

## **Protocol title: UK Consensus Project on Quality in Palliative Care Day Services**

### **Summary**

The UK Consensus Project on Quality in Palliative Care Day Services is funded by Marie Curie and based at Queen's University, Belfast. It is being carried out in collaboration with a number of other academic institutions and key stakeholder organizations. The project will involve and take into account the perspectives of a range of different stakeholders and its outcomes will be relevant to patients, family members, palliative care professionals, and policy makers. The aim is to use an expert consensus process to develop a set of quality indicators for assessment of all aspects [structure, process and outcomes] of quality of care in Palliative Care Day Services. This expert panel will include around 20 people from all over the UK who work in, or have experience of day services. The panel will include a wide range of different professionals and volunteers, as well as people who have experience of attending day services as a patient, a carer or family member.

Agreement on a quality indicator set will be reached using the RAND/UCLA Appropriateness Method [1], a method of reaching consensus based on differing opinions. The first stage of the process will involve a panel of 20 experts individually considering and rating the appropriateness of potential quality indicators. Ratings will be based on their own experience and knowledge, as well as a series of evidence summary tables drawn up based on a systematic review carried out to identify existing indicators relevant to palliative care day services.

Ratings will be analysed and summarised in advance of the second round, at an expert panel meeting. At this meeting quality indicators and their preliminary ratings will be discussed and re-rated. All ratings will be made anonymously. Unlike other consensus development processes, complete agreement is not required. During the meeting, discussions will be focused specifically on any areas of disagreement, in order to understand how and why the variation was found. Indicators will be considered to be "appropriate" if they have a median rating of 7 or more without disagreement. Disagreement will be defined as more than 30% of panel members give a rating of 3 or less to a potential indicator. An indicator will be considered as "not appropriate" if its median score is 3 or less without disagreement (disagreement being when 30% or more of the ratings are 7 or more). When the median rating is between 4 and 6, or if disagreement is observed, the appropriateness of the indicator will be considered as uncertain and it will be discussed at the panel meeting. The following options will be offered to the panel members: acceptance of a quality indicator, rejection or adjustment of a quality indicator, and merging multiple indicators into a single quality indicator.

Panel members will also be asked to identify additional indicators not on the original list, modify existing indicators that may require re-wording and remove those perceived to be irrelevant. Following this discussion, a revised list of indicators will be developed, and panel members will re-rate the appropriateness of each. Panel members will also be asked to rate the feasibility or practicability of measuring each indicator in a typical day service setting using the same 9-point scale. At the end of the process, a set of quality indicators will be developed that passed the first round of individual rating as well as the second-round discussion. This set of quality indicators will be sent to the expert panel by e-mail after the meeting, as well as to other stakeholders, for final approval.

Following this, further work will be conducted to develop and test the suitability of a toolkit which can be used to measure quality indicators in palliative care day services.

[1] 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](http://www.rand.org/pubs/monograph_reports/MR1269).

## **Protocol**

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### **Purpose**

- 1) Development of a set of quality indicators (QIs) for the assessment of all aspects (structure, process and outcome) of quality of care of Palliative Care Day Services (PCDS)
- 2) Development and implementation of a toolkit for assessment of QIs in PCDS

Ultimately, with the assistance of our expert panels we will seek support from palliative care providers and umbrella organisations for the adoption of the QI toolkit in practice and further pilot testing. Whilst economic analysis is beyond the scope of this project, findings from the project will provide information that will be useful in taking forward full economic evaluations of hospice day services.

### **Research Plan**

#### **1. Quality of Care Indicators in PCDS**

There is little consensus around those aspects of care which should be used to evaluate PCDS, and NICE<sup>25</sup> were unable to provide guidance about a best model of practice. Furthermore, there has been no attempt to develop quality indicators (QIs) for PCDS, and the evidence base in the area is generally weak. Yet, service providers are under pressure to demonstrate the value and cost-effectiveness of PCDS in a climate where an ageing population and increasing burden of life limiting illness will lead to increasing demand on these services. The development and implementation of common indicators for PCDS would provide service-providers and commissioners with a means of defining, measuring and comparing the quality of key aspects of care –and in a way that adjusts for demographic, patient-related and external factors, variation across settings and in mode of delivery.<sup>26,27</sup> Quality indicators may be used to stimulate, motivate and evaluate initiatives to improve patient care and may help to target resources in an appropriate and effective way<sup>27</sup>. Furthermore QIs may be aggregated and analysed in ways to test the justification of services, and secure resources from funders and commissioners.<sup>28</sup>

