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The Cancer Nurse Coordinator Initiative Evaluation

Final report

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Nā tō rourou, nā taku rourou, ka ora ai te iwi.
With your contribution and my contribution, the people will thrive.

Executive summary

Introduction

The Cancer Nurse Coordinator Initiative (CNCI) is part of the Budget 2012 package to improve cancer services in New Zealand. The CNCI provided all District Health Boards (DHBs) with at least one full-time equivalent (FTE) Cancer Nurse Coordinator (CNC) role. The CNCI purpose is to improve patient outcomes by coordinating care for patients with complex cancer pathways or complex health, social or other needs to facilitate timely diagnosis and initiation of treatment. CNCs also contribute to identifying system changes to the cancer care pathway.

Evaluation approach

The overall evaluation purpose was to assess the implementation of the CNCI and its outcomes against four success criteria. Between 2013 and 2015, data collection was undertaken to assess implementation and the four success criteria. Data collected included: administrative data to profile patients; system logs on projects being undertaken; baseline and follow-up surveys with patients and family/whānau, CNCs, and health providers interfacing with the role; six DHB case studies; and a survey of senior DHB management.

Evaluation findings

Over the last three years, the CNCI was implemented as intended and has evolved. Offering DHBs flexibility in the implementation of the CNCI has resulted in three broad approaches to fit with the existing nursing workforce and DHB population needs. The approaches are generalist, tumour stream and population-focused. In 2015, there were 71 nurses involved in the CNCI across 20 DHBs. While the CNCI had coverage across all DHBs, CNCs were not located in all tumour streams.

In 2013 (the early establishment phase), there were differing expectations about the CNC roles and how they would work with existing cancer nurse roles. By 2015, CNCs and providers had greater clarity and confidence about the role and its contribution to improving patients' experience and cancer care pathways. Key successes for the CNCI, as noted by CNCs, providers and senior DHB managers, are the CNCs' contribution to improving patient care coordination, improving patient and family experience, and identifying system improvements. An ongoing implementation challenge for the CNCI is the CNCs' ability to deliver all aspects of an advanced and complex nursing and system-focused role.

The CNCI is targeting patients with complex needs. Enrolment of Māori and Pacific patients varies across DHBs and is lower than expected.

In 2015, patients' and whānau feedback on the CNC role was overwhelmingly positive. Patients described their CNC as their 'go-to-person'. Patients appreciated having access to

the clinical nursing expertise of the CNCs. Patients and their family valued having easy access to an expert who understands what they are going through, is able to explain clinical information in lay terms, knowledgeable about the next steps in their care and can navigate the system to ensure the steps occur, and is aware of and can help them access other support services.

Providers acknowledge that the CNCI has contributed to patients having improved coordination of care through increased timeliness of referrals, diagnosis and access to treatment, and other services. Providers comment CNC patients have an increased understanding of their cancer and treatment. While understanding of the role has improved amongst providers, more work is needed to ensure all primary and secondary care providers understand the role. A few providers commented that the introduction of the CNCI has not made a difference or has duplicated existing clinical nurse specialist (CNS) roles.

CNCs are actively identifying system improvement areas and working with other health providers to address them. Common projects relate to patient pathways, supporting multi-disciplinary meetings (MDMs), data collection and developing tools. CNCs indicate these projects are achieving positive outcomes including the creation or implementation of a tool or protocol, and systems are becoming more standardised and streamlined. Some projects are perceived by CNCs to have contributed to improving timeliness along parts of the cancer pathway for specific patients. Barriers impeding the CNCs in their system improvement role include lack of mandate, high CNC workload and lack of IT infrastructure or support.

Conclusions

Overall, the CNCI has met three of the four success criteria, namely:

- improved access and timeliness of access to diagnostic and treatment services for patients
- improved patient experience through diagnosis and initiation of treatment
- identified potential areas for improvement in care coordination and the patient pathway.

One of the success criteria for the CNCI is to target those patients with the greatest need (i.e. patients with complex needs, and Māori and Pacific patients and their family/whānau). The CNCI partially achieved the success criteria of targeting those with complex needs. Patients with a range of cancers and triaged as 1 and 2 (most complex needs) are accessing the CNCI. Māori and Pacific people are accessing CNCI but not at expected levels. Given the existing inequities in cancer outcomes for Māori and Pacific people, identifying and removing the barriers to ensure Māori and Pacific patients are accessing care coordination from the CNC is a critical improvement area for the CNCI.

Areas of focus

Targeting those with complex needs

- Consider how to remove access barriers to the CNCI for Māori and Pacific patients, and increase their enrolment in the CNCI.
- Investigate the benefits of population-based CNC roles as they become more established.
- Increase awareness of primary care of the CNCI and their referrals to CNCs.

Improving service access and timeliness

- Ensure the role and its benefits are well understood by providers to integrate and increase the influence of the CNCI to facilitate patient pathways.
- Continue to facilitate patients to be linked to other services, especially financial and emotional support services.

Enhancing patient experience

- Need to ensure patients have a clear understanding of the role especially if they are assessed as not requiring the support of the CNC (at that point in time).
- Increasing cultural competency of CNCs to ensure access for Māori and Pacific patients and for them to feel their culture, values and beliefs are respected and valued.

Improving patient pathway

- Consider further review of the system projects to assess whether they are having sustained and positive impact on improving the patient experience and pathways.
- Seek to address the ongoing barriers that impede the CNC system improvement role including lack of mandate, high CNC workload and lack of IT infrastructure or support.
- Consider whether further training is required by CNCs on initiating and undertaking service improvement projects.

Introduction



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Introduction

Rationale for the CNCI in NZ

Being diagnosed with a high suspicion of cancer or cancer is extremely traumatic for people and their family/whānau. It is a time when people may be physically unwell and tired, and they and their family/whānau are emotionally fragile and stressed. During the process of diagnosis and treatment, patients and their family/whānau can see a large number of health professionals, and have multiple hospital appointments over several months, sometimes in more than one District Health Board (DHB). The process can be overwhelming and confusing. Across New Zealand, patient experiences can vary with regard to the quality, timeliness and access to cancer care pathways (Ministry of Health 2010, Hill et al 2012).

In Budget 2012, the Government announced a funding package of \$33 million to improve cancer services in New Zealand. Key initiatives include: implementing the faster cancer treatment (FCT) indicators and new FCT target; developing and implementing national tumour specific standards; implementing the cancer service improvement fund; and improving coverage and functionality of multidisciplinary meetings (MDMs). Cancer Nurse Coordinator Initiative (CNCI) is a key part of this package. The CNCI received an investment of \$16 million over four years to provide all DHBs with at least one full-time equivalent (FTE) Cancer Nurse Coordinator (CNC) role.

The CNCI purpose is to improve patient outcomes by coordinating care for patients with complex cancer pathways or complex health, social or other needs to facilitate timely diagnosis and initiation of treatment. CNCs within each DHB also contribute to identifying changes to the cancer care pathway to improve timely diagnosis and initiation of treatment, and the patient experience.

International evidence

In 2012, the introduction of CNC roles in New Zealand followed international trends in countries such as Canada, the United Kingdom, and Australia. Internationally, terminology for the roles varies for example 'patient navigators' in Canada, and 'cancer care coordinators' in Australia and the United Kingdom. The scope of roles and specific responsibilities can also differ. However, all have the same overall goal to improve the patient experience and service coordination across the cancer pathway.

In 2011, a literature review found that cancer coordination roles contribute to improved clinical outcomes for patients, such as improved levels of treatment completion and a reduction in interruptions to treatment (Northern Cancer Network 2011). The international evidence at this time also demonstrated that cancer coordination contributes to the improvement of the quality and capacity of cancer services (Cancer Institute NSW 2011), improved patient experience, and improved communications across health professionals on the cancer team (Yates 2004).

Intended approach

In October 2012, the Ministry rolled-out funding to DHBs for 40 CNCs. DHBs were to fund new clinical positions, focus on the front end of the pathway (ie. diagnosis and early treatment), support streamlining and referral between DHBs, and collaborate regionally when developing and implementing the roles.

