Evaluation of the Cancer Nurse Coordinator Initiative

Annual Report

6 October 2014

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Introduction

CNCI and evaluation purpose

CNCI purpose:

- to improve patient outcomes by coordinating care for patients with cancer and facilitating timely diagnosis and initiation of treatment.

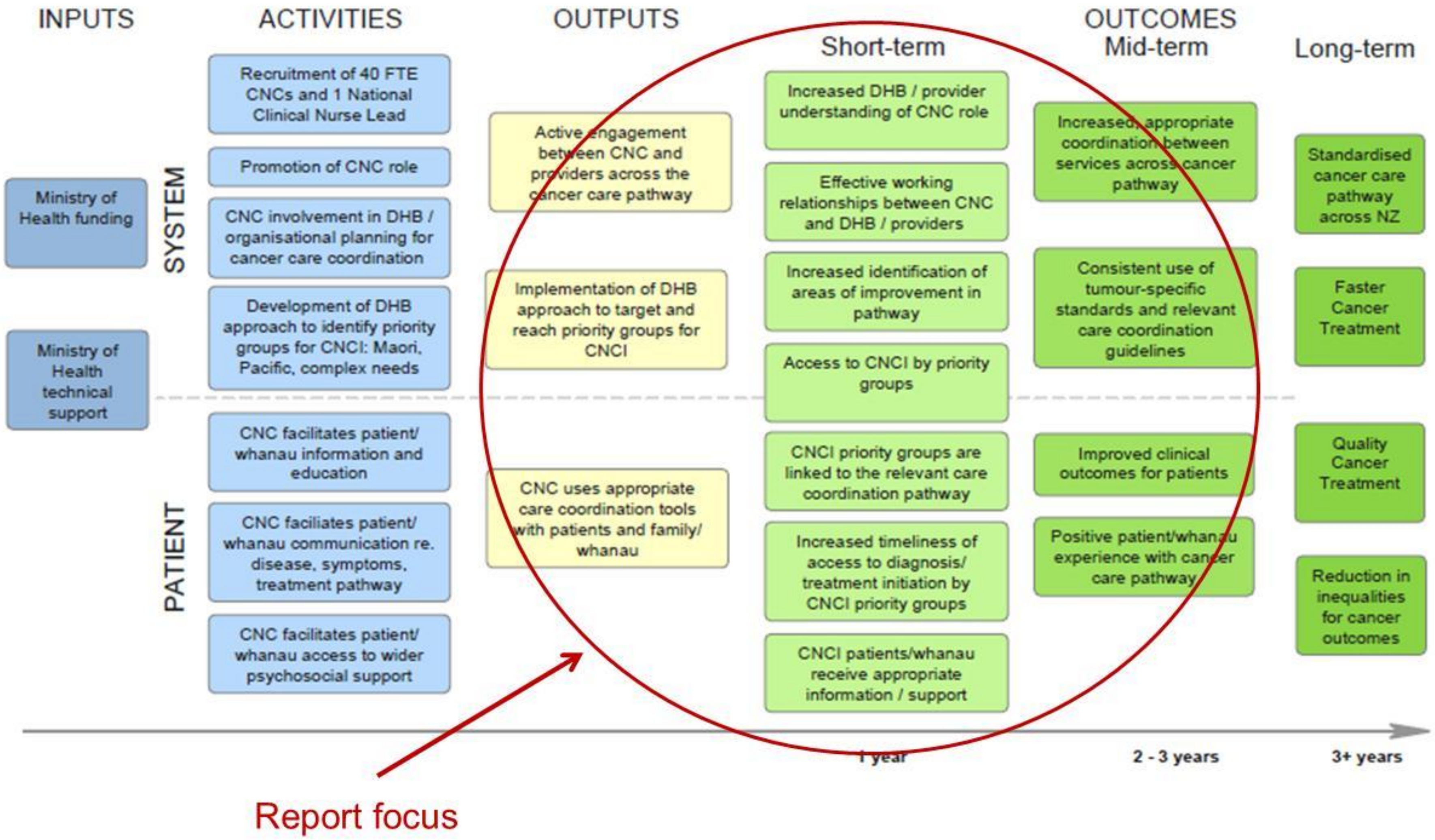
Evaluation purpose to assess CNCI implementation:

- improve patients' experience
- improve access and timeliness of access to diagnostic and treatment services.

CNCI success defined as:

- targeted those with greatest need
- positive patient experience
- identified improvements in care coordination and patient pathway.

Report written to answer agreed outputs and short and mid-term outcomes for CNCI



Report draws on range of data sources

Development phase

The development and testing of surveys and CNCI database was completed in April 2014. The surveys and database were distributed to the CNCs in May 2014 with a view to receiving some preliminary data in June for the first annual report and CNC forum.

Refer evaluation plan for description of methods and CNCI website for tools; tools pretested and informed consent procedures used.

CNCI database provides information about the activity and function of the nurses such as patients accessing CNCI, meetings attended by CNCs, tools used and system initiatives. CNCI database distributed to each CNC in April 2014 and returned June 2014. Thirty-eight CNCs responded.

- Thirty-three CNCs across 16 DHBs provided information on patient care activity (excludes two system-focused DHBs and includes composite data from one DHB).
- Inpatient profile section of the database, there was variation in time periods completed. To consistently profile patients accessing CNCI, a snapshot analysis for a month period was undertaken.
- Five comprehensive reports on system reviews were received from two system-focused DHBs.
- Thirteen CNCs from 12 DHBs also provided information about systems activity.

CNC online survey which profiles CNCs and their activities, contribution and perceived effect on patient experience:

- n=43; response rate 68%; CNC survey profile in Appendix 1.

Provider online survey to assess understanding and perceived effects of CNC role:

- n=485 across 20 DHBs; provider survey profile in Appendix 1.

Patient survey to assess patient experience of new role and its contribution:

- n=204 across 13 DHBs: patient survey profile in Appendix 1.

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.

