



**Clinical
Oncological
Society of
Australia**

Care Coordination Workshop Report

**Held at the 34th Annual Scientific Meeting of the
Clinical Oncological Society of Australia (COSA)
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BACKGROUND

Care of people with cancer is complex and multifaceted, involving a range of services and health professionals, often in different settings. In the absence of appropriate coordination of the different elements of care, patients and their families report becoming 'lost' in the system, often experiencing unnecessary morbidity and distress.¹ Lack of coordination between services can result in fragmented care, sub-optimal management and high health care costs.^{2,3} Such fragmentation of care is exacerbated by the absence of clear referral pathways and suboptimal communication between health care providers and between providers and patients.

The need to improve continuity of care has been highlighted in a number of national reports.^{1,4} The *National Service Improvement Framework for Cancer*⁴ identifies an optimal cancer service as one in which people with cancer '*will experience the cancer journey as seamless and continuous care provided by one integrated service*'. It notes that achieving such continuity of care requires linkages and coordination:

- among different treatment modalities
- among various health professionals and care providers
- among different individuals within the same discipline (eg medical or nursing staff on rosters)
- within any single service, over time
- across the spectrum of cancer care (from detection through treatment to palliative care), and
- across different services types and settings (public and private, inpatient and ambulant, general and specialist hospitals).⁴

Delivery of integrated and coordinated care is likely not only to enhance the patient's experience and minimise the likelihood of further distress, but may also contribute to improved clinical outcomes and efficiency in delivering health care services.

At a jurisdictional level, a range of approaches have been taken to the implementation of care coordination, including appointment of designated Care Coordinator roles and a broader system-based approach. Neither approach has yet been evaluated.

The Clinical Oncological Society of Australia (COSA) has identified cancer care coordination as a priority issue of concern to its members. In 2006, COSA convened a 1-day workshop to:

- define the problem of care coordination
- provide some context for exploring a range of strategies for achieving cancer care coordination at the system, organisational, team and individual levels
- review the evidence and experiences of using care coordinators as a means of achieving care coordination, from the perspective of consumers, care coordinators, health care teams and policy makers.

The workshop identified a range of issues relevant to cancer care coordination, with the importance of achieving a patient-centred rather than disease-centred focus the central theme. A set of Principles was developed to underpin care coordination in Australia at the patient, team and system level (see Appendix I). A report on the outcomes from the 2006 workshop has recently been published.⁵

WORKSHOP OVERVIEW

A 1-day workshop was convened by the Clinical Oncological Society of Australia (COSA) prior to the 2007 Annual Scientific Meeting in Adelaide. The aim of the workshop was to define expected outcomes from cancer care coordination and methods for evaluating those outcomes and potential benefits, including health outcomes and economic outcomes. The ultimate goal of the workshop was for participants to achieve a shared understanding of what can be achieved through coordination of cancer care rather than to identify strategies for the implementation of care coordination.

The workshop was attended by around 50 participants from a range of backgrounds with an interest in cancer care coordination. Attendees included health professionals (including cancer care coordinators), health service administrators, consumers and representatives from cancer and government organisations. In terms of their interest in care coordination, roles included those with a responsibility for undertaking cancer care coordination, those with a funding responsibility, those experiencing care coordination and those with an evaluation role.

WORKSHOP INTRODUCTION

Professor David Currow, CEO of Cancer Australia opened the workshop by emphasising the importance of care coordination in the management of patients with cancer in Australia, highlighting the complexities of Australia's unique geography and mix of public and private health service delivery. He stressed the importance of ensuring that the delivery of patient care is appropriate, timely, efficient and effective and that the process of navigation through the patient journey respects the challenge faced by those diagnosed.

Professor Patsy Yates presented an overview of outcomes from the 2006 workshop, and described the Principles for Care Coordination developed as a result of the workshop. She outlined the objectives for the 2007 workshop, acknowledging that achieving coordination of care is a multilevel issue and that a range of other strategies may also be relevant to its implementation, including development of role descriptions and education of health professionals.

