Overview of the CONNECT Research Program

A/Prof Jane Young
Ms Jennifer Walsh
Mr James Harrison
Dr Rebecca Dennis
Background to the program

- Colorectal cancer is a major health burden in Australia
  - 2nd most common cancer
    - 4483 new cases in NSW in 2005
  - 2nd most common cause of cancer death
    - 1585 deaths in NSW in 2005
- Management is complex – surgery, chemotherapy, radiotherapy

Complex system of health practitioners

- Patients are often required to navigate a complex system in both hospital and community settings, over an extended period of time.
Areas for improvement in cancer care

- Psychosocial support
  - 30-40% cancer patients have unmet needs
  - Higher among those having adjuvant therapy

- Care coordination
  - ‘Joining up’ the patient journey
  - Perceived adequacy predicts perceptions of overall quality of care

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2. Harrison JD, Young JM, Price M, Butow P, Solomon MJ. What are the unmet supportive care needs of people with cancer? A systematic review (under editorial review)


CONNECT research program

- A series of studies to develop and evaluate resources to improve care coordination
- To build capacity in cancer services research
- Funded by Cancer Institute NSW Health Services Research Program Grant
- 3 year program – based at SOuRCe
Study team

- A/Prof Jane Young – SOuRCe
- Prof Phyllis Butow – CEMPED/SOuRCe
- Prof Michael Solomon – SOuRCe
- Prof Glenn Salkeld – SPH/SOuRCe
- Prof Kate White – Faculty of Nursing
- Dr Rebecca Dennis – SOuRCe
- Ms Jennifer Walsh – SOuRCe
- Mr James Harrison – SOuRCe
- Ms Robyn Secomb – SOuRCe
- Ms Colleen Wells – SOuRCe
- Ms Lindy Masya – SOuRCe
- Dr Timothy Dobbins – SPH
- Prof Sally Redman – Sax Institute
- Dr Bruce Hodge – Port Macquarie Base Hospital
- Dr Henry Hicks – Wagga Wagga Base Hospital
- Dr Andrew Gilmore – Orange Base Hospital
- Dr Geoff O’Connor – Dubbo Base Hospital
- Dr Stephen Smith – John Hunter Hospital, Newcastle
- Dr David Hansen – EHRC, CSIRO
- Ms Marilla O’Dwyer – EHRC, CSIRO
1. Definitions and measures
   * What do we mean exactly by ‘care coordination’?
   * How can we measure ‘care coordination’?

2. Developing interventions and resources
   * Development of telephone intervention

3. Evaluation
   * Acceptability & feasibility
     * Effectiveness
   * Cost effectiveness
CONNECT research themes

Definitions and measures

Evaluation

Developing interventions and resources
Definitions and measures

- No agreed definition of ‘care coordination’
  - ‘Improve the patient journey’
  - ‘Continuum of care’
  - ‘Coordination of care’
  - ‘Continuity of care’
  - ‘Seamless care’
  - ‘Integration of care’

- Some components
  - Comprehensiveness (all services needed)
  - Longitudinal (services delivered over time)
  - Communication / relationships (multiple health providers)
  - Accessibility (care available when needed)
  - Flexibility (responsive to patients’ individual needs)
Overview

Systematic literature review
Focus groups and interviews

Subjective measure (patient questionnaire)

Objective measure (medical record audit tool)
Focus groups and interviews

Defining care coordination: A qualitative study

AIMS:

- Identify the essential components of cancer care coordination from the perspective of patients, carers and clinicians
- Identify potential questionnaire items to be incorporated into a measure of cancer care coordination
Defining care coordination: A qualitative study

- **Participants**
  - Clinicians involved in cancer care including specialists, GPs, community and hospital-based nurses (n=29)
  - Patients (n=20)
  - Carers (n=4)
  - Recruited from metropolitan, regional and rural areas of NSW

- **Data collection**
  - Face to face interviews
  - Telephone interviews
  - Focus groups

- **Analysis**
  - A qualitative phenomenological interpretive approach based on grounded theory
Defining care coordination: A qualitative study

Essential Components:

- **Organisation of Patient care**
  
  “....they make all the arrangements, like when you have been told you have cancer, and you think ‘Oh, now I have to go and have X-rays’; it was all done for you, you didn’t have time to even worry about it, and I think that was what kind of got us through, not having to wait for hours on end, and your mind thinking....”

