Robert Bergman

17th March, 2005

The Secretary
Senate Community Affairs References Committee
Suite S1 59
Parliament House
Canberra ACT 2600

Dear Secretary,

# Submission to the Inquiry into Services and Treatment Options for Persons with Cancer

Please accept the following as my submission to the Cancer Inquiry, being reflections on my journey through the Australian medical system as a result of diagnoses with cancers and my final diagnosis of terminal cancer.

## Summary

My summary of the necessary alterations to our current lack of adequate cancer control systems and less than holistic cancer treatment are:

- An urgent need to change the medical system to a patient oriented system and to establish a system of coordination of cancer care. This coordination of cancer care can best be illustrated by a paper authored by Professor Patricia Yates in attachment ‘A’ to this submission and by the strategic principles stated in the NSW Cancer Plan 2004 - 2006 by the Cancer Institute of NSW which in part state that “Cancer control must be well coordinated between the various government departments, cancer agencies, health service providers and community-based groups. Such coordination will ensure that high quality initiatives and knowledge are widely known, that work to accelerate cancer control is collaborative and that available resources have the greatest impact”.
- That a federal oversight and accreditation group be formed with adequate legislative authority and funding to research, organise, disseminate and manage a patient oriented cancer care system throughout Australia and to establish as a core component of this system a professional grouping of Cancer Care Coordinators.
- That these Cancer Care Coordinators be drawn, in the first instance, from the ranks of qualified nursing staff.

## Personal Background

MBA (Hull), Grad Dip Public Health (QUT)
PhD Student – Faculty of Science (QUT)
War Service in Malaysia and Vietnam
Career positions include Engineering Management and Operations Management

## Experience as a Cancer Patient

Late one Friday afternoon in October, 2003, I presented to the local regional hospital with urgent medical symptoms, i.e., urinating blood, but was somehow lost in the melee of hospital understaffing and trauma overload and, with a temporary reduction of symptoms, was advised to go home with no diagnosis.

This was my introduction to more than a year of what I describe as “serial terror” which has impressed on me the urgent need for a complete revision of the practices, services and treatment options currently offered to cancer patients. I am also convinced that such a revision will not arise from within the medical fraternity that currently control the system.

My general practitioner was thorough and, after a series of hurriedly organised tests, urgently referred me to a Renal Surgeon at Hollywood Hospital in Perth. I went through further CTScans, etc and, during an internal bladder inspection by the surgeon, I was informed that I had a large and dangerous tumour in my left kidney and that it and the surrounds had to be removed urgently. Whilst in discomfort and some pain from this medical procedure I attempted to ask questions of the surgeon as to potential alternatives and what this meant for me but received only brief answers that added up to zero choice. This was traumatic for me both as a result of the diagnosis and from the lack of knowledge of my condition and personal options.

I did have a further chance to consult with the surgeon prior to the operation and discovered more information regarding the medical procedures but was not advised as to survival potential either from the operation or from potential metastasis of the cancer. I was not offered or advised of any other services that may have assisted me through this traumatic time, e.g., psychological counselling. I was under the distinct impression that a surgeon will comment only on the area directly under his expertise. This may be due to both lack of knowledge of other areas that affect the patient and/or potential legal difficulties resulting from him commenting on these other areas.

At this point in time I broke the news to my son, daughter and close friends and was disturbed by their obvious hurt and level of concern. I reside in a Royal Australian Air Force Association retirement estate and was able to access a RAAFA Welfare Officer who had some experience in the field of psychology. This person was a great help, assisting me to keep a reasonably positive mental attitude throughout this period. The only other offer of help was from the Hollywood Hospital who offered to have a religious person of my choice attend me prior to the operation. I declined that offer.

I am a Department of Veterans Affairs Gold Card holder and so the financial load of these medical procedures on me was not severe.  I am aware of the extensive medical services that I have accessed and that other patients that I have encountered along the way have been under severe financial stress due to the cost of these services.  There is much evidence in the scientific literature that stress of any kind adversely affects the immune system and hinders healing.  I have never been offered any assistance or advice regarding potential financial problems and I have not observed much in the way of financial counselling for these people.

At about three months into the recovery phase from the radical left nephrectomy (complete removal of kidney and surrounds), I was referred to an eye surgeon to remove a basal cell carcinoma from my right eye socket.  This was as a result of a recommendation from my eye specialist who treats me for glaucoma.  My general practitioner referred me after I requested it.

