

*Evaluation of the role of*

# CANCER CARE COORDINATOR

November 2011

## *Summary report*



Cancer Institute NSW  
Australian Technology Park  
Level 9, 8 Central Avenue  
Eveleigh NSW 2015  
PO Box 41  
Alexandria NSW 1435  
Telephone (02) 8374 5600  
Facsimile (02) 8374 3600  
Email [information@cancerinstitute.org.au](mailto:information@cancerinstitute.org.au)  
Website [www.cancerinstitute.org.au/publications](http://www.cancerinstitute.org.au/publications)

State Health Publication Number (SHPN): (CI) 110270  
ISBN: 978-1-74187-744-1

Published by the Cancer Institute NSW, November 2011.

© Cancer Institute NSW 2011.

This work is copyright. It may be reproduced freely for personal, educational or government purposes subject to the inclusion of acknowledgement of the source. It may not be reproduced for commercial usage or sale. Reproduction for purposes other than those indicated above requires written permission from the Cancer Institute NSW.

## Contents

Background-----	4
Evaluation methodology-----	5
Cancer care coordinator evaluation findings-----	6
Findings of the literature review -----	6
Implementation of the Cancer Services Infrastructure Support Program cancer care coordinator model -----	6
Fostering an area-wide approach to optimising cancer care-----	8
Providing patient-centred care -----	9
Coordinating patient care and providing access to appropriate services-----	12
Supporting multidisciplinary care-----	14
Commitment to continuing professional development-----	16
Acting as an information and education resource -----	17
Different experiences for patients with access to a cancer care coordinator-----	19
Findings about the service model and future support of cancer care coordinators -----	20
Conclusion -----	21
Abbreviations and acronyms -----	22
References-----	23

## Background

The cancer patient's journey may involve many health professionals in different treatment facilities across widespread locations. Patients and carers often need an experienced clinician to coordinate their care, to help them navigate health services, and to provide a single point of contact for information and support. The role of the cancer care coordinator is designed to help fulfill this need.

The Cancer Institute NSW (Cancer Institute) has provided funding for cancer nurse coordinator positions since 2004–2005. For the purpose of this paper, they are referred to as cancer care coordinators. Currently, approximately 50 full-time equivalent cancer care coordinator positions statewide are funded under the Cancer Services Infrastructure Support Program (CSISP), which was called the Clinical Enhancement Program until 2007.

The CSISP is part of the broader 'Better Coordination of Specialised Cancer Care Program', which arose from the *NSW Cancer Plan 2007–2010*.<sup>1</sup> The CSISP aims to provide the basic structure to develop integrated cancer services in future years, through funding key positions across the former Area Health Services (AHSs). The six types of positions are:

- cancer care coordinators
- directors/managers of area cancer services (DACs)
- cancer services development managers (CSDMs)
- lead clinicians
- psycho-oncology staff
- cancer genetics staff.

The aim of each position is to make improvements in at least three of four key areas: clinical leadership, coordination of care, multidisciplinary care, and patient-centred care.

Since 2004–2005, 42 per cent of funding under this program has been expended on cancer care coordinator positions, a greater percentage than on any other position. The cancer care coordinator positions aim to increase access to care coordination for cancer patients in NSW and to develop a model of care coordination that will have an impact across all cancer services.

## The role of a cancer care coordinator

The cancer care coordinator position was originally described in 2005 and updated in 2007. In the 2007 position description, the cancer care coordinator's key roles and responsibilities were aligned with the *NSW Clinical Services Framework for Optimising Cancer Care*<sup>2</sup> and the *NSW Cancer Plan 2007–2010*.<sup>1</sup> They are:

- fostering an area-wide approach to optimising cancer care
- providing patient-centred care
- coordinating patient care and provide access to appropriate services
- supporting multidisciplinary care
- demonstrating a commitment to continuing professional development
- acting as an information and education resource.

The role of the cancer care coordinator varies according to the area in which they are employed, the tumour type (or types) of their patients, and the complexity of their patients' care needs. Metropolitan cancer care coordinators are primarily based at a single institution, and coordinate the care of patients of one tumour type or treatment modality. Rural cancer care coordinators may be community based and generally work across multiple tumour types or treatment modalities. Their patients may receive parts of their treatment outside the area in which they reside.

Cancer care coordinators are employed at the level of a clinical nurse consultant — level 2. They require at least five years relevant nursing experience, with at least three years full-time equivalent experience in the relevant cancer area.

## Evaluation methodology

The objective of the evaluation was to thoroughly investigate the role of the cancer care coordinator, the operation of the model and the outcomes of care coordination. It was undertaken between February 2009 and October 2010 as part of an overall evaluation of the CSISP. The Cancer Institute engaged HealthConsult Pty Ltd to conduct the evaluation.

The project scope required that the evaluation include patients from both metropolitan and rural sectors and identify any differences in the coordination of care between these groups.

The evaluation had to rely on qualitative information as limited, if any, quantitative data have been collected since the inception of the cancer care coordinator positions. With the exception of the patient interviews and patient perception survey, the data generated were also used to support the overall evaluation of the CSISP. Ethics approval was granted by the Population and Health Services Research Ethics Committee, and site specific assessments (SSA) approval was granted from each hospital at the case study sites.

The evaluation framework was based on the key result areas of the cancer care coordinator position description. Data were gathered using the following methods:

- consultation with key Cancer Institute staff
- review of program documentation describing the development of the CSISP
- a literature review of evaluations of other cancer care coordinator roles, in Australia and internationally
- a survey of all CSISP position incumbents to assess each position against the four key goal areas: clinical leadership, care coordination, multidisciplinary care and patient-centred care (110 surveys were received from 132 funded position incumbents, including 50 from 58 cancer care coordinator position incumbents)
- eight service-level case studies (one in each AHS), including interviews and focus groups
- eight patient-level case studies (one in each AHS), including three patients interviews at each site, to give a total of 24 patient interviews
- a patient perception survey distributed at each patient-level case study site, asking patients whether they had access to a cancer care coordinator — either a cancer care coordinator or another person, such as a medical oncologist — and other aspects of their cancer experience (1,000 surveys were distributed).