A National Nurse Lead was appointed to provide nursing leadership, work with DHBs, develop tools/guidelines to support CNCs, and develop a national CNC network.

The CNCI is intended to focus on ensuring that patients and family/whānau with the greatest complexity of need have access to a CNC. 'Complex needs' can have multiple interpretations: a complex process for cancer type and treatment, the complexity of a patient's co-morbidities, and the complexity of a patient's psychosocial and economic needs (Northern Cancer Network 2011). Increasing health inequities for eligible Māori and Pacific patients was acknowledged as a risk for the CNCI, particularly if eligible Māori and Pacific patients experience access barriers.

In New Zealand, the CNC role is an advanced nursing role. The CNCI was designed to capitalise on advanced nursing expertise to enhance the patient experience and improve clinical outcomes. The CNCI was not intended to be a solely administrative role. The expectation was that through the implementation of the CNCI, the cancer nursing workforce capacity and capability would increase.

Outcomes sought from CNCI

In 2013, four success criteria for the CNCI were identified drawing on a literature review, and discussions with key stakeholders and the Evaluation Advisory Group. It was agreed that the CNCI would be defined as successful if the CNCI:

- targeted those with greatest need (i.e. patients with complex needs, and Māori and Pacific patients and their family/whānau). It was acknowledged that not all cancer patients will need or want the support of a CNC, and the CNCI does not cover all DHB tumour streams.
- improved access and timeliness of access to diagnostic and treatment services.
- improved patient experience through diagnosis and initiation of treatment. A positive patient experience was defined as ease of access, coordination, good communication, reliability, responsiveness, respect, trust, emotional support, equity, empathy and continuity.
- identified potential areas for improvement in care coordination and the patient pathway working with the multi-disciplinary team and wider DHB processes, where appropriate.

Appendix 1 contains the outcome framework developed for the CNCI in 2013.

Methodology

Litmus was commissioned in 2012 to undertake a four year evaluation of the CNCI.

Evaluation purpose

The overall evaluation purpose was to assess the implementation of the CNCI against two overarching aims:

- Improving the experience for patients, including their family/whānau with cancer or suspected cancer.
- Improving overall access and timeliness of access to diagnostic and treatment services for patients with cancer.

Evaluation questions

The evaluation objectives are to:

- Describe and assess the implementation of the CNCI
- Monitor and measure impact of the CNCI at a systems and patient level
- Assess the effectiveness of the CNCI in reducing inequalities for Māori and Pacific cancer patients
- Explore any unintended consequences of the CNCI (both positive and negative)
- Describe wider systems learnings and possible improvements to the CNCI.

Evaluation Advisory Group

An Evaluation Advisory Group was set up to provide advice and guidance on the evaluation of the CNCI. The group represented a range of expertise from clinical cancer expertise, nursing, DHB management, equity, and evaluation.

Data collection

Evaluation activities 2013 – 2014

In 2013 and early 2014, a three-year CNCI evaluation plan (Litmus 2013) was developed in collaboration with the Evaluation Advisory Group. Reflecting the evaluation plan, data collection tools, including patient, CNC and provider surveys were developed and reviewed

by the National Nurse Lead, CNCs, patients, the Evaluation Advisory Group and an international expert. The surveys were revised based on their feedback.

In May 2014, the surveys and database were distributed to the CNCs to receive some preliminary data to inform the discussion of progress at the CNC National Forum in late June 2014. Reflecting the limited time period for data collection, the following was achieved:

- **Administrative data** were provided by 33 CNCs in 16 DHBs.
- **System activity information** was returned by 13 CNCs from 12 DHBs. Five comprehensive reports on **system reviews** were received from the two system-approach DHBs.
- **CNC online survey** profiled CNCs and their activities, and their contribution and perceived effect on patient experience profiles. 43 CNCs completed the survey. A response rate 68%.
- **Provider online survey** assessed understanding and perceived effects of CNC role. 485 providers across 20 DHBs who had contact with CNCs completed a survey. The survey was distributed by CNCs via email.
- **Patient survey** assessed patient experience of the role and its contribution. 204 patients across 13 DHBs returned a completed questionnaire. Patients and whānau who received a survey were selected by CNCs as there may be clinical or other reasons for patients not to receive it.
- **Three DHB case studies** were completed. The case studies involved interviews with three patients and their families and the CNCs. The case studies focused on the experience of Māori and Pacific patients and their family/whānau. Kaipuke undertook the qualitative research with Māori patients, and Integrity Professionals with Pacific patients.

The 2014 Annual Report details the data collection methods and their limitations and presents the detailed findings (Litmus 2014). The findings were presented to the EAG before finalising the report.

Evaluation activities 2014 – 2015

Between November 2014 and April 2015, the following data and information were collected to assess the CNCI against its success criteria.

- **Administrative data** were provided by 20 DHBs.
- **System logs** were returned by 19 DHBs detailing 211 system improvement projects CNCs had been involved in or initiated over a 12 to 24 month period.
- **CNC online survey.** 48 out of 71 CNCs completed the CNC survey. The response rate is 68%. The maximum margin of error at a 95% confidence limit, factoring for a small population, is 8.1%.

- **Provider online survey.** 876 providers across 20 DHBs completed the survey. Response rate is estimated at around 60%. The maximum margin of error is 3.3% at a 95% confidence limit.
- **Patient survey.** 664 patients with cancer completed a patient experience survey across 20 DHBs. The maximum margin of error is 3.8% at a 95% confidence limit. 68 patients with a high suspicion of cancer completed a patient experience survey across 11 DHBs. The maximum margin of error is 11.9% at a 95% confidence limit. Response rate for the total patient response is estimated at around 41%.
- **Three DHB case studies** were completed for tumour stream, generalist, and whole-of-system tumour stream CNCI approaches. The case studies involved interviews with three patients and their families and the CNCs, and focused on the experience of Māori and Pacific patients and their family/whānau.
- **Senior management survey** identified perceptions of the CNCI role and its impact. In total, 38 out of 63 senior managers including Directors of Nursing, Service Managers, Cancer Network Managers and nursing leads completed the survey across 20 DHBs and the Regional Cancer Networks. The response rate is 60%.

In 2015, data quality to inform the CNCI evaluation improved. The 2015 Annual Report details the data collection methods and their limitations, and presents the detailed findings (Litmus 2015). The draft findings were presented to the EAG before finalising the report.

Evaluation limitations

The evaluation directly addresses two of the evaluation success criteria, namely improving patient experience and identifying system improvements. The evaluation does not directly measure whether engagement with the CNCI has achieved equity of access or increased timeliness of access. The evaluation does offer insight into who is accessing the CNCI but it is not known who may be missing out. Further, the evaluation assesses perceptions of whether the CNCI facilitates the patients' journey and patient understanding of the next steps in their treatment and care and the likely time involved (proxy measures for improved timeliness).

Ensuring equity of access and improving timeliness of access are central to the CNCI. Evaluation design work was undertaken in early 2015 to explore the feasibility of using more direct measures of equity and timeliness using FCT data or the Cancer Registry data. The design work concluded that using these data sets would not address equity or timeliness questions as it is not possible to isolate the CNCI patient population or a comparative group of patients within these datasets.

Findings



CNCI implementation

Overview

As was intended, the CNCI evolved during its implementation. By 2015, the CNC roles can be organised into three broad models of care:

Generalist model was adopted by 10 DHBs, where CNCs focus on care coordination for all cancer patients in the region. CNCs using a generalist approach tend to be in individual roles based in smaller DHBs. These CNCs have a strong focus on the front of the cancer care pathway. They work with patients considered most at-risk of experiencing problems with care coordination and provide a high level overview of other patients, ready to step in if they need additional support. They are closely linked to FCT work programmes and systems improvement.

Tumour stream model was adopted by 10 DHBs, where specialist nurses are responsible for the care of patients in a particular tumour stream. There are two sub-categories:

- **Front of pathway** - the CNC supports patients with high suspicion of cancer at the front of the pathway, and facilitates their transition to an established CNS or another identified health professional. These CNCs also identify system improvements associated with the front of the pathway. Four DHBs focus on front of pathway.
- **Tumour stream coverage** - the CNC is placed in a tumour stream, where there is no existing Clinical Nurse Specialist (CNS) coverage. In this model, the CNC facilitates care and treatment in a specific part of the patient journey (much like a CNS). The CNC is also responsible for prioritising care coordination activities across the cancer care pathway, particularly from a system perspective and supports the implementation of this across the whole CNS team.

