



# Clinical Oncological Society of Australia

Cancer Care Coordination Interest Group  
Care Coordination Outcome Measures Literature Review Meeting  
20 July 2011

Meeting Notes

## Background and Purpose

The Clinical Oncological Society of Australia (COSA) convened a meeting to consider and progress initiatives from the literature review findings on cancer care coordination outcome measurement tools on July 20, 2011. The meeting was facilitated by Professor Patsy Yates, Chair of the COSA Cancer Care Coordination Interest Group and Professor at the School of Nursing & Midwifery, Queensland University of Technology (QUT).

Professor Yates provided some background on COSA's role in facilitating discussions and agreement amongst key leaders in relation to the role of cancer care coordinators. COSA Cancer Care Coordination Interest Group members have identified as the need for more guidance on how to evaluate the role of cancer care coordination as a priority. She highlighted that COSA's role is not in service delivery, as a regulator or a funder, however as a professional organisation it can provide a forum for discussion on important issues. COSA's has the capacity to bring people together to share wisdom and develop an agreed vision. COSA can assist with development of agreed standards and frameworks to assist Cancer Care Coordinators.

Professor Yates acknowledged the work of Anna Doubrovsky, Project Officer, QUT. The literature search to date shows there are a range of terms that are used to describe care coordination interventions and outcomes. The literature review presented today is preliminary with further searches ongoing.

Prof Yates also outlined the previous work of COSA in this area. Workshops in 2006 and 2007 aimed to explore and define the issues, purpose and expected outcomes of cancer care coordination in Australia. The 2006 workshop led to the development of a set of principles that underpin cancer care coordination at the patient, team and system level. In 2007, some progress was made towards developing a set of indicators, measures and tools to assess the effectiveness of coordinated cancer care as relevant to the patient, service and funder. It was agreed that these outcome indicators and associated measures would form the basis for further discussion and that further validation and refinement would be required.

In 2008, COSA undertook a survey of members who self-identified as practicing in Cancer Care Coordinator roles to elicit information around scope of practice, work experience, referral pathways and learning and support preferences for Cancer Care Coordinators. The survey also sought to obtain feedback on the appropriateness of the outcome indicators identified in the 2007 workshop. The purpose of the survey was to identify areas for improvement, gain insight into the professional support needs of individuals appointed to these roles, and determine the next steps in development and implementation of outcome measures relevant to cancer care coordination interventions. The results highlighted the considerable variation that still exists in practice and perceived outcomes for Cancer Care Coordinator roles.

To continue to progress this important issue, a third workshop was convened by COSA prior to the 2009 Annual Scientific Meeting with a view to exploring and defining practical outcome measures that can be used to measure the impact of the Cancer Care Coordinator role. Professor Yates provided a brief overview of the challenges in defining outcome measures for cancer care coordination. In particular she emphasised the importance of focusing not just on inputs and throughputs – but on measuring the impact of an intervention. She noted that it would be impossible to measure the impact of every aspect of cancer care coordination and that it was important to focus on meaningful measures that could be attributed to the Cancer Care Coordinator role and used to monitor the quality of care and drive service improvement.

## Summary of COSA's Activities in relation to Cancer Care Coordination

|      |   |
|------|---|
| 2006 | CARE COORDINATION WORKSHOP <a href="#">COSA Care Coordination Workshop Report 2006</a>                  |
| 2007 | CARE COORDINATION WORKSHOP <a href="#">COSA Care Coordination Workshop Report 21 December 2007</a>      |
| 2008 | Survey of Scope of Practice to Cancer Care Coordinators   |
| 2009 | COSA Professional Day Funding grant for workshop November 2009 on Care Coordination Outcome Measures    |
| 2010 | CONFERENCE March 2010 <a href="#">COSA Care Coordination Conference Report March 2010</a>               |
| 2010 | Meeting with Professor Kathy Eager (Wollongong Uni) to discuss steps to develop agreed outcome measures |

Professor Yates highlighted the effectiveness of coordinated cancer care as relevant to the patient, service and funder agreed at the 2007 workshop. [http://www.cosa.org.au/cosa\\_assets/files/About%20us%20-%20publications/Carecoordinationworkshop2007.pdf](http://www.cosa.org.au/cosa_assets/files/About%20us%20-%20publications/Carecoordinationworkshop2007.pdf)

| Care Coordination Outcomes – Patient Level      |   |
|---|---|
| Outcome   | Detail  |
| Every patient is aware of their pathway of care | Every patient, irrespective of demographics and health service delivery setting: <ul style="list-style-type: none"><li>• knows what will happen to him/her from the point</li></ul> |