The response rate for the patient perception survey was 26 per cent. This was considered a good result, particularly as not all the survey forms actually reached a patient. The response rate for the survey of CSISP position incumbents was 88 per cent after adjustment for vacant positions.

Unique to this evaluation was the collection, for comparative purposes, of qualitative data from clinicians and patients at cancer services where cancer care coordinator positions have been funded *and* where no cancer care coordinator positions have been funded. The results highlight differences in patients' cancer journeys depending on whether or not they had access to a cancer care coordinator.

These data were gathered at the eight patient-level case study sites: four metropolitan sites and four regional/rural sites. Within each group of four, two were sites with cancer care coordinators and two were sites without cancer care coordinators. The metropolitan sites were all specific to one tumour type.

## Limitations of the evaluation

The evaluation of the role of the cancer care coordinator is largely based on qualitative data. While this data helps us to better understand aspects of the role, there is limited evidence to demonstrate the benefits of the cancer care coordinator role in improving clinical cancer care and patient outcomes.

More research is needed to better understand how the cancer care coordinator role can best value-add to improving the quality of care, survival and quality of life of people living with cancer.

## Cancer care coordinator evaluation findings

### Findings of the literature review

The literature review on the role of the cancer care coordinator (or similar role) aimed to identify the findings of other evaluations as a basis for comparison with the evaluation of the cancer care coordinator role in NSW.

Both the Australian and international studies reviewed endorsed the role of care coordinators, highlighting their important role in navigating the patient through an increasingly complex system. International studies came from the United Kingdom, Canada, Jordan and the USA. Similar roles included: case manager, clinical coordinator, cancer support nurses, follow-up nurses, breast specialist, breast cancer coordinator, lead cancer nurse and patient navigator.<sup>3</sup>

Though named differently, the cancer care coordinator-like positions have similar functions: providing patient-centred care, navigating the patient journey, promoting a multidisciplinary approach and providing patient and clinicians with a central point of contact. Across all studies the cancer care coordinator was found to play a critical role in patient education and linking patients with support services, particularly psychosocial support services.

In Australian studies, patients with access to a care coordinator felt their care was well coordinated and felt well informed on their cancer diagnosis and treatment pathways. Health professionals also recognised the role of the care coordinator in managing the patient's care, providing education and linking patients to other services, particularly psychosocial support services.

Barriers to coordinated care were also similar across studies, particularly with regard to professional recognition of the care coordinator role and issues associated with coordinating the care of patients who live in rural areas. It was noted that without well-functioning multidisciplinary teams, the care coordinator generally finds it difficult to optimise patient care.

### Implementation of the CSISP cancer care coordinator model

Almost all CSISP funding for cancer care coordinators has been used to create new positions, thereby creating additional care coordination capacity in NSW. Almost all CSISP funded cancer care coordinator positions have been filled as a result of a competitive selection process. However, many cancer care coordinators commented on the lack of permanency of the position. They felt this uncertainty presented recruitment and retention issues.

The number of cancer care coordinator positions in each AHS varies (Table 1). Funding was allocated according to population weighted by cancer incidence rates. The AHSs were responsible for the allocation of funding to tumour streams and facilities. One cancer care coordinator position in the Hunter New England Area Health Service (HNEAHS) is employed as an area cancer care coordinator. This role does not include clinical work, although the position does provide some leave relief.

Some AHSs employed mainly part-time cancer care coordinators; others employed all cancer care coordinators on a full-time basis. Cancer care coordinators reported a preference for funding full-time positions to make optimum use of the role. Part-time cancer care coordinators said patients 'were left to fend for themselves' on days they did not work, and if MDT meetings fell on those days it made it difficult for them to do their job.

Of the 50 cancer care coordinators that responded to the survey, 26 worked in tumour-specific roles (breast, lung, haematology, head and neck, gynaecology, upper GI, prostate, urological and palliative care). Eleven positions were spread across two or more tumour groups and 13 were general cancer care coordinators working in regional/rural areas. The model of having tumour-specific cancer care coordinators in metropolitan areas and general cancer care coordinators in regional/rural areas has worked well in terms of workload management for metropolitan cancer care coordinators, but has created service gaps for patients in streams without a cancer care coordinator.

Table 1: Cancer care coordinators by Area Health Service

AHS	Number of funded positions	FTE of funded positions	Number of survey respondents	% survey responses	FTE of respondents	Number working full-time	Number working part-time	Proportion working full-time
SESAHS	12	9.0	8	67%	7.6	7	1	88%
SWAHS	5	6.0	5	100%	5.0	5	0	100%
NSCCAHS	10	8.0	9	90%	6.5	3	6	33%
SSWAHS	8	8.0	6	75%	6.0	6	0	100%
HNEAHS	10	8.0	10	100%	8.0	6	4	60%
NCAHS	4	4.0	4	100%	4.0	4	0	100%
GSAHS	6	4.0	5	83%	3.2	2	3	40%
GWAHS	3	3.0	3	100%	3.0	3	0	100%
<b>Total</b>	<b>58</b>	<b>50</b>	<b>50</b>	<b>86%</b>	<b>43.3</b>	<b>36</b>	<b>14</b>	<b>72%</b>

Source: HealthConsult cancer care coordinator position incumbent survey 2009 (FTE=full-time equivalent)

The evaluation found that the more actively the person occupying the cancer care coordinator role promoted the role, the greater the integration into the cancer services structure. Factors contributing to the long time taken for the role to be embraced included confusion over the scope and definition of the role, and the level at which the position should be paid.

The majority of cancer care coordinator positions said they had multiple reporting lines. Single or dual reporting may be to the DACS, cancer services development manager (CSDM), DON, NUM or community nurse manager. At least one report was usually through the nursing structure, and most cancer care coordinators said they had a supportive and effective working relationship with the NUM/DON. Most cancer care coordinators reported little or no contact with the DACS.

Cancer care coordinators generally considered formal reporting through the nursing structure as appropriate, but felt they should also report to the head of the cancer service in which the cancer care coordinator position is based.

