

Clinical tools to assist with specialist palliative care provision

A Report for the Department of Health (Victoria)

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1 Executive Summary

High quality clinical care in the palliative sector can only be achieved with a systematic and coordinated approach that encompasses comprehensive assessment and care planning. The needs of palliative care patients and their family caregivers are typically complex. By utilising clinical tools that can enhance assessment and guide care delivery across disciplines and settings, improved patient and family outcomes are likely to be achieved.

The aim of this project was to recommend key clinical tools that may assist with the admission and coordination of care provision (in Victoria, Australia) for patients and family caregivers across specialist palliative care settings. The specific strategies included:

1. Identifying clinical tools currently in use in the Victorian palliative care sector
2. Identifying clinical tools from palliative care literature
3. Critically appraising these clinical tools
4. Endorsing a suite of clinical tools considered appropriate for specialist palliative care practice.

The research carried out for this report has led to recommendations regarding a suite of clinical tools covering important domains of palliative care which can be used to assist specialist palliative care services to assess and plan care for patients and their family caregivers.

The process of developing the list of recommended tools has been comprehensive, incorporating a multi-pronged literature review, an appraisal process during which the chief investigators evaluated a large number of clinical assessment tools, and finally a multi-disciplinary specialist focus group meeting to evaluate a shortlist of clinical tools.

The results of this project provide a valuable resource that can enhance assessment and care planning within specialist palliative care.

2 Background

There is a recognised need to monitor and provide consistent quality care in the palliative sector [1, 2]. Quality care for all can only be achieved with a systematic, coordinated approach encompassing a standardised level of care [2, 3]. The needs of palliative care patients and their caregivers are typically complex however, and a multi-disciplinary approach is required [3]. By utilising clinical tools that can enhance assessment and guide care delivery across disciplines and settings, improved patient and family outcomes are likely to be achieved [3, 4].

3 Aims and objectives

The aim of this project was to recommend key palliative care clinical tools that may assist with the admission and coordination of specialist palliative care provision for patients and family caregivers across care settings. The specific objectives included:

- Identifying clinical tools currently in use in the Victorian palliative care sector
- Identifying clinical tools from palliative care literature
- Critically appraising these clinical tools
- Endorsing a suite of clinical tools considered appropriate for specialist palliative care practice.

Relationship to the Palliative Care Outcomes Collaboration (PCOC)

The aims of PCOC differ from those of this project although the recommended clinical tools may overlap, as discussed at the end of this report. According to its website, PCOC is a national voluntary program utilising standardised validated clinical assessment tools to benchmark and measure outcomes in palliative care with the objective of enabling palliative care service providers to improve practice and meet national standards [5].

4 Funding and Governance

Funding

The project was funded by the Department of Health Victoria to support the initiatives of the Palliative Care Clinical Network (VIC).

Investigators

Chief Investigators

- Professor Peter Hudson, Director, Centre for Palliative Care.
- Associate Professor Jennifer Philip, Deputy Director, Centre for Palliative Care.

Project officers

- Dr Adam Bostanci (January 2012 – April 2012)
- Ms Nikola Stepanov, Ms Lisa Willenberg (June 2011-December 2011)

Project Advisory Committee

- Ms Jo Hall (Department of Health)
- Professor Fran McInerney (Palliative Care Clinical Network Representative; Australian Catholic University)
- Chief Investigators, Project Officer(s)

Research ethics approval

Approval was provided from St Vincent's Hospital Research and Ethics Committee for Phase 1 (palliative care sector survey) and Phase 4 (focus group meeting). By the nature of their roles, participants were over the age of 18, capable of legally consenting, and able to read written English. No personal or identifying information was recorded.

5 Research design

Overview

This study involved four phases:

1. Survey of the palliative care sector in Victoria, with the objective of documenting which clinical tools are currently used (Phase 1).
2. Literature review, with the objective of identifying and appraising clinical tools specific to palliative care (Phase 2).
3. An appraisal process, with the objective of establishing a shortlist of clinical tools that merit further consideration (Phase 3).
4. A multi-disciplinary expert specialist focus group meeting, with the objective of endorsing a suite of clinical tools (Phase 4).

Domains of palliative care

The overall analysis for this report was carried out with respect to the following *domains* of palliative care, based on the World Health Organisation definition of palliative care [6], as well as national principles and norms of palliative care practice [3, 7, 8]. Clinical tools known as ‘needs assessments’ and clinical tools that cover several of the domains of palliative care were appraised together.

The domains of palliative care considered in this report were therefore as follows:

- Symptoms
- Pain
- Prognosis
- Psychological/emotional
- Quality of Life
- Spirituality
- Family
- Performance / functional status
- Multi-domain assessment / needs assessment
- Care of the imminently dying patient

5.1 Phase 1: Palliative care sector survey

Objectives

The objective of this sector survey was to identify clinical tools currently used in specialist palliative care services in Victoria. Information was also gained about enablers and barriers to the use of clinical tools.

Design

An online survey was developed with the help of UltraFeedback (web.ultrafeedback.com; a commercial service provider). A pilot of the survey was undertaken by members of the project management and project advisory committees to assess face validity, and minor alterations were made. The questionnaire is available in Appendix 1.

Participants

Sixty specialist palliative care providers funded by the Victorian Department of Health were invited to participate in the survey in August 2011.¹ The manager of each service was asked to nominate a representative with broad awareness of palliative care service delivery in that

¹ At the time of writing in April 2012, a total of 69 palliative care providers (community-based and inpatient providers) were funded by the Department of Health.

setting to complete the online survey. Contact details were provided by the Victorian Department of Health.

Data analysis

The survey results were analysed to obtain percentage distribution on items with different answer options. Items that asked for a rating on a 1 – 5 scale (Strongly Disagree-Strongly Agree) were analysed to obtain an average score as well as a standard deviation. Some items also provided an ‘Other’ option, which permitted free text entry.

5.2 Phase 2: Palliative care literature review

Objectives

The objective of this literature review was to identify clinical tools specific to palliative care.

Design

The literature review proceeded in two stages:

- systematic searches of literature databases (‘bottom-up’ search)
- supplementary data gathering strategies to identify clinical tools not detected by the ‘bottom-up’ search (supplementary searches).

This design reflected the observation, by the authors of reviews of clinical tools in particular domains of palliative care, that systematic (‘bottom-up’) literature searches are unlikely to identify the majority of clinical tools [9, 10].

Systematic searches (‘bottom-up’)

MEDLINE and several other online databases (CINAHL, EMBASE, PubMed, PsychInfo, Cochrane Database of Systematic Reviews, DARE) were systematically searched to identify clinical tools utilised in the palliative care setting. Searches were restricted to literature on adult populations, published in English, and dated from 1998 onwards. The systematic search strategy is outlined in Appendix 2.

The results of these database searches then underwent several rounds of review (by project officers LW, NS) based on the filters outlined in Appendix 2. Initially the objective was to include only articles that focused specific clinical tools and to exclude any articles that were not relevant to palliative care, and subsequently to exclude any articles on clinical tools in

domains that had already been appraised in up-to-date (2010 onwards) systematic literature reviews.

This approach was adopted because by inclusion within existing systematic reviews, these clinical tools had already been appraised elsewhere, and the findings of existing systematic reviews were incorporated into the project during the supplementary literature review stage.

Data extraction

From the remaining articles, data was then extracted in accordance with the following categories.

