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1. BACKGROUND AND PURPOSE

The Clinical Oncological Society of Australia convened a workshop to consider the experiences to date in care coordination and identify key learnings and opportunities and directions for future implementation of care coordination. Workshop participants included key stakeholders with responsibility, experience and expertise in care coordination at the national, state and territory and local level. A list of participants is included as an attachment.

This report provides a summary of the outcomes of this discussion and was prepared by Douglas Smith of PALM Consulting Group, the workshop facilitator.

2. CONTEXT

Professor David Currow, CEO, Cancer Australia, introduced the workshop, suggesting that the key task for the day should be to define the problem and gaps that need to be addressed. This problem definition was needed to enable further consideration of the range of strategies that may be needed to address the gaps and deficits. Professor Currow noted that it was important to ensure that discussions about care coordination be centred around the person with cancer, rather than being provider focused.

The following presentations were provided to set the context for the Workshop:

- Dr Ian Roos – Consumer experiences and expectations of care coordination
  Dr Roos shared a number of examples of gaps and problems that he and fellow consumers had experienced with care coordination. Dr Roos’ key messages centred around the importance of care coordination from the consumer’s perspective. Some examples of consumer focused strategies may include improved access to medical records, sharing of information between the various health professionals and between health care settings involved in a patient’s care, and between health professionals and patients, and the involvement of all persons affected by the cancer in care processes. He emphasised the importance of systems re-design to achieve care coordination, and the risks associated with investing coordination responsibilities with one person.

- Professor Patsy Yates – Review of the literature on the care coordination role.
  Professor Yates provided a review of the literature which emphasised that strategies for achieving care coordination can be identified at a system, organisational, team and individual level. She provided examples from the literature of selected strategies within each of these levels. Professor Yates also reviewed some recent studies on case management roles for people with cancer which had reported improvements in continuity of care and a range of other clinical and psychosocial outcomes for people with cancer. She noted that the models tested in these existing studies involved highly specialised roles and intensive interventions, and that the effectiveness of such approaches in day to day clinical practice had not been tested.

Copies of the Powerpoint presentations are available separately.
3. NATIONAL, STATE AND TERRITORY INITIATIVES

Key issues, challenges and learnings from initiatives undertaken at the national, state and territory level were identified through a panel discussion. Panellists included:

- Dr Alison Evans, National Breast Cancer Centre (NBCC)
- Ms Phillipa Cahill, Cancer Institute NSW
- Ms Elise Davies, Metropolitan Health and Aged Care Services Division Department of Human Services, Victoria
- Ms Violet Platt, Western Australia Cancer and Palliative Care Network, WA Department of Health.

MODELS OF CARE COORDINATION

Jurisdictions had taken a variety of approaches of care coordination. NBCC initiatives focussed on improving communication and coordination, particularly by strengthening linkages between tertiary and community care and progressed demonstration projects on the role of the specialist breast nurse and the multidisciplinary care team.

In Victoria, the approach recognised that care coordination is the responsibility of the whole system and the multidisciplinary team. Initiatives focussed on the system level initiatives including structure (integrated cancer services), local collaboratives around a tumour stream model, patient management frameworks and a quality framework.

In Western Australia, the focus of work will be on system redesign, particularly the creation of speciality services and collaboratives and on the establishment of cancer nurse coordinators (10 metropolitan tumour specific and 10 regional) who will complement existing services.

NSW initiatives also focus on structure, including the appointment of Directors of Cancer in Area Health Services (AHSs) and 55 cancer nurse coordinators. Key elements of the nurse coordinator role included a focus on patient needs, psychosocial screening and referral, patient education and information provision, and support for the multidisciplinary team. The development of performance indicators and evaluation of care coordinator roles are underway. Other coordination strategies included the establishment of clinical networks/collaborative groups, support for multidisciplinary teams, and the development of standardised protocols.

KEY LEARNINGS

From the experience this far, key learnings include:

- the importance of building relationships
- not investing the role in the one position
- flexibility in the use and application of models and using a variety of strategies.

MEASURING SUCCESS

The direct benefits and outcomes of care c-ordination can be demonstrated by measures such as:

- patient views of their experience / satisfaction with the service
- team views of their team functioning
- measurable improvements in service delivery
- utilisation of treatment protocols
- evidence of coordination within and across the system
- evidence of continuity of care.

UNEXPECTED BENEFITS
The implementation of care coordination was seen as an important catalyst in changing practitioner views and mindsets about multidisciplinary care teams, forcing practitioners to think outside their traditional role boundaries and ways of practice.

RISKS
It was acknowledged, however, that there were risks, including the potential for deskilling where the care coordination role was invested in the one person. Other risks included the blurring of professional boundaries, limited capacity for care coordination (recruitment, retention and development), barriers to information sharing, particularly with GPs, lack of flexibility and capacity to respond to local contexts and needs and failing to meet the needs of target populations.

