| CareSearch Project<br>Research Studies Register: Registration Proforma | 0157 |
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**Study Title: Upfront Family Meetings for Community Palliative Care Services**

**Brief description of the study**: This study will translate a new model of family meetings that has been piloted and evaluated in the in-patient palliative care service at Calvary Health Care Sydney into the community setting with the involvement of palliative care nursing staff and in consultation with general practitioners in the primary care setting and clinicians in the tertiary setting, including medical/radiation oncologists and surgeons. The community setting differs from the in-patient unit. Often there is less anxiety related to clinical acuity, and less distress about need for admission and fears about its likely outcome. However community patients who are beginning their relationship with the palliative care service are often negotiating complex service arrangements; they may be transitioning between active treatment and more palliative goals of care but still receiving active treatment. The objectives of this study are to: 1. Improve the transition from acute to palliative care, including • Establishing shared goals of care between patient, family and team soon after referral to palliative care • Reduce patient and family distress at transition 2. Improve co-ordination of care, including • Understanding the support networks of the patient • Understanding the patient's and family's perceptions of who is involved in their care, who is affected by the patient's illness, who needs to be included in decision-making, and the current status of the person's health • Increase family participation in advance care planning, including discussion of what will happen as goals of care shift, alternatives for future care if and when home becomes no longer manageable, what help is available and how to access it, how decisions about treatment and care are usually made, and how the patient and family can be involved in those decisions 3. Identify the potential for the intervention as currently developed in the in-patient unit to be delivered by palliative care nurses in the community

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

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| | Epidemiology |
| **X** | 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): Cancer Institute NSW

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| Has the study received ethics approval? | **X** | Yes | | No | | Not applicable |
| Project starting date: 2014 | | | | | | |
| Project completion date: 2014 | | | | | | |
| Multi site: | | Yes | **X** | No | | Not applicable |
| **Researchers** | | | | | | |
| Principal Investigator (name) **Dr. Christine Sanderson** | | | | | | |
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| Investigator B (Name) Professor Liz Lobb | | | | | | |
| Investigator C (Name) Ms. Eleanor Kough | | | | | | |
| Investigator D (Name) Ms. Anne Johnson | | | | | | |
| Investigator E (Name) | | | | | | |
| **Associated publications / reports:** | | | | | | |
| **Topics (Admin only) Communication, General practitioners, Families** | | | | | | |