- Citation
- Study setting
- Name of tool
- Description of tool
- Primary purpose/intention of tool
- Intended user
- The subject to whom the tool was addressed
- Number of items
- Translated into another language
- Breadth of use
- Administration method
- Validity tested Y/N
- Reliability tested Y/N
- Type of evaluation/testing
- Domains covered
- Number of domains
- Screening or assessment

Supplementary searches

The systematic or 'bottom-up' database searches were followed by several searches and data gathering strategies to identify additional relevant clinical tools.

Grey literature

Searches of grey literature were conducted, including the following resources:

- The online palliative care resource, CareSearch;
- Grey literature search engine SIGLE (pre-2005 literature);
- Key organisations: National Palliative Care Research Centre, Palliative Care Australia, Palliative Care Victoria.

Additional articles

Additional articles were identified through the references of full-text papers identified during the systematic search.

Existing literature reviews

Existing systematic literature reviews of clinical tools relevant to palliative care were reviewed by the chief investigators.

Sector contacts

Finally, additional clinical tools were identified through professional and academic contacts of the research team, and through previous research conducted by the chief investigators.

Synthesis

The results of the supplementary data gathering strategies were reviewed by the chief investigators (PH, JP) to identify any further clinical tools for inclusion in the appraisal process. The clinical tools identified during both stages of this literature review were then sorted according to the domain of palliative care in preparation for the appraisal process.

5.3 Phase 3: Appraisal of clinical tools

Objectives

The objective of the appraisal process was to select clinical tools from the results of the literature review that may have clinical and practical utility for specialist palliative care services.

Design

Copies of clinical tools identified on the basis of the literature review were then obtained and rated by the chief investigators (PH, JP) according to the rating scale outlined in Table 1.

Criterion	Score	Justification
Administered by health care professional?	0-1	Clinical tools should be administered by a health care professional (Yes = 1).
Brief?	0-1	Brevity is important (Yes = 1).
Could be used across settings?	0-3	Aim to indentify clinical tools that are suitable for use in different palliative care settings (Best Score = 3).
Practicality and clinical use?	0-4	Aim to identify clinical tools that are practical and suited to clinical use (Best score = 4).
In widespread use?	0-1	Answered to the best of the knowledge of the reviewers and/or as reported by the literature examined (Yes = 1).

Table 1: Rating scale used during the clinical tool appraisal (Phase 3).

Based on this rating process a shortlist of highest ranked clinical tools was produced.

5.4 Phase 4: Focus group meeting

The final phase of this study involved seeking expert and service provider opinion (by way of a multi-disciplinary focus group meeting) in order to review the clinical utility of the shortlist of clinical tools from Phase 3 and recommend a suite of tools relevant to practice in the Victorian palliative care setting.

Participants

Participants for the focus group meeting were identified via an email to the membership of the Palliative Care Clinical Network, supplemented by purposive sampling to ensure disciplines and different settings of care were represented.

The participants were:

- Dr Juli Moran Director of Palliative Care Services, Austin Health, (physician, metropolitan based practice);
- Ms Kathleen Hendry, Project Officer, Palliative Care & Haematology, Western Health, (nurse, metropolitan based practice);
- Ms Carmel Smith, Executive Manager, Goulburn Valley Hospice Care Service Inc, (nurse, rural based practice)
- Ms Theresa McCarthy, Caritas Christi Hospice, St Vincent's Health, (pastoral care worker, metropolitan based practice)
- Professor Peter Hudson (Chief Investigator)
- Associate Professor Jennifer Philip (Chief Investigator)
- Dr Adam Bostanci (Project Officer)

Method

In preparation for the focus group meeting, participants were emailed scanned copies of all shortlisted tools, with the exception of Pain Assessment Tools and Clinical Pathways for Imminently Dying Patients.

The focus group meeting was facilitated by Associate Professor Jennifer Philip. Time was pre-allocated to discuss clinical tools in each domain of palliative care. If no consensus on a preferred clinical tool appeared to be reached, a Nominal Group Voting Technique was planned to identify a preferred tool.

Notes were taken to record the preferred clinical tool in each domain, along with observations about the shortlisted tools, and recommendations of how the preferred tools were to be used to ensure both the functions of screening and assessment or on-going monitoring were successfully addressed.

In addition, several experts, some of whom were unable to attend the focus group meeting, commented on the clinical tools shortlisted for the project via email.

6 Results

6.1 Phase 1: Palliative care sector survey

Responses

The survey was completed by 38 of the 60 service providers invited to participate; a response rate of 63%. Types of service providers who responded are outlined below.

Service Types

- 68% palliative care community service
- 13% palliative care consultancy service
- 18% palliative care inpatient service

Regional Coverage

- 55% of organisations provide service in rural regions
- 45% regional
- 32% metropolitan
- 5% provide service state-wide

Clinical tools

A small number of clinical tools are widely used in palliative care in Victoria, but a larger number of clinical tools are used sporadically. This is in line with results from a recent survey in Europe [11]. RUG-ADL and the Karnofsky Performance Scale are used by two thirds of respondents and more, respectively.

- Karnofsky Performance Scale (79%)
- RUG-ADL (66%)
- PCOC (47%)
- ESAS (47%)
- LCP (24%)
- ECOG (24%)
- other tools²

The survey provided information on how particular clinical tools are used across the palliative care sector in Victoria, specifically how long each clinical tool had been used in a particular setting, use for either clinical assessment or data collection, about the prompts for introduction of the assessment tool, and who is responsible for data collection and data entry. Full survey results can be found in Appendix 1.

Benefits

Clinical tools were generally reported to be beneficial. Examples included ‘enables prioritising care’, ‘improves quality of care’, or ‘enables benchmarking’. The survey also yielded some observations about the way clinical tool are used at particular sites.

Support

Completion of clinical tools was generally reported to be supported by senior staff within the organisation. For some clinical tools there seemed to be a perception at some sites of lacking Information Technology (IT) support and support for data entry (as indicated by a

² Modified EOLCP, BPI, Abbey Pain Scale, Admission & Readmission Tool Adapted from Bendigo Health and Caritas Christi Hospice, Department of Veteran Affairs Pain and Symptom Control Measurement Tool, Braden Scale, Distress Thermometer, HoRT Tool (pressure areas), Malnutrition Screening Tool, MMSE, Modified ESAS, NSAP, NASP Problem Severity Score, NuDeSc, Organizational symptom assessment tool, Painassess (unsure of origin), PaP, PICD (2x, 1x in acute only), P-SOS Patient Outcome Scale (considering use), Barwon South West Region pain assessment tool, Carer Strain Index, ECOG Bereavement Risk Assessment, ECS-CP, Edinburgh Post Natal Depression Scale, Fraser Health o-v (pain/nausea/vomiting), Pain Chart Assessment, PAINAD, Risk of complicated bereavement tool

bimodal distribution of responses about 'IT support' and 'on-going funding to support data entry').

Overall benefit vs. effort

Overall benefits were reported to outweigh the effort involved for organisation and patients for all common clinical tools identified in the survey.

Conclusion

The survey identified clinical tools currently in use in the Victorian palliative care sector. Clinical tools are perceived to be beneficial and well-supported. For some tools there may be a perception at some sites of lacking IT support and support of data entry.

6.2 Phase 2: Palliative care literature review

Systematic searches ('bottom-up')

The systematic searches of online databases generated 2738 titles, of which 424 were selected for abstract review based on the fact that they referred to a clinical tool within a specialist palliative care setting. Of these 424 papers, 98 were selected for full article review. Three of these articles were unable to be retrieved and seven were eliminated as they did not meet the inclusion/exclusion criteria (see filter #3, Appendix 2). Data extraction, as described in Section 5.2, was carried out on the remaining 86 articles.