Existing quality indicators in palliative care and their methodological specifications are not well specified, and generally have not followed a rigorous or standardised process of development.<sup>26,27</sup> The Q-PAC study<sup>29</sup> in Belgium is the first to apply a scientifically rigorous method to develop a comprehensive and valid quality indicator set for palliative care and to include all three major areas of health care (structure, process and outcome). There are currently no published QIs for PCDS across the international literature. Whilst existing indicators for general palliative care<sup>26,27,30</sup> and other specific healthcare settings<sup>31-33</sup> provide a valuable starting point for the identification and specification of appropriate QIs for PCDS,

there is a need to adapt and supplement these for use in the UK<sup>27,28</sup>, and to adequately reflect the goals of PCDS - with its focus on early intervention, social care, rehabilitation, and its more diverse population. The inclusion of structure and process indicators is particularly key in palliative care<sup>27,29</sup> where patients' health may be deteriorating and not all aspects of quality care will be reflected in outcomes that are readily quantifiable, or may require more creative methods of assessment.<sup>34</sup>

**Work Package 1 will identify using rigorous methods, a set of QIs for UK PCDS, incorporating assessment of structure, process and outcome.**

## **2. Feasibility of Quality Indicators**

QIs need to be clinically relevant and should be operationalised in a way that is amenable to assessment, ideally as part of routine practice.<sup>35,36</sup> Hence, it is key that QIs are developed alongside user instructions<sup>37</sup> incorporating definitions, appropriate inclusion / exclusion criteria (to account for complexity of care, variety of patient preference and variation in populations), so that they are not analysed or represented inappropriately or misinterpreted by decision makers. The burden of their implementation also needs to be assessed. Whilst outcome measurements completed directly with users are most informative<sup>44</sup>, issues of burden and practicality need to be assessed. Databases provide a cheaper and easier option for collecting information around QIs – but may be limited in terms of data quality, completeness and ability to assess all aspects of care.<sup>28</sup>

**Work Package 2 will result in a toolkit to support the assessment of QIs and test their feasibility and acceptability in applied settings across the UK.**

## **Methods**

### **Work Package 1:**

The RAND /UCLA method<sup>40</sup> is the only systematic method for selecting QIs which combines best available scientific evidence with the collective judgement of expert stakeholders. The RAND / UCLA method specifies the following stages and suggested timescales<sup>40</sup>:

1. **An international literature review, development of a conceptual model and review of evidence base for indicators.** The research team will identify candidate indicators from existing research literature and strategy documents in palliative care (internationally), and from synthesised potential 'read across' lessons associated with forms of day time services for other patient groups such as older people and people with disabilities. This will result in a set of candidate indicators and a preliminary model relating these indicators to aspects of care and patient outcomes. The research team will also produce summaries of the evidence for each indicator and its relationship with quality of care / patient outcomes, using the AIRE instrument<sup>41</sup>.
2. **Panel reviews.** Relevant palliative care national umbrella organisations, networks, professional organisations, patient organisations, and service-user groups will be asked to nominate individuals from across the UK to contribute to two expert (one 'professional' and one 'service-user panel) (at least nine members each). The panel compositions will optimise geographic diversity and diversity of practice setting. The panels will be tasked with rating the appropriateness of each of the draft indicators for assessing quality of care of PCDS, and identification of missing indicators. Each panel review consists of a two stage process:
  - a. the indicators are assessed as measures of quality within a postal survey by asking each member to rate the appropriateness of each indicator. Panellists receive the evidence summaries, draft measures, ballots, and instructions. Lay summaries, used in previous research<sup>29,42</sup> will be produced for the expert service-user panel.
  - b. a face-to-face panel meeting bringing the panel together from across the UK. Members of the research team will moderate discussions of each draft indicator, the evidence, and first-round ratings using a modified-Delphi panel

method. Each panellist receives a summary of the first-round ratings for each indicator, their rating relative to the distribution, and the analytic interpretation. After all opinions have been voiced for an indicator, each panellist is asked to rate the appropriateness of the quality indicator again. The RAND / UCLA method provides clear definitions and criteria for the calculation of 'appropriateness'. Only measures that are judged appropriate will be included in the later stages of the project. Following this discussion a final stage will ask panellists to rate (for each 'appropriate' QI) whether the related aspect of care is also 'necessary'. This will provide an indication of those quality indicators that are core and others that could be considered supplementary.

3. **Operationalisation and risk adjustment.** The most appropriate instruments / data for measuring the indicators will be selected by reviewing the research literature and the work of groups such as PRISMA, MoReCare and the EAPC taskforce on patient-reported outcome measurement in palliative care – which are involved with the harmonisation of approaches to outcome measurement in palliative care. These groups however are not currently tasked with identifying process and structural elements of care and the current project will be novel in this regard. Operationalisation of structural and process indicators (specifying what information should be collected, how it should be presented, analysed and interpreted) will be informed by the expert panel discussions, the project advisory board, and literature (where available). In addition, risk adjustment will identify those patient-related and other factors which should be considered alongside QIs or where exclusions should be applied. A summary of the QIs, their operationalisation, and risk adjustment will be sent to the expert panels for comment.
4. **Finalisation of specifications.** The feedback from the expert panels will be incorporated into the quality framework and a final set of quality indicators produced, incorporating operationalisation and risk adjustment.
5. **User documentation.** A draft toolkit for use in practice will be produced – incorporating an instruction manual (what data to collect and from what source(s)), definitions, data collection forms (including questionnaires where appropriate), how to treat missing data, instructions on analysing and presenting results.