The cancer care coordinator's generic position description, as developed by the Cancer Institute, was found to be more relevant where it had been adapted to meet local needs. Some cancer care coordinators were using an AHS clinical nurse consultant position description, which they said was unrealistic due to the high patient workload. Part-time cancer care coordinators reported that they prioritised patient care and coordination over other roles and responsibilities (such as research), due to time constraints. The generic position description needs to be revised if a consistent position description for cancer care coordinators is desired.

Available data are not sufficiently robust to accurately determine the average number of new or ongoing patients cancer care coordinators see per month. However, survey data collected by the evaluation estimated that on average, cancer care coordinators see one new patient per day and have 10 patient contacts per day.

In general, metropolitan cancer care coordinators see a greater proportion of eligible patients attending their cancer service than regional/rural cancer care coordinators: cancer care coordinators in metropolitan AHSs reported seeing more than 80 per cent of the (tumour-specific) eligible patient population, while regional/rural cancer care coordinators saw 20 to 46 per cent of eligible patients (across tumour types). The difference is likely due to metropolitan cancer care coordinators having a smaller eligible patient population than regional/rural cancer care coordinators.

It is clear that although the CSISP has increased capacity in care coordination, there is still a substantial group of cancer patients that do not have access to a cancer care coordinator.

## Fostering an area-wide approach to optimising cancer care

According to the position description, the cancer care coordinator's role in fostering an area-wide approach requires that they:

- maintain professional linkages through the appropriate nurse manager or director of nursing within the AHS and collaborate with relevant lead clinician(s) and the DACS
- help in the integration of multidisciplinary patient focused care and the development of collaborative approaches to health service improvement
- develop linkages and networks with services operating in the private health and community settings
- develop linkages and networks with relevant clinical services and cancer health care professionals in other AHSs
- adopt a leadership role in developing care coordination across the area.

Overall, the evaluation found that the cancer care coordinator positions have developed as service delivery positions and their role in developing an area-wide approach to optimising cancer care has been driven by meeting their patients' needs.

The evaluators commented that the balance in a cancer care coordinator's workload between direct patient care and service development work needs to be carefully considered in any further refinement of the role.

### Professional linkages

Professional linkages between DACS and cancer care coordinators were limited, with most cancer care coordinators reporting little or no contact with the DACS. The DACS have tended not to involve cancer care coordinators in area-wide projects and strategies.

In general, cancer care coordinators' professional interactions tended to be patient and facility specific and centred on day-to-day service delivery rather than strategic issues. The most cited exception was the area cancer care coordinator position in the HNEAHS. This role is well integrated into the HNE Cancer Network and is linked to all 10 cancer care coordinators in the area.

### Linkages with other services

Most stakeholders said cancer care coordinators play an important role in developing links between public and private treatment settings. Most of these links have resulted from cancer care coordinators working with oncologists that work in both settings. Except for the Memorandum of Understanding between Royal North Shore Hospital and Royal North Shore Private Hospital, these links are not formalised. Barriers to formal interaction include lack of shared access to medical records.

Cancer care coordinators have invested considerable time in establishing good communication channels with community services such as BreastScreen, community nursing, cancer support groups and the Cancer Council.

Most cancer care coordinators have also actively promoted their services to general practitioners (GPs) using letters, brochures, calls and visits, but with less success. Cancer care coordinators who routinely sent letters updating GPs about their patients have begun to see an increase in GP referrals to their services. Some cancer care coordinators have established a pro forma for these updates, which are sent after each oncologist consultation and/or MDT meeting. GPs are thereby kept aware of the patient's treatment plan and wellbeing.

Cancer care coordinators in regional/rural areas have developed referral pathways with cancer care coordinators in the metropolitan hospitals to which their patients are generally referred. This allows patients to more easily access services such as accommodation and transport for out-of-area treatments.

### Leadership in care coordination across the area

Stakeholders held mixed views as to whether the cancer care coordinator is a leader in developing care coordination across the AHS. Most stakeholders believed cancer care coordinators have been instrumental in developing care coordination across the area for their patients. However, some felt the cancer care coordinator role is preoccupied with service delivery. Others said the geographic isolation of some cancer care coordinators makes it difficult for them to provide leadership.

Among cancer care coordinators, about 68 per cent reported having adopted a leadership role in care coordination. This varied from 25 per cent in some AHSs to 100 per cent in others. Many cancer care coordinators believed better understanding by health professionals of the cancer care coordinator role would enable them to be more effective leaders across the AHS.

Few cancer care coordinators have developed written protocols about the care coordination services they provide (for example, if lung cancer patient has x symptom refer to y service or z specialist), thereby making the success of the position person, rather than system, dependent.

Most cancer care coordinators have been involved in cancer service improvement initiatives at the facility level. However, cancer care coordinators have not generally been involved in such projects at the area level. This is largely due to the lack of interaction between the DACS and cancer care coordinators.

#### Enablers and barriers

The cancer care coordinators reported that the main enabler to providing an area-wide approach to optimising cancer care was support from cancer service clinicians. Other enablers included good telehealth support and eviQ. The main barrier identified by cancer care coordinators was time.

Other clinicians reported that some cancer care coordinators are restricted due to resistance from medical clinicians at other facilities. The lack of suitable governance arrangements also impedes the cancer care coordinators' ability to have an area-wide approach.

Suggestions to improve the cancer care coordinators' ability to have an area-wide approach included administrative assistance and an integrated IT system across the AHS.

#### Providing patient-centred care

According to the position description, the cancer care coordinator's role in providing patient-centred care requires that they:

- triage patients to determine areas of need and levels of assistance needed
- provide initial psychosocial triage and appropriate referral
- provide information and access to resources tailored to the patient's individual need
- provide education and support based on the patient's individual need in collaboration with the multidisciplinary team members
- contribute to optimal patient outcomes through enabling access to effective health care based on best available evidence and a full range of treatment modalities
- identify opportunities for patients to participate in clinical trials in collaboration with the multidisciplinary team members.

The evaluation found that cancer care coordinators have had a high impact on improving patient-centred care. Almost all CSISP position incumbents reported that cancer care coordinators have had a positive impact. Cancer care coordinators were seen to keep the patient as the main focus and to be aware of psychosocial issues that may affect the patient's treatment pathway. The uniqueness of their role is that they are able to interact with patients throughout the cancer journey.