Supplementary data gathering

Grey literature

Searches of the grey literature did not yield any relevant articles post-1997 and were therefore not included in the selection and review process. Notably, the website of the National Centre for Palliative Care Research (www.npcrc.org) provides a useful collection of copies of clinical tools, sorted by domain of palliative care. A further useful collection of clinical tools and literature references is provided by T.I.M.E. (Toolkit of Instruments to Measure End-of-Life Care; www.chcr.brown.edu/pcoc/toolkit.htm).

Existing literature reviews

We identified a number of high-quality reviews of clinical tools as well as 'needs assessments' relevant to palliative care [9, 12-19]. Clinical tools that were identified on the

basis of these review articles for appraisal by the chief investigators are marked with an asterisk (*) in Section 5.3.

Sector contacts

Contacts of the research team led to the identification of the following clinical tools.

- Carer Support Needs Assessment Tool (CSNAT)[20]
- Needs Assessment Tool: Progressive Disease – Cancer (NAT: PD-C) [21]
- Distress Management Tool – also known as ‘Distress Thermometer’
- Palliative Care Outcome Collaboration (PCOC) Assessment Tools [22]
 - Problem Severity Score
 - RUG-ADL
 - Symptom Assessment Scale
 - Australian Modified KPS
 - Phase
- Taking a Spiritual History Tool [23]
- Spiritual care tools in palliative care (Dr Bruce Rumbold, LaTrobe University)
 - HOPE [24]
 - FICA [25]: Dr Rumbold provided the following information about this tool: general screening tool; at present there is a move to require it as part of all hospital admissions in USA; can be incorporated in the palliative care admissions process to amplify standard religious affiliation questions.
- Help the Hospices National Audit Tools Group (audit tools, not reviewed below)

6.3 Phase 3: Appraisal of clinical tools

The results of the appraisal process of the clinical tools identified for each of the domains of palliative care is reported separately. As noted previously, clinical tools that were identified on the basis of existing systematic review articles are marked with an asterisk (*). Clinical tools that were selected for further consideration in Phase 4 of the project have been highlighted.

Symptom assessment tools

The results of the appraisal process for symptom assessment tools identified through the palliative care literature review are summarised in Table 2.

	Administered by Health Care Professional? (0/1)	Brief? (0/1)	Could be used Across Settings? (0-3)	Practical in Clinical Use? (0-4)	In Widespread Use? (0-1)	Total	Comments / Reference
Agitation Distress Scale	1	1	3	3	0	8	Specialised tool; [26]
Bedside Confusion Scale	1	1	3	1	0	6	[27]
Campas-R	0	0	3	1	0	4	[28]
Communication Capacity Scale	1	1	3	3	0	8	Specialised tool; [26]
Confusion Assessment Method	1	1	3	3	1	9	Specialised tool; [29]
ESAS	1	1	3	4	1	10	[30]
Multidimensional Fatigue Inventory	1	0	3	0	0	4	[31]
Needs at the End of Life Screening Tool	1	0	0	0	0	1	[32]
Patient Dignity Inventory	0	0	2	0	0	2	[33]
SQid	1	1	1	1	0	4	[34]
Symptom Assessment Scale	1	1	3	4	1	10	[35]
Symptom List for Quality Assurance in Palliative Care	0	0	1	2	0	3	[36]
Symptom Management at End of Life in Dementia							Translation unavailable
Memorial Symptom Assessment Scale (condensed)*	1	1	3	2	1	8	Identified in [12]
Symptom Distress Scale*	1	1	3	2	0	7	Identified in [12]
reduced E-STAS*	1	1	2	4	0	8	Identified in [12]; [37]
Symptom Monitor*	0	0	0	1	0	1	Identified in [12]
Canberra Symptom Scorecard*	1	1	3	2	0	7	Identified in [12]

Table 2: Results of the appraisal process for symptom assessment tools. Clinical tools shortlisted for Phase 4 are highlighted.

Assessment tools for performance/functional status

The results of the appraisal process for symptom assessment tools identified through the palliative care literature review are summarised in Table 3. Note that RUG-ADL and Phase of Care will be a future mandatory requirement for payment to palliative care services through Activity Based Funding (ABF).

	Administered by Health Care Professional (0/1)	Brief? (0/1)	Could be used Across Settings? (0-3)	Practicality and Clinical Use? (0-4)	In Widespread Use? (0-1)	Total	Comments / Reference
Australian-modified KPS	1	1	3	4	1	10	[38]
Communication Capacity Scale	1	1	3	4	0	9	Specialised tool; [26]
A Computer-Based Assessment Tool	0	0	0	0	0	0	[39]
Consciousness Level Scale	1	1	3	1	1	7	[40]
ECOG Scale	1	1	3	4	1	10	[41]
Karnofsky Performance Status	1	1	3	4	1	10	Amended as AKPS;
Palliative Performance Scale	1	1	3	2	0	7	[42]
Patient Dignity Inventory	0	0	3	0	0	3	[33]
A Prognostic Scale	1	1	3	2	0	7	Specific to Taiwan; [43]
EFAT-2	1	1	3	2	0	7	[44]
Thorne KPS	1	1	1	3	0	6	[45]

Table 3: Phase 3 results for assessment tools for performance/functional status. Clinical tools that have been shortlisted for Phase 4 are highlighted.

Family/caregiver needs assessment tools

This domain was covered by a recent systematic review by one chief investigator (PH, [13]).

The following tools were shortlisted for consideration during Phase 4:

- Family Inventory of Needs (FIN) [46];
- Carer Support Needs Assessment (CSNAT) [20]

Quality of life

This domain of palliative care was covered by a recent systematic review [18], which ranked the McGill Quality of Life Questionnaire (MQOL) and Measuring the Quality of Life of Serious Ill Patients (QUAL-E) highest for their measurement properties. The authors of this review noted that most quality of life assessment tools had unfavourable measurement properties. One additional clinical assessment tool for scoring was selected from this review.

	Administered by Health Care Professional? (0/1)		Brief? (0/1)		Could be used Across Settings? (0-3)		Practical in Clinical Use? (0-4)		In Widespread Use? (0-1)		Total	Comments / Reference
<i>MQOL*</i>	0	0	2	1	0	3	Identified in [18]					
<i>QUAL-E*</i>	1	0	1	0	0	2	Identified in [18]					
<i>FACIT-PAL*</i>	0	0	3	1	0	4	Identified in [18]					
<i>MVQOLI-R*</i>	0	1	2	1	0	4	Identified in [18]					
<i>EORTC QLQ C30</i>	1	0	3	1	1	6	[47]					

Table 4: Appraisal results for quality of life assessment tools. Clinical tools that have been shortlisted for Phase 4 are highlighted.

Multi-Dimensional tools/needs assessments

The results of the appraisal process for symptom assessment tools identified through the palliative care literature review are summarised in Table 3.