Data sources	Quality	Comments on quality
CNCI database	Low	Incomplete DHB and CNC coverage: In the time available not all CNCs across all DHBs completed or returned the database. Incomplete and inconsistent data: • Missing data in databases completed (eg, system log not completed in all completed databases; this may reflect incompletion or no system initiatives). • Variation in data completion. • Some categories need review as not meaningful (eg, travel codes). • Not known if data validated. Limited time period: for patient profile analysis a 'one-month' period was used and the month completed varied by CNC (ie, some completed April, others May). Note: Quality of data will increase if database is consistently completed.
CNC survey	High	–
Provider survey	Medium	Potential selection bias: providers selected by CNC to reflect engagement; CNCs distribute survey. Potential focus on CNC performance: Use of photos to identify CNC (from other nurses) may create focus on individual performance and not initiative; without photos unknown if providers are focusing on CNCI or other cancer nursing services.
Patient survey	Low	Potential selection bias: Patients and whānau selected by CNCs as may not be clinically appropriate for patients to receive questionnaire. Exclusions: Patients with high suspicion currently excluded due to questionnaire design (under review). Incomplete DHB coverage: Excluding the system-focused DHBs, patient surveys were not received from five DHBs; completion rates varied across DHBs (ranged from 1 to 40); response rates unknown. Note: Quality of data may increase as more CNCs distribute the patient survey across all DHBS excluding system-focused ones.
Qualitative patient interviews	Medium	Sample size: undertaking three Māori, three Pacific and three Pākehā patient interviews means that not all patient experiences will have been identified. However, it is anticipated that significant themes have been identified. Targeted sub-groups: This approach offers no understanding of other groups' CNCI experiences or address the diversity of Māori or Pacific patients.

Report structure

Each findings section corresponds to noted components of the CNCI outcomes model.

The first chart presents a summary of key findings for this section; the following charts present the evidence.

Findings have been presented at a total level as data quality limits analysis by key sub groups.

In future annual reports (assuming data quality has improved), results will be presented by (as appropriate) by CNCI models Generalist, Tumour Stream, System-focused and population.

Graphs are coloured coded to differentiate:

- CNC are green
- providers are blue
- patients are purple.

CNCI profile

Overview of CNCI profile

Four CNCI approaches:

- Generalist, Tumour Stream, System-focused and Population
- System-focused CNCI approaches have no patient interface and appear to be less satisfying for CNCs
- variation in CNCI models adopted as implementation responding to DHB population needs, existing care pathways and nursing structures.

Sixty-five CNCs – very experienced nurses, respected cancer expertise and leadership, settling into role.

Most CNCs in permanent roles.

CNCs' daily activities focused on care coordination (excludes System-focused DHBs):

- communicating with health professionals about patient care management, ensuring patients have timely access to services and effective and timely care coordination for patients.

As reflects intent of CNCI, system improvement activities and direct nursing care are less frequent activities (excludes System-focused DHBs were this is a daily role).

Key enablers of the CNCI are building on existing nursing strengths; IT systems both an enabler and barrier.

Overview of the four CNCI approaches

1. **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.
2. **Tumour stream:** Specialist nurses responsible for care of patents in a particular tumour stream. There are two sub-categories:
    a. **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.

b. **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 CNCs also identify and address systems improvements associated with the front of the pathway.

3. **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.

4. **Systems approach:** The focus of these roles is system improvements in key areas of care that support coordination such as equity, multidisciplinary care and supportive care. Adopted by Capital & Coast and Auckland DHB the CNC role was defined as identifying gaps in service delivery and undertaking projects around the tumour pathway.

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 reconfiguring these roles: Auckland DHB to tumour stream; Capital & Coast to front of pathway.

CNCI – variation in implementation responding to DHB population needs, existing care pathways and nursing base

Type	District Health Board	Number of CNCs 65
System	Auckland	3
	Capital & Coast	3
Tumour stream	Counties Manukau *(population and CNCI lead)*	14
	Waitemata *(population and CNCI lead)*	13
	Waikato *(equity-focus)*	5
	Canterbury	4
	Northland	4
	MidCentral	2
Generalist	Hawke's Bay	2
	Hutt Valley	2
	Southern	3
	Lakes	1
	Nelson Marlborough *(CNCI lead)*	2
	South Canterbury *(CNCI lead)*	1
	Bay of Plenty	1
	Taranaki	1
	Tairawhiti	1
	Wairarapa	1
	West Coast	1
	Whanganui	1

More than the funded number of positions as some DHBs use a whole-of-systems approach so includes other nurses (ie, Counties Manukau, Waitemata).

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.

CNCs very experienced, respected, settling into role

Highly experienced CNCs:

- 88% over 11 plus years; 51% more than 20 years
- 72% postgraduate qualification.

Fifty-eight percent been in role more than 12 months:

- 35% 6–12 months
- 7% less than 6 months.

Ninety-three percent are permanent roles.

Seventy percent on 0.7–1 FTE:

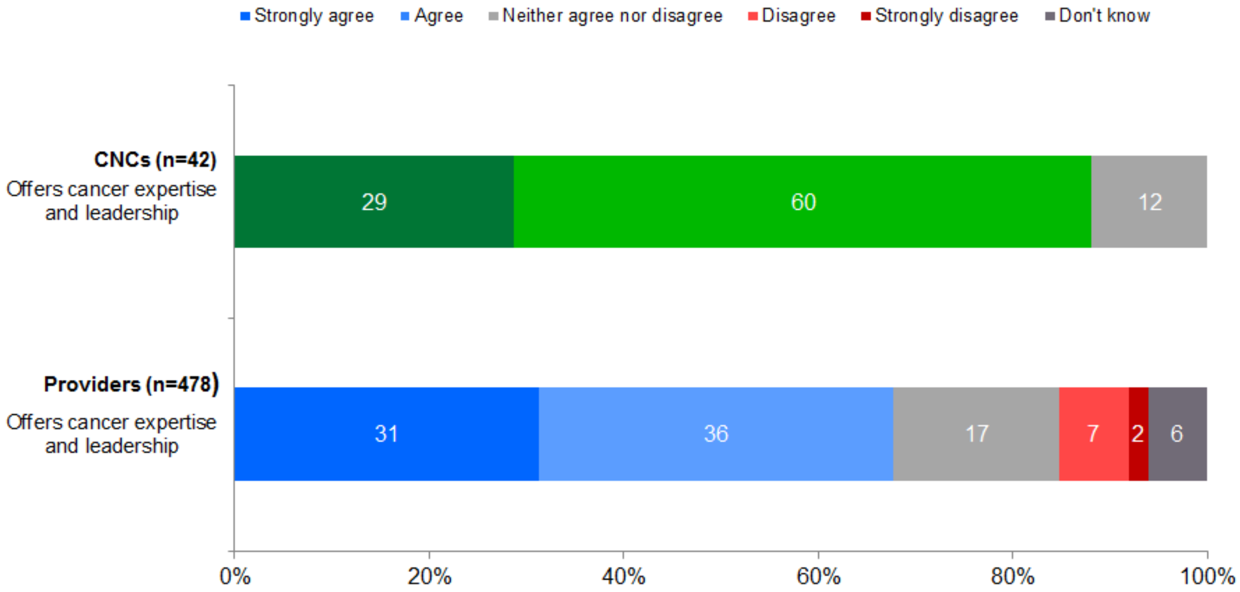
- 37% are on a 1 FTE
- 19% 0.5 FTE or less
- 19% other position in DHB.

