative care clinical record containing evidence of: Spiritual, religious, existential aspects of care	8 (2)	Y	8 (3)	8	N (36)	Supplementary
DQI#143	Number of patients with a palliative care clinical record containing evidence of: Physical aspects of care	8 (2)	Y	8.5 (4)	8	N (45)	Supplementary
DQI#144	Number of patients with a palliative care clinical record containing evidence of: Follow up assessment	9 (2)	Y	7.5 (6)	8	N (36)	Supplementary
DQI#145	Number of patients with a palliative care clinical record containing evidence of: Psychological and psychiatric aspects of care	9 (3)	Y	7.5 (4)	8	N (36)	Supplementary
DQI#146	Number of patients with evidence that the care plan was implemented by all providers consistent with goals of care	1 (7)	Y	-	-	-	-
	Evidence of effectiveness, outcome assessment and measurement						
DQI#147	Number of patients where a validated tool used to monitor	7 (3)	N	8.5 (4)	8	Y (64)	Core

	progress (e.g. Edmonton Symptom Assessment System, Edmonton Functional Assessment Tool, Part A of the McGill Quality of Life Index or the Palliative Care Problem Severity Scale)						
DQI#148	Evidence that the palliative care service is involved in research in palliative care (e.g. authorship of publications, research grants)	1 (8)	Y	-	-	-	-
DQI#149	Number of non-oncological patients receiving palliative care	4 (5)	Y	6.5 (7)	1	N (9)	-
DQI#150	Number of patients with documentation of adverse events	9 (2)	Y	7.5 (4)	7	N (45)	Supplementary
DQI#151	Number of patients with evidence of a documented procedure to analyse and follow up adverse events	9 (2)	N	7.5 (4)	7	N (45)	Supplementary
DQI#152	Number of patients aware of patient complaint procedures	4 (6)	Y	3.5 (7)	4	N (18)	Supplementary
DQI#153	Number of patients where a patient-reported outcome measures (PROMs) is used that has been validated with relevant populations requiring palliative care and which are sufficiently brief and straightforward and that they allow for proxy reports to be collected when the patient is unable to self-report	7 (5)	N	7 (8)	8	N (9)	Supplementary
DQI#154	Number of assessment using outcome measures to assess the needs of unpaid caregivers (family and others) alongside the needs of patients	2.5 (8)	N	-	-	-	-
DQI#155	Evidence of use of change management principles, facilitation and communication to embed outcome measurement into routine clinical practice and evaluate the implementation process to ensure sustained use that penetrates practice within the organisation	3 (8)	Y	-	-	-	-
DQI#156	Evidence of use of quality improvement systems to sustain routine practice of outcome measurement and institute interoperable electronic systems to ensure integration of measures	3 (7)	N	-	-	-	-
DQI#157	Evidence of use of established national and international outcome collaborations that work towards benchmarking to establish and improve care standards	1 (6)	Y	-	-	-	-
DQI#158	Evidence of use of monitoring of palliative care practice through routine collection of outcome data used to establish a minimum dataset of palliative care outcome measures in order to improve and advance care	6 (4)	Y	7 (4)	7	N (36)	Supplementary
	Staff training and education, service and professional development						
DQI#159	Number of staff who receive a standardised induction training within [x] month[s] of employment	9 (2)	Y	3 (5)	4	N (9)	-
DQI#160	All health and social care professionals have standardised learning objectives for continuing basic training in palliative care	4 (5)	Y	4 (4)	1.5	N (0)	-
DQI#161	Number of staff who professionally deal with loss with access to a program for care for the carers	1.5 (8)	N	-	-	-	-
DQI#162	Number of staff assessed for satisfaction with working in the team (e.g. Team Climate Inventory)	7 (6)	Y	6.5 (4)	1	Y (55)	-
DQI#163	Documentation of processes in place to identify the training needs of all workers (registered and unregistered) that take into account the four core common requirements for workforce development (communication skills, assessment and care planning, advance care planning, and symptom management) as	9 (3)	Y	4.5 (4)	8	N (27)	Supplementary

