

## Cancer care coordinators: what are they and what will they cost?

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### Abstract

Health care resources are scarce, and future funding increases are less likely than in the past; reorientation of health services to more efficient and effective delivery is as timely as ever. In this light, we consider the recent funding decision by the Government to provide \$16 million over the next 4 years for cancer coordination nurses. While the intricacies of the role are still being defined, it is likely that cancer care coordinators could benefit patients in terms of access to and timeliness of care, and patient satisfaction.

Our research into the role shows that many coordinating activities for cancer patients are already being done, but often in an ad hoc manner by a number of different personnel. Thus, we estimate that the likely 'true' incremental cost of cancer care coordinators is in fact relatively low when considered in opportunity cost terms because the cancer care coordinator will be able to free up time for other staff enabling them to provide care elsewhere in the health system and reduce tasks being unnecessarily repeated. The funding of cancer care coordinators is a great opportunity to improve the timeliness of care and improve the experience of patients through their cancer journey, but the success of these roles depends on the leadership provided, peer support, continual appraisal and the resources available.

Following the Budget 2012 funding announcements, it was planned that 40 cancer care coordination nurses would be working throughout New Zealand by the end of 2012.<sup>1</sup> \$16 million over 4 years is being invested to provide at least one full time cancer coordination nurse for each District Health Board (DHB).

These nurses act as a single point of contact for patients and coordinate care, providing continuity and support for these individuals from diagnosis through the course of their cancer care. While this additional funding is welcomed, there remain some unanswered questions that need to be addressed in order for cancer services in New Zealand to take full advantage of the newly available funding and optimise outcomes.

What outcomes can we expect? Personalised coordinated care programmes for cancer patients can improve timeliness of care,<sup>2-4</sup> and patient satisfaction with the level of care and support.<sup>4-6</sup> They can also reduce inequity in access to care (in particular allied health and specialist care), for instance, by reducing barriers relating to cultural, language, educational, socioeconomic and/or geographical factors<sup>7,8</sup> and therefore improve quality of the delivery of nursing care and patient education.<sup>4</sup>

Such programmes are of benefit to patients in terms of these outcomes, and probably also translate into improved survival through increased coverage of effective treatments and quicker time to treatment.

We have developed an economic model to evaluate the cost effectiveness of cancer care coordinators (CCCs) in New Zealand as part of a large cost-effectiveness programme; the Burden of Disease, Epidemiology, Equity and Cost-Effectiveness (BODE<sup>3</sup>) programme (refer to <http://www.otago.ac.nz/wellington/research/bode3/index.html> for more information).

Defining the role is a challenging task particularly at a national level where heterogeneity exists between each DHB and “no one size fits all”. Indeed, confusion over the scope and definition of the CCC role was cited as a factor in the long time that it took for the role to be fully embraced within a New South Wales-wide CCC programme.<sup>4</sup>

We currently have no measure of the value of the increased investment (or rather reinvestment of funds from elsewhere in the health budget) in CCCs in New Zealand. The value of CCCs must be balanced against the costs (or opportunities foregone) for other parts of the health sector to enable the new funding. For instance, increased prescription charges were simultaneously announced in the Budget 2012, with the aim of saving \$20 million in the first year and \$40 million in subsequent years to use elsewhere in the health sector.<sup>9</sup>

Later in this article we estimate what a CCC programme might cost – both directly and in terms of opportunities to fund other parts of the health system. The additional funding provides a great opportunity to further streamline and optimise cancer care services, but the best “bang for the buck” will be achieved only if integration of these roles into the cancer system is carefully managed to optimise benefits from time freed up elsewhere in the system.

## **What is the State of Coordination of Current Cancer Services?**

Coordination of cancer services at a systems level in New Zealand has seen big advances with the establishment of Regional Cancer Networks. However, cancer care coordination at the patient level is often fragmented, with individual patients coming into contact with a number of different health care professionals throughout their cancer journey.

Various forms of CCC are already happening around the country and are being carried out by a range of personnel such as oncology nurses, surgical nurses, patient flow coordinators, discharge liaison nurses, and community cancer nurses. In those cancer centres where there are not specified CCC roles, coordination of care at an individual level is still being largely provided in an *ad hoc* manner in a number of cancer centres, with the potential for patients to “slip through the cracks” and not receive the most timely or optimal treatment and follow-up.