#### Triaging patient access to cancer care coordinator services

Cancer care coordinators varied in their approach to triaging patients to determine which patients need access to their services. Fifty-four per cent of cancer care coordinators reported having established a common referral protocol. The results varied widely across AHSs, from 13 per cent through to 100 per cent.

Most cancer care coordinators said that for a triage process to be effective, it needs to ensure patients are assessed early in their cancer journey.

#### Psychosocial and needs assessment

Cancer care coordinator position incumbents reported that they were the clinicians primarily responsible for initial psychosocial distress screening in their cancer services. Where cancer care coordinators were supported by psycho-oncology support staff, a more streamlined screening process was in place.

Just over 50 per cent of cancer care coordinators said they had established a common psychosocial screening tool and 36 per cent had established a common patient needs assessment tool.

There were differences between metropolitan and regional/rural cancer care coordinators: 54 per cent of metropolitan cancer care coordinators reported using no specific psychosocial screening tool, whereas 68 per cent of regional/rural cancer care coordinators reported using the distress thermometer. Cancer care coordinators said the majority of metropolitan cancer services have piloted the distress thermometer, but found the test was too sensitive (it identified almost all patients as being in distress). Most cancer care coordinators see the value in using a standard tool to assess cancer patients in NSW, but many would argue the right tool has not yet been identified.

At the Calvary Mater Newcastle in Hunter New England Area Health Service (HNEAHS), cancer care coordinators reported using a computer based screening tool (QUICATOUCH) in the waiting room, which enabled screening and assessment of all patients.

The patient survey showed that patients with a cancer care coordinator or another health professional coordinating their care were more likely to have their support needs assessed (such as for transport and financial support services) once their cancer diagnosis was confirmed. It was apparent from the patient interviews that most patients were unaware of available services. Patients with no access to a cancer care coordinator were almost never referred to support services except if a chemotherapy nurse became involved.

#### Providing information and access to resources

The patient perception survey found that most patients are provided with information about their cancer, treatment options and side effects. However, if they did not have someone coordinating their care (either a cancer care coordinator or another health professional) they were less likely to receive the information at the time they needed it. Patient interviews showed that patients with a cancer care coordinator were more likely to have the information tailored to their specific needs and explained to them so they understood it.

Patients with access to a care coordinator were more satisfied their circumstances were considered to determine the level of support they needed (93 per cent of patients with a cancer care coordinator and 92 per cent with another health professional, compared to 59 per cent of patients who had no one person responsible for coordinating their care), and more satisfied their emotional needs were considered in planning their treatment (87 per cent and 89 per cent respectively, compared to 55 per cent of patients with no care coordinator).

Patients that had someone coordinating their care were also more satisfied that their family and significant others had the opportunity to be involved in their treatment and care. Eleven per cent of patients without a care coordinator strongly disagreed with the statement that family and significant others were involved in their treatment and care, compared to 2 per cent and 1 per cent of patients with a cancer care coordinator or another health professional coordinating their care respectively.

#### Communication between health professionals

Part of the cancer care coordinator role is to liaise with health professionals across different treatment and support areas in order to streamline their patient's cancer journey. Results from the patient survey suggested patients with someone coordinating their care were more satisfied that health professionals were working together and communicating their progress to their GP. These patients were also more satisfied with communication and information from the MDT meeting process than those that had no one person responsible for coordinating their care (more than 86 per cent of patients with a cancer care coordinator or other care coordinator, compared to 43 per cent of patients with no care coordinator).

#### Providing opportunities to participate in clinical trials

A relatively small proportion of patients seen by cancer care coordinators (1 to 25 per cent) were referred to participate in a clinical trial. Most cancer care coordinators said this was not a key focus of their role, and was more the role of the medical oncologist or other specialist. However, cancer care coordinators with a clinical trial coordinator working in the same facility reported liaising with them to determine trial availability for their patients.

There was some variation in the proportion of patients referred to clinical trials depending on the specialty of the cancer care coordinator (there was no difference between regional/rural and metropolitan cancer care coordinators). Breast cancer care coordinators reported referring the highest proportion of patients to clinical trials, with 40 per cent referring between 26 and 50 per cent of patients

#### Enablers and barriers

The cancer care coordinators reported the main enabler to improving patient-centred care was support from cancer service clinicians. The main barriers were lack of time, lack of psychosocial support services staff, lack of an appropriate physical space to consult privately with patients, and poor delineation of their roles.

Cancer care coordinators suggested that uniform tools to assist in screening and assessing their patients would improve their ability to provide patient-centred care. Clear criteria for when clinicians should refer patients to cancer care coordinators would provide more patients with access to cancer care coordinator services.

## Coordinating patient care and providing access to appropriate services

According to the position description, the cancer care coordinator's role in coordinating patient care and providing access to appropriate services requires that they:

- coordinate a patient caseload ensuring the continuity of care, the provision of information and support, and the transfer of patients between services within the AHS and external to the AHS when needed
- maintain communication and links with other members of the cancer care team, including allied health, and act as a communication conduit between the referring GP and other members of the care team who may not be directly involved in team meetings
- develop a thorough understanding of the patient pathways to effective care available in their area health service
- coordinate the patient journey ensuring that key elements of care occur in an ordered and timely manner and that information is collected and available to ensure appropriate treatment decisions can be made
- ensure that the patient receives early referral for psychosocial support and palliative care where appropriate
- coordinate the implementation of the patient care plan including provision of information and referral to appropriate support services
- monitor the implementation of care against the patient care plan.

The evaluation found that cancer care coordinators have had a high impact on improving care coordination. In the survey of CSISP position incumbents, all CSDMs and most incumbents of other position types felt that cancer care coordinators have had a high positive impact on improving care coordination. All DACS felt the cancer care coordinators have had at least some positive impact on improving care coordination. The DACS highlighted the inequity in the uneven spread of cancer care coordinator positions across cancer facilities.