	they apply to end of life care						
DQI#164	Number of staff with access to curricula for training as part of continuing professional education including palliative care for patients with illness other than cancer	7 (6)	Y	7.5 (3)	7.5	Y (64)	Core
	Access to services and service environment						
DQI#165	Number of patients who have access to diagnostic investigations (e.g. x-rays, blood samples] regardless of the setting	1 (8)	Y	-	-	-	-
DQI#166	Number of patients receiving palliative care provided with transportation to the service	1 (8)	Y	-	-	-	-
DQI#167	Number of patients experiencing a crisis where the following is arranged within [x] hours: admission	1.5 (7)	Y	-	-	-	-
DQI#168	Number of patients receiving the following treatments as needed 24 hours a day, [x] days a week: opioids and other controlled drugs	8 (2)	N	3.5 (7)	4	N (18)	Supplementary
DQI#169	There is a dedicated room where multidisciplinary team meetings within one setting takes place	3 (7)	N	-	-	-	-
DQI#170	Relevant services and care providers should ensure equal access to available day services based on need through appropriate referrals	9 (2)	N	3 (5)	9	N (45)	-
DQI#171	All service users should have equity of access to all day services and support that is available	3 (6)	N	-	-	-	-
DQI#172	If a confidential discussion has to take place then it should take place in private	1.5 (8)	Y	-	-	-	-
DQI#173	The setting of care should meet the preferences, needs, and circumstances of the patient and family to the extent possible	8.5 (4)	N	4.5 (4)	4.5	Y (82)	Core
DQI#174	In rural areas where accessing specialized care is difficult, organizations should institute telehealth and telemedicine communications	4 (6)	Y	3.5 (4)	3	N (0)	-
	Promotion of effective external engagement						
DQI#175	Number of patients provided with access to an up to date directory of local caregivers and organisations	1 (8)	N	-	-	-	-
DQI#176	Number of patients provided with access to dedicated information about the palliative care service: A website	8 (6)	Y	7 (3)	5	Y (82)	Core
DQI#177	Number of patients provided with access to dedicated information about the palliative care service: Leaflets or brochures	9 (7)	Y	6.5 (3)	7	Y (91)	Core
DQI#178	Develop healthcare and community collaborations to promote advance care planning and the completion of advance directives for all individuals(for example, the Respecting Choices and Community Conversations on Compassionate Care programs)	8.5 (4)	Y	8.5 (3)	7	Y (82)	Core
DQI#179	Processes will be in place to manage ethical aspects involving discordant patient, family, and caregiver goals and to handle disputes and uncertainties regarding a patient's previously stated preferences and current family or proxy decisions.	8 (7)	Y	5 (5)	9	Y (55)	Core
	Societal, ethical and legal aspects of care						
DQI#180	Number of patients with documentation of informed consent before therapy	9 (4)	Y	8 (4)	9	Y (91)	Core
DQI#181	Annual reports are produced reporting the activities and characteristics of the service such as team composition, staff composition, resources, referring physicians, patient characteristics	4 (3)	Y	1.5 (8)	3	N (0)	-

DQI#182	All patients living in psychosocial circumstances presenting a high-risk for their health should be identified as soon as possible	3 (2)	Y	-	-	-	-

*Median Appropriateness Score /9 (Range): Appropriateness ratings of 1-3 were categorized as inappropriate, ratings of 4-6 were classified as uncertain and ratings 7-9 were classified as appropriate.

†Agreement between panel Y/N: With a panel size of 16, level of agreement was based on a maximum of four panel members rating a quality indicator outside a three-point region around the median value; with disagreement defined as five or more panel members rating an indicator at the extreme ends of the scale as either inappropriate (1-3) or appropriate (7-9).