One of the most common complaints of those working in cancer centres is that they do not have dedicated personnel with knowledge of the systems and timeframes relating to the pathway of care for each individual cancer patient and that there is simply not time to coordinate individual treatment plans for all cancer patients. There is often no single point of contact for the person receiving treatment or for health professionals providing their care to verify information or obtain more information regarding impending tests and/or further treatment.

If not adequately supported, activities such as ensuring that all appointments are appropriately timed and attended, along with ensuring that the patient is coping and any identified barriers to access have been addressed, can be deprioritised.

In 2010 the New Zealand Ministry of Health acknowledged care coordination as a top national priority of supportive care for adults with cancer.<sup>10</sup> They defined care coordination as “a comprehensive approach that seeks to achieve continuity of care and support, drawing on a variety of strategies that strive for the delivery of responsive, timely and seamless care across a person’s cancer service pathway”.<sup>10</sup>

## **A patient-level cancer care coordinator model for New Zealand**

The Regional Cancer Networks, Ministry of Health and others have been working together to define the CCC role at a national level with variations for each DHB.

Defining the role of a care coordinator is no easy task. Even terminology is inconsistent: terms include: “Patient Navigators”, “Clinical Coordinators”, “Coordination officers”, “Cancer Support Nurses”, “Key Workers”, “Liaison Officers”, “Case Managers”, “and Case Management Nurses”.

With this level of ambiguity, how can we even be sure that we are all talking about the same thing? Certainly, the literature describes numerous programmes that are so diverse that they would be expected to have different costs and outcomes.<sup>8, 11</sup>

Evaluation of CCC programmes internationally has focused largely on community-based programmes, in particular screening programmes.

The specific role of a CCC depends on the setting of the programme (e.g. community based or secondary care), its time-point in the patient care pathway (e.g. a screening programme or a programme in the survivorship phase of care) and the type of cancer. It will also depend on the care coordinator’s experience and training.

Given the lack of a clear delineation of the CCC role, we undertook research as part of a health economics analysis to establish the potential specific tasks and responsibilities of a CCC. We focussed on care coordination in the hospital setting, involving a person with colon cancer requiring surgery followed by chemotherapy as an example.

We were unable to find any studies that described a hospital-based nurse led coordination programme for colon cancer patients from our literature review. Thus, we consulted with surgeons, oncologists and a range of nurses working in different cancer-related roles in the lower North Island of New Zealand.

One of the authors (MS) was able to provide first-hand experience as a clinical nurse specialist (CNS) currently working in a CCC type role in colorectal cancer. This consultation process provided invaluable insight into the care pathway for colon cancer patients, the variety of roles that are involved in patients’ care and the different aspects of care they provide.

We defined the CCC role as working with individual patients and their family/whānau to provide psychosocial support and information support, navigate them through the health system and connect them with necessary health services (such as specialised clinical care, psychosocial referrals and allied healthcare). The CCC would act as a single point of contact for patients and health care staff, and coordinate and track

referrals, investigations and appointments in order to act on delays in diagnosis and treatment.

We concluded that the CCC would need to be an experienced nurse such as a CNS in order to provide expert care with a high level of knowledge about the cancer type, clinical challenges, what regular assessments are needed and to be able to identify when to obtain input from other healthcare staff as well as prioritise patients' clinical needs. The hospital setting of our specified CCC intervention and the point in the care pathway (following provisional diagnosis) also deemed it appropriate for the role to be carried out by a CNS rather than a general registered nurse.

Our research into defining the role of a CCC for colon cancer highlighted the current lack of uniformity of responsibility for coordinating different parts of the care pathway in different cancer centres in New Zealand. We thus designed an event pathway for the individual tasks of a CCC for colon cancer patients (stage III) from the point of provisional diagnosis through to initiating chemotherapy (Figure 1).

We didn't include care during chemotherapy as this is already coordinated by community cancer nurses in some DHBs. While CCCs may prove to play an important role during follow-up after the initial cancer event, we did not model this component of the CCC role because of the complexity of trying to calculate potential changes in patient morbidity and mortality with CCC led follow-up.

The role we have defined addresses each of the three national priority areas of supportive care: care coordination, psychosocial support and information support.<sup>12</sup>

It should also be noted that although we are modelling a CCC intervention from provisional diagnosis (after colonoscopy) to initiation of chemotherapy there are a range of other CCC models existing internationally that have been implemented at different points in the care pathway such as at the screening stage and supportive care stage. Each model of care has differing end points (i.e. uptake of screening, stage at diagnosis) and would require separate analyses of their cost-effectiveness.