At the six monthly post-operative checkup a large tumour was detected in my left lung and I was referred to a cardio-thoracic surgeon who rapidly admitted me to Fremantle Hospital for a lower left lobectomy (removal of a lung lobe) for a diagnosed renal cell carcinoma metastasis.  Subsequent histology reported that it was not that cancer type but a lung cancer. (bronchio-alveolar non-small cell carcinoma).

Post-operative tests showed metastasis of this cancer and that it was inoperable.  The cardio-thoracic surgeon, while sympathetic, would not advise me on future medical possibilities or probabilities and simply referred me to an oncologist and said goodbye.

The oncologist briefly described the cancer in laymans terms and advised me that this particular cancer did not respond to any currently available medications.  He could not or would not offer me any projections on my survivability and simply advised me to come back when the pain became difficult.  This was rather depressing.

While arranging my affairs and attempting to investigate palliative care options I was advised by my house cleaner about an experimental cancer drug trial underway at Sir Charles Gairdner Hospital in Perth.  The cleaning lady had seen a small news item regarding a particular drug trial using an extract from the noxious weed called the Devils Apple.  I contacted the State Department of Health and was referred to the research team under Professor Millward at that hospital.  After much testing and a requested referral from my oncologist, I was accepted on to a drug trial in October, 2004.  My oncologist had not advised me about the existence of these trials.

Whilst there have been some difficult times on this experimental trial the results after one cycle of treatment were that there has been some reduction in the cancer mass, there are no new metastatic sites and there has been a major improvement in my wellbeing.  I have now chosen a different oncologist.

Throughout this period, any assistance I have received to ease my way through the medical maze, to attempt to deal with the knowledge of imminent death and to finally arrange my financial and legal affairs has generally been accidental and usually the result of a few good people volunteering their help.  The only group of people in the medical system who showed what I interpreted as a level of continuing ‘genuine care’ were the nursing staff.  I cannot rate them highly enough both for their technical expertise and for their humanity.

## Cancer Service Provision

My unfortunate experiences are not an isolated case.  In discussions with many other cancer patients about their experiences I have noted a disturbing similarity.  This translates into a lack of coordination of medical and other forms of care that are required for an improved patient journey and, more than likely, an improved outcome. Correction of these deficiencies would translate into a more cost-effective system reducing duplications and streamlining patient transit.

These experiences are echoed in the strategic principles of the NSW Cancer Plan 2004 – 2006 by the Cancer Institute of NSW addressing the need for patient/consumer centered practices when they state that "Cancer is a devastating diagnosis that requires support for the individual patient and their carers from multiple professional and other community groups. Such groups must focus their efforts to meet the individual patient's needs for an optimal outcome. Patient-centred practice is a key principle in the *Clinical Service Framework*, and is endorsed in the *NSW Cancer Plan.* It includes:

- Equity of access to services, regardless of socioeconomic status, ethnic background or place of residence.

- Excellence in the standards of care available for each cancer patient.

- Equity of access to, and effective delivery of, high quality, specialised and relevant information from credible sources, including for non-English-speaking and culturally diverse groups.

- Assistance to patients in empowering decision making, especially at critical intervention points.

- Timely detection, diagnosis, work-up and referral of cancer patients to specialised care.

- Well-informed choices of doctor, service, treatment, timing and follow-up procedures clearly available at any time.

- The opportunity and encouragement to obtain a second opinion at any time in the management process.

- Patients should know the person in charge and the team members responsible for their care.

- Access to appropriate sub-specialised cancer care.

- Appropriate, timely, optimal multidisciplinary sequence of treatment.

- Coordination of multidisciplinary care for the patient's convenience.

- Adequate psychosocial support as required and requested through the cancer journey.

- Protection of privacy and the maintenance of dignity, ensuring respect while receiving care embodied in the notion of patients' rights.

- Early symptom control and effective management of treatment side effects.

- Appropriate and early referral to palliative care services.

- Adequate follow-up care and information.

- Access to participation in clinical trials.

- Representation on committees determining policy or planning services."

The need for Australia-wide planning of cancer services is also well described in the same report when it states that (with modification for an Australia-wide outlook) "This principle is necessary for effective cancer control to address:

- The need for a cohesive approach and to facilitate integration.

- The increasing number of cancer patients needing care.