Population-focused CNCs were established by two DHBs within their wider CNC approach. Population-focused CNCs are tasked with reducing barriers to care through working with a specific population such as Māori, Pacific people or Asian. These CNCs are a key point of contact at the front end of the pathway, and seek to improve equity of access.

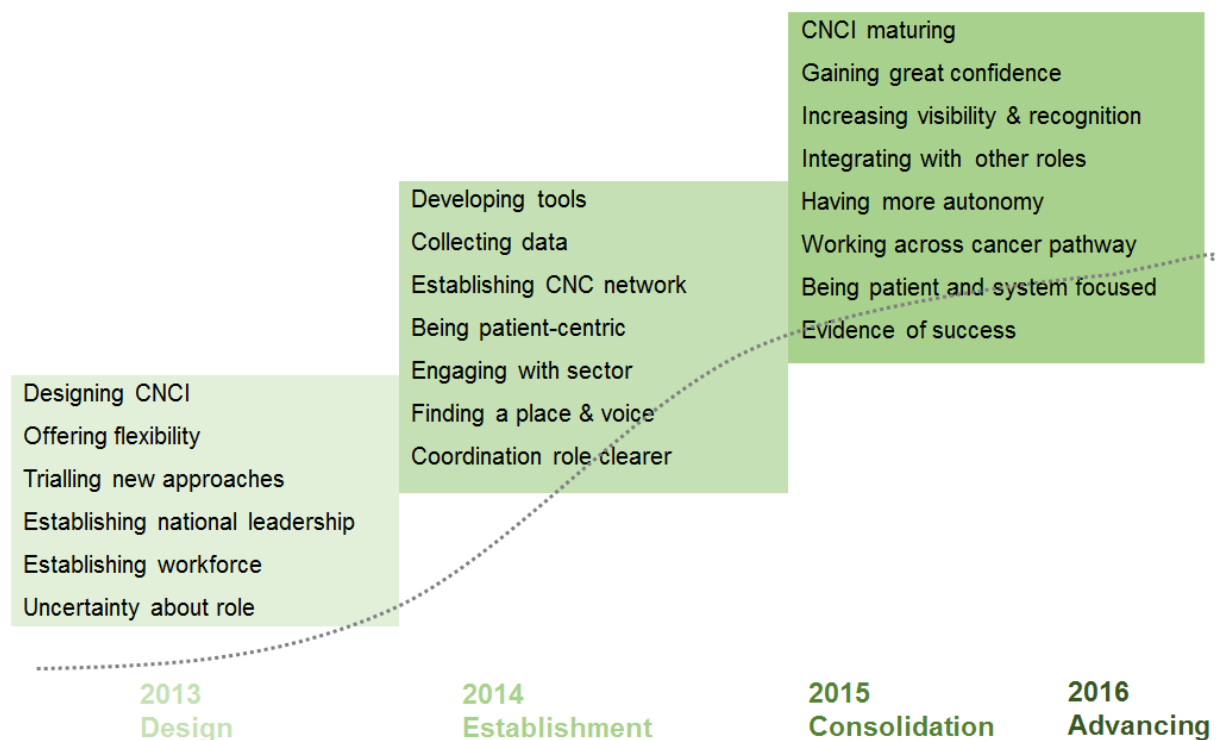
Across the 20 DHBs, the Ministry funds 40 FTE CNC positions. Counties Manukau, Waitematā, and Auckland DHBs have adopted a **whole-of-systems tumour stream approach** so the CNCI includes other nurses working on the cancer care pathway. These DHBs tend to have a lead CNC to inform other nurses' practice on meeting the CNCI requirements. The lead CNC participates in regional and national CNCI activities. In total, there are 71 nurses involved in the CNCI across 20 DHBs. While the CNCI has coverage across all DHBs, CNCs are not located in all tumour streams.

CNCs are highly experienced nurses, and acknowledged as such by their peers. In 2015, most CNCs had over 11 years' experience and 65% had more than 20 years. Eight in ten (83%) had a post-graduate qualification. The majority were in permanent roles (98%) and 71% were on

0.7–1 FTE. CNCs expertise was acknowledged by providers with three quarters (77%) agreeing CNCs offer cancer expertise and leadership (Litmus 2015).

The implementation of the CNCI has evolved through three key stages: design, establishment and consolidation (Figure 1). These phases are discussed below together with their challenges and lessons.

Figure 1: The evolution of the CNCI



Design and early implementation phase

With the introduction of the CNCI, DHBs wanted flexibility to tailor the CNC role to be responsive to their population needs, existing cancer care pathways and workforce gaps. The Ministry and the National Nurse Lead had a clear vision for the CNCI and its implementation as detailed in the service specifications to DHBs.

The National Nurse Lead had an important role in setting a clear vision and direction for the initiative, and navigating challenges arising. At this time, having a National Nurse Lead role was uncommon for new nursing initiatives. The national role was recommended by Western Australian counterparts, who had implemented a similar initiative. The purpose of National Nurse Lead role is to support the creation of regional and national consistency across the CNC roles, while offering flexibility to meet regional need. The National Nurse Lead is also responsible for building nursing capability to support CNCs to negotiate the complexities of balancing priorities between patient care coordination and collaborating with others on system improvements.

Recruitment for CNC roles progressed slower than expected in 2013 due to experienced nurses being in short supply and the South Island seeking a regional approach in the CNCI across DHBs. Feedback from some senior managers also indicated that the initial role description for CNCs was unclear and contributed to delays in recruitment (Litmus 2015).

For DHBs uncertainty existed about the scope of the CNC role. A particular uncertainty related to whether CNCs would work directly with a cohort of patients to coordinate care, and/or focus on improving the cancer care pathway. Most DHBs sought to balance both aims within the role. In contrast, two DHBs experimented with a systems approach, where the CNCs were solely focused on identifying gaps in service delivery and undertaking service improvement projects around the cancer care pathway. System projects undertaken included pathway mapping against tumour standards, supportive care, concurrent treatment and multi-disciplinary meetings (MDMs) projects.

Adopting a system-focused approach meant the CNCs in the two DHBs had no patient interface. Over time, these CNCs found the non-patient focused roles dissatisfying as they were not fully using their advanced nursing expertise. These CNCs also found they lacked a mandate to lead system change across the DHB. In mid-2014, the two DHBs reconfigured their CNCI approach to be front of pathway and tumour stream respectively.

During the design and early implementation phases, there were differing expectations about the fit of the CNC role with existing nursing and other clinical roles, particularly where DHBs had existing cancer care coordination capacity. In response, the National Nurse Lead sought to ensure CNCs, their managers and wider stakeholders had a clear understanding of the scope of the new role. These challenges were also faced when similar roles were established in Western Australia, in particular the variation in health providers understanding of role (Monterosso et al 2011).

During this phase, the shared responsibilities of care coordination and FCT targets were reiterated to CNCs and health providers. These communications recognised achieving improvements to cancer care pathways and patient experience is the shared responsibility of all health providers and not just the role of the CNCs (Regan et al 2012).

Establishment

By October 2014, 65 CNCs had been appointed across 20 DHBs. During this phase, focus was placed on developing tools and networks to support the CNCs in their role. CNCs were predominantly focused on undertaking patient care coordination, and system improvement work was commencing in some DHBs.

The National Nurse Lead developed the draft triage tool (refer appendix 2). The purpose of the triage tool was to support CNCs to consistently identify patients with complex needs and tailor their care coordination accordingly. Recognising that patient needs changes, CNCs are expected to regularly triage patients to assess their complexity of need and determine the appropriate care coordination response (including discharge and transfer to other health providers).