OPPORTUNITIES
Key opportunities to utilise in implementing care coordination include:
- supporting care coordination in the community and strengthening linkages with and the role of GPs
- focussing the effort in care coordination in addressing the gaps in coordination at the system level (building linkages)
- building care coordination functions of the team
- adopting multiple approaches
- strengthening consumers’ capacity to manage the coordination of their care, for example through establishing support groups in the community
- where care coordination roles are established, developing effective systems and service models to support the coordination role, including professional development, career pathways and succession planning.

DIRECTIONS FOR THE FUTURE
Panellists agreed that care coordination was not a single solution or one that could be pursued in isolation of broader system solutions. In fact, care coordination had been shown to be a catalyst to system-wide rethinking and change. Nevertheless, there will be resistance from practitioners and sufficient focus needs to be placed on change management issues, particularly engaging with practitioners and building relationships.

Care coordination also brings professional roles and role boundaries into sharper focus, and the implementation of care coordination will need to be supported by clear role definition.

Current discussions also tend to be provider focused. Less attention is given to the role of the person with cancer themselves and what they may require to effectively engage with the health care system to achieve coordinated care.
4. LOCAL SERVICE DELIVERY MODELS

Individual presentations of initiatives at the local level were provided by:

- Mr Lindsay French, Border Cancer Care, Wodonga Victoria
- Ms Karen Eaton, Prince of Wales Hospital, NSW

The presenters provided an outline of their service delivery model and discussed key learnings, which are recorded in their Powerpoint presentations and which are available separately.

In plenary discussion, participants highlighted a number of key issues / observations which emerged from consideration of these models, including:

- the **demanding** nature of the role of the care coordinator in terms of:
  - large number of functions
  - interactions across the whole team
  - little or no coverage or backup of the position
  - potential for burnout in the role
- the need for strong **support** for the role, particularly in terms of:
  - management support
  - clinical supervision
- the importance of linking in with **GP services**
- addressing the issue of **discharge planning** for patients without GPs.
5. IMPROVING CARE COORDINATION

Table groups were tasked with identifying the key principles which should inform the approach to care coordination and the gaps and opportunities which should be pursued in implementation.

5.1 PRINCIPLES
The suggested principles relate to the following three themes:

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

TEAM FOCUS
Care coordination takes a multidisciplinary team approach and is inclusive of medical and allied health professions as well as management and administrative staff. Care coordination:
- focuses across the continuum of care
- is a shared responsibility, and is not solely the responsibility of an individual coordinator
- relies on the sharing of information and knowledge.

SYSTEMATIC APPROACH
Care coordination 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 settings
- be built on a sound and robust evaluation framework
5.2 KEY GAPS AND OPPORTUNITIES IN CARE COORDINATION

The key gaps and opportunities identified include:

- **address funding** and resourcing issues, including:
  - development and utilisation of new funding models, including optimising the use of MBS items to support care coordination
  - addressing the impact of financial implication on patient decisions

- **build patient empowerment** through:
  - patient held records or electronic records, including patient care pathways
  - improved communication
  - support with transition
  - support with self-management of coordination
  - provision of service directories

- **improve communication** with primary care providers by improving:
  - access to information including treatment plans
  - discharge planning
  - barriers resulting from professional boundaries between GPS and other specialists (for example by enabling GPs to deliver chemotherapy)
  - utilisation of practice nurses

- **build sustainability** in care coordination, through:
  - workforce and career development and succession planning
  - professional development
  - management support
  - mentoring and coaching
  - clinical supervision

- **standardise care** by:
  - defining outcomes, standards and indicators
  - using structured referral pathways
  - measuring achievement against milestones

- **address rural and remote** issues.
6. SUMMARY

Associate Professor Rosemary Knight presented a summary of the workshop discussion. She noted that the workshop comes at a time when there is much to celebrate about cancer control in Australia - the last ten years have seen the establishment of a world class cancer system which is now focussed on system improvement and on addressing the needs of disadvantaged groups. Multidisciplinary care is now established as best practice and the present challenge is to improve coordination of care (rather than care coordination).

The present and future challenges resulting from the increased burden of cancer and the ageing workforce places pressure on the system which demands system improvement and a focus on coordination by the whole care team.

The workshop identified the need for clear definition of roles and the use of multiple and flexible approaches to address local needs and contexts. The roles discussed at the workshop focussed on both the needs of the team and the patient and ranged from educator through to navigator and advocate.

The workshop also identified the need to set clear boundaries around the scope of the role (clarify what care coordination is not), to build sustainability into coordination strategies and ensure the strategies are well integrated into the team and the community.

It will be important to set clear measures evaluating care coordination strategies, ensuring that these are focussed on the patient experience.

In terms of implementation, two success factors are clear – building relationships and identifying and focusing on outcomes. The directions identified at the workshop include:

- defining care coordination needs from the perspective of patients, providers and the health care system
- documenting successful models and solutions at the system, organisational, team and individual health professional level
- analysing gaps
- scaling up the implementation
- developing flexible and locally tailored solutions.

Ultimately, if we more effectively support patients to self manage (for example through the use of patient held records to support this) this will create efficiencies.
## 7. ATTACHMENTS

### 7.1 LIST OF PARTICIPANTS

<table>
<thead>
<tr>
<th>Name</th>
<th>Organisation</th>
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<tbody>
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