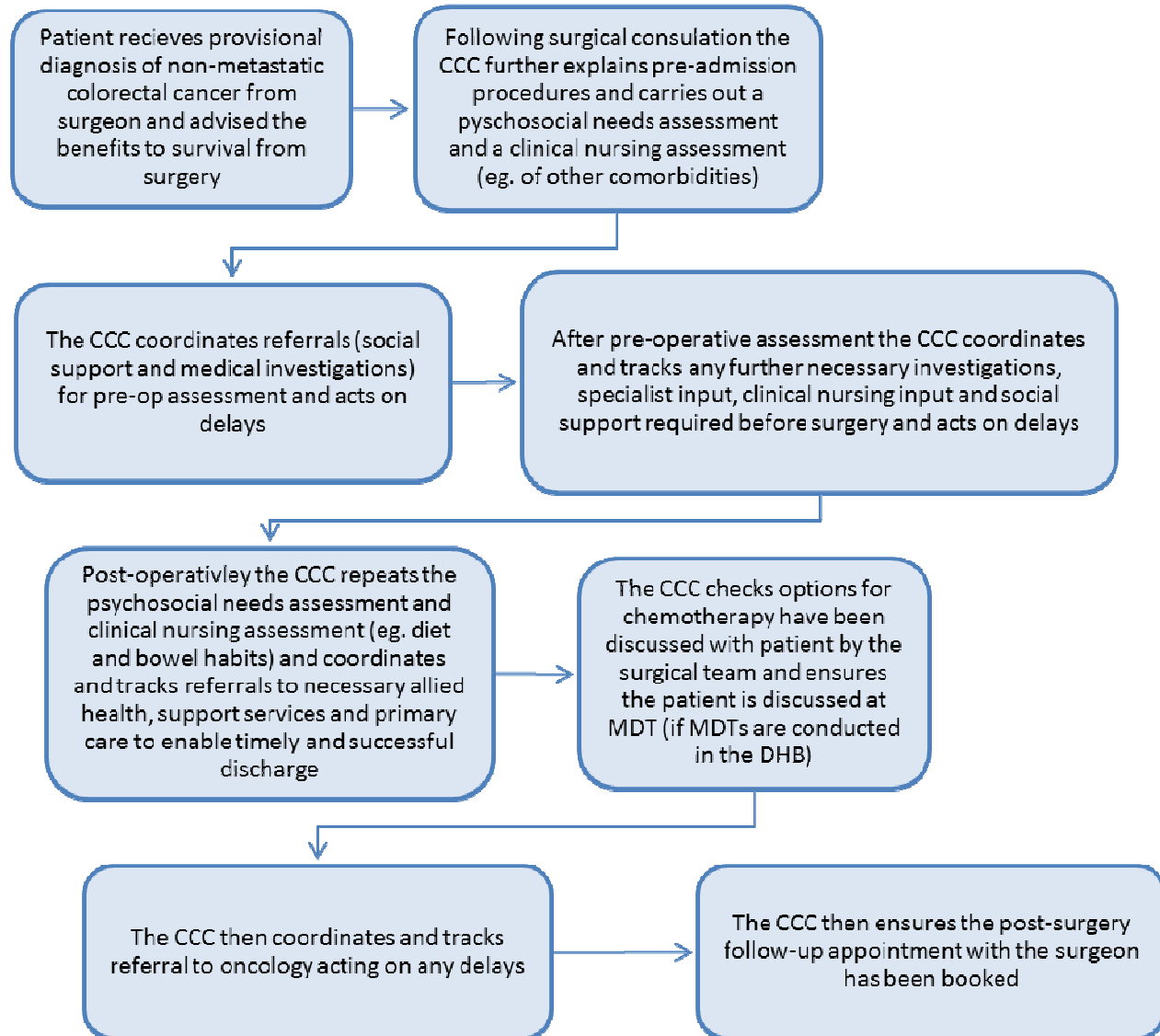
The endpoints for effectiveness of CCC we used in our model were: improved timeliness of care between diagnosis and treatment, improved coverage of chemotherapy, and how each of these impact on survival and a reduction in patient anxiety. Based on evidence in the literature and analysis of a New Zealand colon cancer dataset, we modelled that a CCC programme for stage III colon cancer would lead to a proportionate reduction of 20% in the time in days both between provisional diagnosis and surgery and between surgery and the start of chemotherapy (following confirmed diagnosis) and an increase in chemotherapy coverage post-surgery by 33% of those eligible.