CNCs were also required to monitor their work to inform their clinical practice, and discussions with their managers and the National Nurse Lead about the progress and challenges in the role. Having appropriate IT capacity and capability to monitor patients' journey facilitated the CNC role. However, in a number of DHBs existing information technology systems did not support the identification of patients being supported by the CNCs or monitoring of their patients' journey. A CNCI database was developed to inform CNC practice and assist the National Nurse Lead to support CNCs. The CNCI database also informed the evaluation by profiling patients accessing CNCI. Although the CNCI database was piloted in four DHBs, CNCs found using the database challenging, and frustrating that it did not linked to their existing systems. The latter resulted in double handling of data entry.

During 2014, the National Nurse Lead and the CNCs continued to focus on increasing the visibility and understanding of the role at DHB, regional and national levels. By October 2014, providers interacting with the CNC reported they had an improved understanding of the role, and effective working relationships with the CNCs. In 2014, CNCs reported feeling more confident in their role and its contribution. However, they acknowledged more work was needed to ensure health providers understood the aims of the role and its boundaries. Some providers and managers continued to feel the CNC role duplicated other specialist cancer nursing roles such as CNS (Litmus 2014).

The implementation challenges faced by CNCs varied across DHBs. In smaller DHBs, the CNC role is usually only one person which can create a sense of isolation. CNCs in smaller DHBs commented on the challenges of fitting into the established cancer team and for their role to be seen as a strategic system-based advanced nursing role and not simply an additional nursing FTE. In contrast, CNCs in larger DHBs noted the benefits of having collegial support through the implementation of this new initiative. The challenge of learning on the job without other CNC support has been noted in the US and contributed towards the development of core competencies for nurse navigators (Oncology Nursing Society 2013).

For CNCs, the role of the National Nurse Lead, regular regional CNC network meetings and the annual national CNC forum were important to embed the principles of the CNCI. The CNC regional network meetings strengthened CNC connections across DHBs. Patients and family/whānau benefited from these stronger links as they facilitated patient transfers across services and DHBs. At the annual CNC forum, CNCs shared their practice, discussed challenges and key learnings. The regional network meetings and the annual CNC forum supported the CNCs to become a connected and cohesive nursing group. CNCs working on their own in smaller DHBs particularly appreciated the opportunity to connect with their colleagues and to share challenges and successes.

In their work CNCs are expected to take an overview of the patient's whole cancer pathway. The CNC overview differs from other roles which can be more treatment focused at a particular point in the pathway. Having an overview across the entire cancer care pathway was a challenging both for CNCs and some providers. CNCs' oversight across the pathway required them to cross traditional boundaries to advocate for their patients. This required some CNCs to invite themselves to meetings or forums where normally they would not be present. A few health providers did not perceive their presence as appropriate or needed.

During this time, work on system-improvements began in at least 12 DHBs¹. In these DHBs, CNCs were leading or contributing to system projects on equity, referral pathways across DHBs, patient information, and patient tracking. In 2014, identifying areas to improve the cancer care system was recognised as an area to strengthen for the CNCI. During this period, CNCs became more aware that coordination issues experienced by their patients were the service improvement areas they needed to focus on.

In 2014, following the completion of the Annual Evaluation Report (Litmus 2014), 15 DHB dashboard reports were developed and distributed to relevant DHB.² The dashboard reports were used by the National Nurse Lead to demonstrate progress with the CNCs and senior DHB managers, and to discuss ways to further improve the roles to meet the goals of the CNCI and the DHB.

Consolidation

Between 2015 and 2016, the CNCI continued to consolidate and mature. In 2015, CNCs self-identified their success in building relationships with other health providers to work as a part of an integrated cancer care team across the cancer pathway. Through these relationships, CNCs are able to support and meet patient needs, and facilitate service access. In 2015, CNCs believed their role was being viewed as an advanced cancer nursing role as they worked to (Litmus 2015):

- Identify, using a triage tool, those patients and family/whānau with complex needs and to facilitate their cancer journey from initial contact with the health system through various departments and services in secondary and primary care settings.
- Connect and monitor patients' progress within and across DHBs to ensure appointments are timely and in line with FCT and tumour standards, and that processes are streamlined for patients.
- Support patients and family/whānau to understand both their disease and the treatment options within the context of their lives, and how to navigate the health system.
- Consider the equity of access to services for Māori, Pacific and other patients with complex needs. CNCs interviewed note this is an area for further focus.
- Question existing systems and processes to identify improvements that benefit patient and family/whānau and align with tumour standards. Although in some DHBs consideration of system issues was still in its infancy (Litmus 2015).

Identifying my patient cohort across the continuum of primary to tertiary cancer care within all services/whole system service. **Maintaining visibility/ relationship building** with many many aspects of services i.e. clinicians (Drs, nurses of various

¹ This excludes the two DHBs which were solely focused on system improvements

² Five DHBs had no or insufficient data to develop a dashboard report

disciplines), admin teams, managers... **Balance and timing of work with patients** (individuals) and **systems work** (services & systems) and administrative duties, meeting attendance. (CNC)

In 2015, feedback from providers surveyed was mainly positive about the CNCI (refer next section). Providers perceived there was a more holistic approach to patient care through the CNC being the one point of contact for patients and providing information to patients to increase understanding of their cancer and treatment (Litmus 2015).

As a clinician I get more of a 'window' into how the patient is coping, than simply from the impression gained in a busy clinic. I also know that there is someone else looking out for **my patient ensuring that their pathway** through the medical system **is as smooth and stress-free as possible**. (Provider)

In 2015, senior management surveyed across DHBs were asked what had changed with the introduction of the CNCI. Nearly half acknowledged the CNCs have improved and streamlined the coordination of the patient pathway, especially for patients with complex needs. The CNCs were described as offering patient-centred care which is enhancing patients' experience and easing difficulties for patients in their journey. As a result patients have a better understanding of and timely access to services. CNCs were seen to compliment CNS roles and offer nursing expertise and resource to support other health providers. CNCs were described as having a real-time overview of the system, and were acknowledged as identifying and seeking to address system barriers (Litmus 2015).

There have been a number of changes with the introduction, but most significant is **improved communication between teams leading to better coordination of the cancer journey for patients** as they move from investigation, to diagnosis and on to treatment. There has also been **improvement in systems** allowing for **faster movement of cancer patients and those suspected of having cancer** to move through diagnosis and into the treatment phase of their journey. (Senior DHB manager)

While the CNCI had achieved greater recognition in 2015, there continued to be ongoing challenges for the initiative. CNCs and providers noted that CNCs were constrained by their FTE levels. Some CNCs struggled to deliver all aspects of a complex nursing and system-focused role. In particular, CNCs noted the challenges of identifying all patients with complex needs, working across traditional service boundaries, and being able to speed up processes and appointments for patients. Further, seeking to make system changes was particularly challenging given ingrained processes and a lack of mandate within and across DHBs.

In 2015, CNCs and providers recognised that the role continues to be not well understood or appreciated by all providers, given the diversity of health providers interfacing with CNCs. A few providers believed the introduction of the CNCI had made no difference or duplicated existing CNS roles. This lack of benefit may have reflected CNCs not covering all the cancer care pathways in DHBs due to the models of care adopted and their limited FTE. It may also reflect a lack of appreciation that CNCs operate across the whole cancer pathway to support as needed the patient and family/whānau irrespective of traditional service boundaries. Feedback suggests that the CNCI tended to gain more traction in DHBs where the CNCs report to a manager with responsibilities across the cancer care pathway, and not just one

component of it. McMurray and Cooper (2016) emphasised that in the US (and similar to New Zealand) the uniqueness of nurse navigators is they have the autonomy to choose how best to help patients to move through the system rather than being tied to one service.

I have noticed **duplication of roles with the CNS** which causes confusion as to the area of responsibility. I do not know what the role of the cancer coordinator is for.
(Provider)

In 2015, all DHBs received their Dashboard of results to disseminate and discuss at a local level.