- **Access to and navigation through the healthcare system**

  “So, it’s just really having all that resource and knowing where to get things, and being able to guide them – and the fact that you can do that takes a lot of the frustration – and gives patients some information that otherwise they wouldn’t get, if they come through the private sector, like through the private hospital system, they often miss out on those sort of things.”

  “Sometimes you don’t know where to access services in the first place, because when my mother passed away or prior to that, I didn’t know there was such a thing as respite care because nobody told me and I never knew that sort of thing existed. So I wouldn’t have known where to go for other services, other than what I’ve already had.”
Defining care coordination: A qualitative study

- **Allocation of a key contact person**
  
  "So I think if they’ve got one person who they can ring up and say, you know, I’ve just been to see the radiation oncologist, he said now I need to go back to the surgeon, why would I do that? Those kinds of things I think, that’s what the patient is looking for."

  "…different specialists have a different idea about follow-up, who’s seeing the patient, who’s the key person at that time in the patient’s care… Um, so that can be an issue, with communication…"

- **Recognition and understanding of medical team roles**
  
  "Particularly groups of patients who go from surgeon to medical oncologist, to radiation oncologist perhaps, they’re often uncertain who’s actually looking after them."

  "…there’s a lot of confusion about nurse consultants, care coordinators and who does what…”

  "…we really feel out of the coordination loop, we don’t know who’s coordinating what and I think that most GPs would feel that they would want to have an active role in that.”
Defining care coordination: A qualitative study

- **Effective communication and cooperation amongst the multidisciplinary team and other health service providers.**

  “I think the folk who do well, and you’ll meet them, you’ll come across those teams, is they know what each other does, there is never any argument about who does what, they report very clearly to each other, they have good rapport with each other and so if there is a problem, there is no concern or issue about bringing that problem up.”

- **Delivery of services in a complimentary and timely manner.**

  “I think when Patient X was told he had cancer, everything moved so quickly, you really didn’t have time to sit down and dwell about it, from having your blood tested, to being weighed, to having your operation – it was just bang, bang, bang…”

  “…getting timely appointments…., because there can be a wait and we don’t have oncologists on site, it may be 4-6 weeks before they might see an oncologist. So in that process from point of diagnosis to the time they actually see the oncologist, they don't know what the plan is for them. That seems to be an anxious point.”
Defining care coordination: A qualitative study

- **Needs Assessment**

  “….two patients with the same disease, depending on what treatment or treatment choices there are, they may have actually quite different needs…”

  “Every time I see them, the situation changes all the time for people and so it’s always reminding them that there are services available to them..”

- **Sufficient and timely information to patient.**

  “I think patient information - getting that information first up as quick as possible after diagnosis is what patients want and that’s what alleviates anxiety and um…. Keeping patients informed is very important, at all stages of the journey. So, when a change comes about or a plan’s made that the patient is kept in that loop, so when anyone knows, you know the patient’s the first to know….”
Development of quantitative measures of cancer care coordination

- Development of comprehensive set of questionnaire items based on systematic literature review and results of qualitative interviews and focus groups

- Two versions of questionnaire
  - Patients’ perceptions of cancer care coordination
  - Carers’ perceptions of cancer care coordination

- Draft questionnaires are currently being tested

- Objective measure of care coordination (medical record audit tool) will also be developed
CONNECT research themes

Definitions and measures

Evaluation

Developing interventions and resources

* Telephone intervention
Development of the telephone intervention

- Centralised ‘remote access’ cancer care coordination
- Based on:
  - Systematic review of literature review about cancer patients’ unmet supportive care needs
  - Clinical experience
- Standardised nurse-delivered telephone intervention for all post-operative patients with colorectal cancer
Aims of telephone service

↑ Care coordination

↑ Quality of life by reducing unmet psychosocial need

↑ Patient satisfaction with care

↓ Unplanned health service utilisation
Process of patient assessment & referral

- Standardised assessment of patient needs using a checklist
- Provision of information and support
  - Local referral if patient has a significant need or problem
  - Immediate direct contact with local health team if serious problem
## Telephone intervention “checklist”