	Administered by Health Care Professional? (0/1)		Brief? (0/1)		Could be used Across Settings? (0-3)		Practical in Clinical Use? (0-4)		In Widespread Use? (0-1)		Total	Comments / Reference
<i>Problem Severity Score</i>	1	1	3	4	1	10	[22]; PCOC					
<i>NEST 13+</i>	1	0	3	1	0	5	[32]; Could use parts for screening					
<i>POS</i>	1	1	3	3	1	9	[48, 49]					
<i>STAS</i>	1	1	3	4	1	10	[48]; Precursor to POS					
<i>SPEED</i>	0	1	1	2	0	4	[50]; ED only					
<i>NAT: PD-C</i>	1	1	3	4	?	9	[21]; Care planning tool					
<i>CNAT*</i>	1	0	2	0	0	3	Identified in [9]					
<i>SCNA-SF34*</i>	0	0	1	1	0	2	Identified in [9]					
<i>Symptom & Concern Checklist*</i>	1	0	3	3	0	7	Identified in [9]					
<i>CARES Short Form*</i>	0	0	1	1	0	2	Identified in [9];					
<i>Cancer Care Monitor*</i>	0	0	1	0	0	1	Identified in [9]; Tablet PC required					
<i>Concerns Checklist*</i>	0	1	1	1	0	3	Identified in [9]; not very multi-domain					
<i>Distress Measurement Tool</i>	-	-	-	-	-	-	Shortlisted in psy/em domain					

<i>IHA Form*</i>	-	-	-	-	-	-	Identified in [9]; Unavailable
<i>Needs Evaluation Questionnaire</i>	1	1	1	2	0	5	Identified in [9]
<i>PNAT*</i>	1	1	1	2	1	6	Identified in [9]
<i>CAMPAS-R</i>	1	1	2	3	0	7	[28]; Symptoms (patient and carer)
<i>Patient Dignity Inventory</i>	0	0	2	0	0	2	[33]; Dignity only
<i>Social Difficulties Inventory*</i>	0	0	1	1	0	2	Identified in [9]
<i>Problems Checklist*</i>	0	1	1	2	0	4	Identified in [9]; highlights points not routinely identified

Table 5: Phase 3 results for multi-domain assessment tools and needs assessments. Clinical tools that have been shortlisted for Phase 4 are highlighted.

Psychological/emotional assessment tools

In this domain in particular, the focus of the appraisal process was on identifying assessment tools that could be employed for screening. Recent, in-depth reviews [15, 16] have drawn attention to the ‘Distress Thermometer’ (formally known as Distress Measurement Tool), as a popular patient instrument with some extensions of under development. CES-D and GHQ 12 are identified as short measures with potential as screening tools. An assessment tool commonly used in this area is the Hospital Anxiety and Depression Scale (HADS).

The following tools were shortlisted for Phase 4:

- Distress Management Tool (a.k.a. ‘Distress Thermometer’)
- General Health Questionnaire (GHQ 12)
- Hospital Anxiety and Depression Scale (HADS)

This was also based on advice from Professor Brian Kelly (University of Newcastle, Australia) regarding recommended screening tools for psychological distress.

Pain assessment tools

An international expert panel has recently carried out an evaluation of pain assessment tools, in particular whether existing assessment tools address the dimensions of pain relevant for palliative care pain assessment [19]. Many were found to contain too few pain dimensions or number of items to provide meaningful pain information. Most single items in more general symptom assessment tools ask only about pain intensity, and only three of the reviewed assessment tools covered all of the highest-ranked dimensions of pain. These tools were not deemed suitable for use in palliative care. A number of pain assessment tools were identified in our systematic literature search, and additional assessment tools for appraisal were selected from [19], as summarised in Table 6.

	Administered by Health Care Professional? (0/1)		Brief? (0/1)		Could be used Across Settings? (0-3)	Practical in Clinical Use? (0-4)	In Widespread Use? (0-1)	Total	Comments / Reference
Abbey Pain Scale	1	1	2	2	0	6	[51]; Dementia		
A Belgian Pain Scale	1	1	3	2	0	7	[52]; Dementia		
Verbal Rating Scale	1	1	3	4	1	10	[53]; Unidimensional		
Visual Analogue Scale	1	1	3	3	1	9	[53]; Unidimensional		
Numerical Rating Scale	1	1	3	4	1	10	[53]; Unidimensional		
Faces Scale	0	1	3	3	0	7	[53]		
Descriptive Scale of Pain Intensity	0	?	2	2	0	5	[53]		
Pain Behaviour Observation	1	1	2	1	0	5	[53]		
McGill Pain Questionnaire	0	0	0	0	1	1	[53]		
PainAid	1	1	3	3	1	8	[52]; Good for dementia.		
Brief Pain Inventory	0	0	3	2	1	6	[54]		
Borg Category Ratio*	1	1	1	0	1	4	Identified in [19]		
Initial Pain Assessment Tool*	1	0	3	2	1	7	Identified in [19]		
Integrated Pain Score*	0	1	1	2	0	4	Identified in [19]		
McGill Pain Questionnaire-SF*	1	0	3	2	0	6	Identified in [19]		
Memorial Pain Assessment Card*	0	1	3	2	0	6	Identified in [19]		
Pain Assessment Questionnaire	1	0	3	3	0	7	Identified in [19]		
Pain Disability Index*	0	1	1	1	1	3	Identified in [19]		
Wisconsin Brief Pain Questionnaire*	-	-	-	-	-	-	Identified in [19]; Early version of BPI		
WHO-QOL Pain*	0	0	2	1	0	3	Identified in [19]		
ESAS	1	1	3	3	1	9	[30]; One pain item only.		
Aberdeen Low Back Pain*	0	0	1	0	0	1	Identified in [19]		
Brief Pain Diary*	0	1	1	1	0	3	Identified in [19]		

Table 6: Appraisal results for pain assessment tools. Shortlisted clinical tools are highlighted.

Spirituality

The results of the appraisal process for symptom assessment tools identified through the palliative care literature review are summarised in Table 7.

	Administered by Health Care Professional? (0/1)		Brief? (0/1)	Could be used Across Settings? (0-3)	Practical in Clinical Use? (0-4)	In Widespread Use? (0-1)	Total	Comments / Reference
<i>Life Closure Scale</i>	1	0	3	1	0	5	[55]	
<i>Needs at the End of Life Screening Tool (NEST)</i>	1	1	3	2	0	6	[32]; Multi-domain	
<i>POS</i>	1	1	3	1	0	6	[48]; Multi-domain	
<i>PEACE Scale</i>	1	1	2	2	0	6	[56]; Existential/psychological.	
<i>SPEED</i>	1	1	3	2	0	8	[50]; For Emergency Department	
<i>Hope</i>	-	-	-	-	-	-	[24]; Not rated, deemed unsuitable.	
<i>Spiritual Needs Inventory (SNI)</i>	0	0	3	3	0	6	[57]	
<i>STAS</i>	1	1	2	2	0	6	[48]; Multi-domain	
<i>Taking a Spiritual History Tool</i>	1	0	3	4	0	8	[23]	
<i>FACIT-Sp*</i>	1	1	3	4	0	9	Identified in [58]; Modification for use in Australia not possible (pers. comm. Dr Rumbold)	
<i>FICA*</i>	1	1	3	4	1	10	Identified in [58];	

Table 7: Results of the appraisal process for spiritual history tools. Clinical tools shortlisted for Phase 4 are highlighted.

Prognosis

From a review of prognostic tools for palliative care [17], the following were selected for further consideration during Phase 4 of the project.

- Palliative Prognostic Score (PaP) [59]. PaP uses Karnofsky Performance Status, a Clinical Prediction of Survival, Total White Blood Cell Count, Lymphocyte Percentage, as well as dyspnoea, anorexia.
- Palliative Prognostic Index (PPI) [60]. PPI uses the Palliative Performance Scale, oral intake, and the presence and absence of dyspnoea, oedema, and delirium.

Cultural assessment tools

No cultural assessment tools were detected by our 'bottom up' literature searches, nor the hand searches of the literature. For this reason, no such clinical tool was taken forward to the next phase of the project, the Focus Group Meeting.

Shortlisted Clinical Tools

Table 8 summarises the clinical tools that were shortlisted for evaluation during Phase 4 of the project (as highlighted above).