It was out of our current scope to model CCCs for other cancers but it is likely that coordination needs will differ by cancer type due to variation in treatment pathways. Nevertheless, we expect that CCC roles will more likely be determined by generic factors such as stage at presentation, the rapidity of disease progression, and the age of presenting patients.

In order to compare the CCC programme with the status quo we carried out a baseline assessment of present service provision for stage III colon cancer by surveying 16 healthcare professionals in a cancer centre where no specific CCC role exists. The

methods we used explicitly account for the fact that currently these tasks are being undertaken by a range of different personnel at different hospitals (and within hospitals). The baseline averages across the various nurses and doctors currently carrying out coordination activities, while the intervention is modelled as all such tasks being carried out by a CNS.

**Figure 1. Cancer care coordinator (CCC) intervention pathway for colon cancer (Stage III) from provisional diagnosis to initiation of chemotherapy**



### What does a Cancer Care Coordinator Programme cost?

There is little known about the expected costs of a CCC programme for New Zealand other than the direct costs of the nurses' salaries.

The New South Wales Cancer Institute provides useful cost information from five years' experience with a programme employing 50 full-time equivalent CCCs.<sup>4</sup> The programme costs Aus\$4.5 million annually, or Aus\$90,000 per care coordinator (presumably including overheads).

Evaluation of the NSW programme showed that each coordinator saw 23 new patients per month (276 per year), and had 10 patient contacts per day and 2300 per year.<sup>4</sup> This equates to 8.3 contacts per patient in a year. Using a "back of the envelope" approach we can approximate the cost per patient. Based on 10 patient contacts per day, we can estimate that each patient contact is approximately 30 minutes, and each new patient requires a total of about 4 hours of care coordinator time. The cost per new patient (Aus\$90,000/276) would be Aus\$326, or Aus\$78 per hour of care coordinator time.

However, this approach fails to consider the true economic impact of a care coordinator programme. The new funding in New Zealand allows 40 new roles to be created. If these new staff take over some aspects of the patient's care that were previously being carried out by other staff, then the value of the latter's time is effectively released back into the health care system and the net cost of the care coordinator programme is reduced by that amount when considered from an opportunity cost perspective.

In order to estimate costs for New Zealand, we carried out a survey of a variety of health professionals (16 surgical and cancer nurses, house surgeons, registrars and consultants) to estimate the time spent on activities that we identified as part of the CCC role for patients with colon cancer.

The aim was to identify the personnel involved and the amount of time that was already being spent on these "coordinating" activities in hospitals that did not have a CCC programme in place for colon cancer, with Wellington Public Hospital as an example. This was then compared with time spent on these activities in a hospital with specified roles similar to those outlined in our CCC event pathway (Palmerston North Hospital as an example). The cost per minute of activity was then calculated based on an average salary for the type of health care professional who performed each activity; for reasons outlined above we assumed that the CCC would be a CNS (see Table 1 for further detail on cost methods).<sup>13-15</sup>

It is important to note that our economic analysis is an incremental analysis versus the current status quo. Thus, even if the status quo improves (e.g. with the introduction of the Faster Cancer Treatment initiative) CCCs may still be expected to provide some (albeit probably less) additional gain above this.

For the period between provisional diagnosis of colon cancer and initiation of chemotherapy, we found that where a CCC-type programme was in place in NZ, CCCs spent on average about 5 hours per patient carrying out coordinating activities. This is similar to the NSW estimate. However, in hospitals we surveyed that did not have specified CCC roles, about 4 hours of such activity was already being provided in an ad hoc manner by various personnel. Thus, the incremental cost of CCCs relates only to that additional hour of activity.

Furthermore, if the CCC takes over an activity from a more highly paid type of personnel such as a consultant, this can have cost savings (if the time spent on the

activity is not much more). Consequently, the incremental cost of salaries (plus overheads) when a CCC programme was in place in our analysis was only about \$70 per patient more than the current standard of care during the stages between provisional diagnosis and initiation of chemotherapy.

Importantly, our results suggest that if a CCC programme is funded, four hours of care per patient will be freed up in other parts of the cancer service. For the funding of CCCs to achieve value for money, this freed up time must be used effectively by other health care professionals either by allowing them to spend more time with patients where necessary for certain tasks or being able to see more patients in the time available.