<table>
<thead>
<tr>
<th>Domains of need</th>
<th>Does the patient have a problem / unmet need for this issue?</th>
<th>Briefly comment on the problem</th>
<th>Briefly comment on action taken (if applicable)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>PHYSICAL</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wound care</td>
<td>❑</td>
<td>❑_2</td>
<td></td>
</tr>
<tr>
<td>Pain</td>
<td>❑_1</td>
<td>❑_2</td>
<td></td>
</tr>
<tr>
<td>Appetite &amp; Fluids</td>
<td>❑_1</td>
<td>❑_2</td>
<td></td>
</tr>
<tr>
<td>Energy &amp; Tiredness</td>
<td>❑_1</td>
<td>❑_2</td>
<td></td>
</tr>
<tr>
<td>Bowel function</td>
<td>❑_1</td>
<td>❑_2</td>
<td></td>
</tr>
<tr>
<td>Stoma care</td>
<td>❑_1</td>
<td>❑_2</td>
<td>(note if not applicable)</td>
</tr>
<tr>
<td>PSYCHOLOGICAL</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxiety &amp; Depression</td>
<td>❑_1</td>
<td>❑_2</td>
<td></td>
</tr>
<tr>
<td>Getting out and about</td>
<td>❑_1</td>
<td>❑_2</td>
<td></td>
</tr>
<tr>
<td>Other worries or concerns</td>
<td>❑_1</td>
<td>❑_2</td>
<td></td>
</tr>
<tr>
<td>INFORMATION (written / verbal)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cancer</td>
<td>❑_1</td>
<td>❑_2</td>
<td></td>
</tr>
<tr>
<td>Medications &amp; side effects</td>
<td>❑_1</td>
<td>❑_2</td>
<td></td>
</tr>
<tr>
<td>Treatments</td>
<td>❑_1</td>
<td>❑_2</td>
<td></td>
</tr>
<tr>
<td>SUPPORTIVE CARE</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ability to self-care</td>
<td>❑_1</td>
<td>❑_2</td>
<td></td>
</tr>
<tr>
<td>Managing about the house</td>
<td>❑_1</td>
<td>❑_2</td>
<td></td>
</tr>
<tr>
<td>Support services</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(e.g. community services)</td>
<td>❑_1</td>
<td>❑_2</td>
<td></td>
</tr>
<tr>
<td>REHABILITATION / FOLLOW UP</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Follow up appointments</td>
<td>❑_1</td>
<td>❑_2</td>
<td></td>
</tr>
<tr>
<td>(e.g. GP, specialist)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>OTHER</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anything else?</td>
<td>❑_1</td>
<td>❑_2</td>
<td></td>
</tr>
</tbody>
</table>
Schedule of calls after discharge

- 3 days
- 10 days
- 1 month
- 3 months
- 6 months
CONNECT research themes

Definitions and measures

Evaluation

Developing interventions and resources
CONNECT evaluation studies

1. Feasibility study
   * Non-randomised
   * RPAH
   * Colorectal cancer (n=41)

2. Single site pilot RCT
   * Randomised
   * RPAH
   * Colorectal cancer (n=75)

3. Multi-centre RCT
   * Randomised
   * 11 public and private hospitals in NSW
   * Colorectal cancer (n=720)
Feasibility study - Aims

- Aims:
  - To determine acceptability and feasibility of the telephone intervention
  - To determine acceptability of outcome assessment (mode, timing and content of questionnaires)
    - SCNS
    - FACT-C
  - care coordination items
  - health service utilisation
  - To obtain baseline data on outcomes for future project planning


Eligible patients

- Aged ≥ 18 years
- Have had surgery for newly diagnosed primary colorectal cancer (July – Dec 2006 at RPAH)
- Have access to telephone
- Are not hearing impaired
- Reside in Australia for next 6 months
- Are able to speak English or have family/friends that can translate for them
Participants: Non-randomised

- 67 admitted patients
  - 51 eligible
    - 41 consented (80% response rate)
      - 21 intervention
      - 20 control
  - 16 ineligible
    - 5 no interpreter available
    - 4 cognitively impaired
    - 2 deaf/no telephone
    - 2 not aware of diagnosis
    - 3 missed
Follow-up schedule