§Median Feasibility Score /9: Feasibility was assessed using the same 9 point scale as appropriateness, and level of agreement was based on a maximum of three panel members rating a quality indicator outside a three-point region around the median value; with disagreement defined as four or more panel members rating an indicator at the extreme ends of the scale as either inappropriate (1-3) or appropriate (7-9). Level of agreement data for feasibility are not shown

¶Rated as necessary by panel members Y/N (% yes).

Supplementary file 2: Derivation of final indicator set (n=30) from original candidate indicators, including indicators combined during RAM round 3

	Final indicator description following phase three of RAND/UCLA Appropriateness Method	Original (combined) candidate indicators
	A. Physical care and support, assessment and treatment	
A1	Proportion of service users with assessment of pain severity at screening using a valid measure	#01
A2	Proportion of service users with moderate or severe pain assessed to explore possible causes of pain	#03,#10,#11
A3	Proportion of service users with assessment of breathlessness at screening using a valid measure	#12
A4	Proportion of service users with assessment of fatigue at screening using a valid measure	#24
A5	Proportion of service users with assessment of functional status to identify daily activity limitations completed before a multidisciplinary care plan	#30
	B. Psychological care and support, assessment and treatment	
B6	Proportion of service users screened for depression at screening using a valid measure	#38
B7	Proportion of service users screened for anxiety at screening using a valid measure	#41
B8	Proportion of service users with assessment of cognitive functioning	#55
	C. Spiritual and emotional care and support	
C9	Proportion of service users with documentation of a spiritual aspects of care discussion or assessment completed before a multidisciplinary care plan	#68;#71
	D. Information and Communication with Service Users	
D10	Proportion of service users who report that they are provided with sufficient, appropriately tailored information or advice on their condition and on intervention options to support decisions on agreed care planning	#177,#179
	E. Co-ordination and continuity of care	
E11	Proportion of service users with a comprehensive needs assessment completed before a multidisciplinary care plan to identify main symptoms and concerns and their effect	#59,#85,#109
E12	Service has a written care pathway for assessment and management of moderate or severe pain including appropriate onward referral routes	#10,#11
E13	Proportion of service users with documentation of re-assessment at regular review in line with time points agreed in the multidisciplinary care plan	#128,#136,#137,#147
E14	Service has a written standard operating procedure defining timeframes for time to initial contact, completion of needs assessment and multidisciplinary care plan	#33, #94
E15	Proportion of service users with documentation of appropriate intervention in line with the agreed, multidisciplinary care plan	#39, #70, #76
E16	Proportion of service users with documented communication between the service and the General Practitioner providing information on care needs and the agreed care plans	#77,#135
E17	Proportion of service users with a care plan available as specified by the service's written standard operating procedure for development and usage of multidisciplinary care plans	#129,#141
E18	Proportion of service users with documented evidence of being offered the opportunity for completion of advance care planning	#178
E19	Proportion of service users with quality of life assessed using a valid measure at screening and at regular review in line with time points agreed in the multidisciplinary care plan	#51
	F. Care planning, goal setting and shared decision making with service users	
F20	Service has a written standard operating procedure for development and usage of multidisciplinary care plans	#109
F21	Proportion of service users with documentation of main care goals in the multidisciplinary care plan	#32,#33,#45,#69,#94,#113
	G. Evidence of effectiveness, outcome assessment and measurement	
G22	Service has a written policy for reviewing and updating standard operating procedures and care pathways	
G23	Proportion of service users re-assessed at regular review who report that main care goals are met in line with the multidisciplinary care plan	#14,#26,#29,#40
G24	Proportion of service users with assessment of satisfaction with overall care and support performed using a valid measure	#37
G25	Proportion of service users with assessment of satisfaction with involvement in shared decision making	#106, #108, #116
	H. Staff training and education, service and professional development	
H26	Extent to which staff have access to training around core components of care as part of continuing education and personal development	#164
	I. Access to services and service environment	
I27	Proportion of service users with a record of time in days from referral date to first attendance date offered by service	#134
I28	The service provides suitable equipment and settings to deliver care	#92,#173
I29	Service has a written policy for defining standards for equipment and settings which are available for delivery of care	#92
	J. Societal, ethical and legal aspects of care	
J30	Number of service users with correctly completed documentation of informed consent to treatment or medical intervention	#180