- The increasing costs of drugs, equipment, facilities and personnel to deliver optimal care.

- The necessity to coordinate multidisciplinary teams often in association with expensive capital developments, such as radiotherapy machinery.

- The need to develop highly specialised expertise for less common cancers.

- The need to match the training of cancer specialists and professional groups with workforce projections.

- The need to provide adequate resources to achieve best practice in a cost-effective manner within budget constraints.

- The remote nature of many communities in Australia.

- The need for Area Health Services to cooperate in the provision of expensive services and to support each other with cross-border patient flows.

- The need to plan new facilities for high-volume ambulatory care.

Such Nation-wide planning will provide a method of predicting the requirements of the Area Health Services for future cancer service infrastructure."

## Conclusions

My traumatic experience has demonstrated that extensive and immediate alterations to the medical system are required to address the current lack of adequate cancer control systems and less than holistic cancer treatment. These alterations should eventually encompass both technical and social aspects of mainstream and alternative medical knowledge but, in the short term must recognise:

- An urgent need to change the medical system to a patient oriented system and to establish a system of coordination of cancer care. This coordination of cancer care can best be illustrated by a paper authored by Professor Patricia Yates in attachment ‘A’ to this submission and by the strategic principles stated in the NSW Cancer Plan 2004 - 2006 by the Cancer Institute of NSW which in part state that “Cancer control must be well coordinated between the various government departments, cancer agencies, health service providers and community-based groups. Such coordination will ensure that high quality initiatives and knowledge are widely known, that work to accelerate cancer control is collaborative and that available resources have the greatest impact”.
- That a federal oversight and accreditation group be formed with adequate legislative authority and funding to research, organise, disseminate and manage a patient oriented cancer care system throughout Australia and to establish as a core component of this system a professional grouping of Cancer Care Coordinators.
- That these Cancer Care Coordinators be drawn, in the first instance, from the ranks of qualified nursing staff.

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# Attachment A

## To Senate Cancer Inquiry submission by Robert Bergman

The following is a paper attributed to Professor Patricia Yates

# Cancer Care Coordinators: Realising the Potential for Improving the Patient Journey

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A person diagnosed with cancer can receive multiple treatments in a variety of different health care settings over extended periods of time[1]. During this time, they come into contact with multiple health care providers. For example, one recent UK study reported that cancer patients with a diagnosis of less than one year had met 28 doctors on average since their diagnosis[2]. Add to this the many other health professionals with whom the patient will come into contact during their illness and the complex maze that can characterise the patient's cancer journey is obvious.

The *Optimising Cancer Care in Australia* report[3] published in 2003 by the peak cancer organisations in Australia concluded that there are many places for the person with cancer to get lost in the system, causing unnecessary morbidity and undue distress. The lack of an integrated care system for people with cancer was identified as a major failing of today's health system[3].

A number of states in Australia have moved to appoint cancer care coordinators as a strategy to address such problems. In Queensland, cancer coordination positions have been established in a number of Health Service Districts in the Southern and Central Zone of the State, initially to scope patterns of care, referral pathways and to define a cancer coordination model for their regions that is consistent across the state, but able to meet the local needs of the population. To support its Cancer Clinical Service Framework, the NSW Health Department plans to recruit up to 50 cancer nurse coordinators. Cancer nurse coordinators in NSW will work through Lead Clinicians and Directors of Area Cancer Services to support oncology team meetings, develop care pathways and protocols, and provide a direct source of contact for patients and primary care physicians accessing cancer services[4], In Victoria, a number of program coordinators and regional nurse coordinators have been introduced as part of the breast services enhancement program. Individual institutions have also established nurse coordinator roles for specific tumour streams.

The cancer care coordinator role is a rapidly emerging one with a mandate to achieve some potentially far-reaching reforms to systems of care. To ensure these developments realise their potential, it is timely to consider the most effective ways to design and implement models of care coordination that achieve the improvements being sought for the Australian cancer care system.

## What is care coordination?

A variety of terms are used in the health care literature to reflect efforts to improve the patient journey, including continuum of care, coordination of care, discharge planning, case management, integration of services and seamless care[5]. In the context of managing a chronic disease such as cancer, continuity of care has been defined as the delivery of services by different providers in a coherent, logical and timely fashion, consistent with the patient's medical needs and personal context[5]. A service system that facilitates continuity of care is characterised as one where all services needed (comprehensiveness) are delivered over time (longitudinally) by service providers who establish secure and dependable relationships (relationships) and when appropriate care is available (accessibility) and flexible enough (responsiveness) to meet patient needs[6].