In providing their opening comments, Professor Currow and Professor Yates made reference to other relevant initiatives, such as the Cancer Australia CanNETs project, which aims to map the pathway from suspicion of cancer to the development of a definitive treatment plan, and the Continuing Professional Development project for cancer professionals, which is funded by Cancer Australia and conducted by a consortium led by the Centre for Innovation in Professional Health Education and Research at the University of Sydney.

PANEL DISCUSSION

A short panel discussion was held to provide some context for the workshop. Joining Professor David Currow and Professor Patsy Yates on the panel was Professor Bruce Barraclough (Medical Director, Australian Cancer Network).

In outlining their views on care coordination, panel members agreed that the patient experience should be the focal point. Given that outcomes for many cancers in Australia are good by international standards, it is important to tease out what can or cannot be improved by better care coordination.

The panel discussed the importance of demonstrating both clinical and non-clinical outcomes from care coordination, recognising that there may be a number of intermediate points at which outcomes can be measured between the traditional 'checkpoints' of diagnosis and death. They concluded that improved patient satisfaction alone would not be sufficient to justify significant investment in improvements in coordination of care. However, it

was argued that other non-clinical outcomes that are important to patients may influence a patient's response to treatment and improve health service utilisation: for example improvements in the patient experience may in turn increase patient engagement, improve compliance and reduce downtime in health service utilisation. The importance of considering longer term impacts of care coordination as well as immediate effects was emphasised as was the need to clearly identify outcomes in order to engage the community about benefits beyond mortality. It was suggested that better care coordination may result in improvements in patient survival and morbidity by ensuring that patients are referred for the right care and treatments in a timely fashion.

While the aim of the workshop was not to discuss strategies for care coordination, the panel emphasised the importance of care coordination being seen as a shared responsibility across the entire health care team rather than being the role of one or two individuals. It was emphasised that care coordination is a system-based approach that relies on linkages across the health care system, including both public and private and tertiary and primary care.

BACKGROUND TO EVALUATION AND OUTCOMES

To provide some context for discussion of evaluation and outcomes, Dr Marian Haas, from the Centre for Health Economics and Research Evaluation at the University of Technology Sydney, gave a brief presentation outlining key issues for consideration.

In the context of health service delivery, Dr Haas described evaluation as being more than an audit – because it measures associated and causative factors – and less than research, which is about achieving knowledge for its own sake. However, she explained that the subject matter is the same in that evaluation measures the extent to which the delivery of health services meets pre-determined objectives.

Dr Haas highlighted four key features of evaluation:

- structure (the organisational framework)
- inputs (the resources used)
- process (the activities undertaken)
- outcomes (the impact and cost of activities).

Participants were encouraged when thinking about outcomes of care coordination to consider how they would know that care is coordinated at the patient, health service and system level. Examples were given to demonstrate what should be considered at each of these levels.

WORKSHOP OUTCOMES

Workshop outcomes were achieved through small multidisciplinary group discussion, followed by facilitated feedback and refinement at a plenary level. Time limitations precluded a full consensus approach and the outcomes reported summarise areas of convergence within the group.

Participants were asked to consider issues at a national level using three main frames of reference:

1. people who make investment decisions – funders/system level
2. people who provide care – health services/teams/networks
3. people who receive care – cancer patients/consumers.

OUTCOMES FROM COORDINATED CARE

Participants identified the outcomes they would expect to see at a patient, service network and investor level within 12–18 months of implementation of a coordinated approach to cancer care. There was some overlap in proposed outcomes for the three levels.

In considering outcomes, two essential components of care coordination were identified, namely the need for:

1. clearly defined patient care pathways
2. management of care through effective multidisciplinary teams.

Participants agreed that these components should be in place across the whole system, regardless of geography, social or cultural differences and whether care is delivered in the public or private sector. While the workshop did not consider individual strategies for achieving care coordination, in defining these outcomes, participants recognised the need to consider potential workforce and resource implications of the approaches listed.