Supplementary file 3: Extract from the QualPalUK toolkit, showing data extraction required for quality indicator A1 (Proportion of service users with assessment of pain severity at screening using a valid measure)

LOGO	**PALLIATIVE DAY SERVICE QUALITY INDICATOR SET: DATA ABSTRACTION FORM A [PATIENT LEVEL INDICATORS]**	**ABSTRACTOR:**	**DATE:**	**SITE:**

DATA SAMPLE & REFERENCE PERIOD:	***e.g. 15 consecutive service users discharged in period (INSERT DATES)***

QI	**DENOMINATOR**	
A1	Number of sample attending day hospice during reference period	*N=15*
	NUMERATOR	
	Number of service users with assessment of pain severity at screening using a valid measure	-

Required criteria:

- ☑ Pain severity assessment documented in notes
- ☑ Pain severity assessed completed during screening [within 1-3 visits]
- ☑ Pain severity assessed using a valid measure

Key terms/definitions:

- Service users: Patients attending day hospice
- Pain severity: Unidimensional assessment of current pain level using a valid measure and accepted descriptors of pain severity or intensity (e.g., Pain Visual Analogue Scale (VAS), Pain Numerical Rating scale (NRS) or Pain Verbal Rating Scale (VRS)**
- Screening: Processes of assessment undertaken during the early stages (within 1-3 visits) of attendance at day service, at triage, or at the beginning of a new episode or phase of care
- Valid measure: The measure is appropriate and has acceptable validity and reliability when used according to specific instructions

** Observational or other non, self-reported measures are not included in assessment of this indicator

Please use table to abstract the required information from each clinical record

#	Assessment documented	Assessment during screening	Valid Measure used	State measure used	Comments
1	☐	☐	☐		
2	☐	☐	☐		
3	☐	☐	☐		
4	☐	☐	☐		
5	☐	☐	☐		
6	☐	☐	☐		
7	☐	☐	☐		
8	☐	☐	☐		
9	☐	☐	☐		
10	☐	☐	☐		
11	☐	☐	☐		
12	☐	☐	☐		
13	☐	☐	☐		
14	☐	☐	☐		
15	☐	☐	☐		

Supplementary file 4: Practice test results: combined (across 5 settings) mean performance on each indicator.

QI	Patient and staff level indicators*	Mean (%)	SD	Range
A1	Pain severity assessed at screening using a valid measure	76.8	10.2	67-93
A2	If moderate or severe pain present, patient assessed to explore possible causes of pain	63.8	15.1	50-87
A3	Breathlessness assessed at screening using a valid measure	73.2	13.8	55-86
A4	Fatigue assessed at screening using a valid measure	68.8	16.6	47-93
A5	Functional status assessed to identify daily activity limitations prior to formulating care plan	64.8	17.3	46-93
B6	Depression assessed at screening using a valid measure	49.4	21.3	27-75
B7	Anxiety assessed at screening using a valid measure	45.6	9.2	34-56
B8	Cognitive function assessed	56.0	17.1	32-78
C9	Spiritual aspects of care discussion or assessment completed before care plan	59.8	21.6	26-85
D10	Patient provided with sufficient information or advice to support decisions on care planning	16.4	4.5	10-21
E11	Comprehensive needs assessment completed before care plan	42.2	29.2	0-78
E13	Re-assessment made at regular review in line with time-points agreed in care plan	71.8	28.8	23-93
E15	Appropriate intervention documented in line with the agreed care plan	54.6	25.5	28-93
E16	Communication between the service and general practitioner documented	89.2	17.6	58-100
E17	Care plan available as specified by standard operating procedure	15.0	22.4	0-54
E18	Opportunity offered for completion of advance care planning	56.0	20.3	37-90
E19	Quality of life assessed using a valid measure	11.0	15.6	0-38
F21	Care goals documented in care plan	65.2	20.9	32-86
G23	Care goals met at regular review in line with care plan	35.0	33.4	12-93
G24	Assessment of satisfaction with overall care and support using a valid measure	43.4	27.9	0-78
G25	Assessment of satisfaction with involvement in decision making	17.6	36.1	0-82
I27	Time in days from referral date to first attendance date offered	95.8	6.2	86-100
J30	Documentation of informed consent to treatment or medical intervention correctly completed	93.4	11.2	74-100
H26	Staff with access to training around core components of care	100.0	0.0	100-100