These definitions emphasise that care coordination is an integral component of continuity of care. Care coordination ensures that someone manages the care process, including the development and communication of the care plan and ensures that all of the care needed is arranged and delivered[6]. Various models for care coordination have been described to reflect the needs of the population being served. Case management is one such example that evolved from efforts to decrease fragmentation of services for patients whose care was complicated, being seen as a cost-effective way to provide quality care to high-risk patient groups and improve selected patient outcomes[7]. While no agreed definition is evident in the literature, nurse case management roles are generally seen to encompass a very broad range of responsibilities which may include assessment and screening of needs and goals, education, bridging gaps, promoting self efficacy, enhancing self -care capabilities, coordinating care across settings, brokering and developing networks of services, advocating for patients and providing hands on care[8],[9]. The development of standardised care protocols, such as care maps, pathways and guidelines have also been identified as an important mechanism for achieving coordinated and continuous care[6].

While coordination of care, case management and care pathways are processes designed to promote continuity, on their own they do not necessarily ensure that a patient experiences a system that is connected and coherent[5]. Studies suggest that patients and their families experience continuity when they perceive that providers know what has happened before, that different providers agree on a management plan, and that a provider who knows them will care for them in the future[6]. Such studies emphasise that what is likely to be highly valued by patients is not simply a managed care process, but rather, a relationship with a clinician that is characterised by understanding, trust and mutual respect[10].

Care coordination may therefore be most effective when it achieves continuity across several interrelated dimensions of the patient's cancer experience, including:

-Informational continuity, or the efficient transfer of information about the
patient's disease as well as their preferences, values and context in order to
bridge separate care events and ensure a responsive service[5];
-Management continuity, or the delivery of services in a complementary and
timely manner that are consistent and flexible[5];
-Relational/interpersonal continuity, or the linkage that is made between past to
current and future experiences[5],[11] ; and
-Team continuity, or the extent to which care is delivered within a shared
management plan[5],[11].

These dimensions emphasise that the experience of a connected and coherent service is intricately linked to organisational, interpersonal and relational aspects of the health system.

**What is the evidence for care coordination?**

Two major reviews of evidence regarding coordination of cancer care were published in 2003. The National Institute of Clinical Excellence in the UK undertook a systematic review of literature published between 1966 and March 2003 to determine the current state of evidence on interventions to improve service configurations for supportive and palliative care for those affected by cancer[12]. In the area of coordination of care, 13 individual studies were identified which had evaluated interventions including appointment of nurse coordinators, multidisciplinary team interventions, introduction of standardised guidelines and protocols and implementation of methods for improving communication, such as patient held records. The reviewers concluded that the evidence shows good coordination enables services to complement each other and provide better quality supportive care services. Of particular note, however, is that 11 of the 13 studies identified in this review involved coordination of services for patients receiving palliative care.

The Clinical Practice Guidelines for Psychosocial Care for Adults with Cancer[1] published in Australia similarly discusses evidence around four main types of interventions designed to promote continuity of care: identification of a care coordinator; the role of specialist oncology nurses; multidisciplinary care; and patient held records. The review concluded that Level 2 evidence exists to support the following interventions:

- Specialist breast nurses improve understanding and provide continuity of care throughout the treatment process for women with breast cancer; and
- Patient held records improve continuity of care.

While care coordination is not the sole focus of the Specialist Breast Nurses' practice, the establishment of such positions in Australia has represented an important development in efforts to improve coordination and support for women with breast cancer. The National Breast Cancer Centre (NBCC) Specialist Breast Nurse Project identified that the presence of a specialist breast nurse contributed to a range of improvements including: improved team functioning and appropriate utilisation of each professional's skills and resources; care being delivered more smoothly, including referrals; other health professionals having improved information about patients and breast cancer issues; and women being prepared for each treatment stage[13]. The recent report on the NBCC Multidisciplinary Care Demonstration projects reinforced this important role that specialist oncology nurses play as a coordinator of care and facilitator of effective communication amongst the team and with patients[14].