Patient level outcomes

Outcome	Detail
1. Every patient is aware of their pathway of care	<p>Every patient, irrespective of demographics and health service delivery setting:</p> <ul style="list-style-type: none"> • knows what will happen to him/her from the point at which symptoms are reported/detected • can identify a key point of contact at each stage in the journey • is provided with consistent information throughout their journey. <p>As a result, patients will have increased confidence in the system.</p>
2. The time from diagnosis to treatment is appropriate	The timing of treatment is efficient, appropriate and takes account of patient preferences.
3. The patient experience is positive	Every patient feels valued, in control and respected.

Service network outcomes

Outcome	Detail
4. A clear pathway is defined for each patient, and information moves with the patient through the system	Key elements in the pathway include: <ul style="list-style-type: none"> • structured interdisciplinary communication • an evidence-based approach.
5. There is an effective multidisciplinary team relevant for each cancer	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. Team membership may vary according to the stage in the patient journey. It was noted that membership of an effective team may lead to improved satisfaction for participating health professionals.
6. Transfer points are well managed across networks and sectors	The process for transfer of care at each stage of the patient journey is clear and well managed. Key elements include: <ul style="list-style-type: none"> • knowledge by health professionals of relevant contacts at primary and tertiary levels • provision of relevant information at the point of transfer • clear definition of entry and exit points to the pathway.

Funder outcomes

Outcome	Detail
7. 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.
8. Patients receive appropriate treatment	Improvements in treatment will include: <ul style="list-style-type: none"> • improvements in time to treatment in line with recognised benchmarks (taking account of patient preferences) • reduced variation in treatment.*
9. Knowledge of and access to services, especially primary care, is improved	
10. Variation and duplication of service provision is reduced*	

*It was noted that reduced variation in treatment does not automatically lead to cost savings, given that the system currently involves a mix of under- and overuse of treatment and the extent to which these balance each other out is not known.

Participants also identified the importance for funders of evidence of sustainability. However, it was agreed that this would not necessarily be an outcome of coordinated care, rather a requirement of strategies to implement coordinated care.

MEASURES FOR ASSESSING THE EFFECTIVENESS OF COORDINATED CANCER CARE

The outcomes identified at each level were grouped according to common themes. Participants were asked to consider each outcome and to identify what measures could be used to show that progress towards these outcomes was being made. The outcomes, measures and suggested tools for measuring progress are provided below. The measures do not represent performance indicators, but rather point to broad dimensions that could be used to show whether an outcome is being achieved.

Outcome	Measures	Tool
1. Clear referral pathways are in place for patients irrespective of location or service delivery setting	<ul style="list-style-type: none"> Existence of a documented referral pathway for each patient 	<ul style="list-style-type: none"> Audit of patient records Assessment of compliance of treatment with protocols
2. Transfer points are well managed across networks and sectors	<ul style="list-style-type: none"> Frequency of involvement of primary care and the patient in decisions at key transfer points Proportion of patients who report that transfer has been smooth Proportion of patients who have a patient-held record 	<ul style="list-style-type: none"> Survey of levels of involvement of the GP and patient Patient survey data
3. Patients receive appropriate treatment	<ul style="list-style-type: none"> Proportion of patients for whom care is planned by a multidisciplinary team based on current standards 	<ul style="list-style-type: none"> Audit of patient records Analysis of situations where care is not aligned with evidence of best practice Quality of life tools
4. The patient experience is positive	<ul style="list-style-type: none"> Proportion of patients who report being involved in decisions about their care Frequency of repetition by patients of their medical history to different service providers Level of consumer involvement in service planning and education for health professionals (indirect measure) 	<ul style="list-style-type: none"> Patient surveys about their experience Documentation of patient preferences Analysis of complaints
5. Patients have access to multidisciplinary care	<ul style="list-style-type: none"> Proportion of newly diagnosed patients who are referred to and discussed by a multidisciplinary team for prospective treatment planning Number of protocols that exist about referral to multidisciplinary teams 	<ul style="list-style-type: none"> National Breast Cancer Centre Indicators of Multidisciplinary Care and Audit tool ACHS MDT indicator
6. Multidisciplinary teams function effectively (and practitioner perspectives are positive)	<ul style="list-style-type: none"> Proportion of multidisciplinary meetings that are attended by appropriate health professionals Evidence that the documented treatment plan is actioned 	<ul style="list-style-type: none"> Multidisciplinary meeting attendance log Growth/sustainability of teams Audit of case notes

NEXT STEPS

The workshop identified a range of outcomes and measures that could be used to show whether care coordination is being achieved. The outcomes from this one-day workshop were developed through a consultative process, rather than through a comprehensive analysis of available evidence in this field. The outcomes and measures identified during this workshop provide a useful starting point to guide those with an interest in improving care coordination. They require ongoing refinement and validation.