|   |   |
|---|---|
|   | <p>at which symptoms are reported/detected</p> <ul style="list-style-type: none"> <li>• can identify a key point of contact at each stage in the journey</li> <li>• is provided with consistent information throughout their journey.</li> </ul> <p>As a result, patients will have increased confidence in the system.</p> |
| The time from diagnosis to treatment is appropriate | The timing of treatment is efficient, appropriate and takes account of patient preferences.   |
| The patient experience is positive                  | Every patient feels valued, in control and respected.   |

| <b>Care Coordination Outcomes – Service Level</b>  |  |
|--|--|
| <b>Outcome</b>   | <b>Details</b>   |
| A clear pathway is defined for each patient, and information moves with the patient through the system | <p>Key elements in the pathway include:</p> <ul style="list-style-type: none"> <li>• structured interdisciplinary communication</li> <li>• an evidence-based approach.</li> </ul>  |
| There is an effective multidisciplinary team   | <ul style="list-style-type: none"> <li>• An effective multidisciplinary team is one in which team members have the necessary expertise for managing the patient's cancer, and in which team roles are clearly defined and interactions are effective and of a high quality.</li> <li>• Team membership may vary according to the stage in the patient journey.</li> <li>• It was noted that membership of an effective team may lead to improved satisfaction for participating health professionals.</li> </ul> |
| Transfer points are well managed across networks and sectors   | <p>The process for transfer of care at each stage of the patient journey is clear and well managed. Key elements include:</p> <ul style="list-style-type: none"> <li>• knowledge by health professionals of relevant contacts at primary and tertiary levels</li> <li>• provision of relevant information at the point of transfer</li> <li>• clear definition of entry and exit points to the pathway.</li> </ul>   |

| <b>Outcomes – Funder Level</b>  |  |
|---|--|
| <b>Outcome</b>  | <b>Detail</b>  |
| More patients are cared for by an effective multidisciplinary team  | Includes increases in referrals to multidisciplinary teams as well as increased numbers of effective multidisciplinary teams   |
| Patients receive appropriate treatment  | <p>Improvements in treatment will include:</p> <ul style="list-style-type: none"> <li>• improvements in time to treatment in line with recognised benchmarks (taking account of patient preferences)</li> <li>• reduced variation in treatment.</li> </ul> |
| Knowledge of and access to services, especially primary care is improved<br>Variation and duplication of service provision is reduced |  |

The 2010 meeting with Professor Kathy Eager sought some guidance on the steps to develop outcome measures. Key points emphasised at this meeting were:

- Health service delivery is very complex and being able to clearly illustrate the attribution made by Cancer Care Coordinators is affected by many factors
- Outcomes occur at various levels, e.g. patient, provider system and for short intermediate and long term

- Cancer Care Coordinators may not influence all outcomes of patient care. The team factor may influence the outcome
- Selection of measures depends on the context in which the cancer care coordinator is working and the nature of the intention.

Recommendations by Professor Eager were:

- Seek a standard measurement for the patient experience to provide administration and clinical feedback
- Routine data can be collected at turnstile events
- Measurement at the provider and system level may be best handled at two yearly intervals
- Think about the collection of data in routine clinical practice and work at service improvements and also try to bench mark against other centres.

Professor Eager noted that the Cancer Care Coordinator role involves patient transition. She suggested that the COSA interest group begin with developing measures around the patient experience. She referred to work done through the Picker institute which has existing frameworks in particular the Continuous Quality Improvement Model (CQI). <http://pickerinstitute.org/>

### Meeting Objectives

Attendees agreed that the Cancer Care Coordination role varies in terms of context and a package of recommended tools could not meet the variations in work. There was also agreement that there needs to be further enquiry around patient needs particularly in relation to fundamentals of pathway of care and its relevance.

There was consensus that the best way to move forward is to define some principles which could give guidance to those working in the role of cancer care coordinators but also acknowledging cancer care coordinators work in different ways. The literature review findings will help inform and identify the priority areas.

Therefore the agreed objectives for the meetings were:

- Provide recommendations on :
  - Principles of evaluation
  - Frameworks for evaluation
  - Potential tools for measurement
  - Guidance for selecting tools
- To participate in further discussion on the:
  - Gaps and next steps
  - Implementation issues
  - Opportunities for collaboration

### Literature Review Findings

Anna Doubrovsky outlined her search strategy and findings. She observed that over half the papers defined the work as qualitative measures. The primary countries undertaking research in this field are Canada, Netherlands, United States and Australia. The search has also unveiled a vast range of different measures some of which have not been tested. It is important to note that the key word, 'navigation' in the American context is often described as patient navigator, cancer navigator or nurse navigator. This is an example of non-descript terminology that limits the findings of the research.