Implementation lessons

Over the last three years a number of factors have enabled implementation, namely:

- Being a part of the national programme to improve cancer services in New Zealand meant there was focus on the CNCI and it was linked into other work on tumour standards, MDM and FCT.
- Linking with and learning from international care coordination programmes, and national research programmes (e.g. Collinson et al 2013).
- Having the National Nurse Lead ensured leadership on the strategic direction and embedded the CNCI principles, created links to the international evidence-base, enabled the navigation of regional and DHB issues with the new roles at a senior level as well as focusing on building nursing capability and a cohesive CNC workforce.
- Having senior clinical champions to support the CNCI and CNCs regionally and locally.
- Establishing the CNC regional network meetings and annual CNC forum were important to share learnings and create a connected and cohesive CNC national nursing network across 20 DHBs.
- Offering flexibility to DHBs to fit CNCs into known gaps in the existing cancer nursing workforce and to meet regional population needs assisted with the integration of the CNC roles.
- Having effective recruitment across DHBs that aligned with the expertise needed in the new role with a particular focus on the front of the cancer pathway.
- Making the cancer care coordination role an advance nursing role rather than an administrative role offered patients and their family/whānau the benefits of having an experienced nurse as their key point of contact rather than a non-clinical person. Gilbert et al (2011 in McMullen et al 2013) emphasised the following benefits of a nurse performing this role: skills to clinically assess patients; provide support and education; manage the complexity of the cancer diagnosis; communicate and collaborate with other health providers.

- Developing a triage tool for CNCs enabled the identification of patients with complex needs and tailored their care coordination needs.
- Being able to record patient interaction in a database enabled CNCs to monitor patients enrolled with the CNCI and determine appropriate action as their needs changed.
- Having an evaluation that provided annual feedback enabled meaningful discussions on progress with the CNCs, Regional Cancer Networks and DHB management.

In contrast, factors have impeded implementation progress were:

- The FCT focus, while an enabler for the CNCI, also distracted with some CNCs being required to support FCT data collection.
- Not being able to determine whether any patients with complex needs are not being referred to the CNC (discussed next section).
- Health providers having differing expectations of the role and its scope due to a lack of role clarity and uncertainty about the fit of the role in the existing workforce.
- Difficulties gaining system change due to existing DHB processes blocking change and the challenge of getting agreement across the multi-disciplinary team for the change (discussed next section).
- A lack of IT functionality and support for the role.

Assessing the CNCI

Introduction

In 2014 and 2015, data collection activities were undertaken to assess the CNCI implementation against the outcomes model (refer appendix 1). In determining the success (or otherwise) of the CNCI, the findings from the two annual evaluation reports have been synthesised against the agreed success criteria, specifically whether the CNCI is:

- targeting those with greatest need
- improving access and timeliness of access to diagnostic and treatment services for patients
- improving patient experience through diagnosis and initiation of treatment
- identifying potential areas for improvement in care coordination and the patient pathway.

Detailed evaluation findings for the CNCI can be found in the annual evaluation report (Litmus 2015).

Targeting those with complex needs

One of the success criteria for the CNCI is to target those patients with the greatest need (i.e. patients with complex needs, and Māori and Pacific patients and their family/whānau). In assessing this success, it is acknowledged that CNCs do not cover all cancer pathways therefore not all cancer patients will be referred to a CNC.

Overall assessment

Overall, the CNCI partially achieved the success criteria of targeting those with complex needs. Patients with a range of cancers and triaged as 1 and 2 (most complex needs) are accessing the CNCI. Māori and Pacific people are accessing CNCI but not at expected levels. Given the existing inequities in cancer outcomes for Māori and Pacific people (Hill et al 2012), identifying and removing the barriers to ensure Māori and Pacific patients are accessing care coordination from the CNC is a critical improvement area for the CNCI.

The evaluation was unable to assess the proportion of priority patients not accessing CNCI as no comparative group was available (refer evaluation limitations).

Referrals to the CNCs

In 2015, CNCs were engaging and building relationships with a wide range of health providers in secondary care across the cancer pathway. CNC engagement with primary care was less well developed across most DHBs. As noted, there continues to be room to improve awareness across the diversity of health providers across the cancer care pathway.

Reflecting their engagement, CNCs receive referrals from a range of sources. Half of patients enrolled with CNCs (50%) are referred by surgeons, physicians and MDMs. Referral sources vary by DHBs, dependent on CNC location and relationships. Across DHBs, CNCs are active in sourcing patients for referral to the CNCI via review of admissions and ED databases. This proactive sourcing is important for the CNCs to ensure those most at risk of experiencing coordination issues have access to the CNCI. In 2015, primary care had referred 6% of patients enrolled with CNCs, reinforcing the need to increase awareness of the CNCI in primary care.

Referrals to the CNCs are timely. Seven in ten patients enrolled with CNCs (71%) were referred to the CNC within a month of their referral to the DHB, and 41% in less than a week. Those patients referred to the CNCI three months or more after referral to the DHB (12%) may be patients with cancer whose care has become increasingly complex thereby triggering the referral. Of those patients enrolled with CNCs, 92% were discharged in under three months to wider cancer services.

On referral, CNCs use the triage tool to assess patients' needs³. Patients triaged as level one or two are enrolled in the care of the CNC and a comprehensive assessment is undertaken⁴. Patients triaged as level three or four are registered with the CNC and their care is managed by established cancer services in the DHB. Across time CNCs will reassess patients' triage levels to determine whether their needs have changed and they should be enrolled in the care of the CNC, or discharged and transferred as appropriate.

Profile of patients enrolled with CNCs

In a six month period in 2015, 6008 patients had contact with CNCs. Priority groups are accessing CNCs with 45% of CNC patients being classified as triage level 1 and 2 and 26% triage level 3. Māori and Pacific patients are accessing the CNCI and more than half of Māori and Pacific people accessing the CNCI have a triage score of 1 or 2 (most complex needs). As a result, they will be assessed by the CNC and receive individualised nursing support.

Enrolment of Māori and Pacific patients varies across DHBs and is overall lower than expected.

³ Auckland DHB has adopted a priority patients process to support Māori and Pacific patients who DNA at ADHB Cancer and Blood Services.

⁴ The CNCI is working with the new psychological workforce on distress screening tool for patients.

- Access for Māori patients is higher in Tairāwhiti (38%), Bay of Plenty (24%), Lakes (22%) and Hawke's Bay (20%) DHBs.
- Access for Pacific patients is higher in Counties Manukau (16%), Auckland (9%) and Capital & Coast (8%) DHBs.

More work is needed by the CNCI to remove access barriers for Māori and Pacific patients to the CNCI. Given the low level of enrolment, the CNCI risks increasing inequities for Māori and Pacific patients in access to cancer care and in cancer outcomes. The introduction of population-based CNC roles may assist in removing access for some in two DHBs. However, it is the responsibility of all CNCs and other health providers to address the structural and system barriers to improve the cancer care pathway for Māori and Pacific patients.

Patients with lung cancer (18%), skin cancers (17%), lower gastrointestinal cancers (14%), and upper gastrointestinal cancers (11%) are more frequently enrolled with a CNC. Other tumour streams supported by the CNCI include gynaecological, urological, breast, head and neck, haematological, brain/central nervous system, sarcoma, thyroid and others. The range of tumour sites highlights that CNCs are focusing on a range of patients with complex cancers. As capacity allows and interest in the CNC role grows, CNCs in generalist approaches intend to increase their support across the range of tumour streams. However, some providers are not interested in working with the CNCs which limits access to some tumour streams.

Areas of future focus

- Consider how to remove access barriers to the CNCI for Māori and Pacific patients, and increase their enrolment in the CNCI.
- Investigate the benefits of population-based roles as they become more established.
- Increase awareness of primary care of the CNCI and their referrals to CNCs.

Improving service access & timeliness

The evaluation cannot definitively answer whether the CNCI has improved access and timeliness of access to diagnostic and treatment services for patients referred to CNCs. This reflects that there is no comparative group of cancer patients to benchmark changes in access and timeliness (refer evaluation limitations). Assessment of CNCI's contribution to improving timeliness of access and treatment has been based on proxy indicators drawn from the provider and patient surveys and interviews with patients (Litmus 2015).