<table>
<thead>
<tr>
<th>3 DAY</th>
<th>10 DAY</th>
<th>1 MONTH</th>
<th>3 MONTH</th>
<th>6 MONTH</th>
</tr>
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<tbody>
<tr>
<td>Nurse</td>
<td>Nurse</td>
<td>Nurse</td>
<td>Nurse</td>
<td>Nurse</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Nurse</td>
<td></td>
</tr>
<tr>
<td>Telephone Health Service Utilisation</td>
<td>Telephone Health Service Utilisation</td>
<td>Telephone Health Service Utilisation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Needs / QoL / Distress</td>
<td>Needs / QoL / Distress</td>
<td>Needs / QoL / Distress</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

INTERVENTION

CONTROL

Telephone Health Service Utilisation

Needs / QoL / Distress

Needs / QoL / Distress
## Patient characteristics

<table>
<thead>
<tr>
<th></th>
<th>Intervention group (n=20) n (%)</th>
<th>Control group (n=21) n (%)</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mean age (years)</strong></td>
<td>66.9</td>
<td>64.5</td>
<td></td>
</tr>
<tr>
<td><strong>Male</strong></td>
<td>12 (60)</td>
<td>10 (50)</td>
<td>0.4</td>
</tr>
<tr>
<td><strong>Born in Australia</strong></td>
<td>14 (70)</td>
<td>13 (62)</td>
<td>0.6</td>
</tr>
<tr>
<td><strong>English spoken at home</strong></td>
<td>18 (90)</td>
<td>17 (81)</td>
<td>0.4</td>
</tr>
<tr>
<td><strong>Dukes stage of cancer</strong></td>
<td></td>
<td></td>
<td>1.0</td>
</tr>
<tr>
<td>A</td>
<td>4 (20)</td>
<td>4 (19)</td>
<td></td>
</tr>
<tr>
<td>B</td>
<td>6 (30)</td>
<td>7 (33)</td>
<td></td>
</tr>
<tr>
<td>C</td>
<td>6 (30)</td>
<td>5 (24)</td>
<td></td>
</tr>
<tr>
<td>D</td>
<td>3 (15)</td>
<td>3 (14)</td>
<td></td>
</tr>
<tr>
<td>Unknown</td>
<td>1 (5)</td>
<td>2 (9)</td>
<td></td>
</tr>
<tr>
<td><strong>Adjuvant therapy</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Received pre-operatively</td>
<td>4 (20)</td>
<td>8 (38)</td>
<td>0.2</td>
</tr>
<tr>
<td>Planned post-operatively</td>
<td>7 (35)</td>
<td>9 (43)</td>
<td>0.6</td>
</tr>
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</table>
## Intervention evaluation

<table>
<thead>
<tr>
<th></th>
<th>Day 3</th>
<th>Day 10</th>
<th>1 Month</th>
<th>3 Months</th>
<th>6 Months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient responses n=20</td>
<td>19</td>
<td>19</td>
<td>20</td>
<td>19</td>
<td>17</td>
</tr>
<tr>
<td></td>
<td>(95%)</td>
<td>(95%)</td>
<td>(100%)</td>
<td>(95%)</td>
<td>(85%)</td>
</tr>
<tr>
<td>Total needs/issues requiring intervention</td>
<td>27</td>
<td>21</td>
<td>22</td>
<td>18</td>
<td>8</td>
</tr>
<tr>
<td>Ave time per call (mins)</td>
<td>18</td>
<td>19</td>
<td>17</td>
<td>13.5</td>
<td>16</td>
</tr>
</tbody>
</table>
Needs identified during nurse phone calls

- General health
- Wound care
- Information
- Investigations and appointments
- Psychosocial
- Colorectal advice

No of patients with a need:
- 3 days
- 10 days
- 1 month
- 3 months
- 6 months
Unmet supportive care needs identified in survey
Change in SCNS domain scores – 1 month to 3 months