### Search Strategy

- Original research peer-reviewed articles in English from 1989 through to July 2011 were obtained from the Scopus database.
- Terms that were synonymous with measurement were used to develop the search strategy used below. (measurement OR measuring OR measure) OR (evaluation OR evaluate) OR (assessment OR assess) AND "care coordination" AND cancer.
- This strategy identified 243 English papers in Scopus that contained the search terms.

### Data Abstraction

- The 243 articles were further restricted to only original research publications.
- Papers which were not primarily about care coordination or were not relevant were eliminated (207 articles). The research collection was summarised under the following categories:-
  - 1) Year
  - 2) Country where research was performed
  - 3) Study design
  - 4) Methods used (including data analysis if relevant)
  - 5) Sample characteristics (participant and setting)

- 6) Number of participants
- 7) Outcome measures
- 8) Tools
- 9) Comments/Conclusions

The review findings to date indicate:

- Broad range of measures used
- Many focus on narrow definitions
- Few use clear frameworks or provide rationale for selection of measures
- Attribution is not dealt with very well

Some evaluation frameworks and resources relative to care coordination and worthy of note were:

- The Donabedian Model (1966). This model of effectiveness measures were designed by Donabedian. The model suggests four levels of assessment for quality of care in health organisations: structural, process, outcome, and attitudinal. <http://www.jstor.org/pss/3348969>
- The Care Coordination Measurement Atlas Framework 2010 [<http://www.ahrq.gov/qual/careatlas/careatlas.pdf>]
- The Care Coordination Measures Atlas Appendix (Tools and Instruments) [<http://www.ahrq.gov/qual/careatlas/careap4.pdf>]
- National Quality Forum Endorsed Framework for Measuring Care Coordination 2006 Preferred Practices and Performance Measures for Measuring and Reporting Care Coordination: A CONSENSUS REPORT [Abridged report only], [http://www.qualityforum.org/Publications/2010/10/Preferred\\_Practices\\_and\\_Performance\\_Measures\\_for\\_Measuring\\_and\\_Reporting\\_Care\\_Coordination.aspx](http://www.qualityforum.org/Publications/2010/10/Preferred_Practices_and_Performance_Measures_for_Measuring_and_Reporting_Care_Coordination.aspx)]

Recommended readings provided were:

- Journal of the National Cancer Institute Monographs Vol 40 2010 “Toward Improving the Quality of Cancer Care: Addressing the Interfaces of Primary and Oncology-Related Subspecialty Care”. Closing the Quality Gap: A Critical Analysis of Quality Improvement Strategies Volume 7—Care Coordination. [<http://www.ncbi.nlm.nih.gov/books/NBK44015/pdf/TOC.pdf>]
- Coordination of Care: Missed Opportunity? This is a collection of brain storming sessions which presents an Americanised view of what care coordination is, including terms such as navigation and medical home. The 2007 ABIM Foundation Summer Forum Illustrated [Slides; USA focused; font may be a bit hard to read; [http://www.abimfoundation.org/~media/care\\_coordination.ashx](http://www.abimfoundation.org/~media/care_coordination.ashx)]

### Summary of Search Findings

The main findings from the literature search to date were outlined by Professor Yates. She noted that many tools used in measuring outcomes relate to a narrow definition of the cancer care coordination and do not reflect the broader concept of cancer care coordination. Very few of the studies looked at are using clear framework or provide a rationale for selection of measures. Overall, there are limitations to the quality of the work currently available.

Key points of the AHRQ framework for evaluating care coordination interventions are that:

- it incorporates description of structure, a process and outcome measures
- it provides emphasises that selection of measures is dependent on context of care coordination.

Professor Yates proposed that COSA could play a role in providing background information and reference material so that Cancer Care Coordinators have guidance with respect to evaluation of their role in the context of the health team and health service more broadly. It was suggested that COSA could support cancer care coordinators by preparing a tool kit which can provide reference material to assist with key areas of work. The tool kit could consist of:

1. A framework to determine goals of any evaluation of their service, and how this fits with other evaluations of cancer care services more broadly
2. Examples of Patient Experience Tools or other measures that might be sensitive to care coordination interventions –
3. Principles around data types and what the difference types of data offer, highlighting the importance of context and environment and provide some types of resources
4. Guidance on how to analyse and interpret the data

There was consensus that any evaluations or surveys, such as a *patient experience tool* should be linked to standard quality improvements. Also, Cancer Care Coordinators need to understand the principles of research and what data sources are on offer.