Domain of Palliative Care	Shortlisted Clinical Tools
Symptoms	Edmonton Symptom Assessment Scale (ESAS) Symptom Assessment Scale (SAS) Memorial Symptom Assessment Scale
Quality of Life	Measuring the Quality of Life of Seriously Ill Patients (QUAL-E) McGill Quality of Life Questionnaire (MQOL) FACIT-Pal
Psych/Emotional Health	General Health Questionnaire (GHQ12) 'Distress Thermometer' Hospital Anxiety and Depression Scale
Multi-domain Assessments / Needs Assessments	Problem Severity Score (PSS) Palliative Outcome Scale (POS) Needs Assessment Tool Progressive Disease – Cancer (NAT PD-C) Needs at the End of Life Screening Tool (NEST13) Distress Management Tool (a.k.a. 'Distress Thermometer')
Family / Caregiver Tools	Carer Support Needs Assessment (CSNAT) Family Inventory of Needs (FIN) Quality of Life During Serious Illness – Family Carers (QOLLI-F)
Performance Status / Function	ECOG Performance Status Palliative Performance Scale (PPS) Edmonton Functional Assessment Tool (EFAT) Australian KPS
Pain	Numerical, Verbal, VA Rating Scale (part of ESAS) Brief Pain Diary Brief Pain Inventory (PBI) Initial Pain Assessment Tool
Prognosis	Palliative Prognostic Score (PaP) Palliative Prognostic Index (PIP)
Spirituality History Tools	FICA Spiritual History Tool Taking a Spiritual History Spiritual Needs Inventory
Care pathway for imminently dying patient	Liverpool Care Pathway (LCP) Palliative Care for Advanced Disease (PCAD) Pathway

Table 8: Clinical Tools shortlisted during Phase 3 by domain of palliative care.

6.4 Phase 4: Focus group meeting

Framing and consensus

Discussions were framed by a requirement for a suite of clinical assessment tools to cover initial screening assessments as well as comprehensive assessment in a particular domain and follow-up. Assessment tools were thus identified as being more appropriate for either of these tasks.

In addition, two principal approaches with respect to multi-domain assessment tools were discussed. One stance might be that multi-domain assessment tools replicate what is assessed by domain-specific tools, hence adding an additional and possibly unnecessary layer of on-going assessment.

By contrast, the other stance might be that multi-domain assessment tools could be understood as providing a framework for an initial screening assessment, with subsequent comprehensive assessment and follow-up monitoring with domain-specific tools. After discussion, this approach was favoured by the group.

Hence, the recommendations in this report envisage that an initial screening assessment would be carried out for each patient, followed by comprehensive assessment with domain-specific tools and follow-up.

Focus group members readily reached a consensus on the preferred assessment tool for each domain of palliative care, and for the suite of tools recommended overall.

Initial screening assessment

Both the Problem Severity Score (PSS) and Distress Management Tool (also known as 'Distress Thermometer') were endorsed as suitable multi-domain clinical tools for use during an initial screening assessment.

Comprehensive assessment and follow-up

The following suite of tools was endorsed with respect to comprehensive assessment and follow-up.

The Symptom Assessment Scale (SAS) was the preferred symptom assessment tool, suited to on-going monitoring of areas such as pain. It was recommended that single question items can be added to the SAS to cover for example Anxiety/Depression or Quality of Life.

Among pain assessment tools, the Initial Pain Assessment Tool was identified as an example of a suitable tool for a detailed assessment once pain had been flagged up as a problem with either of the recommended screening tools (PPS, Distress Thermometer) or during monitoring with the Symptom Assessment Scale.

The group discussed the merits of including a Quality of Life Assessment Tool. Quality of Life figures centrally in the WHO definition of palliative care, yet many of the instruments in this area are neither suitable for clinical use nor do they lead to an easy interpretation.

Among the shortlisted Quality of Life assessment tools, FACIT-Pal was preferred because it was simpler and contained more positively framed items. It was noted that such an instrument could also be a basis for a more general patient discussion, which would highlight what is important to the patient.

Psychological distress was covered by the relevant items of the Distress Thermometer or Problem Severity Score. As a second, more formal screening assessment, the General Health Questionnaire 12 (GHQ12) was preferred. In other words, the GHQ 12 could be administered when there was an indication of psychological distress based on the aforementioned initial screening tools and then a follow-up comprehensive psychological assessment as pertinent.

Among the family/caregiver tools, the Carer Support Needs Assessment (CSNAT) was preferred. This is a new tool being developed with the intention of widespread implementation in England.

With respect to performance status/functional assessment tools, the Australian-modified Karnofsky Score was recommended. It was noted that RUG-ADL and Phase of Care will be a future mandatory requirement for payment to palliative care services through Activity Based Funding, which will not guide clinical decisions or activity but is rather concerned with funding services appropriately. Further, it was noted that the Palliative Performance Scale (PPS) provides a broader performance assessment, which may also assist with care planning (also see Prognosis below).

Among Spiritual History Tools, FICA was identified as a practical tool that is used widely. FICA could potentially be introduced followed screening with the Problem Severity Score or Distress Thermometer.

Finally, the Liverpool Care Pathway for Dying Patient was endorsed as a care pathway for those patients identified as imminently dying.

Prognosis

Both the Palliative Prognostic Score (PaP) and the Palliative Prognostic Index (PPI) were endorsed as potentially useful prognostic tools. They differ with respect to the incorporated patient parameters (most notably PaP uses the results of a blood test, while PPI uses the Palliative Performance Scale) and provide different types of prognostic information. Hence, where use of a prognostic tool is indicated, users could adopt either of the endorsed prognostic tools, depending on what information is locally available and depending on what kind of prognostic information is useful.

Other observations

It was also noted that the Needs Assessment Tool Progressive Disease (NAT PD-C) provided a good care planning tool.

It was noted that these tool recommendations did not cover paediatric palliative care.

While the aims of this project differed from those of PCOC, as discussed in Section 2, there is thus some overlap in the clinical assessment tools preferred during the focus group meeting (e.g. SAS, AKPS, and PSS are also part of Palliative Care Outcomes Collaboration).

7 Recommendations

Based on the research described above, this project has identified the palliative care clinical assessment tools listed in Table 9 that may assist with the admission and co-ordination of specialist palliative care provision for patients and family caregivers across care settings.

Table 9 also provides details of where a copy of the relevant clinical tool can be found for inspection (either in Appendix 3 or on the internet) as well as details of the organisation should be contacted for formal permission to use the relevant clinical tool. These details are provided to the best of our knowledge but their correctness should not be relied upon.

Finally, the Table 9 provides details of recent publications on the measurement properties of the recommended clinical tools. It must be noted however that the measurement properties of the recommended clinical tools have not been independently assessed for this report.

As discussed above, the Needs Assessment for Progressive Disease (NAT PD-C) provides a useful care planning tool [21, 61].

Domain of Palliative Care	Clinical Tool	Initial / Screening Assessment	Comprehensive Assessment	Follow-Up	Special Situation	Comment	Copy of Clinical Tool	Permissions / Reference	Measurement Properties
Multi-Domain Assessment / Needs Assessment	Problem Severity Score	✓		✓		With SAS	Appendix	PCOC [22]	
	Distress Thermometer	✓		✓			Internet	NCCN [62]	[15, 16]
Pain	Initial Pain Assessment Tool		✓				Appendix	Credit [63]	
Family / Caregiver	Carer Support Needs Assessment Tool		✓				Appendix	Form in Appendix	Forth-coming
Emotional Distress	GHQ12		✓			Screening	Internet	MAPI Trust [64]	[15, 16]
Spirituality	FICA Spiritual History Tool		✓				Internet	GWISH [65]	[66]
Symptoms	Symptom Assessment Scale	✓		✓		Monitor symptoms	Appendix	PCOC [22]	[35]
Performance / Function	Australia modified KPS	✓				^{3, 4}	Appendix	[38]	[38, 67]
Quality of Life	Facit-Pal		✓			Optional	Internet	FACIT [68]	[69]
Prognosis	PaP				✓		Appendix	[59]	[17, 70]
	PPI				✓		Appendix	[60]	[17, 60]
Care of Dying Patient	Liverpool Care Pathway				✓		Internet	MCPCIL [71]	[72]

Table 9: Overview of the clinical tools recommended by this report.