QI	Service level indicators*	% of services meeting the QI
E12	Care pathway for assessment and management of pain including onward referral routes	40% (2/5)
E14	Written standard operating procedure defining timeframes	20% (1/5)
F20	Written standard operating procedure for development and usage of care plans	40% (2/5)
G22	Written policy for reviewing and updating standard operating procedures and care pathways	40% (2/5)
I28	The service provides suitable equipment and settings to deliver care	60% (3/5)
I29	Written policy for defining standards for equipment and settings available for delivery of care	60% (3/5)

*Abbreviated indicator names

Recommendations for the Conducting and REporting of DElphi Studies (CREDES)*

CREDES Recommendation			Yes /No	Authors' comments
1.	Justification	The choice of the Delphi technique as a method of systematically collating expert consultation and building consensus needs to be well justified. When selecting the method to answer a particular research question, it is important to keep in mind its constructivist nature	✓	RAND UCLA method (modified Delphi technique) has been justified (p4)
2.	Planning and process	The Delphi technique is a flexible method and can be adjusted to the respective research aims and purposes. Any modifications should be justified by a rationale and be applied systematically and rigorously	✓	The RAND/UCLA method is a modified Delphi technique. We have used the method specified in the RAND/UCLA manual[6] (p4)
3.	Definition of consensus	Unless not reasonable due to the explorative nature of the study, an a priori criterion for consensus should be defined. This includes a clear and transparent guide for action on (a) how to proceed with certain items or topics in the next survey round, (b) the required threshold to terminate the Delphi process and (c) procedures to be followed when consensus is (not) reached after one or more iterations	✓	The RAND/UCLA method does not require *consensus.* There are however predefined criteria for selection of items to proceed in the next round, which we have adhered to. These are specified on pp 7-9.
4.	Informational input	All material provided to the expert panel at the outset of the project and throughout the Delphi process should be carefully reviewed and piloted in advance in order to examine the effect on experts' judgements and to prevent bias	✓	All materials provided to the expert panel, including the evidence tables, instructions, and ratings forms were reviewed by both the research team (which includes palliative care clinicians) and two end user representatives. (p8)
5.	Prevention of bias	Researchers need to take measures to avoid directly or indirectly influencing the experts' judgements. If one or more members of the research team have a conflict of interest, entrusting an independent researcher with the main coordination of the Delphi study is advisable	✓	Researchers involved with the coordination of the RAND/UCLA process had no conflicts of interest. The expert ratings (judgements) were all completed independently. Standardised instructions were provided to panellists. (p8)
6.	Interpretation and processing of results	Consensus does not necessarily imply the 'correct' answer or judgement; (non)consensus and stable disagreement provide informative insights and highlight differences in perspectives concerning the topic in question	✓	As in 3 above, consensus is not required for the RAND/UCLA process. However, there are predefined criteria for 'agreement' about the appropriateness and feasibility of individual