Agreement CNCs have cancer expertise and leadership:

- 67% agreement providers *(source provider survey)*
- 89% agreement CNCs.

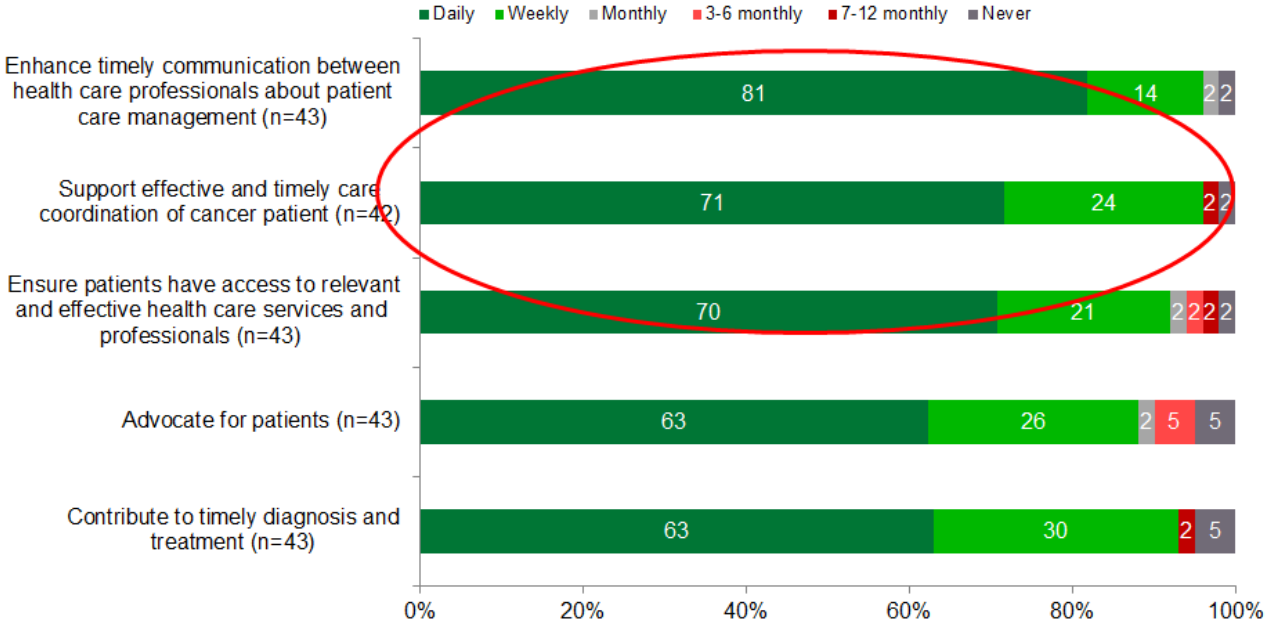
Source: CNCs who answered the survey (n=43); refer Appendix 1.

CNCs and providers perceive role offers cancer expertise and leadership; providers rated tumour stream CNCs higher than generalist CNCs on cancer expertise and leadership



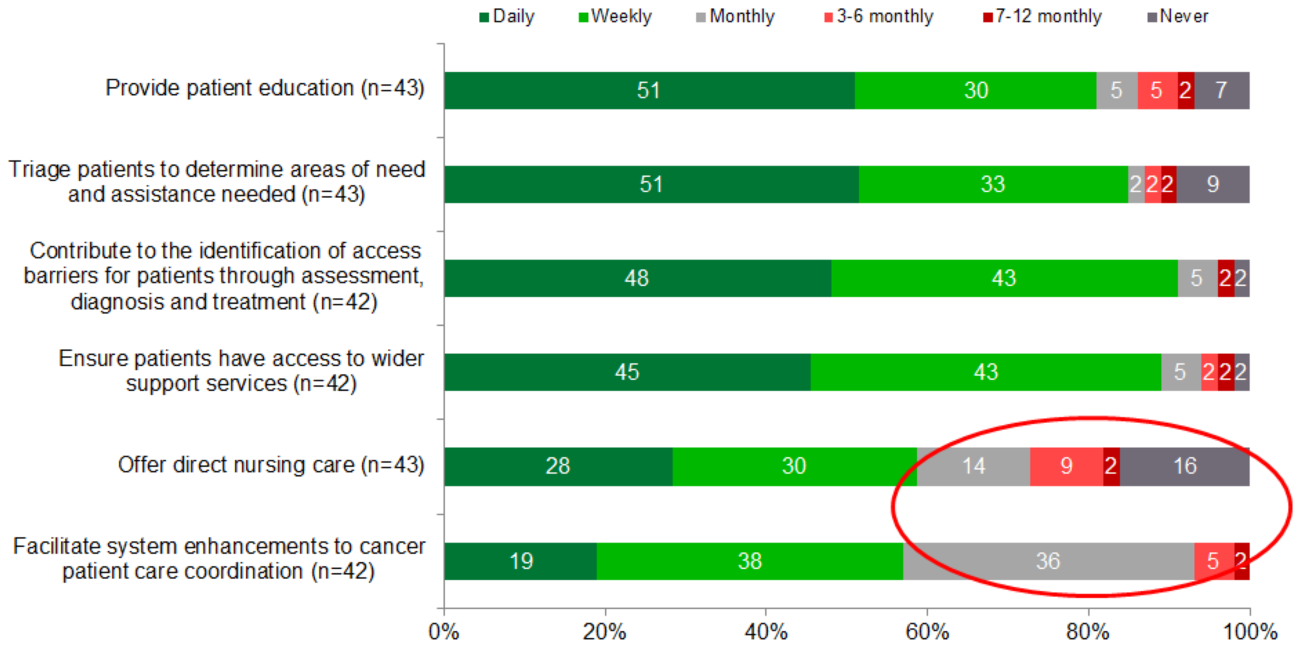
Base: CNCs and Providers who answered questions
Please tick if you agree or disagree that your/the Cancer Nurse Coordinator role…

Care coordination role a daily activity (except for system-focused roles)



Base: CNCs who answered questions
As a Cancer Nurse Coordinator, how often do you undertake the following roles….