Overall assessment

Based on proxy indicators, the CNCI is contributing to the improvement of patient access and timeliness of access to diagnostic and treatment service. Providers and senior managers perceive the CNC role is contributing to timely diagnosis through improved patient care

coordination. Importantly, patients enrolled with CNCs report they are aware of the appointment process and likely timeframes involved.

International studies also found improvements in timeliness of care and transitions between services for patients with access to CNCs or their equivalent (Manderson et al 2012 and Simon et al 2015 in McMurray and Cooper 2015, Whop et al 2012, Case 2011, Crane-Oakada 2013).

Patient perception

A proxy measure was used to assess patients' perceptions of the timeliness of their care. Patients were asked whether they understood their cancer pathway and length of time to getting appointments and test. In 2015, most patients who returned a survey agreed their CNC helped them to know the next steps in their treatment (84%). Patients surveyed strongly agreed or agreed that their CNC:

- explained the appointment and test process (86%)
- explained the likely length of time to their appointments and tests (80%).

It was helpful and reassuring to ring her, especially in the beginning when I was waiting for various appointments and tests to be done. **She helped well explaining processes and timings to expect.** (Patient)

Qualitative feedback from patients highlighted CNCs helped them to navigate the complexity of cancer services and appointments at a time when they were tired, stressed, and physically and emotionally unable to cope with this additional burden. Patient appreciated CNCs knowledge of the health system, and their ability to facilitate patients' progress along the pathway, particularly when patients needed to travel across DHBs boundaries.

When placed in 'the system' you are confronted with a myriad of people, specialists, therapists, receptionists - each one a new face every time, some you see more than once. But **the co-ordinator is the one constant part of contact which helps to avoid that 'lost' feeling.** A very essential part. (Patient)

In 2015, CNCs were putting patients in touch with other services as needed including financial support, emotional support, other health and cultural support and transportation. Feedback from patients indicated further support was needed to link them to financial and emotional support services. It is acknowledged that in 2015 CNCs referrals to emotional support services were constrained by a lack of services.

In 2015, when asked a quarter of patients informed their CNC they had transport issues. Patients in more rural areas in particular struggled with the distance to appointments especially when no transport is available. Patients' mention of transport issues was higher in the following DHBs: Hawke's Bay (50%); South Canterbury (63%); Tairāwhiti (70%); West Coast (81%); and Wairarapa (99%).

Someone to advocate on my behalf. Ensured **all my appointments and treatments were coordinated**. She made herself available at any time if I had any concerns (provided me with contact to her as needed). (Patient)

Provider perception

Providers surveyed acknowledged the CNC role is facilitating appointments and timing of treatment to contribute to a timely diagnosis. Specifically, providers strongly agree or agree that CNCs:

- facilitate patients' appointments and timing of treatments (83%)
- contribute to timely diagnosis for patients (71%)
- reduce the number of patients who do not attend (DNA) their appointment (57%). A quarter of providers (26%) are uncertain about CNCs contribution to reducing DNAs.

Patient flow through the diagnostic pathway has **improved with better coordination and timely investigations**. (Provider)

Areas of future focus

- Ensure the role and its benefits are well understood by providers to increase the CNC influence in facilitating patients' cancer care pathways.
- Continue to facilitate patients to be linked to other services especially financial and emotional support services.

Enhancing patient experience

Overall assessment

Overall, the CNCI achieved the success criteria of enhancing patients' experience through diagnosis and initiation of treatment. Patients acknowledged the CNC role of undertaking care coordination resulted in a smooth and less stressful engagement with the health system. Providers were also reassured that CNCs are offering their patients care coordination and have noticed a more positive patient experience. Patients and family/whānau who have previously had or supported people with cancer commented on how the CNC role had improved the diagnosis and treatment process.

The only exception is patients who had initial contact with the CNC and then no further interaction. This is likely to reflect that the patient was triaged as having less complex needs and left to be managed by normal cancer services. Thygesen et al (2011) found that the mutual connection and trust built up the nurse navigator can result in patients feeling rejected when referred to other services.

International research also found that CNCs or their equivalent improve patient experience. A randomised control demonstrated that CNC equivalents decrease symptom distress, fatigue and improve quality of life in patients with lung and breast cancers (Gilbert et al 2010, and Swanson et al 2010 in Shejila et al 2015). Other effects highlighted were patient navigation improved adherence to cancer care (Robinson et al 2010 in Shejila et al 2015), and improved patient satisfaction with their care (Case 2011, Fiscella et al 2012, Johnson 2015, Hook et al 2012 in Shejila et al 2015).

Patient experience

Being diagnosed with a high suspicion of cancer or cancer is extremely traumatic for people and their family/whānau. It is a time when people may be physically unwell and tired and they and their family/whānau are emotionally fragile and stressed. People and family/whānau, who have little exposure to the health system, can find the diagnosis process bewildering, particularly if they have other health, emotional or social needs.

In this context, patients describe their CNC as their 'go-to-person' who enables the coordination of the process by ensuring appointments are set up, and they can access their appointments. For patients, CNCs' clinical nursing expertise underlies the benefits they gain from the role, by having an expert who understands what they are going through, is able to explain clinical information in lay terms, knowledgeable about the next steps in care and how to navigate the system to ensure they occur, and being aware of other support services and how to access them.

Someone to advocate on my behalf. **Ensured all my appointments and treatments were coordinated.** She made herself available at any time if I had any concerns (provided me with contact to her as needed). (Patient)

Feedback suggests being referred to the CNC early in the diagnosis process maximises patients' benefits. Although for some patients with a high suspicion of cancer being referred to a CNC can be concerning as the word 'cancer' in their title can be seen to confirm they have cancer.

Patients who completed a survey strongly agree or agree CNCs listen to their concerns (91%), answer questions (91%), are accessible (87%) and supportive (83%).

Was able to co-ordinate all of my treatment and get first access to the necessary specialists when needed made it a more enjoyable journey by **offering support and guidance through a very difficult time for myself and whānau.** Non-judgmental caring a human force in the face of adversity who never made you feel like you were not valued. (Patient)

As a result of interacting with CNCs, patients strongly agreed/agreed that they are more confident about process (86%), knowledgeable about their treatment and care (88%) and cancer (83%), and that the CNC is an important part of their treatment team (86%).

Feedback from patients, who have had cancer or experience of cancer services before the initiative, suggests the introduction of CNCs has enhanced their and their family/whānau service experience compared to their pre-CNCI experience of cancer services.

After seeing the specialist, being able to sit down over a cup of tea with [CNC] and have her go over everything with us, answer our questions and explain in depth how everything is going to happen from that point on. That was **incredibly helpful and reassuring** and we can away feeling fully **supported and informed**. Also having that person available for contact later if questions arose. **Having experienced a previous cancer diagnosis 20 years ago it was a vastly different experience this time around**, due in part to the role of the Cancer Nurse Coordinator whose presence was much appreciated throughout. (Patient)

Referral to Māori support services continues to be the key activity used by CNCs to improve the experience of Māori patients and their whānau in the cancer pathway, as well as ensuring timely communication, and inclusion of whānau. Three quarter of patients strongly agreed/agreed that CNCs respected their cultural, values and beliefs. While CNCs are meeting some patients' cultural needs, this attribute is not rated as highly as others. Given the need to improve access to the CNCI for Māori and Pacific people, this is an area for strengthening.

By sharing herself on a personal level, pertaining to why she does the job. Having **some competencies with Te Reo Māori**. May even need a support person to assist her with cultural aspects. Providing a **warm welcoming environment** to meet over a cuppa- 1st meeting. (Patient)

Around 5% of patients who completed the survey had little contact with the CNC, did not understand the role, and gained no benefit from their initial contact. It is possible these patients were assessed as not having complex needs and therefore not enrolled with the CNC. The latter is a valid nursing decision in ensuring those with the greatest need access the CNC. However, the feedback from these patients indicated that CNCs need to enhance the management and communication of this process. These patients need to be informed of the reasons they are not being enrolled with the CNC and aware of their key contacts.

