

24 September 2014

Cancer Nurse Coordinator Initiative Year 1 Annual Evaluation Progress report Lessons and Insights

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 Year 1 Cancer Nurse Coordinator Initiative and implementation

The Cancer Nurse Coordinator Initiative (CNCI) purpose 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) positive patient experience; 3) identified improvements in care coordination and patient pathway.

DHBS were tasked with establishing the CNC roles in a way that best responded to their population needs, existing cancer care pathways and nursing structures. These new CNC positions were in addition to existing cancer nurse roles. The evaluation considers the new CNC roles only.

Across New Zealand the CNC roles can be organised into four broad categories:

- **Generalist** - specialist nurses who focus on care coordination for all cancer patients in the region. Generalist CNCs tend to be individual roles based in small 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.
- **Tumour stream** - specialist nurses responsible for care of patients in a particular tumour stream. There are two sub-categories:
 1. Tumour stream coverage - Where a DHB does not have full CNS coverage in all tumour streams, a CNC is placed in a tumour stream where there is no existing CNS. 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 systems perspective and supports the implementation of this across the whole CNS team.
 2. 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 where they are in place. These CNC's also identify and address systems improvements associated with the front of the pathway.
- **Population focus** - specialist nurses focus on reducing barriers to care through working with a specific population such as Māori, Pacific and Asian patients. These CNCs are a key point of contact at the front end of the pathway, and are focused on improving equity and ensuring timely access to treatment.
- **Systems approach** - the focus of these roles is system improvements in key areas of care that support coordination such as equity, multi-disciplinary care and supportive care. Adopted by Capital and Coast and Auckland DHB the CNC role was defined as identifying gaps in service delivery and undertaking project improvement.¹

¹ The system-focused CNCI approach has no patient interface and feedback from the nurses in the roles suggest it is less satisfying for CNCs. Both DHBS are re-configuring these roles: Auckland DHB to tumour stream; Capital and Coast to front of pathway.

Across New Zealand, there are 65 CNCs who are very experienced nurses with respected cancer expertise and leadership. Most CNCs are in permanent roles. CNCs' daily activities focus on care coordination, communicating with health professionals about patient care management, ensuring patients have timely access to services and effective and timely care for patients (excludes system-approach DHBs).

Evaluation activities 2013 – 2014

The focus in 2013 and early 2014 was working with the CNCI Evaluation Advisory Group (EAG) to develop an evaluation plan to assess the CNCI over the next three years with completion of the evaluation in June 2016. Reflecting the evaluation plan, patient, CNC and provider surveys were developed and reviewed by the CNCI National Nurse Lead, CNCs, patients, the CNCI EAG and an international expert. The surveys were revised based on feedback received.

A CNCI database was developed to inform CNC practice (reflecting the lack of IT support in some DHBs), and to assist the National Nurse Lead to support CNCs. The CNCI database also informs the evaluation by profiling patients accessing CNCI, and offering an overview of system initiatives. The CNCI database was piloted in four DHBs.

In April 2014, the development and testing of surveys and CNCI database was completed. In May 2014, the surveys and database were distributed to the CNCs to receive some preliminary data by June 2014 to provide high level insight into progress at the CNC Forum in late June 2014, to inform the first annual evaluation report, and to assess how well the data collection tools and distribution worked in practice. The timeframe to undertake the distribution of the surveys and input into the CNCI database was short and added to CNCs workload. For some DHBs, due to leave and other priorities, only a few or no patient surveys could be distributed.

Reflecting the limited time period for survey distribution and use of database, the following was achieved:

- 38 CNCs completed and returned the CNCI database. 33 CNCs across 16 DHBs provided information on patient care activity (includes composite data from one DHB). Five comprehensive reports on system reviews were received from the two system-approach DHBs, and 13 CNCs from 12 DHBs provided information about their system-focused activity.
- 43 CNCs completed an online survey which profiles CNCs and their activities, contribution and perceived effect on patient experience (response rate 68%).
- 485 providers across 20 DHBs who had contact with CNCs completed an online or hard copy survey to assess their understanding and the perceived effects of CNC role. The survey was distributed by CNCs via email to those providers they had contact with.
- 204 patients across 13 DHBs completed and returned a hard copy questionnaire about their experience of new role and its contribution. An online survey version was available but few patients used this option. 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.

Litmus also undertook qualitative interviews with three Māori, three Pacific and three Pākehā patients in three DHBs to understand their experience of CNCI. Kaipuke undertook the qualitative research with Māori patients, and Integrity Professionals with Pacific patients.

Strengthening data collection and data quality

Data collected to inform the 2014 annual report provides high level insight into implementation of the CNCI. However, incomplete data collection, the potential for selection bias in sampling and data quality issues means that it is not possible at this stage to be definitive about the initiative or to analyse findings by CNCI categories or regions.

The following table summarises issues raised by CNCs and CNCI EAG about the initial round of data collection and the changes being made to address them.

