CareSearch Project Research Studies Register: Registration Proforma	0083

Study Title: Needs based access to specialist palliative care services: Development and preliminary evaluation of a Consumer Toolkit

Brief description of the study: The purpose of this project is to develop and evaluate an evidence-based
Consumer Toolkit that includes information regarding health care resources for people with advanced cancer and their caregivers and a self-administered needs assessment tool to identify level of unmet needs. It is anticipated that the Toolkit will optimise patients' and caregivers' management of their supportive care needs and assist in navigating health care resources. Initially, development of the Toolkit was based on a comprehensive review of existing information sources to consumers (eg, booklets from cancer organisations) and the most up-to-date, scientific evidence available. The Toolkit's sections were determined by the *Palliative Care Needs Assessment Guidelines*[1] to focus on previously identified key areas of needs for patients with advanced cancer. This preliminary version was reviewed by researchers or individuals working in psycho-oncology (n=7) and patients diagnosed with advanced cancer (n=2). In addition, the Toolkit was revised at two focus groups with individuals diagnosed with advanced cancer and their caregivers (n=21). Participants' comments were integrated and a reworked version of the Toolkit will be distributed to patients and health care professionals shortly for further content evaluation. The aim of the preliminary evaluation is to determine the comprehensiveness of the Toolkit and its suitability, credibility, usefulness, and readability. A more comprehensive evaluation of the Tooklit will be undertaken in a second phase.

[1] Girgis A, Johnson C, Currow D, Waller A, Kristjanson L, Mitchell G, Yates P, Neil A, Kelly B, Tattersall M & Bowman D (2006). *Palliative Care Needs Assessment Guidelines*. The Centre for Health Research & Psycho-oncology (CHeRP), Newcastle, NSW, 2006. (A summary of the Guidelines can be found at: http://www.newcastle.edu.au/research-centre/cherp/professional-resources).

Study Methodology: (Please mark with an x which type of study methodology)

	Epidemiology
	Health Services / Health Economics / Quality Improvement
X	**Qualitative, Observational or Descriptive**
	Mixed Method
	Systematic Review
	Intervention: RCT
	Intervention: Comparative or cohort study
	Intervention: Case series

Project details:

Funding source (Optional): NHMRC; Cancer Council NSW						
Has the study received ethics approval?	**X**	Yes		No		Not applicable
Project starting date: May 2007						
Project completion date: In Progress						
Multi site:		Yes		No	**X**	Not applicable

RESEARCHERS

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Associated publications / reports: None yet	
Topics (Admin only) Patients, Caregivers, Cancer care	