### Principles for Evaluating Cancer Care Coordinator Interventions

The attendees contributed to outlining key components and skills of the cancer care coordinator role alongside potential factors influencing an effective evaluation process for these roles.

| Cancer Care Coordination Role & Skills  | Environmental Influences & Enablers  |
|---|--|
| <ul style="list-style-type: none"> <li>- Patient and family centred</li> <li>- Capacity to Screen</li> <li>- Needs assessment</li> <li>- Patient planning</li> <li>- Needs based</li> <li>- Reflects equity</li> <li>- Effective and efficient</li> <li>- Contributes to service improvement</li> <li>- Provide synchronisation '<i>right person at right time</i>'</li> <li>- Networking</li> <li>- Signposting</li> </ul> | <ul style="list-style-type: none"> <li>- Executive buy in</li> <li>- Team role in evaluation</li> <li>- Strategic approach</li> <li>- Shared sense of what it is about</li> <li>- Reflects contemporary environment</li> <li>- Focuses on achievable /practical/useful</li> <li>- Makes reference to existing models &amp; frameworks</li> <li>- Considers range of perspectives</li> <li>- Considers purpose and timing of interventions</li> <li>- Understands what is being asked of care coordinator and the contribution they make</li> <li>- Understand what is the correct tool (different tools have different purposes)</li> <li>- Understanding of the care coordinator place in the system</li> <li>- Links with service model</li> <li>- Identifies gaps and risks</li> <li>- Use for continuous improvements in practice and system</li> <li>- Understands impact of measurements</li> <li>- Considers efficiency – best use of skills</li> <li>- Understands positioning in the wider system</li> <li>- Considers what care coordinators influence and attribute to</li> </ul> |

**Next Steps**

Professor Yates concluded the meeting by thanking participants for their input. She said there will be further work to refine the literature review and build on a program of work. There will be a widening of the search to include other terms looking at studies on facets of care coordination such as navigation currently not described by their authors as care coordination. Professor Yates also spoke of future work in seeking research funds, such as, an Australian Research Council (ARC) grant or other funds to test some of the relevant identified tools.

## APPENDIX 1: MEETING AGENDA

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**COSA CANCER CARE COORDINATION  
OUTCOME MEASUREMENTS MEETING  
LOCATION: 1/120 CHALMERS STREET  
SURRY HILLS, SYDNEY**

**WEDNESDAY 20 JULY 10.00 AM - 3.00PM AEST**

| <b>Time</b>     | <b>Item</b>   | <b>Speaker</b>        |
|-----------------|---|-----------------------|
| 10:00am         | Welcome & Introduction                                  | Professor Patsy Yates |
| 10:15 am        | Literature Review: Key Themes                           | Anna Doubrovsky       |
| <b>11:00 am</b> | <b>Morning Tea</b>                                      |                       |
| 11:20 am        | Defining a Framework and Scope for Outcome Measurements | Open discussion       |
| 12:00 am        | Operationalising Outcome Measurements                   | Open discussion       |
| <b>1:00 pm</b>  | <b>Lunch</b>  |                       |
| 1:30 pm         | Future research and development opportunities           | Open discussion       |
| 2:30 pm         | Next steps  | Patsy Yates           |
| <b>3:00 pm</b>  | <b>Meeting Closure</b>                                  |                       |

## APPENDIX II: PARTICIPANT LIST

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| Name               | Position   | State            |
|--------------------|--|------------------|
| Sanchia Aranda     | Director Cancer Services & Information, Cancer Institute   | NSW              |
| Lillian Daly       | Project Manager, Cancer Institute  | NSW              |
| Tracey Doherty     | Clinical Practice Nursing Director - Cancer Services   | SA               |
| Anna Doubrovsky    | Project Officer, School of Nursing and Midwifery, Queensland University of Technology  | QLD              |
| Spiri Galektakis   | Program Manager, Victorian Integrated Cancer Services Cancer Strategy and Development  | VIC              |
| Renae Grundy       | Cancer Care Coordinator, Hobart  | TAS              |
| Sue Hadfield       | Director Cancer Control, Queensland Health   | QLD              |
| Sue Hausmann       | Assistant Director of Nursing, Cancer Services Princess Alexandra Hospital, Woolloongabba  | QLD              |
| Meinir Krishnasamy | Deputy Director of Cancer Nursing Research, Department of Nursing and Supportive Care Research, Peter MacCallum Cancer Centre, Melbourne         | VIC              |
| Leanne Monterosso  | Associate Professor Cancer Nursing, WA Centre for Cancer and Palliative Care, Faculty of Health Sciences, Curtin University of Technology, Perth | WA               |
| Violet Platt       | Director of Nursing, WA Cancer & Palliative Care Network<br>Adjunct Associate Professor- Curtin University                                       | WA               |
| Sue Sinclair       | General Manager, Service Delivery & Clinical Practice<br>Cancer Australia  | Cancer Australia |
| Maja van Bruggen   | Project Manager, CanNET, Department of Health  | NT               |
| Patsy Yates        | Director of Research, School of Nursing and Midwifery, Queensland University of Technology   | QLD              |