A number of actions were agreed, some requiring action at a service level, others requiring national input, and some requiring coordination at a jurisdictional level.

1. At a **service level**, it will be important for health professionals to determine relevant referral pathways to guide how patient care will be provided. Existing frameworks, such as the Victorian Patient Management Frameworks, and examples of pathways developed by individual teams will be helpful in guiding discussions.
2. At a **patient level**, it will be important to increase awareness by patients and the broader community of the critical nature of multidisciplinary care in the management of cancer.
3. At a **national level**, it will be important to determine the key elements of cancer care coordination and to develop clear outcomes and indicators that can be adopted across jurisdictions. Decisions about what roles are important in implementing cancer care coordination should be taken at a **jurisdictional level**.

Attendees requested ongoing forums to facilitate sharing of knowledge and information about what is and is not working effectively and about what is happening at a policy level to inform care coordination.

ACKNOWLEDGEMENTS

The workshop was sponsored by Cancer Australia and The Cancer Council Australia. COSA gratefully acknowledges the input and support of the workshop facilitator, Lynette Glendinning from PALM Consulting and the Chair of the workshop committee, Professor Patsy Yates. Thanks also to Dr Madeline King and Dr Marion Haas for their input to the workshop presentations.

REFERENCES

1. National Cancer Control Initiative. Optimising Cancer Care in Australia. Melbourne: NCCI, 2002.
2. Williams P, Rankin N, Redman S. National survey of women with breast cancer: their perceptions of care. Sydney: National Breast Cancer Centre, 2001.
3. National Cancer Strategies Group. Priorities for action in cancer control 2001-2003. Canberra: Department of Health and Ageing, 2001.
4. National Health Priority Action Council. National Service Improvement Framework for Cancer. 2004.
5. Yates P. Achieving Coordinated Cancer Care: Report on the Clinical Oncological Society of Australia Care Coordination Workshop. Cancer Forum, 2007; 31(3): 169–172.

APPENDIX I: PRINCIPLES FOR CANCER CARE COORDINATION

Patient Focus

Care co-ordination should:

- be patient, carer and family-centred
- be a key focus across the entire cancer journey
- enable patient choice (to not receive care co-ordination)
- emphasise patient empowerment
- improve patient access to services
- address equity of access
- improve care outcomes.

Team Focus

Care co-ordination takes a **multidisciplinary team** approach and is inclusive of medical and allied health professions as well as management and administrative staff. Care co-ordination:

- focuses across the continuum of care
- is a shared responsibility, and is not solely the responsibility of an individual co-ordinator
- relies on the sharing of information and knowledge.

Systematic Approach

Care co-ordination should:

- be evidence-based
- be sustainable and supported
- take a system-based approach
- be capable of use across different platforms, including public and private systems, metropolitan and rural and remote geographical settings and various care setting
- be built on a sound and robust evaluation framework.

