

17 November 2015

Cancer Nurse Coordinator Initiative Evaluation Report Summary of Findings – Year 2

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!

Overview of the Cancer Nurse Coordinator Initiative and implementation

The purpose of the Cancer Nurse Coordinator Initiative (CNCI) is to improve patient outcomes by coordinating care for patients with cancer and facilitating timely diagnosis and initiation of treatment. CNCI success has been defined as: 1) reached those with greatest need; 2) improved access and timeliness of access to diagnostic and treatment services; 3) positive patient experience; 4) identified improvements in care coordination and patient pathway.

During the introduction of the CNCI, DHBs wanted the flexibility to tailor the role to be responsive to their population, existing cancer care pathways, and nursing structures. Across New Zealand, the Cancer Nurse Coordinator (CNC) roles can be organised into three broad models of care:

1. **Tumour stream model** where specialist nurses are responsible for care of patients in a particular tumour stream. There are two sub-categories:
 - I. **Tumour stream coverage** - the CNC is placed in a tumour stream, where there is no existing Clinical Nurse Specialist (CNS) coverage. While a focus of this role is facilitating care and treatment in a specific part of the patient journey (much like a CNS), the CNC also prioritises care coordination activity, particularly from a system perspective and supports the implementation of this across the whole CNS team.
 - II. **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 systems improvements associated with the front of the pathway.
2. **Generalist model** 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 pathway. They work with patients considered most at-risk of experiencing problems with care coordination, and they are closely linked to Faster Cancer Treatment (FCT) work programmes and systems improvement.
3. **Population-focused** – the CNC focuses on 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 are focused on improving equity of access.

A **systems approach** was initially adopted by two DHBs to identify gaps in service delivery and undertake projects around the cancer care pathway. The system-focused CNCI approach had no patient interface, and the roles were less satisfying for nurses. In mid-2014, the two DHBs using a system model reconfigured their CNCI approach to be front of pathway and tumour stream respectively.

Across the 20 DHBs, Ministry of Health funds 40 FTE CNC positions. Counties Manukau, Waitemata, 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 the 20 DHBs.

Evaluation activities 2014 – 2015

Based on the results from the 2014 annual CNCI report and in consultation with the CNCI Evaluation Advisory Group (EAG), the CNCI evaluation data collection tools were reviewed and refined. Between November 2014 and April 2015, the following data and information were collected to assess the CNCI against its success criteria.

The **CNCI database** provided information about the activity and function of the nurses such as the demographic profile of patients accessing the CNCI, meetings attended by CNCs, and nursing actions taken. All 20 DHBs provided information on patient profile and care activity. One DHB provided collated data.

Systems logs detailed the system improvement projects CNCs have been involved in or initiated over the last six months. In total, 19 DHBs returned systems logs detailing 211 system projects that are currently being undertaken or completed in the last 12–24 months.

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. The case study focused on the experience of Māori and Pacific patients and their whānau.

CNC online survey profiled CNCs and their activities, and their contribution and perceived effect on patient experience. 48 out of 71 CNCs completed the 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 assessed understanding and perceived effects of CNC role. 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 assessed patient experience of the role and its contribution. 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%.

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%.

Compared to 2014 CNCI, data quality to inform the CNCI evaluation in 2015 has improved. The *Evaluation of the CNCI, Second Annual Report (21 October 2015)* details data quality and the full evaluation results.

Acknowledging the evaluation's limitations

The evaluation design directly addresses two of the evaluation success criteria, namely improving patient experience and identifying system improvements in care coordination and the patient pathway. 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 via the CNCI database 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 to diagnostic and treatment services are central to the intent of 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 and Cancer Registry data. The design work concluded that using these data sets would not address equity or timeliness questions as it was not possible to isolate the CNCI patient population or a comparative group of patients.

Evaluation insights October 2015

Compared to 2014, CNCs appear to have greater clarity and confidence about their role and its contribution to improving patients' experience and cancer care pathways. Key successes for the CNCI, as noted by CNCs, providers and senior managers, is the CNCs' integration into the existing workforce enabling improved and timely patient care coordination, improved patient and family experience, and the identification of system improvements. Ongoing implementation challenges for the CNCI is the FTE level which constrains CNCs' ability to deliver all aspects of an advanced and complex nursing and system-focused role.

Patients' and whānau feedback on the CNC role is overwhelmingly positive. Patients describe their CNC as their 'go-to-person' who enables the coordination of the process by ensuring appointments are set up, and that they can access their appointments. CNCs acknowledge the limitations of their influence to speed up processes and appointments for patients. CNCs particularly highlight the challenge of working across the established boundaries of the cancer care pathway.

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 and how to access other support services.

Improvement areas suggested by patients and whānau are improved explanation of the CNC role particularly for patients who have limited contact, better information sharing and handover to other services, and more regular contact.

Providers surveyed 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 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 CNS roles.

CNCs are actively identifying system issues and working with other professionals to address them. Common projects relate to patient pathways, supporting 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 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 buy-in, high CNC workload and lack of IT infrastructure or support.

Evaluation assessment of CNCI October 2015

Drawing on the evaluation findings from across the data streams, an assessment of the CNCI was made against the agreed success criteria for the initiative. Overall, the CNCI has, where measureable, met the success criteria set for the initiative in 2013. The table below summaries the evaluative judgements, the assessment rationale, and areas for consideration to strengthen the CNCI, going forward.

*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 came 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)*

CNCI success criteria	Evaluative judgement	Assessment rationale	Area of future focus
Targeted those with greatest need	Partially achieved	Unable to assess proportion of priority patients not accessing CNCI. 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 high levels.	<ul style="list-style-type: none"> Consideration is needed on how to remove access barriers to the CNCI for Māori and Pacific patients. The benefits of population based roles require further investigation as they become more established. CNCs need to focus more on ensuring cultural needs and beliefs are met. Consideration is needed on the role of primary care in referring patients to the CNCI.
Improve access and timeliness of access to diagnostic and treatment services	Not measureable Perception CNCI is contributing to timely access and treatment	No definitive measure on timeliness. Providers and senior managers perceive the CNC role is facilitating timely process, and contributing to timely diagnosis through improved patient care coordination. Patients are aware of the appointment process and likely timeframes.	<ul style="list-style-type: none"> Ongoing focus on ensuring the role and its benefits are well understood by providers to integrate and increase the influence of the CNCI to facilitate patient pathways.
Positive patient experience	Achieved	Patients' and providers' feedback indicate positive patient experience. Exception is patients who have an initial CNC contact and then no further interaction due to being triaged a 3 or 4 (less complex needs).	<ul style="list-style-type: none"> 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). Continue to facilitate patients to be linked to other services especially financial and emotional support services. Increase focus on whānau involvement and involving patients in decisions. Improve information sharing and handovers and offer (if appropriate and possible in FTE allocation) more regular contact.
Identified improvements in care coordination and patient pathway	Achieved	Systems projects are occurring across all DHBs. Some are demonstrating positive change.	<ul style="list-style-type: none"> Consider further review of the system projects being undertaken 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 buy-in, high CNC workload and lack of IT infrastructure or support.

Evaluation focus 2015-2016

The focus for 2015-16 is to prepare the final evaluation report based on the data collected to date.

Contact

Please contact Liz Smith, Partner Litmus if you have any queries about the CNCI evaluation liz@litmus.co.nz 04 473 3885.

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