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 between 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)

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<th>Epidemiology</th>
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<td>Health Services / Health Economics / Quality Improvement</td>
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<tr>
<td>Qualitative, Observational or Descriptive</td>
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<td>Mixed Method</td>
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<td>Systematic Review</td>
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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

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<th>Has the study received ethics approval?</th>
<th>Yes</th>
<th>No</th>
<th>Not applicable</th>
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Project starting date: June 2006

Project completion date: April 2009

Multisite: Yes

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<th>Multi site</th>
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**RESEARCHERS**

Principal Investigator (name)  
Dr Odette Spruyt, Director, Department of Pain and Palliative Care  
Peter Mac Callum Cancer Centre  
Melbourne, Australia

Contact Details  
Odette.Spruyt@petermac.org

Investigator B (Name)  
Dr David Thomas

Investigator C (Name)

Investigator D (Name)

Investigator E (Name)

**Associated publications / reports:** DOHA report submitted April09

**Topics (Admin only)** Cancer, Paediatric Palliative Care, Settings of palliative care