System improvements and direct nursing care present but less frequent activities



Base: CNCs who answered questions
As a Cancer Nurse Coordinator, how often do you undertake the following roles…

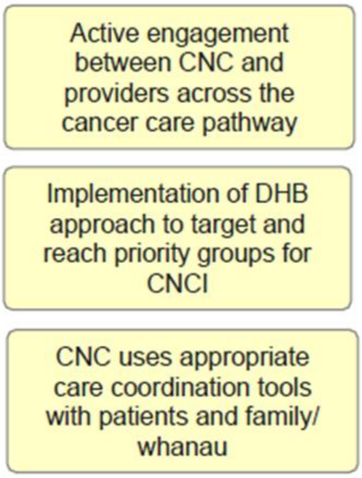
Nursing expertise an enabler for CNCI implementation; IT is an enabler and barrier

Enablers	Barriers
Multidisciplinary governance groups to create wider provider buy-in	Establishing awareness and understanding of CNCI amongst other health professionals
Building and strengthening existing nursing structures particularly around CNS roles	Managing the range of activities including managerial, administrative, IT and reporting
Role location to enable early access to patients (ie, where patients are referred into the DHB)	Lack of IT support/ too much data collection for a range of purposes which are not interlinked
IT capacity and capability to monitor patients' journey	Geographical reach in rural areas
CNCI is a nursing initiative so able to offer patients and their whānau clinical nursing support and contribute to MDMs	Lack of resources/ capacity
CNC regional and national network fosters connections within and across DHBs	Identifying eligible patients
CNCI tools enable practice (eg, triage tool)	
Input at MDMs	
CNCI nurse lead	

Source: CNC survey refer Appendix 4; provider survey refer Appendix 5.

Engagement and patient profile

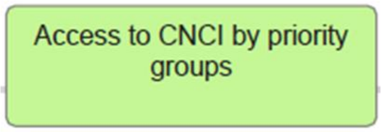
Outputs


Active engagement between CNC and providers across the cancer care pathway

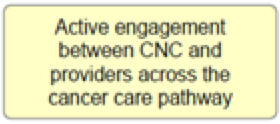
Implementation of DHB approach to target and reach priority groups for CNCI

CNC uses appropriate care coordination tools with patients and family/ whanau

Short-term outputs

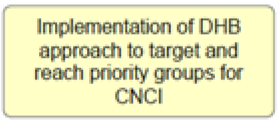

Access to CNCI by priority groups

Provider engagement and patient profile


Active engagement between CNC and providers across the cancer care pathway

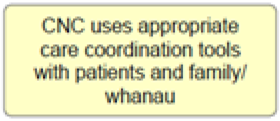
Evidence of engagement with providers across the cancer pathway:

- Refer Appendix 1 for providers who engaged with CNCs and completed survey and for providers' location compared to location of CNC they engaged with.

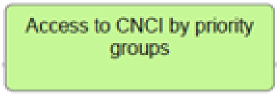

Implementation of DHB approach to target and reach priority groups for CNCI

Triage tool being used to assess patients by 31 CNCs across 15 DHBs *(refer Appendix 6 for draft triage tool)*.

- Distress Screen & Comprehensive Assessment to be developed.


CNC uses appropriate care coordination tools with patients and family/ whanau

Surgeons and physicians make half the referrals in 15 DHBs (31 CNCs); 9% of patient referrals are from primary care.


Access to CNCI by priority groups

Evidence of some priority groups accessing CNCs *(indicative only as data from CNCI databases incomplete across DHBs and CNCs)*:
half of CNC patients classified as Triage 1 and 2

- Māori represented (13%) but not known if this is an under- or over-representation due to incomplete data
- No evidence Pacific people are accessing CNCs due to missing data from one DHB with higher Pacific populations and two DHBs with high Pacific populations are system-focused.
- DHBs targeting strategies not known – prioritisation tool under-development.

Half of patient referrals in 15 DHBs are from surgeons and physicians; 9% from primary care

Referrer Base: Patients for which referrer details were completed in CNCI database	**Number n=527**	**% n=527**
Surgeon	206	39%
Physician	81	15%
GP	55	10%
Systems referral (eg, lab result or review of admission database)	50	9%
Booking clerk / administrative	34	6%
Other nurses	26	5%
MDM	21	4%
CNS	20	4%

Source: CNCI database of 600 patients for 31 CNCs across 15 DHBs for one-month period.

Active engagement between CNC and providers across the cancer care pathway

Māori patients and those assessed as triage 1 and 2 accessed CNCI; Pacific patients not present

Access to CNCI by priority groups

Due to data quality issues, we are unable to assess if Māori patients are under- or over-represented.

Ethnicity	**Number n=639**	**%**
Māori	82	13%
Pacific people	7	1%
NZ European	461	72%
Chinese	10	2%
Indian	3	0%
Other ethnicity	52	8%
Not coded	23	4%

Pacific patients are not represented which reflects missing data from one DHB with high Pacific populations; two DHBs are system-focused and CNCs do not have patients.

Source: CNCI database of 639 patients for 33 CHCs across 16 DHBs for one-month period.

Triage	Number n=600	%
1	95	16%
2	207	35%
3	175	29%
4	57	10%
Not coded	66	11%

Triage Māori	Number n=75	%
1	11	15%
2	41	55%
3	17	23%
4	5	7%
Not coded	1	1%

Source: CNCI database of 600 patients for 31 CNCs across 15 DHBs for one-month period.

Older patients accessing CNCI

Access to CNCI by priority groups

Age range	Number n=639	%
15–24 years	5	1%
25–34 years	19	3%
35–44 years	27	4%
45–54 years	56	9%
55–64 years	120	19%
65–74 years	201	31%
75+ years	180	28%
Not coded	31	5%

Biological sex	Number n=639	%
Female	330	52%
Male	306	48%

Source: CNCI database of 639 patients for 33 CHCs across 16 DHBs for one-month period.