				items. Agreement (or lack of agreement) on individual items is provided in supplementary file 1.
7.	External validation	It is recommended to have the final draft of the resulting guidance on best practice in palliative care reviewed and approved by an external board or authority before publication and dissemination	✓	The development of the indicators was funded, and endorsed by Marie Curie (UK palliative care provider). In response to feedback from end users we are currently developing an electronic version of the toolkit, and have sought funding to support the implementation of the toolkit in UK palliative day services. We will seek validation for the electronic quality indicator toolkit from palliative care organisations and care providers.
8.	Purpose and rationale	The purpose of the study should be clearly defined and demonstrate the appropriateness of the use of the Delphi technique as a method to achieve the research aim. A rationale for the choice of the Delphi technique as the most suitable method needs to be provided	✓	The purpose of the study and the appropriateness of the RAND/UCLA method (modified Delphi technique) is clearly defined on p 4.
9.	Expert panel	Criteria for the selection of experts and transparent information on recruitment of the expert panel, sociodemographic details including information on expertise regarding the topic in question, (non)response and response rates over the ongoing iterations should be reported	✓	Criteria for the selection of experts and information on recruitment of expert panel members is provided on p7, including a summary of the professional background and expertise of panel members.
10.	Description of the methods	The methods employed need to be comprehensible; this includes information on preparatory steps (How was available evidence on the topic in question synthesised?), piloting of material and survey instruments, design of the survey instrument(s), the number and design of survey rounds, methods of data analysis, processing and synthesis of experts' responses to inform the subsequent survey round and methodological decisions taken by the research team throughout the process	✓	The methods have been described in detail, and are informed by the processes, steps, and criteria specified in the RAND/UCLA manual[6]. The survey instruments (rating forms) are also adapted from the RAND/UCLA manual. The number and design of rounds, methods of data analysis and decision-making re items are described, and adapted from the RAND/UCLA manual[6].
11.	Procedure	Flow chart to illustrate the stages of the Delphi process, including a	✓	A flowchart detailing the phases of the

		preparatory phase, the actual 'Delphi rounds', interim steps of data processing and analysis, and concluding steps		research, including the RAND/UCLA rounds, and the results at each stage is provided.
12.	Definition and attainment of consensus	It needs to be comprehensible to the reader how consensus was achieved throughout the process, including strategies to deal with non-consensus	✓	As in 3 above, *consensus* is not required. We have however described how decisions were made about the progression of items between rounds.
13.	Results	Reporting of results for each round separately is highly advisable in order to make the evolving of consensus over the rounds transparent. This includes figures showing the average group response, changes between rounds, as well as any modifications of the survey instrument such as deletion, addition or modification of survey items based on previous rounds	✓	We have reported the results of each round separately. Supplementary file 1 provides a detailed description of the scores for each individual item at round 1 (including median appropriateness scores and agreement), and at round 2 (including median appropriateness and feasibility scores, and necessity ratings). Supplementary file 2 provides details of indicators combined at round 3.
14.	Discussion of limitations	Reporting should include a critical reflection of potential limitations and their impact of the resulting guidance	✓	A critical summary of limitations is provided in the discussion section (p18)
15.	Adequacy of conclusions	The conclusions should adequately reflect the outcomes of the Delphi study with a view to the scope and applicability of the resulting practice guidance	✓	The conclusions reflect the results of the RAND study. We have commented on scope and applicability of the indicators, including further work required. (p15-17)
16.	Publication and dissemination	The resulting guidance on good practice in palliative care should be clearly identifiable from the publication, including recommendations for transfer into practice and implementation. If the publication does not allow for a detailed presentation of either the resulting practice guidance or the methodological features of the applied Delphi technique, or both, reference to a more detailed presentation elsewhere should be made (e.g. availability of the full guideline from the authors or online; publication of a separate paper reporting on methodological details and particularities of the process (e.g. persistent disagreement and controversy on certain issues)). A dissemination plan should include endorsement of the guidance by	✓	The final indicator set is provided within the publication (table 1). The authors can be contacted for a copy of the toolkit used to abstract data relevant to the indicator set. An abstract of the toolkit is provided in supplementary file 3. As described on pp 17-18 we are, in response to feedback from users, currently developing an electronic version of the indicator toolkit which will be subsequently assessed for feasibility and appropriateness in practice. We will seek

		professional associations and health care authorities to facilitate implementation		endorsement from palliative care organisations for the final electronic toolkit, and will work in collaboration with these organisations to implement use of the indicators in palliative day services throughout the UK.