Further evidence to support the role of nurse coordinators in improving outcomes for people with cancer has emerged since the publication of these evidence reviews. A US based study by Goodwin et al[15] evaluated a nurse case management intervention in a randomised controlled trial involving 335 women over 65 years of age newly diagnosed with breast cancer. Findings demonstrated that women who received the support of a nurse case manager were more likely to be seen by a radiation oncologist and receive radiotherapy after breast conserving surgery and that they were more likely to have normal arm functioning in the recovery period than women who did not receive case management support. Similarly, a three-year demonstration project in the US involving patients with advanced lung cancer found that where nurse case managers were employed, higher rates of advance care planning and referral to hospice programs and improved symptom management was achieved[16].

The available evidence thus suggests that the appointment of someone to coordinate care may have many benefits for patients and the team. The actual processes of care that contribute to improved patient outcomes are, however, not always clearly described. That is, exactly what is it that nurse case managers or care coordinators do that makes a difference? Findings from a qualitative study involving those women with cancer who received a nurse case management intervention identified that patients felt they had been helped through practices including managing co-existing problems, providing informational and emotional support, providing education about procedures and self-care, and assisting with activities of daily living[17]. Navigating the health system was also a key part of the case management intervention that was seen by women as being especially helpful and this included making appointments, explaining procedures, reinforcing information from other health care providers and ensuring comprehensive recording of patient information in health records [17]. Families of patients in this study reported the nurse case managers helped by providing advocacy, support, education and monitoring of their relative's progress[17].

Similarly, findings from a qualitative study of the practices of nurse case managers working in a state-wide program in California for uninsured men with prostate or bladder cancer identified that nurse case manager's scope of practice was extremely broad and required ‘skilful tailoring and execution’ of a range of interventions including:

- assessment and collection of data from a variety of sources to identify patient needs;
- synthesis of this assessment data with their own clinical expertise and understanding of the clinical, social and emotional context for the individual patient;
- use of facilitation strategies to promote successful self-action and expedite movement within the health care system;
- advocacy strategies including obtaining records or information that patients needed and representing patient needs and preferences;
- coordination strategies to link agencies, care providers and patients, such as coordinating appointments, obtaining records, completing paper work, making referrals and arranging supplies;

- teaching to fill gaps in information or understanding;
- support through reassuring, listening and supporting decisions; and
- collaborative problem solving through active listening, purposeful questioning, elicitation of preferences, identifying actions and reinforcing capabilities[4].

### What issues should be considered in implementing care coordination roles?

Published studies concerning care coordination interventions have typically involved evaluation of quite structured programs of nurse intervention, with participating nurses being well supported and educated to perform in their roles. In reality, however, coordination roles are more likely to be implemented in diverse contexts with varying levels of structure, guidance and support. As such, outcomes for patients and for the system have the potential to be far more varied than evidence from the more controlled evaluation studies might suggest. For example, a comprehensive descriptive study of the practices of 153 breast care nurses in Victoria found that the breast care nurse role in working with and involving other health professionals in women's care was varied, that joint consultations with other health professionals were not always a routine part of practice and that referral rates by all breast care nurses to some professional groups was limited[18]. Indeed, despite a belief that continuity of care interventions are inherently good, some studies of coordination interventions outside of the cancer context (mostly in primary care settings) have reported conflicting conclusions as to their value[19].

There are likely to be many reasons for such variations in practice and outcomes, including inadequate preparation of care coordinators and other members of the team, poorly designed interventions, or simply lack of access to appropriate services and systems of support to enable collaborative practices to occur. The findings from the Victorian Breast Nurse Workforce study are an important reminder that while care coordinator roles may have enormous potential, careful consideration needs to be given to how such roles are designed and implemented. The brief review presented in this paper raises some important questions for further consideration.

### What is the scope of practice and associated competency requirements for a cancer care coordinator?

Qualitative studies describing the practices which contribute to patient's experience of a coordinated system identify an enormous array of administrative, counselling, educational, advocacy and clinical functions that may be performed by nurses in care coordination roles. There is, however, no consistent definition of the scope of practice, or clear description of the capabilities and competencies required to be an effective cancer care coordinator. For example, to what extent should such roles focus on management and coordination of the various parts of the service system ( eg. a type of case management or systems navigator role ), more direct care provision in terms of meeting individual patient supportive care needs ( eg. counselling and education, such as provided by the Specialist Breast Care Nurse), or a combination of these functions? Inherent in this is the question of how the care coordinator's role differs to or complements the role of other cancer specialists such as that of breast care nurses. A prescriptive model of care coordination is, of course, unlikely to meet the diverse needs of people with cancer. Nevertheless, addressing key questions about role definition will be crucial for developing evidence-based models of care coordination that are appropriate for the populations being served. Such clarity will also assist consumers and other health professionals to better understand their relationship with care coordinators, as well as minimise role confusion and the perception that care coordinators can be 'all things to all people'.