Two-thirds of patients (where there was data) were referred to CNCs in under a month; a third in less than a week

Time from referral to DHB and referral to CNC	Number n=486	% n=486
Within 1 week	177	36%
More than 1 week, within a fortnight	61	13%
More than a fortnight, within 1 month	73	15%
1–3 months	85	17%
3–6 months	45	9%
6–12 months	23	5%
1–2 years	7	1%
2–5 years	8	2%
5+ years	7	1%

Source: CNCI database of 600 patients for 31 CNCs across 15 DHBs for one-month period; for 114 patients this data was not completed.

Knowledge of CNCI role

Increased DHB / provider understanding of CNC role

Understanding of CNCI role building amongst providers but more work to do to increase understanding and fit of role

Two-thirds CNCs perceive their role is not well understood by health professionals:

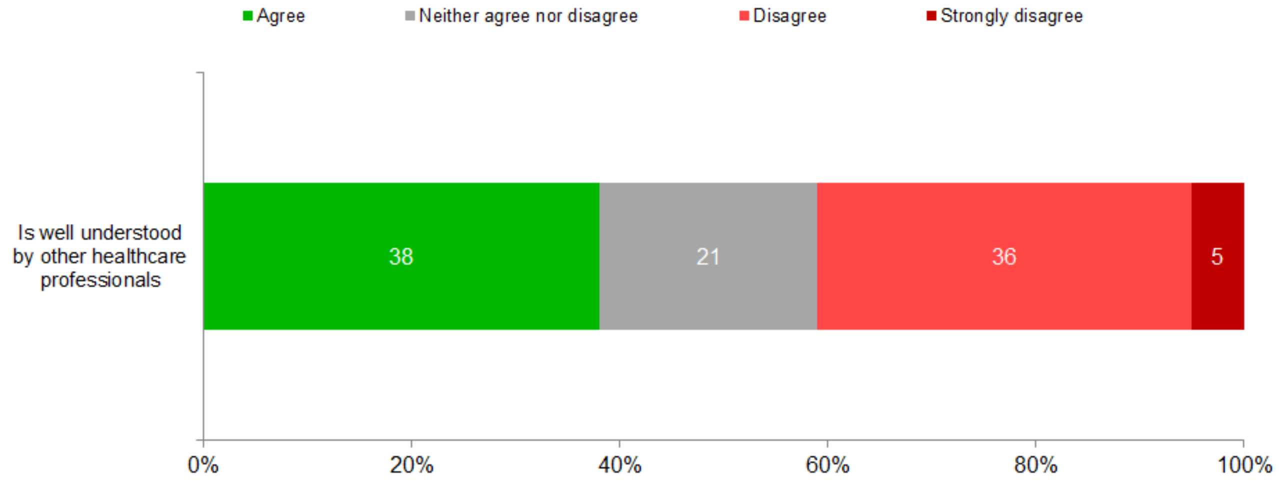
- Qualitative feedback from CNCs highlights relationships building with other health professionals is both their biggest success and greatest challenge.

Most providers understand CNC role is about care coordination, timely communications, patient advocacy, service access and system improvement.

Less agreement by providers that CNC role enables timely diagnosis and provides direct nursing care:

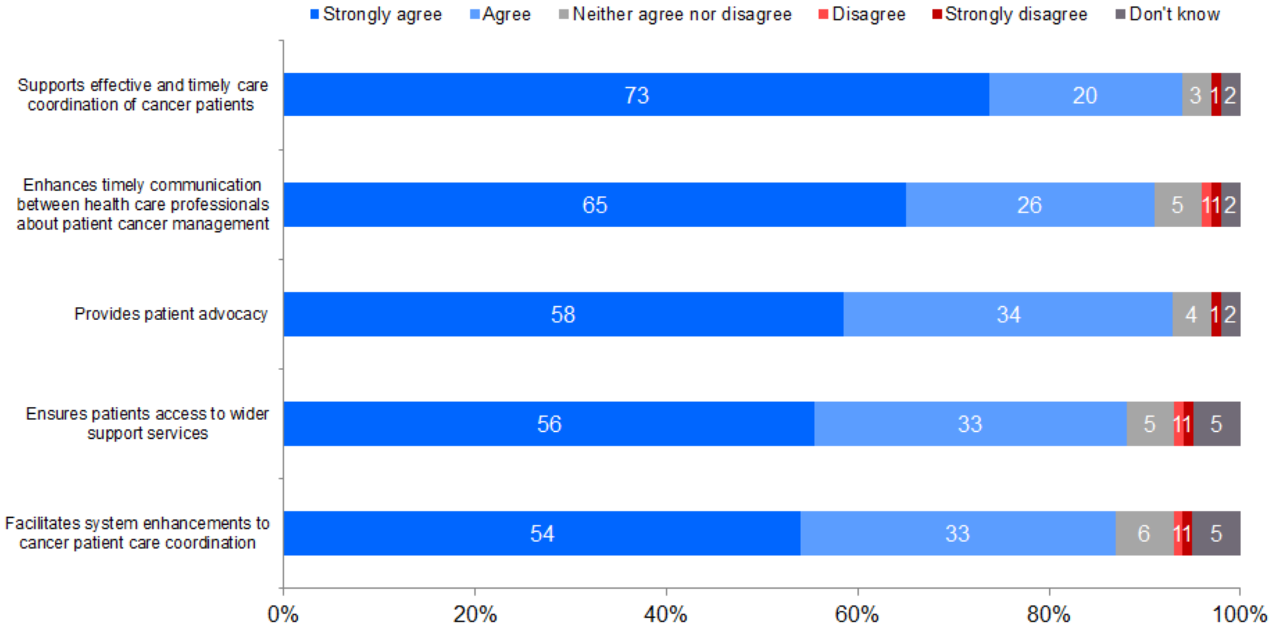
- as providers were selected by CNCs, it would be expected their understanding of the CNC role would be high. It likely non-responders to the provider survey may have less understanding about the role, which would reflect the CNCs' perceptions
- providers' suggestions to improve CNC role reflected a lack of understanding of the criteria for the CNC role, and the boundaries with other health professional roles (refer Appendix 5).