Data source	Issues raised	Proposed solutions for 2015 data collection
CNCI database	<p>Existing IT database – double handling by CNCs if they already collect data for different purposes (eg FCT or tumour stream databases).</p> <p>Burden on CNCs.</p> <p>Incomplete and inconsistent data:</p> <ul style="list-style-type: none"> ▪ Missing data in databases completed (e.g. system log not completed) ▪ Variation in data completion ▪ Some categories need review as not meaningful (e.g. travel codes). 	<p>Litmus accepts collated data from existing databases. To ensure consistency and comparability of data across DHBs, Litmus has prepared a data specification for CNCI data (e.g. number of patients seen by CNCI by age, gender, ethnicity, triage code, discharge status, time to refer to CNC from referral to DHB etc.).</p> <p>Litmus will focus on a six month period of data collection from (1 October 2014 - 31 March 2015).</p> <p>Litmus is currently working with CNCs to review and revise categories to be more meaningful and improve usability.</p>
Provider online survey	<p>Potential selection bias: providers selected by CNC to reflect engagement. CNCs distribute the online survey.</p> <p>Sample selection: Staff from Regional Cancer Network want to complete survey.</p> <p>Providers receiving multiple surveys: Providers who work with multiple CNCs may receive multiple copies of the survey. These providers may have differing opinions on the CNCI if they are working across different CNCI models.</p> <p>Potential focus on CNC performance: Photos were used to identify CNC (from other nurses) which may have created a focus on individual performance and not initiative.</p>	<p>CNCI EAG suggested that Regional Cancer Networks distribute the survey to providers on their databases. This option was explored. It was determined that the approach was not feasible due to workload and the potential for confusion if the survey is distributed by Regional Cancer Networks. A suggestion was made to contact DHB quality managers to facilitate the distribution of the provider survey. This suggestion is being explored for 2015.</p> <p>An approach is being explored to ensure other key stakeholders are included (e.g. Directors of Nursing, Chief Operating Officers and Regional Cancer Networks).</p> <p>Provider survey is being revised to move the question on which DHB the CNC is located in to the front of the survey and to offer providers the opportunity to complete the survey for multiple DHBs if they want to or to select the one DHB they are offering feedback on.</p> <p>If survey distributed by Regional Cancer Networks, photos will be removed.</p>
Patient hard copy survey	<p>Timeframe: Inadequate time to distribute patient survey and differing distribution approaches.</p> <p>Potential selection bias: Patients and whānau selected by CNCs as it may not be clinically appropriate for patients to receive questionnaire.</p> <p>Exclusions: Patients with high suspicion currently excluded due to questionnaire design.</p>	<p>The patient survey will be distributed on an ongoing basis so CNCs can determine 'the right time' to distribute to patient and whānau.</p> <p>Patient surveys to be mailed to patients with a paid return envelope to Litmus.</p> <p>The questionnaire is being reviewed to ensure it is meaningful for patients with a high suspicion of cancer. Litmus has developed a letter to support the questionnaire to enable the inclusion of patients with a high suspicion of cancer.</p>
CNC online survey	<p>Some CNCs were on leave so unable to complete.</p> <p>CNCs have the right not to complete the survey.</p>	<p>Extend distribution period for CNC survey.</p>

Acknowledging the evaluation's limitations

Ensuring equity of access and improving timeliness of access to diagnostic and treatment services are central to the intent of the CNCI. As discussed at the CNCI EAG, the evaluation is unable to categorically measure the contribution of the initiative in assessing whether it is targeting those with the greatest need and increasing service timeliness. To undertake this analysis will require access to the FCT data and Cancer Registry data which is beyond the contracted scope of the evaluation. As noted by the CNCI EAG using FCT data as a comparison point for timeliness and patient profile would be misleading as not all patients referred to DHBs with cancer or a high suspicion of cancer are on the FCT database.

Currently, it is being explored whether this analysis could be undertaken at a DHB or regional level.

Evaluation insights June 2014

CNCI has been implemented across 20 DHBs using four delivery models that reflect DHBs' existing cancer care structures and population profile.

In contrast to 12 months ago, there is evidence that providers who interact with the role understand the role is about care coordination, service access and system improvements. Providers agree that CNCs have an important role in the treatment team and contribute to improving communication between health professionals about patient care. Providers do not perceive that the CNC role is duplicating existing roles.

CNCs acknowledge that further work is needed to increase health professionals understanding of the role and fit in the cancer treatment team.

CNCs are identifying system issues in system-focused DHBs and in generalist and tumour stream approach.

CNCs are seen by providers and patients as contributing to a more coordinated patient journey by facilitating timely appointments and connecting them to other services as needed. The CNC is described by patients as their 'go-to-person'. Feedback from patients and providers suggest the CNCI is making a difference to patients and their family/ whānau. Patients strongly agree CNCs listen to them, answer their questions in a way they understand, and are accessible and offer support. Patients agree CNCs make them feel confident about what is happening and to know more about their treatment and care.

Based on patient feedback, areas of focus are ensuring patients' cultural needs are met; they are linked to appropriate services, and facilitating patients' involvement in their treatment and care decisions.

DHB dashboard reports

Where possible and reflecting the 2014 data collection, Litmus has prepared DHB dashboard reports to offer feedback to CNCs to inform their practice.

Contact

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

She is probably one of the most important people there. She draws things together... I had two lots of treatment and was dealing with various surgeons and oncologists. Dealing with [CNC] feels like I have one person who has an overview... I could give her name to mum when I was in [out of region hospital]. I just said mum if you have any problems ring [CNC] she will know what's going on....I think it is vital to someone like me. It is a point of contact that I can ring. There are so many unknowns from my side. (Patient)

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