APPENDIX II: LIST OF ATTENDEES

Name	Affiliation
Ms Kristin Linke	Cancer Clinical Network, Royal Adelaide Hospital
Mr Ray Araullo	Social Worker, Cancer Services, Royal North Shore Hospital
Professor Bruce Barraclough	Medical Director, Australian Cancer Network
Mr Douglas Bellamy	Area Cancer Care Coordinator, NSW
Ms Sharon Bowering	Cancer Care Coordinator AYA, Children's Youth & Women's Health Service, SA
Dr Stephen Byrne	GP, Goolwa Medical Centre, SA
Ms Philippa Cahill	Manager Clinical Workforce, The Cancer Institute NSW
Ms Sandy Cleghorn	Paediatric Care Coordinator, Department of Health SA
Ms Shoni Colquist	Manager, Queensland Cancer Control Analysis Team
Ms Angela Cotroneo	President, Oncology Social Work Australia (OSWA)
Professor David Currow	CEO, Cancer Australia
Ms Tracey Doherty	Oncology Nurse Practitioner, Flinders Medical Centre
Ms Cecilly Dollman	Royal Adelaide Hospital
Ms Maeve Downes	Nurse Unit Manager, Paediatric Haematology/Oncology, Children's Youth & Women's Health Service, SA
Ms Mary Duffy	Peter MacCallum Cancer Centre
Ms Jacinta Elks	Cancer Care Coordinator, Sunshine Coast Health Service District
Ms Rita Evans	National Manager, Cancer Australia
Ms Kate Fernandez	Cancer Care Coordinator, Central Nervous System Tumours, Women's and Children's Hospital, CYWHS, SA
Dr Linda Foreman	GP, Chandlers Hill Surgery SA
Ms Spiri Galetakis	Acting Director, Integrated Cancer Services, Department Human Services Victoria
Ms Alanna Geary	Nursing Director Cancer Care Services, Royal Brisbane and Women's Hospital
Ms Phillipa Hartney	Program Manager, Bendigo Regional Breastsreen
Ms Lauren Holland	Network Development Manager, Cancer Clinical Network, Department of Health, SA
Ms Beth Ivimey	Cancer Care Coordinator, Cancer Care Centre, Prince of Wales Hospital
Ms Lena Leone	Cancer Support Programs, The Cancer Council South Australia
Ms Alison Love	Cancer Care Coordinator
Ms Mirela Mathews	Project Officer, North Eastern Metropolitan Integrated Cancer Service (NEMICS)
Mr Adam Monkhouse	Clinical Service Planning, Cancer Clinical Network, SA
Ms Caroline Nehill	Program Manager, National Breast Cancer Centre
Professor Ian Olver	CEO, The Cancer Council Australia

Ms Megan Plaster	AYA Cancer Care Coordinator, WA Cancer & Palliative Care Network
Ms Violet Platt	Director of Nursing, WA Cancer & Palliative Care Network
Ms Sharon Reinbrecht	Rural Cancer Care Coordinator, Southern Adelaide Health Service
Ms Nicole Robert	Cancer Support Nurse, Royal Darwin Hospital
Dr Ian Roos	Chair, Cancer Voices Victoria
Ms Margaret Ryan	Coordinator Cancer Support Programs, The Cancer Council South Australia
Ms Gayle Salkield	Director of Nursing Cancer Services, Southern Area Health Service
A/Prof Tim Shaw	Director, Program Development, Centre for Innovation in Professional Health Education and Research, University of Sydney
Ms Heather Shepherd	PhD Candidate/Research Nurse, Medical Psychology Research Unit University of Sydney
Ms Helen Smith	Director of Cancer Services, The Cancer Council Northern Territory
Professor Bernard Stewart	Director of Cancer Services, South Eastern Sydney and Illawarra Area Health Service, NSW
Ms Maggie Stowers	Cancer Coordination Manager, Barwon South Western Regional Integrated Cancer Service (BSWRICS)
Ms Pauline Tanner	Cancer Care Coordinator (Gynaecology), WA Cancer & Palliative Care Network
Ms Celia Taylor	Director, The Cancer Council Tasmania
Ms Janet Thoseby	Cancer Nurse Coordinator, Gosford Hospital
Ms Dagmar Voss	Cancer Care Coordinator, Wagga Wagga Community Health, Greater Southern Area Health Service, NSW
Dr Pauline Wachtel	GP, The Medical Clinic Millicent
Ms Liz Wilson	Nursing Director, Medicine, Nambour Hospital
A/Prof Marion Haas	Deputy Director, Centre for Health Economics Research & Evaluation (CHERE), University of Technology Sydney
Professor Patsy Yates	Director of Research, School of Nursing, Queensland University of Technology
Ms Lynette Glendinning	Workshop Facilitator, PALM Consulting
Dr Alison Evans	Report author, Alison Evans Consulting