### Processes implemented to improve care coordination

Cancer care coordinators have been proactive in implementing new systems and processes to improve care coordination: all cancer care coordinators indicated that they had done so. Initiatives included processes for coordinating patients' access to multidisciplinary care and mechanisms to ensure patients are referred early for psychosocial support and palliative care where appropriate. Some cancer care coordinators have helped implement clinics for patients to see all members of the multidisciplinary team.

### Care coordination services provided by the cancer care coordinator

Cancer care coordinators were asked to indicate how often they were referred patients from specific sources. For metropolitan cancer care coordinators, the main sources of referrals were MDT meetings, lead clinicians, medical oncologists, radiation oncologists and outpatient clinics. For regional/rural AHSs, the main sources of referrals were other cancer care coordinators, staff on wards, MDT meetings and medical oncologists. Most cancer care coordinators reported difficulty in obtaining referrals from surgeons and GPs.

Cancer care coordinators see most patients face-to-face and in the hospital setting, and most cancer care coordinators provide care to the patient with their family/carer present. Regional/rural cancer care coordinators see a larger proportion of their patients than metropolitan cancer care coordinators at the patient's home and at other non-hospital settings (such as support groups, private cancer clinic rooms or community health centres). Regional/rural cancer care coordinators are also more likely to have non-face-to-face contacts, including by email and text messaging. A small number of cancer care coordinators, mostly in regional/rural areas or in small cancer services, reported issues with the space in which they consult with their patients.

The evaluation found that in many cases, the services provided by cancer care coordinators are ongoing. About 50 per cent of cancer care coordinators in regional/rural AHSs and 25 per cent of cancer care coordinators in metropolitan AHSs discharge patients at the end of active treatment. However, many cancer care coordinators were unable to describe a distinct discharge point in the cancer journey due to variable patient needs. Comments included 'when it is appropriate'; 'it's a chronic disease so maybe never', and 'we are always available to our patients — that's our job'. Some stakeholders felt cancer care coordinator patient caseloads were unmanageable for this reason.

### Referrals to other services

Metropolitan cancer care coordinators reported that they refer a greater proportion of patients to support services, with 50 per cent indicating they refer between 76 and 100 per cent of their patients compared to 18 per cent of regional/rural cancer care coordinators. Patients with access to a cancer care coordinator were more likely to see an allied health professional (such as a psychologist or social worker) than patients without access to a cancer care coordinator (83 per cent compared to 42 per cent).

Some cancer care coordinators aim to refer to other services so as to reduce cancer patients' hospital admissions (for example, to radiology services to get fluid drained). For patients without access to a cancer care coordinator, unexpected symptoms may result in a visit to the emergency department.

Support services staffs (such as social workers, psychologists and physiotherapists) in areas with and without cancer care coordinators were consulted regarding their views on the appropriateness and timeliness of referrals. They reported that when a cancer care coordinator refers a patient, compared to another clinician, it was more likely that the referral was appropriate, timely and contained accurate information about the patient and their situation.

Consultations at cancer services where there was a social worker or psychologist but no cancer care coordinator revealed that formal processes for cancer patients to access social work and/or psychology services were often lacking. The evaluators concluded that the model of care works best if a cancer care coordinator is co-located with a social worker, psychologist and/or clinical psychologist.

The patient perception survey showed that patients who had someone coordinating their care were more likely to be satisfied that they were referred to support services in a timely manner. Those patients with a cancer care coordinator coordinating their care had higher satisfaction levels than those with another health professional coordinating their care.

However, patients with another health professional coordinating their care reported that they were more likely to be referred to treatment services in a timely manner than patients with a cancer care coordinator or no one person coordinating their care.

### Patient views on how well their care was coordinated

Patients who had a cancer care coordinator or other health professional coordinating their care were asked to report their satisfaction with three aspects of the care coordination service: whether they could contact their care coordinator for support and assistance when they needed to; whether they felt that the care coordinator provided valuable information to help them deal with their cancer experience; and whether the care coordinator provided valuable support to help them deal with their cancer experience (such as pain control and symptom management).

Overall satisfaction levels were marginally higher for patients with access to a cancer care coordinator compared with those that had another health professional coordinating their care. For example, 98 per cent of patients with a cancer care coordinator agreed or strongly agreed they could contact their care coordinator for support and assistance, compared with 92 per cent of patients with another professional coordinating their care. Agreement levels for whether the care coordinator provided valuable information were 95 per cent for patients with a cancer care coordinator compared with 94 per cent for patients with another care coordinator. Agreement levels for whether the care coordinator provided valuable support were 95 per cent compared with 91 per cent.

### Enablers and barriers

Cancer care coordinators identified the main enabler to improving care coordination as support from cancer service clinicians and the Cancer Institute. In the HNEAHS, most cancer care coordinators also identified support from the area cancer care coordinator as an enabler, and pointed to the value of the Aria application as a documentation and reporting tool to support coordinated care.

The main barriers to improving care coordination were lack of time, lack of administrative and IT support, and lack of data collection tools. Barriers to working with the private sector included limited or no access to patient information and slow flow of information back to the public sector. Some cancer care coordinators were unsure if their role should be extended into the private sector.

Suggested changes to the cancer care coordinator role that would improve care coordination include establishing processes for referral to the cancer care coordinator and determining an appropriate caseload for cancer care coordinators.

## Supporting multidisciplinary care

According to the position description, the cancer care coordinator's role in supporting multidisciplinary care requires that they:

- collaborate as part of the multidisciplinary team and coordinate the patient's access to multidisciplinary care
- support the delivery of multidisciplinary care and participate in MDT meetings
- participate in running MDT meetings in accordance with the accepted protocols for their institution or centre and ensure that outcomes from the meetings are incorporated into the care plan for patients
- advocate on patients' behalf, including at multidisciplinary team meetings.

The evaluation found that cancer care coordinators have had a high impact on improving multidisciplinary care. All CSDMs agreed that cancer care coordinators have had a high impact, and almost all cancer care coordinators (96 per cent) and psycho-oncology staff (85 per cent) felt that the cancer care coordinator role has had at least some (predominantly high) positive impact on improving multidisciplinary care. The DACS indicated that the cancer care coordinator role has had the highest impact in improving multidisciplinary care across the AHS.

