CareSearch Project Research Studies Register: Registration Proforma	0057

Study Title: Improving Palliative Care Services for Adolescents and Young Adults with Cancer

Brief description of the study:

The overall objectives of the project are to

- Improve collaboration between services involved in providing care
- Support the transition betweens settings of care
- Develop and implement a model of care that looks after the young patient in their local community.

Project Aims:

- Develop an understanding of the barriers to referral to specialist palliative care within a comprehensive cancer centre in the adolescent and young adult (AYA) population
- Develop a model of palliative care service delivery for adolescents and young adults within a comprehensive cancer centre, in which specialist palliative care is intimately integrated with primary health care provision.

Key Activities

Developmental Phase

- Retrospective Audit of all deceased AYA patients involved with the onTrac@PeterMac Service
- Focus Groups with primary treating teams & community palliative care services
- Pilot of model

Implementation Phase

- 12 month trial if integrated model of specialist palliative care service delivery for AYA with cancer through the onTrac@PeterMac Cancer Service
- Identification of AYA patients with palliative care needs by the Palliative Care nurse appointed to the onTrac@PeterMac Cancer Service
- Assessment of the palliative care needs of AYA patients
- Care planning for AYA patients with palliative care needs
- Collaboration between services involved in providing care to AYA patients

Evaluation

Level 1

- Comparison to Retrospective audit of all deceased patients from both Pilot & Implementation Phases and comment on changes
- Outcomes analysis of Care Plans utilizing assessment tools

Level 2

- Focus Groups with primary treating teams & community palliative care services to determine impact
- Case Conferences – descriptions, details, comments, individual outcomes to determine impact

Key issues or outcomes: yet to be determined, however AYA found to be a complex patient population, where the early intervention of palliative care appears to be of benefit.

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

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

Project details:						
Funding source (Optional): Department of Health and Ageing – Local Palliative Care Grants Program Funding Round Three – Care Planning						
Has the study received ethics approval?	**x**	Yes		No		Not applicable
Project starting date: June 2006						
Project completion date: April 2009						
Multi site:		Yes	**x**	No		Not applicable
RESEARCHERS						
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Investigator E (Name)						
Associated publications / reports: DOHA report submitted April09						
Topics (Admin only) Cancer, Paediatric Palliative Care, Settings of palliative care						