Was very disappointed in contact from cancer nurse. First phone call was good when first diagnosed, **but after that very little contact from her**. (Patient)

Areas of future focus

Patients surveyed were generally very happy with the CNC role. Future areas to strengthen are:

- Need to ensure patients have a clear understanding of the role especially if they are assessed as not requiring the support of the CNC (at that point in time).
- Increasing cultural competency of CNCs to ensure access for Māori and Pacific patients and for them to feel their culture, values and beliefs are respected and valued.

Improving patient pathway

The fourth success criteria for the CNC is identifying potential areas for improvement in care coordination and the patient pathway working with other providers and wider DHB processes, where appropriate.

Overall assessment

Overall, this success criteria was achieved as CNCs are contributing to patients having a coordinated patient journey and systems projects are being undertaken across all DHBs to strengthen the patient pathway. McMurray and Cooper 2015 comment that nurse navigators (CNCs) through integrating services around patient needs are contributing to quality and safety and responsive care, as well as the sustainability of the health system.

CNC contribute to coordinated patient journey

Patients surveyed strongly agreed that CNCs helped them to know the next steps in their treatment, and helped them navigate the complexity of cancer services and appointments.

*You have the transition period from hospital to whatever department you are thrown into but the **cancer nurse fills the gap in the middle**. (Māori whānau)*

CNCs are identifying system improvement areas

CNCs are actively identifying system issues and working with other health providers to address them. CNCs' system-focused role is acknowledged by providers. In 2015, CNCs in 19 DHBs were or are involved in 211 system projects (Litmus 2015). Projects are similar across DHBs. The most common system projects being undertaken across DHBs are:

- Reviewing and revising patient pathways including the mapping of tumour streams and seeking tumour stream improvements. For example, a tumour stream project where six tumour streams with the largest volume of patients are being mapped and CNCs are working across the hospital to improve pathways and processes to meet FCT targets.
- Developing or supporting MDMs. These projects are more likely to occur in DHBs with a CNCI tumour stream approach. For example a DHB neurosurgery oncology MDM to ensure all patients with diagnosed or potential tumours relative to neurosurgery are registered at MDM. The project has resulted in weekly meetings, creation of a proforma, timeliness of documented outcomes and improved referral process.
- Developing and implementing protocols and tools. Examples include patient tracking system, MOSAIQ, DNA reminder system, Screening for Distress and Triage.
- Enabling FCT data collection, advice or system development. These projects are more likely to occur in DHBs with a CNCI generalist approach.

- Equity projects. Examples include Screening for Distress, DNAs, National Travel Assistance, and improving cancer care pathway for Māori. CNCs at one DHB implemented a project to increase the E Te Iwi Cancer education programme. This programme aims to increase Māori education around cancer and involves the delivery of information at various hui. Positive feedback has been received from participants and facilitators. This programme is also improving CNC relationships with primary care and Whānau Ora health services.

CNCs note that there are a number of barriers that impede their system improvement role. The most frequently mentioned barriers are⁵:

- Lack of mandate or buy-in from other health providers including some providers not undertaking agreed duties, and a general resistance to changing existing protocols and practice. Other challenges noted by CNCs included difficulties in coordinating and communicating across a diverse group of people with a range of opinions, personnel changes, and a lack of awareness of the system component of the CNC role.
- High CNC workload resulting in a lack of time for system projects.
- Current IT systems or the lack of IT support can hinder the implementation of the desired system improvements. For example one DHB was unable to implement mandatory coding of ED patients presenting with a high suspicion of cancer as the IT team was unavailable to set up the mandatory field in the patient admission forms.

Feedback from CNCs indicate projects are achieving positive outcomes including the creation or implementation of a tool or protocol, and systems becoming more standardised and streamlined. Some projects are perceived by CNCs to have contributed to improving timeliness along parts of the cancer pathway for specific patients.

Areas of future focus

- Consider further review of the system projects to assess whether they are having sustained and positive impact on improving the patient experience and pathways.
- Seek to address the ongoing barriers that impede the CNC system improvement role including lack of mandate, high CNC workload and lack of IT infrastructure or support.
- Consider whether further training is required by CNCs on initiating and undertaking service improvement projects.

⁵ The National Lead also noted that not all CNCs have the skills required to propose or lead system projects and this is a development area.



Conclusions

Future considerations

Conclusions

Over the last three years, the CNCI was implemented as intended and the initiative has evolved to meet DHB and region cancer care needs. Offering DHBs flexibility in the implementation of the CNCI has resulted in three broad models of care to fit with the existing nursing workforce and population needs: generalist, tumour stream and population-focused.

Initially, health providers were uncertain about the CNCI and how it would integrate with other services. Over time most health providers have come to value CNCs as an advanced nursing role. CNCs, like their overseas counterparts, have a front of pathway focus on diagnosis and treatment, provide information and support to patients and their family/whānau, link with other health providers in the diagnosis and treatment process, monitor patient progress and timely access to treatment, and act as a single point of contact (Shejila et al 2015). The CNCI is unique as CNCs overview patient progress along the cancer pathway using an iterative triage process, and are focused on identifying and contributing to system improvements. By 2015, only a few health providers continue to be uncertain about the role, mainly due to the perceived duplication with the CNS role.

The development of a cohesive CNC nursing workforce across DHBs has increased the senior nursing voice in New Zealand. The CNCI was facilitated by having a National Nurse Lead and regional and national forums. The National Nurse Lead also had an important role in addressing role uncertainty, building nursing capacity and tools, and ensuring the CNCI delivered both patient care coordination and contributed to system improvement.

Patients, health providers and senior managers acknowledge that the CNCI is positively contributing to improvements in cancer services and outcomes for patients. The CNCI has met three of the four success criteria set for the initiative in 2013: contributing to improving access and timeliness of access, positive patient experience and to system improvements. The exception is targeting those with greatest needs. While patients with complex needs are enrolled, the enrollment of Māori and Pacific people is lower than expected.

Future considerations

Kua tawhiti ke to haerenga mai, kia kore e haere tonu;
he tino nui rawa ou mahi, kia kore e mahi tonu.
We have come too far not to go further,
we have done too much not to do more!

Sir James Henare

Achieving equity of access

There is risk the CNCI may be contributing to ongoing inequities in cancer care for Māori and Pacific people. Ensuring equity of access and outcomes requires CNCs to acknowledge that equity is the responsibility of all CNCs and not just those in population roles. In striving for equity, CNCs need to partner with Māori and Pacific leaders to support their work and understanding.

To ensure access to the CNC for Māori and Pacific patients and their family/whānau requires the identification and removal of systems and structures that impede access. Consideration could also be given to the cultural nursing frameworks that would support engagement and positive outcomes for Māori and Pacific people.

Ongoing development of the role

Over the last three years, health providers and senior managers have gained a deeper understanding and appreciation of the CNCI. However, not all are aware of the role or support it. To enable collaborations across the cancer care pathway requires increased understanding of the uniqueness of the role and the benefits gained by working with CNCs. In particular, more work is needed in connecting with primary care to support referrals to the CNCI. Increasing understanding of the CNCI and its achievements may increase the influence of the role in effecting system improvements.

Enhancing positive patient experience

Patients and their family/ whānau are very positive about their engagement with CNCs and the benefits gained. The CNC role can be further strengthened by ensuring that patients referred to the CNC and not enrolled understand this triage decision. Other suggested improvement areas are involving patients and family/whānau in decision making, and improving information sharing at handovers to other services. Patients are also seeking to be connected to emotional and financial support services.

Improving cancer care pathways and health systems

CNCs have an important role in contributing to system improvements. Further investigation is needed to assess whether the system projects completed or underway are having sustained and positive impact on improving the patient experience and pathways. The barriers that impede the CNC system improvement role need to be addressed to enable effective collaboration. Further work is needed on developing CNCs' expertise in service improvements and change management.

Areas for further investigation

As the formal evaluation concludes consideration is needed on the ongoing monitoring required for the CNCI to assess its ongoing value and contribution, and inform quality improvements discussions and actions. Key indicators should at a minimum cover: equity of access, timeliness, patient experience, and system improvements.