### When is care coordination required; to whom and under what circumstances?

In the cancer context, the specific patient circumstances that will benefit most from support provided by care coordinators are yet to be clearly identified. Studies that have evaluated case management interventions have tended to involve patients with complex health or social needs[15],[16],[20]. In the primary care context, studies similarly suggest that continuity of care interventions are associated with more positive outcomes for more vulnerable patients[21]. Furthermore, while studies demonstrate the potential benefits of care coordination interventions in both the treatment phase[15] as well as palliative phase of illness[16], the best timing and length for care coordination interventions is not well defined. Few studies have reported on coordination activities in post-treatment or follow up stages of the patient's journey.

A host of questions arise when considering issues regarding delivery and timing of coordination interventions. For example: Do all patients require services provided by a care coordinator? What is an appropriate casemix and caseload for care coordinators? Should the cancer nurse coordinator work within one institution, a primary care setting, or work between several organisations? It is likely that the multitude of pathways that a person with cancer may follow, combined with the unique features of Australia's geography and population distribution, will mean that there is no one answer to these questions. Nevertheless, ensuring equity of access and appropriate use of resources will remain critical policy considerations.

### Who can best fulfil the role of cancer care coordinator?

The majority of evidence relating to the coordination of cancer care has involved the use of nurses as case managers or in structured support roles, such as that of the specialist breast nurse. The Clinical Practice Guidelines for Psychosocial Care for people with cancer identified that specialist oncology nurses, in both inpatient and outpatient settings, playa major role in ensuring continuity of care by coordinating the patient's path through treatment, liaising with different members of the team; and monitoring the person with cancer[1]. The guidelines also suggest that GPs can be useful in ensuring continuity of care as they have knowledge of patient's social and medical background, especially in relation to follow up and management of co-morbid conditions. There are, however, few studies in the cancer context to assess the interest, abilities or capacity of GPs to perform these roles. Other health professionals, such as social workers may also play an important role in care coordination[22].

It is possible that different disciplines will have different coordination roles at different times of the patient journey and moreover, that all health professionals have some role in ensuring continuity of care. Indeed, the Psychosocial Clinical Practice

Guidelines recommends that the patient should be given a choice as to whom they wish to be the coordinator of their care. At the very least, the key question that should drive decisions about who is best placed to act as a care coordinator is: What are the support and coordination needs of patients in, this context?

### How does the care coordinator's practice interface with that of other health professionals ?

Perhaps the most challenging feature of care coordination interventions is the interface between the functions of an appointed care coordinator and those of other members of the health team. A review of the type of activities that are suggested to be within the scope of practice for care coordinators highlights the potential for role overlap, role conflict, and duplicated and fragmented efforts. Despite these concerns, the NBCC Specialist Breast Nurse Project found that while some practitioners initially expressed concern that the specialist breast nurse role may corrode other professional's role, or provide confusing or conflicting information, such concerns were unfounded and where role overlap did occur, this was resolved or used to advantage[13]. For care coordination roles to be effective and efficient, high quality communication and considerable flexibility will need to be practised as various members of the health team negotiate blurred and changing practice boundaries. The relationships between care coordinators and other specialist cancer nurses will require especially careful negotiation in day-to-day practice.

## Conclusions

The high priority currently being given to developing a more coordinated care system represents an important shift towards a person-centred approach to cancer care. The strategies required for achieving such improvements are multifaceted and are likely to involve developments in multidisciplinary care, improved communication systems and, as this review suggests, the identification of personnel whose core business it is to facilitate as smooth a journey as possible for patients. The available evidence suggests that the appointment of care coordinators has the potential for improving the patient's cancer experience. Importantly, however, the success of care coordination roles will depend on further development of appropriate systems of support and interdisciplinary approaches to care. The development of evidence-based frameworks that clarify scope of practice, competency standards and related training requirements for care coordinators also remains a priority .

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