*reproduced from: Junger S, Payne SA, Brine J, et al. Guidance on Conducting and REporting DElphi Studies (CREDES) in palliative care: Recommendations based on a methodological systematic review. *Palliat Med* 2017;31:684-706.

PALLIATIVE MEDICINE AUTHOR SUBMISSION CHECKLIST

Please complete this checklist for all papers submitted. Please indicate, very briefly, how this has been addressed. This checklist is a mandatory upload on submission.

Item	Explanation	How this has been addressed (briefly, a sentence will suffice)
Article title	***WHY: Because we want readers to find your work.*** Have you followed our guidelines on writing a good title that will be found by search engines? (E.g. with methods in the title, use of common words for the issue addressed, no country names, and possibly indicating findings). If your study has an acronym is it included in the title?	Yes. We have included key terms and method (modified Delphi Technique).
Abstract	***WHY: Because structured abstracts have more detail for readers and search engines.*** Have you followed our guidelines on writing your structured abstract? Please remember we have separate abstract structures for original research, reviews and case reports. There should be **no** abbreviations in the abstract, EXCEPT a study acronym which should be included if you have one. If a trial (or other design formally registered with a database) have you included your registration details?	We have included a structured research abstract. We have combined the sub-headings 'design' and 'setting', as we believe this to be more appropriate and concise for our study characteristics.
Key statements	***WHY: Because readers want to understand your paper quickly.*** Have you included our key statements within the body of your paper (after abstract and before the main text is a good place!) and followed our guidelines for how these are to be written? There are three main headings required, and each may have 1-3 separate **bullet** points. Please use clear, succinct, single sentence separate bullet points rather than complex or multiple sentences.	We have included several clear succinct statements under each of the 3 headings.
Keywords	***WHY: Because MeSH headings mean it is properly indexed.*** Have you given keywords for your study? We ask that these are current **MeSH** headings unless there is no suitable heading for use (please give explanation in cover letter). https://meshb.nlm.nih.gov/search	We have included 5 current MeSH headings.
International relevance	***WHY: We have readers from around the world who are interested in your work.*** Have you contextualised your work for an international audience and explained how your work contributes to an international knowledge base? Avoid drawing from policy from one context only, think	We have explained that our quality indicator set is relevant to palliative day internationally. We

	how your work could be relevant more widely. Do define terms clearly e.g. hospice has a different meaning in many countries.	have also provided the results of the international systematic scoping review (182 original indicators) which can be used by other jurisdictions to modify their indicators if necessary.
Publishing guidelines	***WHY: Because clear and robust reporting helps people interpret your work accurately*** Have you submitted a completed checklist for a relevant publishing guideline as a supplementary file? http://www.equator-network.org/ These include CONSORT, PRISMA, COREQ checklists, but others may be more relevant for your type of manuscript. If no published checklist exists please create one as a table from the list of requirements in your chosen guideline. If your study design does not have a relevant publishing guideline please review closest matches and use the most appropriate with an explanation.	There are no reporting guidelines for a RAND/UCLA appropriateness study specifically. However, as the RAND/UCLA method is a modified Delphi technique, we have used the Recommendations for the Conducting and REporting of DElphi Studies (CREDES), published in Pall Med and available via the EQUATOR website.
Word count	***WHY: Because readers want to find the core information quickly.*** Does your paper adhere to our word count for your article type? Please insert number of words in the box to the right. Remember that tables, figures, qualitative data extracts and references are not included in the word count.	Yes. Word count (excluding tables, figures, references and abstract) is 2999/3000.
Figures and tables and/or quotations	***WHY: Because readers want to find the core information quickly.*** Have you adhered to our guidelines on the number of tables and figures for your article type? Data (e.g. quotations) for qualitative studies are not included in the word count, and we prefer that they are integrated into the text (e.g. not in a separate table).	Yes. We have included 1 figure and 1 table in the main document, and additional information in 4 supplementary files.
Study registration	***WHY: Because this means readers understand how you planned your study*** Where appropriate have you included details (including reference number, date of registration and URL) of study registration on a database e.g. trials or review database. If your study has a published protocol, is this referenced within the paper?	n/a