**Table 1. Overview of methods for estimating costs of cancer care coordinating (CCC) activities in local hospitals**

<b>Cost components</b>	(i) Salaries plus 50% overheads (to account for space and utilities) (ii) Costs for increased allied health referrals <ul style="list-style-type: none"> <li>• Psychosocial referral rate based on NSW estimates<sup>4</sup> (83% with CCC vs 42% with standard care); 6 contacts per referral (key informant)</li> <li>• Dietician referral for 50% of colon cancer patients; 2 contacts per referral (key informants)</li> </ul>
<b>Cost sources</b>	(i) DHBNZ Collective Agreements (MECA) for salary and conditions (ii) Ministry of Health/DHBNZ national price for the outpatient purchase unit for a social worker (NZ\$164) or dietician (NZ\$116) contact
<b>Cost principles</b>	Opportunity cost approach; for those not in care coordinator roles, each hour spent on patient-related coordinating activity is assumed to be equivalent to the loss of an hour spent on activities relating to the care of patients in another capacity. Salary is applied only over the periods of the individual's work time that was potentially patient-related activity time: estimated to be 62.5% of each day (i.e. 5 hours of an 8 hour day), and excluding public holidays, annual leave and sick leave.
<b>Outcomes</b>	Incremental cost for cancer care coordinator: total cost of cancer care coordinator time plus cost of increase in allied health referrals <i>minus</i> cost of time currently spent on care coordinating activities performed by other personnel in the absence of a specified care coordinator

DHBNZ = District Health Boards New Zealand.

Our results indicate that house surgeons would have 30 more minutes available per patient with colon cancer, registrars 20 minutes, and consultants 10 minutes if they were not doing coordinating activities that could instead be done by a CCC but were still doing those activities that require input from a doctor. This time could be transferred to the care of other patients to reduce waiting times or other activities to improve the timeliness and quality of cancer services.

Other costs may arise from more patients receiving chemotherapy following surgery with the presence of a CCC as shown by a study in breast cancer,<sup>16</sup> however the improvements in survival would potentially also be substantial.

In addition CCCs are likely to increase the rate of referral of patients to allied health care providers by both being aware of the services available and being in a good position to identify patients' needs and put them in contact with appropriate services. Depending on the cancer, CCCs may also increase appropriate referrals for patients to

other health professionals more often; for instance, dieticians for colon cancer patients.

We estimated that the cost of these increased referrals, averaged across all patients, adds around \$500 per patient compared with current ad hoc care (see Table 1 for methods). This is likely to benefit the patient, but evaluation is needed to ensure that the benefits justify the additional costs.

Lastly, initiation of these new roles will require guidance and governance and training, which will generate costs. CCCs may also require time accounted for outside of patient contact time to develop solutions to systems issues.

On the other hand, there may be other cost-saving effects of CCC programmes, such as reduced length of hospital stay,<sup>17, 18</sup> reductions in the number of failed discharges and avoidable non-acute hospital admissions and presentations to the emergency department.<sup>19</sup> Monitoring these outcomes will be key in determining the value of the CCC programmes for New Zealand.

Indeed, a UK analysis found that one-to-one support in cancer care could be potentially cost saving overall for a number of cancers, but this was less likely for metastatic cancer.<sup>20</sup>

## **The Value of a Cancer Care Coordinator Programme**

Internationally, evidence of effectiveness of CCC-type interventions is starting to emerge with regards to uptake of cancer screening, earlier stage at diagnosis, timeliness of care, hospital utilisation and patient satisfaction.<sup>3, 5, 6, 21-27</sup>

A randomised controlled trial (RCT) in the US showed a culturally tailored navigator programme increased screening rates for colorectal cancer from 12% to 27% ( $p < 0.001$ ) in a low-income, ethnically diverse population.<sup>21</sup> Another US based RCT in low-income ethnic minority women showed improved adherence to follow-up diagnostic investigations following abnormal screening (odds ratio 4.48, 95% confidence intervals 2.08-9.64).<sup>28</sup>

Improving timeliness of care has been demonstrated by CCC-type interventions in disadvantaged populations with one study showing a reduction in 18 days from abnormal screening to diagnostic investigations<sup>5</sup> and another study showing a reduction in 22 days from cancer diagnosis to treatment initiation.<sup>3</sup>