³ RUG-ADL and Phase of Care will be a future mandatory requirement for payment to palliative care services through Activity Based Funding.

⁴ Palliative Performance Scale (PPS) provides broader assessment and may help with care planning.

8 Conclusion

The research carried out for this report has led to recommendations regarding a suite of clinical tools covering important domains of palliative care which can be used to assist specialist palliative care services to assess and plan care for patients and their family caregivers.

The process of developing the list of recommended tools has been comprehensive, incorporating a multi-pronged literature review, an appraisal process during which the chief investigators evaluated a large number of clinical assessment tools, and finally a multi-disciplinary specialist focus group meeting to evaluate a shortlist of 30 clinical tools.

The results of these processes, in particular as summarised in Tables 2-9 of this report, should provide a valuable resource for professionals in palliative care.

Although some policy documents emphasise the importance of addressing 'cultural needs' in palliative care service provision [8, 74], the literature searches and other methods carried out for this project did not lead to the identification of relevant cultural assessment tools. Further work in the area of cultural assessment may be warranted.

The research undertaken for this report has limitations. Above all, any comprehensive review of clinical tools with utility for specialist palliative care must be acknowledged to be challenging, as previous review authors have noted [9, 10]. One simply cannot guarantee that every potentially relevant clinical tool has been identified. Moreover, clinical tools used in practice are often adaptations of those described in the literature, on which we have primarily drawn [9].

Second, our overall analysis was guided by nine key domains of palliative care and tools were evaluated accordingly. This led to the exclusion of some potentially interesting but specialised clinical tools.

Third, we have not considered some issues of implementation such as cost, copyright, policy, and resource issues. Although we have evaluated the clinical utility of relevant tools, others have pointed out that there is a lack of testing of such tools in practical care, and we know little about the responsiveness, feasibility, appropriateness and acceptability of many needs assessments [9]. Presumably, this also applies to the use of several such instruments in conjunction.

Finally, the measurement properties (validity, reliability) of the recommended clinical tools have not been independently assessed for this report.

We suggest that subsequent work be undertaken to explore the pragmatic implications of systematically implementing these clinical tools into standard specialist palliative care practice. This will need to involve consideration of cost, copyright, policy and resource

issues. In addition, training for staff would also be required. Finally, evaluation of the implementation would need to be undertaken.

9 Appendices

9.1 Appendix 1: Results of the palliative care sector survey

[CATPC Survey Results Exported](#)

The survey results have been reproduced in full (60 pages) in the printed submitted copy of this report.

9.2 Appendix 2: Systematic literature review ('bottom-up')

Search Strategy

A search of MEDLINE was conducted as follows:

Syntax: (Clinical Assessment Tools OR (Needs Assessment AND Palliative Care)) AND Filters

Population Terms

1. Palliative Care/ [MH]
2. Terminal Care/ [MH]
3. Hospice Care/ [MH]
4. Hospices/ [MH]
5. Terminally Ill/ [MH]
6. (palliative * or terminally or hospice or end of life).ti, ab
7. or/ 1-6

Clinical Tool Terms

8. Needs Assessment/ [MM]
9. (assess* or measure* or scale or tool* or pathway*).ti, ab
10. or/8-9
11. #7 and #10
12. (child or pediatric* or paediatric* or infant* or neonate*). ti, ab
13. #11 not #12

In addition to using the above strategy, searches were restricted to literature on adult populations, published in English, dated from 1998 onwards, with an available abstract and limited to publication type.

Online databases searched

In addition to MEDLINE, the following databases were searched using a similar search strategy:

- CINAHL
- EMBASE
- PubMed
- PsychInfo
- Cochrane Database of Systematic Reviews (CDSR)
- DARE (Database of Abstracts of Reviews of Effectiveness)

We also specifically searched for systematic reviews that were not included in the Cochrane data base.

Data collection

Title Phase and inclusion/exclusion criteria

Selection of studies

Titles of all literature to assess which studies met the initial inclusion criteria (Table 1) were acquired.

Table 1 – Filter 1	
EXCLUSION CRITERIA	INCLUSION CRITERIA
(1) the wrong patient group (i.e. non-palliative patients, paediatric)	(1) studies directly relevant to palliative care
(2) do not relate to clinical tool/s	(2) focuses on a clinical tool/s
(3) published prior to 1998	(3) names a specific clinical tool
(4) commentary on ethical, legal or regulatory issues	
(5) on technical/medical/pharmaceutical interventions (i.e. chemotherapy, lasers, stents, etc)	
(6) editorials or personal narratives	
(7) about professional palliative care education	
(8) not published in English	

Abstract Phase

The abstracts of the selected titles were then reviewed by LW and NS based on the inclusion/exclusion criteria listed in the table below. This phase was known as filter #2. The inclusion criteria used for this selection phase was more specific than filter #1, with studies being selected on the basis of the specific clinical tool's relevance to at least one or more of the domains of palliative care.

Table 2 – Filter 2	
EXCLUSION CRITERIA	INCLUSION CRITERIA
(1) the wrong patient group (i.e. non-palliative patients, paediatric)	(1) the study describes an instrument relevant to at least one or more of the domains of palliative care
(2) do not relate to a critical or clinical tool/s (i.e. studies re: care pathways)	(2) the study measures/reports the impact of the tool on patient/caregiver outcomes – i.e. physical, psychological, social
(3) published prior to 1998	(3) palliative population
(4) commentary on ethical, legal or regulatory issues	(4) reports on a specific pre-identified clinical tool
(5) on technical/medical/pharmaceutical interventions (i.e. chemotherapy, lasers, stents, etc)	(6) patient already in a palliative care/specialist PC setting
(6) editorials or personal narratives/experiences	(5) focus on the utilisation of the tool (within PC/specialist PC) and the way in which it is being used to assist with care planning, be it – physical, psychological, social, etc.

(7) about professional palliative care education	
(8) study aims and methods were unclear	
(9) not published in English	
(10) professional opinion piece (on tools)	
(11) health care utilization studies	
(12) extrapolations from existing literature	
(13) primary focus of the study was not on the tool itself	
(14) studies examining quality of care provided (i.e. family carer satisfaction)	
(15) studies reporting on palliative patient experiences (i.e. tools not utilised to improve patient/caregiver outcomes)	
(16) tool/measure relates to attitudes/personal opinion with regards to palliative care	
(17) tool being used for research purposes and not clinical purposes (i.e. used to assess relationships between two variables, draw inferences)	
(18) tool used for auditing purposes or to assess service provision	
(19) study is evaluating the utilisation of the tool	
(20) tool used for referral to PC, not utilised within PC itself	
(21) bereavement*	

*Bereavement was a domain being undertaken in a separate review process and so was excluded from this review.

Full text phase

Where available, full papers were obtained from the remaining abstracts for further review, using the same inclusion/exclusion criteria as stage 2.