<table>
<thead>
<tr>
<th>Domain</th>
<th>Intervention</th>
<th>Control</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical &amp; daily living</td>
<td>11.1</td>
<td>0.6</td>
<td>0.03</td>
</tr>
<tr>
<td>Health system and information</td>
<td>3.3</td>
<td>16.8</td>
<td>0.008</td>
</tr>
</tbody>
</table>
Quality of life

Baseline
1 month
3 months
FACT-C

Intervention
Control
Conclusions

- Feasible and acceptable intervention
- Promising improvement in patient outcomes (QoL)
- Supportive care needs outcomes are varied
- Telephone administration of outcome measures a potential burden to some participants
- Non-randomised small sample…need continued research!
CONNECT evaluation studies

1. Feasibility study
   * Non-randomised
   * RPAH
   * Colorectal cancer (n=41)

2. Single site pilot RCT
   * Randomised
   * RPAH
   * Colorectal cancer (n=75)

3. Multi-centre RCT
   * Randomised
   * 11 public and private hospitals in NSW
   * Colorectal cancer (n=720)
Randomised single site pilot

- Similar eligibility criteria to non-randomised study
- Assess the acceptability of randomisation
- In response to non-randomised study:
  - Baseline SCNS data collected
  - Changed method of administration of SCNS & FACT-C questionnaires to postal
  - HSU completed over the telephone
Randomised single site pilot study

112 admitted patients
(July ’07 – June ’08)

- 85 eligible
- 27 ineligible

- 75 consented
  (88% response rate)

- 11 no interpreter available
- 7 cognitively impaired
- 3 deaf/no telephone
- 3 lived overseas
- 3 missed/other

- 39 intervention
- 36 control
Randomised single site pilot study

- All baseline, one and three month data collected

- Interim analysis there is no significant impact of the intervention in the immediate post-operative period on unmet needs and quality of life from baseline to 1 month

- However, longer term follow-up has the potential to show differences

- Loss to follow up expected to be about 15%
1. Feasibility study
   * Non-randomised
   * RPAH
   * Colorectal cancer (n=41)

2. Single site pilot RCT
   * Randomised
   * RPAH
   * Colorectal cancer (n=75)

3. Multi-centre RCT
   * Randomised
   * 11 public and private hospitals in NSW
   * Colorectal cancer (n=720)
Multi-centre randomised trial

AIMS:

- Determine the effectiveness of the telephone intervention to:
  - Improve patient QoL
  - Improve satisfaction with care
  - Improve care coordination
  - Reduce unplanned health service utilisation
  - Improve evidence-based practice in post-operative period

- Also to determine:
  - Economic evaluation (cost utility) of the intervention
  - Acceptability of the intervention to patients and clinicians
Design of study and recruitment

- Randomised controlled trial
- 720 patients who have surgery for a newly diagnosed colorectal cancer
- Randomised to intervention (telephone service) or control (usual care) group
- Surgeons operating at 11 public and private hospitals (initially) across NSW, including regional and rural areas, will recruit patients
Recruitment sites
Recruitment and baseline data

- Patients will be recruited in surgeon’s rooms during pre-surgery consultation (usually 1 – 2 weeks prior to surgery)
- For patients who are emergency admissions, surgeons will invite them to participate during post-operative hospital stay
- At baseline, surgeons will provide basic clinical information
- Patients will complete a baseline questionnaire
- On receipt of this, patients are randomised
Baseline patient questionnaire

- Basic demographic and contact details
- FACT-C
- Distress thermometer
- Number of GP visits, emergency department presentations, and hospital admissions in previous 12 months
Follow-up and outcome measures

- Intervention group – 5 calls from nurse in 6 months post-discharge

- All participants – self-complete written questionnaires at 1, 3 and 6 months
  - FACT-C
  - Distress thermometer
  - Supportive Care Needs Survey
  - Care coordination

- All participants – health service utilisation in 6 months post-discharge
  - Hospital admissions
  - ED presentations
  - GP visits
Update on study progress

- Approval at RPAH
- Patient recruitment commenced at RPAH
- 12 patients recruited so far
- SSAs submitted for Wagga, John Hunter, St Vincent’s
- Private hospital approval received for Wagga, Orange, Port Macquarie, Newcastle
Different response rate online?

- We will trial online surveys with patients who have internet access
Contact details

- connect@sswahs.nsw.gov.au
- 02 9515 3200