Patient navigation in the community to improve uptake to screening and adherence with diagnostic procedures has shown a reduction in later stages being diagnosed (9.4% vs 16.8% stage IV,  $p < 0.05$ ) and an increase in earlier stages being diagnosed (25.8% vs 12.4% stage 0,  $p < 0.005$ ) in a medically underserved population.<sup>23</sup>

An increase in patient satisfaction and a reduction in patient anxiety have also been demonstrated by CCC-type interventions. An RCT in the US for patients with abnormal mammograms showed patient navigation to reduce mean anxiety scores and improve patient satisfaction.<sup>5</sup> Another study showed oncology nurses playing an important role in supportive care improving patients' satisfaction with the hospital, the doctors and team looking after them.<sup>6</sup>



Our opinion is that introducing CCC nurses will largely improve the way that care is delivered (by one person taking responsibility for coordination activities), rather than requiring a substantial increase in the amount of time and resources for patient care.

These roles will improve efficiency by shifting coordination responsibilities from ad hoc delivery by different members of the health care team (often duplicated and often not in a timely manner) to a nominated individual. This single point of contact will not only improve efficiency via better communication between services and healthcare staff but will also provide patients better continuity of care with an accessible and familiar port of call.

Such programmes may not be as costly upfront as anticipated when the economic value of the time of other personnel that will be freed up is also considered (i.e. enabling healthcare staff to care for more patients within the same timeframe). However, one of the greatest challenges may be how to turn these “economic savings” into real savings for DHB budgets.

We must ensure that when these resources are liberated they are then put to the next most efficient use within the cancer services rather than simply being reabsorbed. Beyond staff time, it must be noted that a successful CCC programme will increase coverage of effective interventions (e.g. chemotherapy) that – whilst being cost effective and beneficial for the patient in their own right – incur increased costs to the health system.

Structures need to be put in place to ensure that new funding for CCCs produces positive outcomes across the cancer service. An important part of this will be ensuring that systems are in place to evaluate the outcomes of the CCC programmes.

Guadagnolo et al<sup>29</sup> suggest metrics for evaluating the impact of CCC-type interventions on health outcomes and quality of care depending on where in the care pathway the intervention is in place. These include: timeliness of care metrics e.g. time in days between key time points such as diagnosis date and treatment date or the proportion of patients with diagnostic resolution at different time points; continuity of care metrics by measuring loss of patients to follow-up clinics; measures of whether treatment meets recommended guidelines; whether treatment was completed; the number of days of missed treatment; the frequency of unplanned admissions; care coordination metrics e.g. whether ancillary services were recommended or received; and clinical outcomes e.g. survival and recurrence data. They suggest the benchmark be the institution-specific baseline and progress measured against quality targets defined by guidelines i.e. regional and/or national clinical guidelines.

The funding for CCCs has occurred in an environment where other changes to improve the cancer journey and outcomes for patients are being simultaneously addressed, for instance strategies to reduce cancer wait times. As cancer services become more efficient, the incremental value of the CCC as defined here is likely to change. However, there are potentially other roles that CCCs can take on to further improve outcomes for patients once waiting times have been addressed. For example, CCCs could coordinate follow-up investigations post-treatment and run follow-up clinics, contribute to reducing ‘did not attend’ rates and improving timeliness of clinic appointments (ensuring investigation results are available) as well as contribute to post-operative nursing care to reduce length of stay post-operatively.

Our hope is that the new funding for CCCs will result in improvements in patient outcomes and, if appropriately implemented, improve access and reduce inequalities in cancer outcomes between Māori and non-Māori, and by socioeconomic position.<sup>30</sup> This will require a clear definition of the role, good leadership, support and governance, an understanding of the expected outcomes, and a means to measure and evaluate these outcomes.

Evaluation of CCCs must consider disparities in institution-specific baseline service provision regionally and between cancer types as this will influence the incremental benefit of CCCs. Care coordination remains a responsibility of the whole healthcare system; however, CCCs can work to identify and where possible provide solutions to system and process issues whilst aiming to avoid accentuating strain upon the system.

We need to consider the ability of the current system to adapt to potentially increasing numbers of patients being referred to allied health services and/or other treatments such as chemotherapy.

Finally, it is refreshing to see a Government clearly talking about reprioritisation of funding within health services; just as New Zealand has led the world in maximising the bang for our buck with pharmaceuticals, so too we need to enhance rigour in the evaluation and implementation of the most cost-effective configurations of services.

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