Table 3 – Filter 3	
EXCLUSION CRITERIA	INCLUSION CRITERIA
(1) the wrong patient group (i.e. non-palliative care patients, paediatric)	(1) the study describes an instrument relevant to at least one or more of the domains of palliative care
(2) do not relate to a critical or clinical tool/s (i.e. studies re: care pathways)	(2) the study measures/reports the impact of the tool on patient/caregiver outcomes – i.e. physical, psychological, social
(3) published prior to 1998	(3) palliative population
(4) commentary on ethical, legal or regulatory issues	(4) reports on a specific pre-identified clinical tool
(5) on technical/medical/pharmaceutical interventions (i.e. chemotherapy, lasers, stents, etc)	(6) patient already in a palliative care/specialist PC setting
(6) editorials or personal narratives/experiences	(5) focus on the utilisation of the tool (within PC/specialist PC) and the way in which it is being used to assist with care planning, be it – physical, psychological, social, etc.

(7) about professional palliative care education	
(8) study aims and methods were unclear	
(9) not published in English	
(10) professional opinion piece (on tools)	
(11) health care utilization studies	
(12) extrapolations from existing literature	
(13) primary focus of the study was not on the tool itself	
(14) studies examining quality of care provided (i.e. family carer satisfaction)	
(15) studies reporting on palliative patient experiences (i.e. tools not utilised to improve patient/caregiver outcomes)	
(16) tool/measure relates to attitudes/personal opinion with regards to palliative care	
(17) tool being used for research purposes and not clinical purposes (i.e. used to assess relationships between two variables, draw inferences)	
(18) tool used for auditing purposes or to assess service provision	
(19) study is evaluating the utilisation of the tool	
(20) tool used for referral to PC, not utilised within PC itself	
(21) bereavement*	

*The bereavement domain, being subject of a separate review process, was excluded from this review.

9.3 Appendix 3: Recommended Clinical Tools

Problem Severity Score [22]



Problem Severity Score

Instructions:

- The problem severity is an overall score of the patient/client and family.
- Score at episode start, at phase change and episode end

0 = Absent 1 = Mild 2 = Moderate 3 = Severe	The degree of overall pain of the patient.	Record the degree of overall other symptoms of the patient. The following list may be used as a guide:		Record the score for overall degree of psychological / spiritual problems of the patient. The following list may be used as a guide:		Record score for the overall degree of family / carer problems. The following list may be used as a guide:	
		Nausea Vomiting Constipation Dialhorrea- Dyspnoea Incontinence Iritation	Wound Confusion Delirium Oedema Weakness Fatigue Anorexia	Agitation Anxiety Fear Anger Sadness	Unrealistic Goals Request To Die Confusion Depression	Denial Caregiver Fatigue Unrealistic Goals Anger Cultural Accommodation Legal	Sensory Impairment Non English Speaking Difficult Communication Family Carer Anxiety
Date Assessed	PC pain	PC other symptom		PC Psych/ spiritual		PC Family/ Carer Score	

Triggers:

- A score of 2 or 3 for Psych/spiritual may trigger Pastoral or Social Work referral or intervention
- A score of 2 or 3 for family/carer may trigger Pastoral or Social Work referral or intervention

References

1. Smith, M. & Firms, P. (1994) Palliative care case mix Classification – Testing a Model in a Variety of Palliative Care Settings – Preliminary Results. Conference proceedings from the 6th national Case mix Conference. Commonwealth Department of Human Services and Health.
2. Eagar, K., Cromwell, D. Kennedy, C. & Lee, L. (1997) Classifying Sub-Acute and Non-Acute patients results of the NSW Case mix Area Network Study. Australian Health Review, Vol 20, No 2,26-42
3. Smith, M. (1998) Palliative Care case mix – Stage 2 Development: a national Classification for any site of Care. The 8th national case mix Conference. Commonwealth Department of Human Services and health.
4. Eagar, K., Gordon, R., Green, J., & Smith, M (2004) An Australian case mix classification for palliative care: lessons and policy implications of a national study. Palliative Medicine, 18:227-233

Distress Management Tool

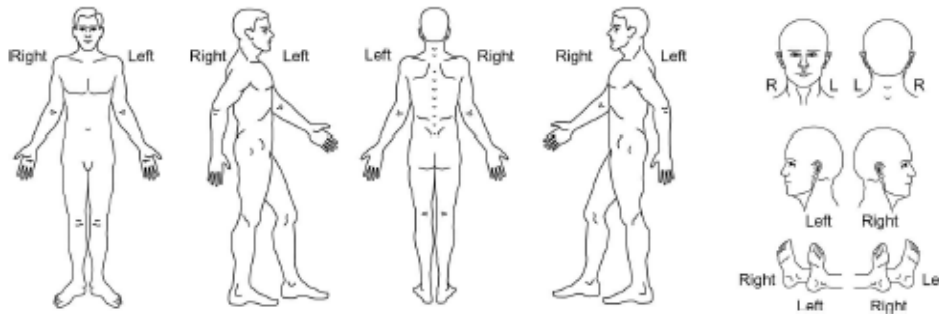
Reproduction requires permission from NCCN [62]. A number of implementations of this tool are readily available on the internet and a link to one current at the time of writing is provided in Table 9.

Initial Pain Assessment Tool [63]

Form 1.1 Initial Pain Assessment Tool

Date _____
 Patient's Name _____ Age _____ Room _____
 Diagnosis _____ Physician _____
 Nurse _____

1. LOCATION: Patient or nurse mark drawing.



2. INTENSITY: Patient rates the pain. Scale used _____

Present pain: _____ Worst pain gets: _____ Best pain gets: _____ Acceptable level of pain: _____

3. IS THIS PAIN CONSTANT? ____ YES; ____ NO IF NOT, HOW OFTEN DOES IT OCCUR? _____

4. QUALITY: (For example: ache, deep, sharp, hot, cold, like sensitive skin, sharp, itchy) _____

5. ONSET, DURATION, VARIATIONS, RHYTHMS: _____

6. MANNER OF EXPRESSING PAIN: _____

7. WHAT RELIEVES PAIN? _____

8. WHAT CAUSES OR INCREASES THE PAIN? _____

9. EFFECTS OF PAIN: (Note decreased function, decreased quality of life.)

Accompanying symptoms (e.g., nausea) _____

Sleep _____

Appetite _____

Physical activity _____

Relationship with others (e.g., irritability) _____

Emotions (e.g., anger, suicidal, crying) _____

Concentration _____

Other _____

10. OTHER COMMENTS: _____

11. PLAN: _____

May be duplicated for use in clinical practice. Copyright Pasero C, McCaffery M, 2008. As appears in Pasero C, McCaffery M. Pain: Assessment and pharmacologic management, 2011, Mosby, Inc.

Carer Support Needs Assessment Tool (CSNAT) [20]

The Carer Support Needs Assessment Tool (CSNAT)

Your support needs

We would like to know what help you need to enable you to care for your relative or friend, and what support you need for yourself. For each statement, please tick the box that best represents your support needs at the moment.

Do you need more support with...	No	A little more	Quite a bit more	Very much more
...understanding your relative's illness?				
...having time for yourself in the day				
...managing your relative's symptoms, including giving medicines?				
...your financial, legal or work issues?				
...providing personal care for your relative (eg dressing, washing, toileting)?				
...dealing with your feelings and worries?				
...knowing who to contact if you are concerned about your relative (for a range of needs including at night)?				
...looking after your own health (physical problems)?				
...equipment to help care for your relative?				
...your beliefs or spiritual concerns?				
...talking with your relative about his or her illness?				
...practical help in the home?				
...knowing what to expect in the future when caring for your relative?				
...getting a break from caring overnight?				
...anything else (please write in)?				