## References

1. Dawkins L, Gallini A. Gaining the views of service users in a specialist palliative day care setting. *Cancer Nursing Practice* 2005, 4(10), 35-39.
2. Bradley SE, Frizelle D, Johnson M. Patients psychosocial experiences of attending specialist palliative day services: A systematic review. *Palliative Medicine* 2010, 25(3), 210-228.
3. Schofield P. Snoezelen within a palliative day care setting: a randomised controlled trial investigating the potential. *International Journal of Disability and Human Development* 2009, 7, 234-239.
4. Miyashita M, Misawa T, Abe M, Nakayama Y, Abe K, Kawa M. Quality of life, day hospice needs, and satisfaction of community-dwelling patients with advanced cancer and their caregivers in Japan. *Journal of Palliative Medicine* 2008, 9, 1203-1207.
5. Goodwin DM, Higginson IJ, Myers K, Douglas HR, Normand CE. Effectiveness of palliative day care in improving pain, symptom control and quality of life. *Journal of Pain and Symptom Management* 2003, 25, 202-212.
6. Sviden GA, Furst CJ, van Koch L, Borell L. Palliative day care – a study of well-being and health related quality of life. *Palliative Medicine* 2009, 23, 441-447.
7. Payne M. Social objectives in cancer care: the example of palliative day care. *European Journal of Cancer Care* 2006, 15, 440-447.
8. Stevens E, Martin CR, White CA. The outcomes of palliative care day services: A systematic review. *Palliative Medicine* 2010, 25(2) 153-169.
9. Carr A, Higginson IJ. Are quality of life measures patient centred? *British Medical Journal* 2001, 322: 1357-1360.
10. Waldron D, O'Boyle CA, Kearney M, Moriarty M, Carney D. Quality of life measurement in advanced cancer: assessing the individual. *Journal of Clinical Oncology* 1999, 17: 3603-3611.
11. Stiel S, Pastrana T, Balzer C, Elsner F, Ostgathe C, Radbruch L. Outcome assessment instruments in palliative and hospice care- a review of the literature. *Supportive Cancer Care* 2012, 20, 2879-2893.
12. EuroQol Group. EuroQol – a new facility for the measurement of health-related quality of life. *Health Policy* 1990, 16: 199-208.
13. Cohen SR, Mount BM, Bruera E, Provost M, Rowe J, Tong K. Validity of the McGill Quality of Life Questionnaire in the palliative care setting: a multicentre Canadian study demonstrating the importance of the existential domain. *Palliative Medicine* 1997; 11: 3-20.
14. O'Boyle CA, Browne J, Hickey A, McGee HM, Joyce CRB. *Schedule for the Evaluation of Individual Quality of Life (SEIQoL): a Direct Weighting Procedure for Quality of Life Domains (SEIQoL-DW) Administration Manual*. Dublin, Department of Psychology, Royal College of Surgeons in Ireland. 1993.
15. Hearn J, Higginson IJ. Development and validation of a core outcome measure for palliative care: the Palliative Care Outcome Scale. *Quality in Health Care* 1999, 8: 219-227.
16. Harding R, Higginson IJ. PRISMA: share best practice in end-of-life cancer care research and measurement. *European Journal of Palliative Care* 2010, 7(4), 182-185.
17. Coast J, Flynn TN, Natarajan L, Sproston K, Lewis J, Louviere JJ, Peters TJ. Valuing the ICECAP capability index for older people. *Social Science and Medicine* 2008, 67: 874-882.
18. Fitzpatrick R. Measurement issues in health-related quality of life: Challenges for health psychology. *Psychology and Health* 2000, 15, 99-108.
19. Catania G, Costantini M, Beccaro M, Bagnasco A, Sasso L. Does quality of life assessment in palliative care look like a complex screening program? *Health and Quality of Life Outcomes* 2013, 11: 7.
20. Albers G, Echteld MA, de Vet HCW, Onwuteaka-Philipsen BD, van der Linden MHM, Deliens L. Evaluation of quality of life measures for use in palliative care: a systematic review. *Palliative Medicine* 2010, 24: 17-37.
21. Bruley DK. Beyond reliability and validity: analysis of selected quality of life instruments for use in palliative care. *Journal of Palliative Medicine* 1999, 2(3), 299-309.