### Processes implemented to improve multidisciplinary care

Most cancer care coordinators participate in MDT meetings, have established mechanisms to ensure that the patient is advocated for at MDT meetings, have developed processes to ensure that the outcomes of the MDT meetings are discussed with the patient, and have established processes to ensure other primary care providers (such as GPs) are notified of MDT meeting outcomes in a timely manner.

However, cancer care coordinators in some AHSs reported difficulties implementing many systems and processes due to lack of clinician motivation and lack of understanding of the cancer care coordinator role.

### Involvement of cancer care coordinators in MDT meetings

The majority of cancer care coordinators attend MDT meetings either weekly or fortnightly. Cancer care coordinators attending MDT meetings in metropolitan AHSs are more likely to find medical staff in attendance. In regional/rural AHSs, mainly nursing and supportive care staff attend the MDT meeting, as medical staff are often not based in regional/rural cancer services.

In most cases, the role of the cancer care coordinator in MDT meetings has evolved over time from administrator to participant, substantially as a result of funding provided by the Cancer Institute for administrative support. The level of involvement in meetings depends on support from medical staff. Some cancer care coordinators reported that although they attend, they are not invited to sit at the table and are never asked for their opinion. Some cancer care coordinators and psycho-oncology support staff said they meet immediately after the MDT meeting (without the medical staff) to discuss the supportive care needs of patients that were not discussed during the meeting.

Cancer care coordinators with an active role in MDT meetings perform functions such as:

- organising which patients will be discussed at MDT meetings
- identifying patients with possible psychosocial issues and referring them to appropriate services
- identifying patients that would benefit from care coordination
- updating patient files as a result of MDT meeting discussions
- raising patient specific issues that may alter the treatment approach taken by specialists
- making follow-up appointments for the patient with specialists.

Cancer care coordinators who do not have an active role in meetings will follow up specialists and other clinicians after the meeting to discuss concerns or suggestions.

Patient survey data showed that patients with access to a cancer care coordinator were more likely to report that their diagnosis and treatment plan were discussed at an MDT meeting and were more likely to report that they were informed in advance of the MDT meeting, compared with patients who had another health professional or no one person coordinating their care.

### Patient advocacy

Most stakeholders said they saw the cancer care coordinator as a patient advocate as cancer care coordinators have the knowledge base and networks to advocate on the patient's behalf, particularly in MDT meetings where the patient is not likely to be present.

In fact, most stakeholders depend on the cancer care coordinator advocating on the patient's behalf, and think the cancer care coordinator is the only clinician that can do so as they have a holistic view of the patient's situation. One clinician commented that 'a lot of the time doctors only see the treatment plan and do not see the patients; the cancer care coordinator sees the patient, they are the pivotal point in patient care and the rest of us circulate around them'. Health professionals at sites without cancer care coordinators identified the lack of an advocate for the patient as a gap in service delivery.

All patients interviewed with access to a cancer care coordinator greatly appreciated the role, especially in cases where the patient's care crossed multiple facilities, area boundaries, or private and public sectors. Patients with access to a cancer care coordinator:

- tended to have their views and concerns addressed
- were more at ease about their treatment journey compared to patients without a cancer care coordinator
- were never unsure who to call if they needed something or had a question.

Patients without access to cancer care coordinators were more likely to report putting up with a situation they were unhappy about because they didn't think anything could be done about it. If patients had an issue regarding a doctor, there were more likely to discuss it with a nurse than with other doctors.

### Enablers and barriers

Cancer care coordinators identified support from cancer service clinicians and administrative support as the main enablers to improving multidisciplinary care. Generally, administrative support was considered an enabler when the cancer care coordinator had access to an MDT coordinator. The major barrier identified was time.

Suggestions to further improve cancer care coordinators' ability to support multidisciplinary care included ensuring cancer care coordinator positions are full-time and permanent, raising the profile of the cancer care coordinator as a vital and important member of MDT meetings, and including cancer care coordinators on rounds in oncology wards.

Further development of the structure of MDT meetings is required to ensure cancer care coordinators are consulted regarding all aspects of the patient when determining the most appropriate treatment plan.

## Commitment to continuing professional development

According to the position description, a commitment to continuing professional development requires that the cancer care coordinator:

- maintain ongoing professional development including education and training relevant to the role and that provided by the Cancer Institute
- maintain links with the Cancer Institute, Statewide Oncology groups and professional organisations
- maintain a willingness to undertake further education in the conduct and development of the multidisciplinary approach to health care provision
- maintain current knowledge in relevant clinical area and in relation to cancer control
- contribute to the evaluation and research related to the cancer care coordinator role.

The evaluation found that cancer care coordinators have a high level of commitment to continuing professional development. They have actively participated in activities such as in-service education sessions, conferences, workshops and the Cancer Institute professional development group. On average, regional/rural cancer care coordinators have attended more professional development activities than metropolitan cancer care coordinators.

Cancer care coordinators identified that participating in professional development activities was increasingly difficult due to the high demands on time.

About half the cancer care coordinators have undertaken postgraduate education, with the remainder already having their Masters degree before taking up the cancer care coordinator role.

Most cancer care coordinators have developed links with one or more professional groups, such as a NSW Oncology Group (NSWOG), Cancer Nurses Society of Australia (CNSA), Clinical Oncological Society of Australia (COSA), Haematology Society of Australia and New Zealand (HSANZ), and the former Greater Metropolitan Clinical Taskforce (GMCT). Only 4 per cent of cancer care coordinators said they did not belong to any professional group. There was no difference between metropolitan and regional/rural cancer care coordinators.

## Implementation of new knowledge

Sixty-four per cent of cancer care coordinators reported that they had developed or enhanced resources and/or processes to improve patient care as a result of attending professional development activities. Examples included:

- introducing a standard protocol of sending a letter or making a phone call to the patient's GP after each consultation with a hospital doctor
- defining clinical pathways and developing referral pathways to smooth transition between AHSs
- implementing projects within their own cancer service (such as hand hygiene).