Four in ten of CNCs perceive their role is not understood by other health care professionals



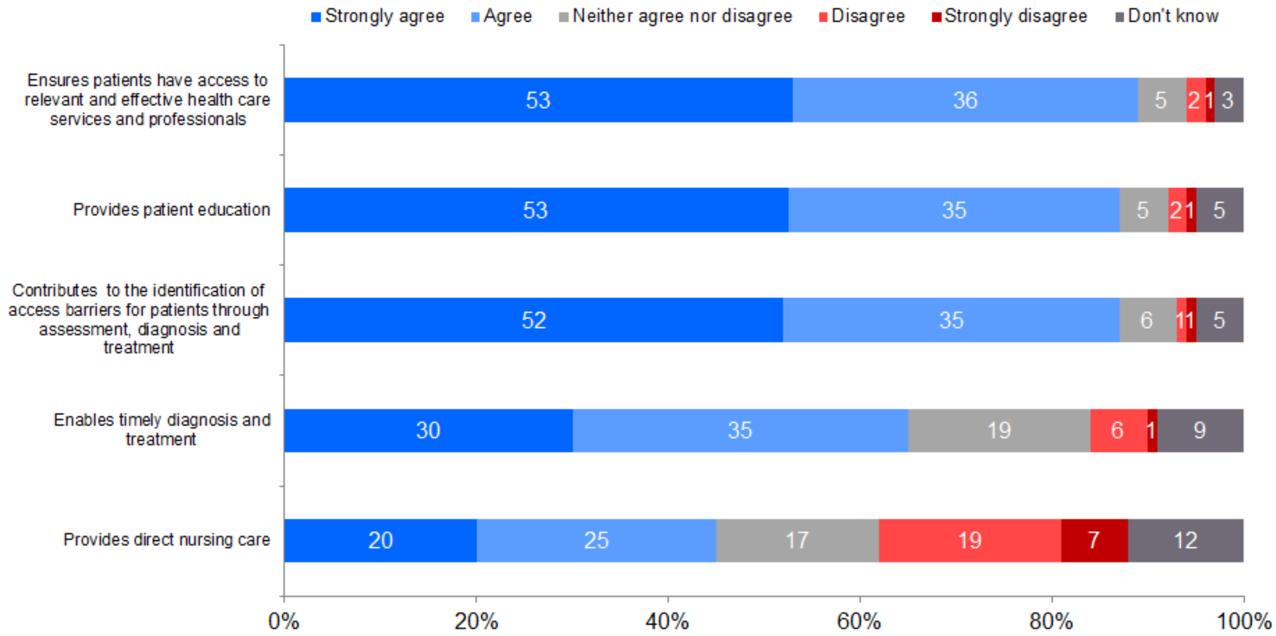
Base: CNCs who answered question (n=42)
Please tick if you agree or disagree that your Cancer Nurse Coordinator role… Is well understood by other healthcare professionals

Providers who responded to survey understood CNC role about care coordination, timely communications, patients advocacy, service access and system improvement



Base: Providers who answered survey (n=485)
Please click if you agree or disagree that the following is the role of the Cancer Nurse Coordinator…

Less agreement by providers that CNC role enables timely diagnosis and provides direct nursing care



Base: Providers who answered survey (n=485)

Please click if you agree or disagree that the following is the role of the Cancer Nurse Coordinator …

Relationship between CNC and providers

Effective working relationships between CNC and DHB / providers

Evidence of effective working relationship with health professionals engaged

Majority of CNCs and providers surveyed note an effective working relationship.

Most providers who responded to survey agreed:

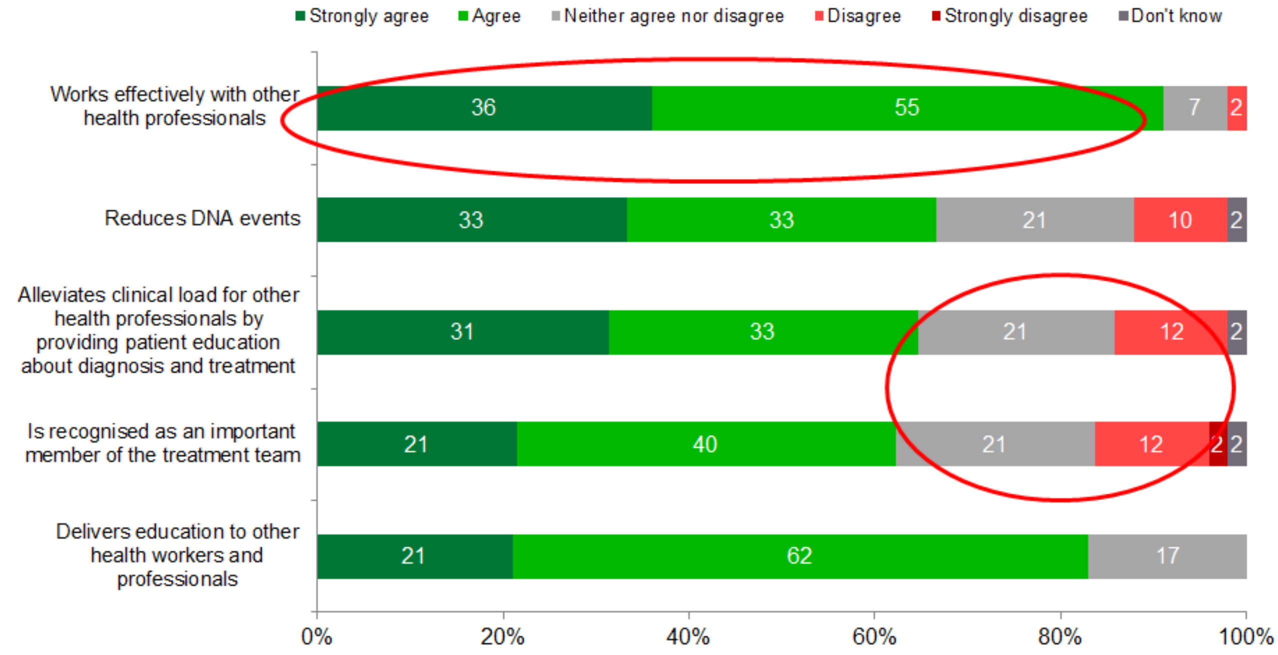
- CNCs improve communication about patient care management
- CNCs are important team member:
  - a third of CNCs do not agree with this which may reflect their awareness of those health professionals who do not understand their role.

Over half of providers feel CNCs alleviate clinical workload by providing patient education and reduces DNA events:

- Providers who answered survey are more likely to agree Tumour Stream CNCs alleviate clinical workload (67% agree/ strongly agree) than Generalist CNCs (54%).