22. Hearn J, Higginson IJ. Outcome measures in palliative care for advanced cancer patients: a review. *Journal of Public Health Medicine* 1997, 19: 193-199.
23. Mularski RA, Dy SM, Shugarman LR, Wilkinson AM, Lynn J, Shekelle PG, Morton SC, Sun VC, Hughes RG, Hilton LK, Maglione M, Rhodes SL, Rolon C, Lorenz KA. A systematic review of measures of end of life care and its outcomes. *Health Services Research* 2007, 42: 1848-1870.
24. Donabedian A. Quality assurance: structure, process and outcome. *Nursing Standard* 1992, 7(11):4-5.
25. National Institute of Clinical Excellence. *Supportive and palliative care for adults with cancer*. London: NICE, 2004.
26. Roeline H, Pasman W, Brandt HE, Deliens L, Francke AL. Quality Indicators for Palliative Care: A systematic review. *Journal of Pain and Symptom Management* 2009, 38, 145-156.
27. Pasman HR, Brandt HE, Deliens L, Francke AL. Quality indicators for palliative care: a systematic review. *Journal of Pain and Symptom Management* 2009, 38(1):145-56.
28. Payne S, Leget C, Peruselli C, Radbruch L. Quality Indicators for palliative care: debates and dilemmas. *Palliative Medicine* 2012, 26(5), 679-680.
29. Leemans K, Cohen J, Francke AL, Stichele RV, Claessen SJJ, Van den Block L, Deliens L. Towards a standardised method of developing quality indicators for palliative care: protocol of the Quality indicators for Palliative Care (Q-PAC) study. *BMC Palliative Care* 2013, 12:6.
30. Health Improvement Scotland. *Palliative and end of life care: Draft Quality Indicators, 2012*. [www.healthimprovementsscotland.org](http://www.healthimprovementsscotland.org)
31. Nelson JE, Mulkerin CM, Adams LL, Pronovost PJ. Improving comfort and communication in the ICU: a practical new tool for palliative care performance measurement and feedback. *Qual Saf Health Care* 2006, 15(4):264-271.
32. Peruselli C, Marinari M, Brivio B, Castagnini G, Cavana M, Centrone G, Magni C, Merlini M, Scaccabarozzi GL, Paci E. Evaluating a home palliative care service: development of indicators for a continuous quality improvement program. *Journal of Palliative Care* 1997, 13(3):34-42.
33. Twaddle ML, Maxwell TL, Cassel JB, Liao S, Coyne PJ, Usher BM, Amin A, Cuny J. Palliative care benchmarks from academic medical centers. *Journal of Palliative Medicine* 2007, 10(1):86-98.
34. Raleigh VS, Foot C. *Getting the measure of quality: opportunities and challenges*. The King's Fund, 2010. London: The King's Fund.
35. Council of Europe. *Recommendation Rec (2003) 24 of the Committee of Ministers to member states on the organization of palliative care*. [www.coe.int/T/E/Social\\_Cohesion/Health/Recommendations/Rec\(2003\)24.asp](http://www.coe.int/T/E/Social_Cohesion/Health/Recommendations/Rec(2003)24.asp)
36. Marshall MN, Campbell SA, Roland M, Hacker J. *Quality Indicators for General Practice: A Practical Guide for Primary Health Care Professionals And Managers*. Royal Society of Medicine Press Ltd: London, 2002.
37. SPPC *Response to the HIS Consultation on Palliative and End of Life Care Indicators, 2012*. Scottish Partnership for Palliative Care.
38. Schag CC, Heinrich RL, Ganz PA. Karnofsky performance status revisited: Reliability, validity, and guidelines. *Journal of Clinical Oncology* 1984, 2:187-193.
39. Garratt AM, Ruta DA, Abdalla MI, Russell IT. SF-36 health survey questionnaire: II. Responsiveness to changes in health status in four common clinical conditions. *Quality in Health Care* 1994, 3, 186-192.
40. Fitch K, Bernstein S, Aguilar M, Burnand B, LaCalle J, Lazaro P. *The RAND/UCLA Appropriateness Method User's Manual*. Santa Monica, CA: RAND Corporation; 2001
41. *Appraisal of Indicators through Research and Development (AIRE) Instrument*. Available from [www.aire-instrument.com](http://www.aire-instrument.com). Accessed 12 March 2013
42. Claessen SJ, Francke AL, Belarbi HE. A new set of quality indicators for palliative care: process and results of the development trajectory. *Journal of Pain and Symptom Management* 2011, 42(2):169-82.
43. Gysels MH, Evans C, Higginson IJ. Patient, caregiver, health professional and researcher views and experiences of participating in research at the end of life: a critical interpretative synthesis of the literature. *BMC Medical Research Methodology* 2012, 12:123.

44. Kotter T, Schaefer FA, Scherer M, Blozik E. Involving patients in quality indicator development – a systematic review. *Patient Preference and Adherence* 2013, 7, 259-268.