## Training provided by the Cancer Institute NSW

Most cancer care coordinators (86 per cent) said they had completed training or professional development activities provided by the Cancer Institute. Cancer care coordinators valued the initial support from the Cancer Institute in coordinating the development of the cancer care coordinator role.

However, most were disappointed that the Cancer Institute provided little ongoing support. As the cancer care coordinator position does not exist in the nursing structure, there are few specific professional development opportunities.

## Enablers and barriers

Cancer care coordinators identified support from the Cancer Institute as the main enabler of being involved in professional development activities. The main barriers were funding and time.

Barriers specific to regional/rural cancer care coordinators included limited local opportunities, limited tumour-specific activities and limited access to tele/video-conference equipment.

## Acting as an information and education resource

According to the position description, the cancer care coordinator's role in acting as an information and education resources requires that they:

- act as a resource for patients (and their carers), a first point of call for contact, information and support
- provide patient education, supply resources, direction or referral as needed
- provide information specific to the patient's diagnosis, treatment and possible side effects
- work with the Cancer Institute and other coordination staff in the development of resources and the updating of information in clinical service directories
- act as a resource for staff in the provision of information, referral and advice on matters relating to patient-centred care, multidisciplinary care and coordination.

### Cancer care coordinators' role in the development of resources

Most cancer care coordinators (90 per cent) said they had developed processes to ensure patients are educated about their cancer and treatment options, supplied with resources (such as packages by cancer type or treatment type) and informed about referrals that are available to them.

Fewer cancer care coordinators (66 per cent) had worked with the Cancer Institute or other care coordination staff in developing the resources. Most improvements have been facility based and are not standardised across AHSs, except in HNEAHS where the area cancer care coordinator has assisted in area-wide standardisation. Most cancer care coordinators suggested that the Cancer Institute should standardise patient and staff information.

### Cancer care coordinators as an education resource

Stakeholders said they saw the cancer care coordinator as an important education and information resource. The information cancer care coordinators provide is considered valuable, appropriate and timely in meeting the needs of both patients and health professionals.

Stakeholders commented that cancer care coordinators have been particularly effective in tailoring information to suit the needs of the patients and considered that the cancer care coordinator is best positioned to provide such information. Stakeholders at sites where there is no cancer care coordinator highlighted patients' lack of access to information, or too much information from various sources. Patients at these cancer services relied on a mixture of health professionals to provide information, and it was often up to the patient to 'sift through the information and try to make sense of it.'

### Cancer care coordinators as a point of contact

The evaluation found that patients with access to a cancer care coordinator considered him/her to be the first point of contact. They emphasised their appreciation for a single contact point, particularly during a crisis or when they were extremely unwell. Patients without access to a cancer care coordinator identified crisis points at which they presented at the emergency department.

The patient survey showed that 52 per cent of patients with no one person coordinating their care were not satisfied there was a cancer care professional they could talk to, who in turn would speak on their behalf if they had concerns regarding their treatment, care or progress. This figure compared to 4 per cent and 7 per cent of patients with a cancer care coordinator or another health professional coordinating their care respectively.

Patients without access to a cancer care coordinator in regional/rural areas often identified the chemotherapy unit nurses as a contact if they had concerns.

### Enablers and barriers

Cancer care coordinators identified support from cancer service clinicians and the Cancer Institute as the main enablers to acting as an information and education resource. The main barriers were lack of time and administrative support.

Cancer care coordinators said that approved study leave, clinic space and additional resources such as laptops, projector screens, space to keep resources, and computer skills would help them be a more effective education and information resource.

Stakeholders suggested establishing a central body for evaluating patient information and developing tumour-specific information packs. This would ensure patients have access to consistent evidence-based information and would reduce duplication of effort by cancer care coordinators.

Another suggestion was to develop sessions for ward staff about the signs and symptoms experienced by cancer patients. Cancer care coordinators would need a suitable space to do this.

## Different experiences for patients with access to a cancer care coordinator

The evaluation found there were few differences between treatment options offered to patients with access to a cancer care coordinator and those without access to a cancer care coordinator. In addition, most cancer patients were satisfied with their overall care experience — though more so if they had someone to coordinate their care, either a cancer care coordinator or other health professional, than if they did not.

Patients without access to a cancer care coordinator, however, were unaware of services they were not receiving. There were important differences between patients with access to a cancer care coordinator and those without:

- patients with access to a cancer care coordinator were more likely to receive appropriate and timely referrals to psychosocial and other support services
- patients with access to a cancer care coordinator consistently received education and information resources, whereas patients reliant on other health professionals for information may have received no information or received it in an ad hoc manner
- patients with access to a cancer care coordinator were satisfied they had someone to call if they need assistance or advice; this contrasted to the patients without access to a cancer care coordinator.

Furthermore, patients who had someone coordinating their care were more satisfied with the opportunities provided for them to be involved in making decisions about their care, compared with patients who had no one person responsible for their care.

The patient survey showed that 88 per cent of patients believed access to a cancer care coordinator is an essential part of their cancer care.

## Findings about the service model and future support of cancer care coordinators

Funding for cancer care coordinators was allocated to AHSs based on population weighted by cancer incidence. The AHSs were responsible for the allocation of funding to tumour streams and facilities. The cancer care coordinator positions have benefited patients and cancer service clinicians with access to these positions, but have also created inequities for patients; the evaluation found no evidence as to why cancer care coordinators are located in certain hospitals. As patients become more aware of the role of the cancer care coordinator, it is likely that more and more will request access to a cancer care coordinator.

The evaluation found that while no one service model is clearly superior, there are elements that have been important in the success of the role:

- Positions funded on a full-time basis (allowing for job sharing arrangements) are better able to service their patients and colleagues
- Reporting to the NUM/DON as well as to the head of the cancer service has resulted in better integration of the positions into the nursing and cancer services structure
- The development of cancer as its own clinical network stream in the AHS provides more structure for the role of cancer care coordinators within cancer services.
- Referral pathways should be well articulated
- Well-functioning MDT meetings require cancer care coordinators to be participants, not observers
- Cancer care coordinators co-located with a social worker, psychologist and/or clinical psychologist are more able to support their patient's needs
- There should be cover to ensure cancer care coordinator services are maintained during annual leave or illness. This is required in the funding agreement, but often does not occur. The absence of leave cover undermines the importance of the role and leaves patients feeling unsupported.