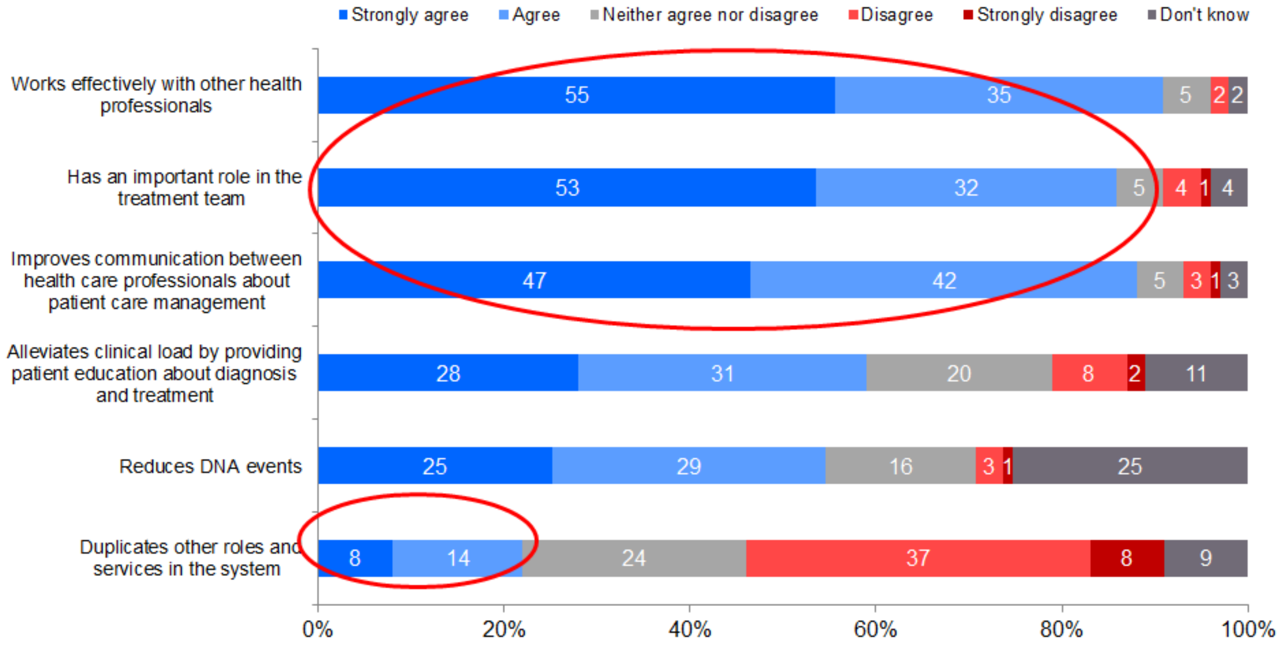
Only two in ten providers agree CNC role duplicates other roles and services.

CNCs agree they work effectively with other health professionals; some uncertain about team role and alleviating clinical load of other health professionals



Base: Cancer Nurse Coordinators who answered question (n=42)
Please tick if you agree or disagree that your Cancer Nurse Coordinator role…

Providers agree there is an effective working relationship with CNCs; CNCs not duplicating other roles



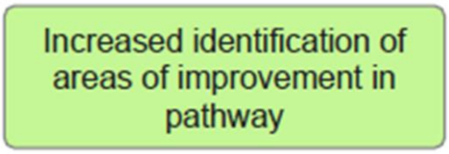
Base: Providers who answered question (n=478)
Please click if you agree or disagree that the Cancer Nurse Coordinator role…

Providers feedback on strengths *(CNC is single point of patient contact)* and improvements *(more CNCs and clarification of role)*

Best thing about CNCs	Improvements to CNC role
Dedicated person tasked with patient oversight	Increase FTE and number of CNC roles
Patients having a single point of contact	Clarification of criteria for CNC role
Improved coordination of patient cancer pathway and treatment process	Better clarification of role boundaries in patient cancer pathway
Improved communications and relationships across health professional team	Increase awareness and understanding of CNC role with other health care professionals
Facilitates system enhancements by identifying and addressing service delivery barriers and gaps	Better clarification of cancer patient criteria for CNC service

Source: Provider survey refer Appendix 5.

Contribution to system improvements


Increased identification of areas of improvement in pathway

Evidence CNCs are identifying system issues in system-focused DHBs and Generalist and Tumour Stream DHBs

Most CNCs and providers both agree that the CNC role is identifying system barriers to patients' cancer care coordination and facilitating enhancements.

In the two system-focused DHBs, a range of projects have been initiated around pathway mapping against standards, supportive care, concurrent treatment and MDMs:

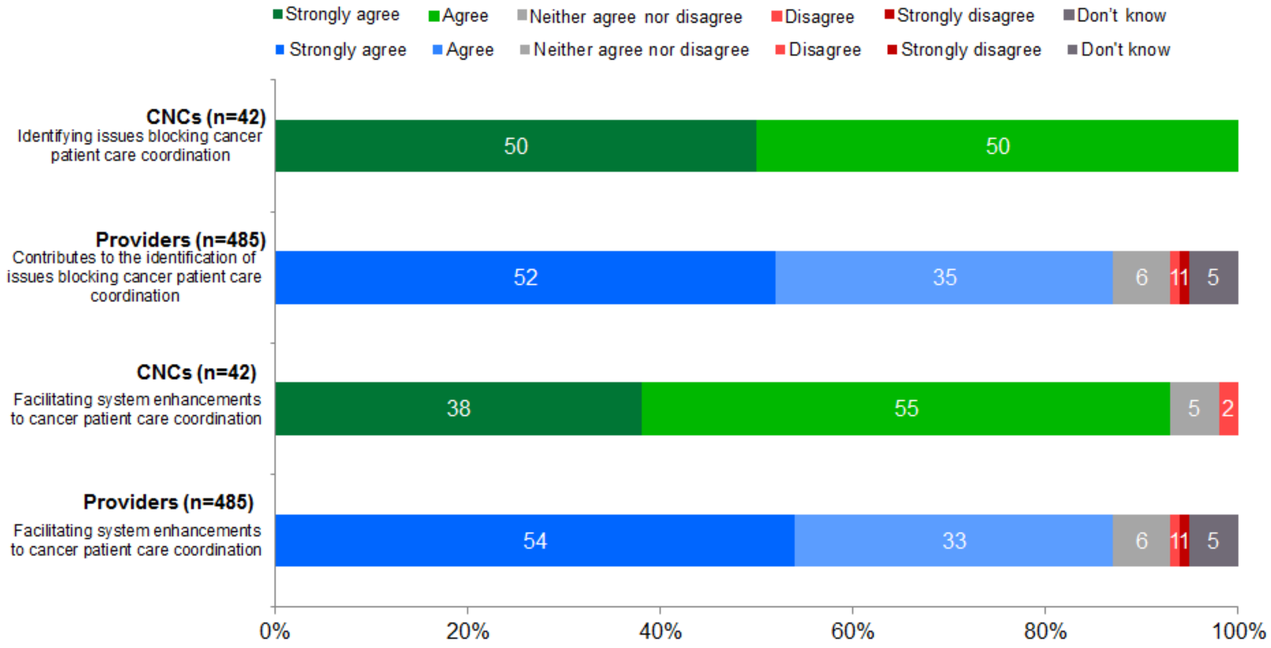
- some evidence of system change; impact on patient experience not known.

