Palliative and End of Life Care Resources sourced by CareSearch (January 2015)

The NSW Agency for Clinical Innovation commissioned CareSearch (Palliative and Supportive Services, Flinders University) to identify local, national and international tools and resources potentially able to be employed to improve local action on each of the ten (10) essential components of care in the Palliative and End of Life Care Blueprint for Improvement.

CareSearch Palliative Care Knowledge Network (or more simply CareSearch) is a suite of palliative care information and resources funded by the Commonwealth Department of Health and available at www.caresearch.com.au. The portal is designed to support health professionals involved in providing palliative care and those needing palliative care and their families and friends. The site does not host or receive funding from advertising or from the display of commercial content.

The set of tools and resources provided are not endorsed by the NSW ACI and not intended to be exhaustive, but to contain key items relevance to clinicians in New South Wales working within a palliative and end of life care context.

In some cases, especially where tools are subject to copyright or a registration process, the portal is unable to provide direct access to the tool. For this reason, users should include time in their project schedule for achieving access.

Methodology

CareSearch undertook the following search strategy -

1. **Identification of criteria for including and excluding identified tools and resources**
   To be included in the collection, tools and resources were required to be in English, be applicable to the Australian context and be supported by evidence (such as published validation studies, clinical guidelines representing expert consensus, or advice from expert clinicians who were consulted.

   The set of tools and resources provided is not intended to be exhaustive, but to contain key tools and resources of relevance to clinicians in New South Wales working within a palliative care context. In addition, for the listed tools and resources, there is evidence of their validity, usefulness and/or current utilisation by experts in the field.

2. **A formal search** beginning with ACI sourced documents identifying tools of interest or currently in use. A systematic search of the published literature and of grey literature on specialist websites was conducted. The search strategy was designed to capture tools and resources relevant to each of the ten (10) essential components of the blueprint. Key concepts were searched using MeSH (Medical Subject Headings), other suitable thesaurus headings and text words (natural language terms). The databases and search terms used are shown below.

Databases -	Search terms -

PubMed
Medline
CINAHL
Cochrane
Joanna Briggs
Scopus (includes Embase records)
NICE
TRIP
Google Scholar
Google
	Including (but not limited to):
	
	Terms associated with tools:
	    algorithm*
	    assess*
	    checklist*
	    "decision aid*"
	    index
	    indicator*
	    instrument*
	    measur*
	    questionnaire*
	    scale*
	    score*
	    screen*
	    template*
	    tool*
	
	combined with (using the AND operator)
	
	Terms associated with palliative care:
	    Advance care planning
	    Advanced cancer
	    "end of life"
	    palliat*
	    Terminal care
	    Terminal illness
	    Terminal* ill
	
	(in Medline and PubMed the Palliative Care Search Filter was used http://www.caresearch.com.au/caresearch/tabid/377/Default.aspx)
	Death literacy
	Death education
	
	("patient held record" OR "patient held records" OR PHR) in combination with palliative care terms
	
	Community awareness in combination with palliative care terms
	
	MeSH: Health Knowledge, Attitudes, Practice* and Marketing of Health Services* in combination with palliative care search filter
	
	Online learning OR online education in combination with palliative care terms
	
	Guideline* in combination with palliative care terms

- Hand searches of identified relevant systematic reviews and other core documents and tools collections were also conducted.
- Candidate tools and resources were also sourced from documents and advice provided by ACI and suggestions from expert clinicians consulted during the course of the project.

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- A copy of reviews dealing with tools and resources for the CareSearch Review Collection was checked as was a set of online tools repositories and collections.

3. Screening of the search results

Once the tools and resources had been located, they were screened against the inclusion criteria. Those that did not meet the criteria were excluded.

4. Tool and Resource selection

During the searching period, the tools and resources were reviewed against the 10 Blueprint for Improvement's Essential Components of Care for relevance and applicability, and allocated to one or more of the components.

5. Consultation

When the search activity was close to being finalised, a meeting was held with palliative care researchers and clinicians within the discipline of palliative and supportive services to help consolidate relevant tools and resources for inclusion in the report. A mini Delphi consisting of communication with colleagues in varying disciplines in the fields of oncology, palliative care and aged care, chiefly in the Eastern Australian states followed to further refine the search results.

Search Limitations

The following caveats should be borne in mind in relation to the set of tools and resources supplied.

- In some cases, there may be dispute within the field about which tool should be preferred or used.
- Some tools may be context-specific. When selecting a tool, the clinician needs to be mindful of the particular context for their patient and their patient's specific needs (for example a tool may have only been validated for elderly patients).
- Tools and resources can be used in different areas which reflect the components identified. One tool may be aligned with several of the 10 essential components.
- Content and links are accurate at the time of writing, January 2015, but may change over time.

Definitions

Tools
Instruments or questionnaires aiding clinical work in palliative and end of life care, including assessment and management of symptoms, pain, prognosis, psychological/emotional, quality of life, spirituality, family, performance / functional status, multi-domain assessment / needs assessment and care of the imminently dying patient

Core palliative care tools
Tools assisting with common care issues in the context of clinical palliative and end of life care

Symptom assessment tools
Clinical tools aiding assessment of symptoms reported in palliative and end of life care.

Resources
Sources of information or guidance relevant to palliative and end of life care

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Core Resources
Sources of information or guidance on common and everyday matters relating palliative and end of life care

Additional tools for the care of specific populations
Tools aiding the palliative and end of life care assisting of people with special needs reflecting their age, functional state or care setting

Additional resources for the care of specific populations
Sources of information and guidance aiding the palliative and end of life care of people with special needs reflecting their age, functional state or care setting