Please consider which of the above you most need support with at the moment. A hospice nurse will then be able to discuss these support needs with you.

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CSNAT Permission Form



Permission to use the Carer Support Needs Assessment Tool (CSNAT)

Thank you for your interest in the Carer Support Needs Assessment Tool (CSNAT). We are very happy to grant permission for use of the CSNAT provided the following conditions are met:

- the person applying for permission specifies the purpose(s) for which the CSNAT is to be used;
- the CSNAT is used in its entirety, and that it is neither adapted nor edited for research or other purposes;
- it is used only by the persons to whom, and the purposes for which, permission has been granted;
- a person to whom permission has been granted may not authorise or permit its use by any unauthorised person;
- the owners of the copyright are provided with a copy of any outcome or publication that makes use of it;
- the text of the CSNAT is not to be copied in any publications or research reports.

All copies of the CSNAT must include the following text:

© Gail Ewing and Gunn Grande 2009. All rights reserved. No part of this instrument may be produced, stored in a retrieval system, or transmitted in any form or by any means without the prior written permission of the copyright owners. For permission to use the CSNAT tool, contact Dr Gail Ewing, Centre for Family Research, University of Cambridge, Free School Lane, Cambridge CB2 3RF (ge200@cam.ac.uk)

Note that the CSNAT is a copyrighted tool and can only be used with permission.

The undersigned agrees to abide by the terms of this agreement:

Signatures

Researcher/Practice Organisation

Date

Gail Ewing / Gunn Grande

Date

3rd May 2012

Please complete your name and contact details below and some further information to help us understand the purposes to which the CSNAT is being used.

Researcher / Practice organisation (delete as appropriate):

Name:

Organisation:

Address:

..... Post code:

Telephone: Fax:

Email Address:

Researchers:

Name of research study or evaluation:

Study design: Qualitative Quantitative Mixed methods

Method(s) of data collection:

How will the CSNAT be used? Intervention Process measure

Outcome measure Specify other:

Sample size:

Practice organisations:

Type of service provided:

Who will be using the CSNAT? Clinical nurse specialist Registered Nurse

Health Care Assistant Doctor Specify other:

How will the CSNAT be used? Home visits Telephone contacts Day therapy

Sent to carers to self complete and return Specify other:

Estimated number of carer assessments using CSNAT per month:

May we keep in contact with you about the CSNAT? Yes No

Complete form and return to: Dr Gail Ewing, Centre for Family Research, University of Cambridge.
email: ge200@cam.ac.uk Fax: +44 (0) 1223 330574.

General Health Questionnaire (GHQ 12)

Reproduction requires permission from MAPI Research Trust [64]. An internet link to a copy of this clinical tool is provided in Table 9.

FICA

For permission requests, contact The George Washington Institute for Spirituality & Health [65]. This copyrighted tool is readily available on the internet, and a link current at the time of writing is provided in Table 9.

Symptom Assessment Scale

Symptom Assessment Scale



Please circle the number that matches your level of distress caused by each of these symptoms

Symptom	No Distress → Worst Distress										
Insomnia	0	1	2	3	4	5	6	7	8	9	10
Appetite	0	1	2	3	4	5	6	7	8	9	10
Nausea	0	1	2	3	4	5	6	7	8	9	10
Bowels	0	1	2	3	4	5	6	7	8	9	10
Breathing	0	1	2	3	4	5	6	7	8	9	10
Fatigue	0	1	2	3	4	5	6	7	8	9	10
Pain	0	1	2	3	4	5	6	7	8	9	10

Australia modified Karnofsky Performance Scale

Reproduced from [38].

Table 1: Comparison of the original Karnofsky Performance Status Scale (KPS), Thorne-modified Karnofsky Performance Status Scale (TKPS), and the Australia-modified Karnofsky Performance Status Scale (AKPS). Italicised areas reflect the original KPS instrument.

Score (Category)	Original Karnofsky (KPS)	Thorne-modified Karnofsky (TKPS)	Australia-modified Karnofsky (AKPS)
100 (A)	<i>Normal; no complaints; no evidence of disease.</i>	<i>Normal; no complaints; no evidence of disease.</i>	<i>Normal; no complaints; no evidence of disease.</i>
90 (A)	<i>Able to carry on normal activity; minor signs or symptoms.</i>	<i>Able to carry on normal activity; minor signs or symptoms.</i>	<i>Able to carry on normal activity; minor signs or symptoms.</i>
80 (A)	<i>Normal activity with effort; some signs or symptoms of disease.</i>	<i>Normal activity with effort; some signs or symptoms of disease.</i>	<i>Normal activity with effort; some signs or symptoms of disease.</i>
70 (B)	<i>Cares for self; unable to carry on normal activity or to do active work.</i>	<i>Cares for self; unable to carry on normal activity or to do active work.</i>	<i>Cares for self; unable to carry on normal activity or to do active work.</i>
60 (B)	<i>Requires occasional assistance but is able to care for most of his needs.</i>	Requires professional visits less than once a week.	<i>Requires occasional assistance but is able to care for most of his needs.</i>
50 (B)	<i>Requires considerable assistance and frequent medical care</i>	Requires professional visits more than once a week.	<i>Requires considerable assistance and frequent medical care</i>
40 (C)	<i>Disabled; requires special care and assistance.</i>	In bed more than 50% of the time.	In bed more than 50% of the time.
30 (C)	<i>Severely disabled; hospitalisation necessary; active supportive treatment is necessary.</i>	Almost completely bedfast.	Almost completely bedfast.
20 (C)	<i>Very sick; hospitalisation necessary; active supportive treatment is necessary.</i>	Totally bedfast and requiring extensive nursing care by professionals and/or family.	Totally bedfast and requiring extensive nursing care by professionals and/or family.
10 (C)	<i>Moribund; fatal processes progressing rapidly.</i>	Comatose or barely arousable.	Comatose or barely arousable.
0	<i>Dead.</i>	<i>Dead.</i>	<i>Dead.</i>

FACIT (Pal)

Reproduction requires permission from FACIT.org [68]. An internet link to a copy of this clinical tool is provided in Table 9.

Prognosis

Palliative Prognostic Score (PaP)

Reproduced from [73].

CRITERION	ASSESSMENT	PARTIAL SCORE
Dyspnoea	No	0
	Yes	1
Anorexia	No	0
	Yes	1.5
Karnofsky Performance Status	≥30	0
	10 - 20	2.5
Clinical Prediction of Survival (weeks)	>12	0
	11-12	2
	7-10	2.5
	5-6	4.5
	3-4	6
	1-2	8.5
Total WBC (x10 ⁹ /L)	≤8.5	0
	8.6 - 11	0.5
	>11	1.5
Lymphocyte Percentage	20 - 40%	0
	12 - 19.9%	1
	< 12%	2.5
RISK GROUP	30 DAY SURVIVAL	TOTAL SCORE
A	>70%	0 - 5.5
B	30 - 70%	5.6 - 11
C	< 30%	11.1 - 17.5

Palliative Prognostic Index (PPI)

Reproduced from [60].

Performance status/Symptoms	Partial score
Palliative Performance Scale	
10–20	4
30–50	2.5
≥60	0
Oral Intake	
Mouthfuls or less	2.5
Reduced but more than mouthfuls	1
Normal	0
Oedema	
Present	1
Absent	0
Dyspnoea at rest	
Present	3.5
Absent	0
Delirium	
Present	4
Absent	0

Interpretation

PPI score > 6 = survival shorter than 3 weeks

PPI score >4 = survival shorter than 6 weeks

PPI score ≤4 = survival more than 6weeks

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