Other study publications?	***WHY: So readers can understand the full context of your study*** If there are other publications from this study are these referenced within the body of the paper? Please do not reference papers in preparation or submitted, but in-press publications are acceptable.	We have referenced the published protocol of the scoping review - which produced the original candidate quality indicators used in the study.
Scales, measures or questionnaires	***WHY: So readers can understand your paper in the context of this information*** If your study primarily reports the development or testing of scales/measures or questionnaires have you included a copy of the instrument as a supplementary file?	We have developed a set of 30 quality indicators, which are provided within the main document. We have also provided an extract of the data extraction toolkit as a supplementary file, and detailed contact information for parties interested in using the toolkit.
Abbreviations	***WHY: Because abbreviations make a paper hard to read, and are easily misunderstood*** Have you removed **all** abbreviations from the text except for extremely well known, standard abbreviations (e.g. SI units), which should be spelt out in full first? We do not allow abbreviations for core concepts such as palliative or end of life care.	There are no abbreviations in the text.
Research ethics and governance approvals for research involving human subjects	***WHY: We will only publish ethically conducted research, approved by relevant bodies*** Have you given full details of ethics/governance/data protection approvals with reference numbers, full name of the committee(s) giving approval and the date of approval? If such approvals are not required have you made it explicit within the paper why they were not required. Are details of consent procedures clear in the paper?	Yes. These details are included in the text.
Date(s) of data collection	***WHY: So readers understand the context within which data were collected*** Have you given the dates of data collection for your study within the body of your text? If your data are over 5 years old you will need to articulate clearly why they are still relevant and important to current practice.	Yes. These details are included in the text.
Structured discussion	***WHY: So readers can find key information quickly*** Papers should have a structured discussion, with sub headings, summarising the main findings,	Yes. We have included a structured discussion.

	addressing strengths and limitations, articulating what this study adds with reference to existing international literature, and presenting the implications for practice.	
Case reports	***WHY: So that participants are protected, and its importance made clear*** If your study is a case report have you followed our clear structure for a case report, including highlighting what research is needed to address the issue raised? Have you made clear what consent was required or given for the publication of the case report? Have you provided evidence of such consent as a supplementary file to the editor?	n/a
Acknowledgements and declarations	***WHY: So readers understand the context of the research*** Have you included a funding declaration according to the SAGE format? Are there acknowledgements to be made? Have you stated where data from the study are deposited and how they may be available to others? Have you conflicts of interest to declare?	Funding declaration, acknowledgements and conflicts of interest are included. Additional data is available as a supplementary file.
Supplementary data and materials	***WHY: So the context is clear, but the main paper succinct for the reader*** Is there any content which could be provided as supplementary data which would appear only in the online version of accepted papers? This could include large tables, full search strategies for reviews, additional data etc.	Yes. There are 4 supplementary files, including two large table showing the derivation of the quality indicators, an extract from the data extraction toolkit, and results from the practice test.
References	***WHY: So people can easily find work you have referenced*** Are your references provided in SAGE Vancouver style? You can download this style within Endnote and other referencing software.	Yes.
Ownership of work.	Can you assert that you are submitting your original work, that you have the rights in the work, that you are submitting the work for first publication in the Journal and that it is not being considered for publication elsewhere and has not already been published elsewhere, and that you have obtained and can supply all necessary permissions for the reproduction of any copyright works not owned by you.	Yes, I confirm this.