Bibliography

- Cancer Institute NSW. 2011. *Evaluation of the role of Cancer Care Coordinator*. Cancer Institute New South Wales, Alexandria, Aus.
- Case M A B. 2011. Oncology Nurse Navigator: Ensuring Safe Passage. *Clinical Journal of Oncology Nursing*, 15(1), 33 - 40.
- Collinson L, Foster RH, Stapleton M, Blakely T. 2013. Cancer care coordinators: what are they and what will they cost? *The New Zealand Medical Journal*. Volume 126 Number 1381
- Crane-Okada R. 2013. Evaluation and Outcome Measures in Patient Navigation. *Seminars in Oncology Nursing*. 29(2), 128 - 140.
- Hill S, Sarfati D, Robson B, Blakely T. 2012. Indigenous inequalities in cancer: what role for health care? *ANZ Journal of Surgery*. Royal Australasian College of Surgeons
- Hook A, Ware L, Siler B, et al. 2012. Breast Cancer Navigation and Patient Satisfaction: Exploring a Community-Based Patient Navigation Model in a Rural Setting. *Oncology Nursing Forum* 39(4), 379 - 385.
- Litmus. 2014. *Evaluation of the Cancer Nurse Coordination initiative. Annual Report 2014*. Wellington: Ministry of Health.
- Litmus. 2015. *Evaluation of the Cancer Nurse Coordination initiative. Annual Report 2015*. Wellington: Ministry of Health.
- McMurray A and Cooper H. 2016. The Nurse Navigator: An evolving model of care. *Collegian* (2016), <http://dx.doi.org/10.1016/j.colegn.2016.01.002>
- Ministry of Health. 2010. *Guidance for Improving Supportive Care for Adults with Cancer in New Zealand*. Wellington: Ministry of Health.
- Monterosso L, Platt V, Krishnasamy M, and Yates P. 2011. *Evaluation of the Western Australian Cancer Nurse Coordinator Role - Final Report*. Health Department Western Australia, Fremantle Aus.
- Northern Cancer Network. 2011. *Regional Cancer Care Coordination Model – Targeted Literature Review*.
- Oncology Nursing Society. 2013. *Oncology Nurse Navigator Core Competencies*. Retrieved from https://www.ons.org/sites/default/files/ONNCompetencies_rev.pdf

Regan M, Mills J and Ristevski, E. 2012. Cancer care coordinators' relationships with the multidisciplinary team and patients: Everything to everyone. *The Australian Journal of Cancer Nursing*, 13(1).

Shejila CH, Mamatha SP, Fernandes DJ. 2015. Oncology Nurse Navigator Programme – A Narrative Review. *Nitte University Journal of Health Science*. Vol 5, No 1, March 2015.

Thygesen M K, Pederson B D, Kragstrup J, et al. 2011. Benefits and challenges perceive by patients with cancer when offered a nurse navigator. *International Journal of Integrated Care* 11, 1 -12.

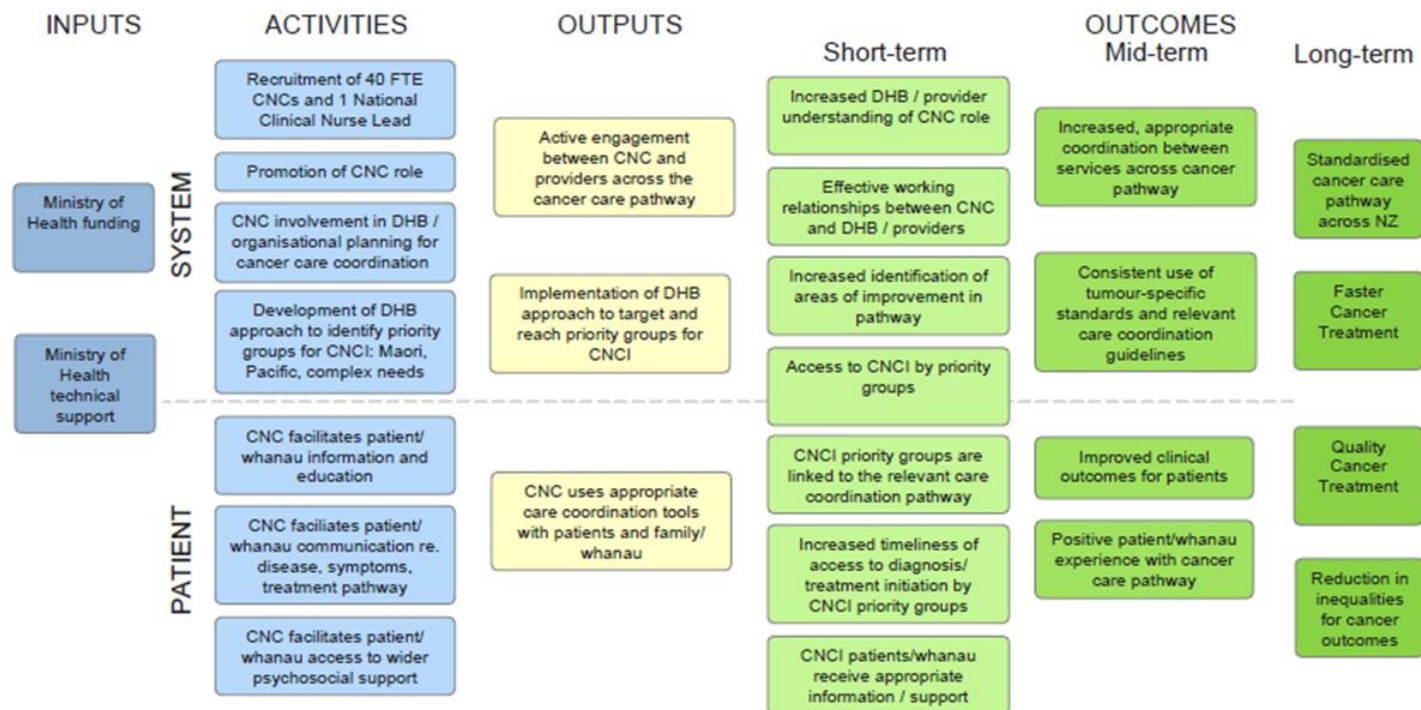
Whop L J, Valery P C, Beesley V L. 2012. Navigating the cancer journey: A review of patient navigator programs for Indigenous cancer patients. *Asia-Pacific Journal of Clinical Oncology*, 8, 89 - 96.

Yates P. 2004. Cancer Care Coordinators: Realising the Potential for Improving the Patient Journey. *Cancer Forum* 28(3):128-132.

Appendices

Appendix 1: CNCI outcomes model

Figure 1: Outcomes model for CNCI Evaluation



Appendix 2: Draft triage tool

Triage Category	Presentation	Action	Outcome
1	Confirmed diagnosis Requires psycho-social support AND/ OR Has complex care coordination needs Has poor understanding of treatment trajectory Nurse Coordinator acts as primary nurse	Comprehensive assessment Liaise with MDM to identify a coordinated plan of care Act as first point of contact Lead role in facilitating care Patient care is focused on symptom management, information and supportive care Recognise barriers in care and opportunities to progress service development	Patient is enrolled in care of Cancer Nurse Coordinator
2	High suspicion of cancer or confirmed diagnosis Requires psycho-social support AND/ OR Has complex care coordination needs Clear treatment pathway identified Engaged with HCP at key points on treatment trajectory	Comprehensive assessment Liaise with MDM to identify a coordinated plan of care Patient care is focused on support and information Manage transition between treatment services Referral to support services Recognise barriers in care and opportunities to progress service development	Patient is enrolled in care of Cancer Nurse Coordinator
3	Confirmed cancer diagnosis Single modality treatment Psychosocial needs are met Does not meet DHB criteria for complex care coordination Engaged with established treatment team	Review referral and patient information Liaise with treatment teams as necessary Signpost availability of information and education materials Update patient records as required Maintain data	Patient registered with Cancer Nurse Coordinator Patients care will be managed by established DHB (cancer) services
4	High suspicion of cancer Psychosocial needs met Does not meet DHB criteria for complex coordination Patient has clear understanding of the diagnostic pathway	Review referral and patient information Liaise with treatment team as necessary e.g. GP, MDM Update patient records as required Maintain data	Patient registered with Cancer Nurse Coordinator Initiative

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