Some confusion has arisen because the acronym for cancer nurse coordinators is the same as that for a clinical nurse consultant. Role clarity will be improved by changing the position title to cancer care coordinator. It was suggested that the Cancer Institute might look to other bodies, such as COSA and CNSA, to assist in the professional development of the cancer care coordinator positions.

## Support for the cancer care coordinator positions

Funding of MDT coordinator positions has relieved cancer care coordinators of some of their administrative burden. Support to cancer care coordinators in promoting their role is now required. The evaluation found that the role of the cancer care coordinator has been under-promoted by those in leadership positions, requiring cancer care coordinators to spend a considerable amount of their time marketing their services.

The role of the DACS should include advocating for the role of the cancer care coordinator to other clinicians. The Cancer Institute could further support the work of cancer care coordinators through initiatives such as:

- progressing development of a set of quantitative and qualitative outcome measures, and systems for generating them from routinely reported data
- evaluating and implementing (or developing) standardised tools for psychosocial and needs assessment
- developing a guide for clinicians on when they should refer patients to cancer care coordinators
- ensuring cancer care coordinators have time available to systematically document referral pathways relevant to their cancer service, to better retain knowledge that currently rests with the occupant of the cancer care coordinator role
- developing systems for cancer care coordinators to routinely identify any clinical trials suitable for their patients
- providing opportunities for cancer care coordinators to share information about successful strategies for improving communication between GPs and other members of the cancer care team
- establishing a program for cancer care coordinators who are participation experiencing difficulties in being full participants in MDT meetings to attend a meeting where there is strong participation by the cancer care coordinator and a more holistic focus on the patient
- evaluating (or developing) patient cancer information packs to ensure patients have access to the same evidence-based information.

## Conclusion

The Cancer Institute NSW's temporary demonstration funding for cancer care coordinator positions has made an important contribution to improving the quality and capacity of cancer services in NSW.

The evaluation found that the cancer care coordinator role has had a high impact on three key areas: providing patient-centred care; improving care coordination; and supporting multidisciplinary care.

Cancer care coordinators have demonstrated a high level of commitment to continuing professional development, actively participating in a range of activities.

They are an effective information and education resource, tailoring information to suit patients' needs and explaining it in a way that patients understand. Patients highly value having a single point of contact for any questions or concerns.

In terms of developing an area-wide approach to optimising cancer care, the cancer care coordinator role has been largely driven by meeting the needs of patients and developing links with private and community-based services. Their ability to adopt a leadership role has been constrained by their day-to-day service delivery commitments and by their lack of involvement in projects and strategies at the area level. Some DACS, CSDMs and lead clinicians see the cancer care coordinator role as purely a service delivery position and not an area-wide infrastructure/service development position.

The evaluation found there were few differences between treatment options offered to patients with access to a cancer care coordinator and those without. However, patients were more satisfied with their overall care experience if they had someone to coordinate their care — either a cancer care coordinator or other health professional — than if they did not.

Cancer care coordinators were particularly effective (compared to other health professionals) in ensuring appropriate and timely referrals to psychosocial and other support services, and in consistently delivering timely education and information. Patients, clinicians and service managers expressed high levels of appreciation of the cancer care coordinator role.

According to the evaluation data, the approximately 50 FTE cancer care coordinator positions funded by the CSISP, while not the only cancer care coordinator positions in NSW, add considerably to the capacity of cancer services. Provided at a cost of \$4.5 million per annum, these positions have resulted in the following:

- Cancer care coordinators have about 10 patient contacts (often with their family/carer present) per day
- Cancer care coordinators see about 23 new cancer patients per month
- Each cancer care coordinator has about 2,300 patient contacts per year
- Approximately 11,500 or 30 per cent of cancer patients in NSW accessed cancer care coordinator services in 2009, receiving 115,000 occasions of services.

The focus of the cancer care coordinator positions has been direct service delivery. Given the quantum of direct patient services provided, cancer care coordinators have been limited in their ability to develop service delivery infrastructure, such as systems, data, protocols, referral pathways and screening tools.

The value of the cancer care coordinator positions has been clearly demonstrated in the evaluation. Care coordination for cancer patients is highly valued by both patients and cancer colleagues.

The challenge will be to use the findings of this evaluation to increase contemporary, high-quality care coordination activity in NSW cancer services with limited funding. New models and a more standardised approach to cancer care coordination will need to be developed in order to respond to the increasing incidence of cancer. The demonstration funding provided by the Cancer Institute has made a significant impact on service delivery models and the quality of patient care and support.

## Abbreviations and acronyms

AHS	Area Health Service
CCC	Cancer Care Coordinator
CNSA	Cancer Nurses Society of Australia
COSA	Clinical Oncological Society of Australia
CSISP	Cancer Services Infrastructure Support Program
CSDM	Cancer Services Development Manager
DACS	Director/Manager of Area Cancer Services
DON	Director of Nursing
FTE	Full-Time Equivalent
GP	General Practitioner
GSAHS	Greater Southern Area Health Service
GWAHS	Greater Western Area Health Service
HNEAHS	Hunter New England Area Health Service
MDT	Multidisciplinary Team
NCAHS	North Coast Area Health Service
NSCCAHS	Northern Sydney Central Coast Area Health Service
NSW	New South Wales
NUM	Nurse Unit Manager
SESAHS	South Eastern Sydney Illawarra Area Health Service
SSWAHS	Sydney South West Area Health Service
SWAHS	Sydney West Area Health Service

## References

- 1 Cancer Institute NSW: NSW Cancer Plan 2007–2010. Sydney, November 2006.
- 2 NSW Department of Health: A clinical service framework for optimising cancer care in NSW. Sydney, May 2003
- 3 Farber J, Deschamps M, Cameron R: Investigation and assessment of the “navigator role” in meeting the informational, decisional and educational needs of women with breast cancer in Canada. Canada, The Education Strategy Committee of the Canadian Breast Cancer Research Initiative, Canada Health, 2002