CNCs in 12 DHBs have also focused on equity projects, referral pathways across DHBs, patient information, and patient tracking:

- system change is occurring in these DHBs, the effectiveness of the system projects to create sustainable change is not known.

The extent to which CNCs in the remaining six DHBs are identifying system improvements in care coordination and patient pathway is not known.

CNCs and providers agree CNCI contributes to identifying system issues and facilitating change



Base: CNCs and Providers who answered questions
Please tick if you agree or disagree that your /the Cancer Nurse Coordinator role contributes to improving the patient experience across the following areas....

CNCI system roles (two DHBs): analysing and supporting system change

Pathway map and standards review

- Mapped pathway for patients with CRC and lung cancer from high suspicions to first treatment and identified barriers and system improvement, and set up CR and lung tumour working groups.
- Understanding patient experience from diagnosis under GP care through to first treatment.
- Established working groups to implement best practice in the total management of bowel and lung cancer.
- Regional review against National Bowel and Lung Cancer Standards.
- Developed head and neck treatment pathways.

Supportive care projects

- Tested the acceptability and feasibility of a psychosocial screening tool.
- Implemented supportive care screening across all tumour streams.
- Integrated Shared Care into Cancer and Blood Service to facilitate patient self-care management and improve information visibility between primary and secondary care.
- Developed oncology specific communications skills programme for health professionals.

CNCI system roles (two DHBs): analysing and supporting system change

Multidisciplinary care

- Tele-health solution to support Cancer MDM.
- Cancer MDM stocktake and gap analysis.
- Gynae-oncology combined MDM.
- MDM Terms of Reference.
- Scoped and developed administrative support role for MDMs.

Concurrent treatment

- Removing communication barriers Medonc and Radonc schedulers.
- Integrated referral pathway to remove risk of delays and process variance.
- Combined clinics to reduce the number of patient appointments.
- Referral process.

Other CNCs in 12 Generalist and Tumour Stream DHBs focused on system projects

13 CNCs from 12 DHBs noted their involvement in the following system projects
Equity projects (Screening for Distress, DNAs, National Travel Assistance, improving cancer care pathway for Māori)
Referral process – secondary care
Referral process – primary care
Regional patient tracking system
Review of patient pathway and experience
Patient information resources
Professional development programme for other nurses working with patients and whānau effected by cancer
Multiple site; one service model (eg, MDM)
Increase understanding of tumour standards; review
Develop protocols and tools (eg, electronic patient record template, DNA, Screening for Distress and Triage)
Improve communication processes to ensure timeliness of support and services
FCT data

Coordination of patient pathway

CNCI priority groups are linked to the relevant care coordination pathway

CNCs contributing to a more coordinated patient journey

Nine in ten patients agreed CNCs helped them to know the next steps in their treatment:

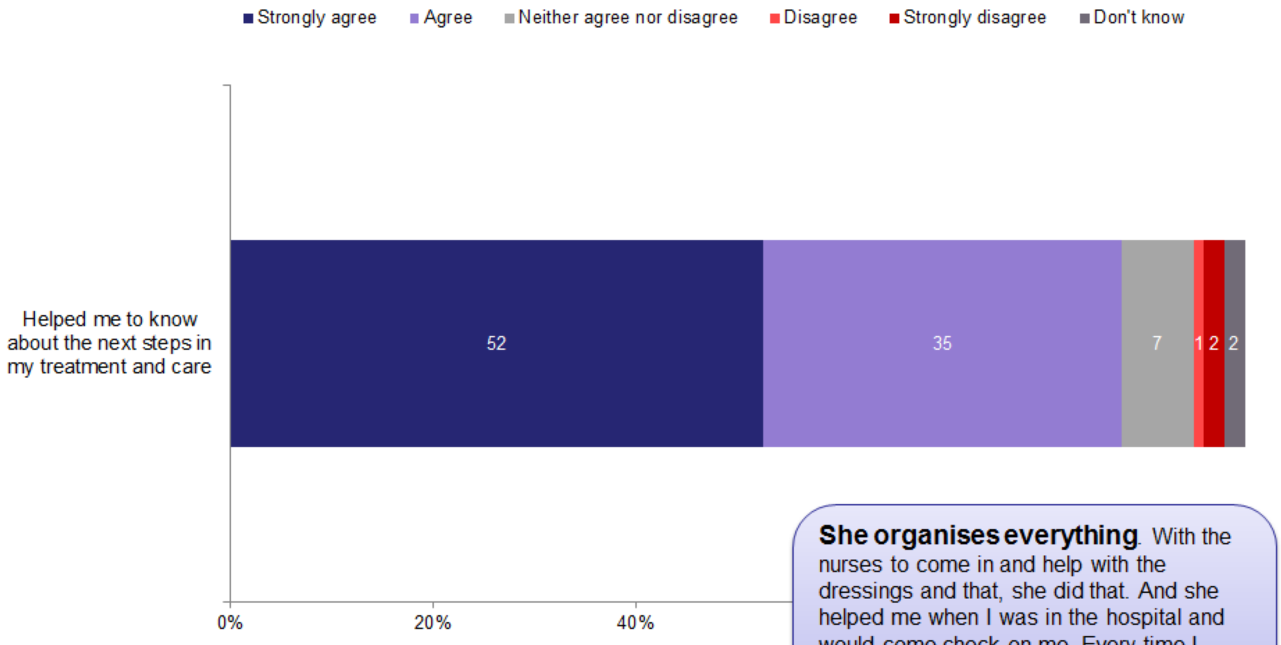
- Qualitative interviews with patients highlighted a key benefit was the ability of the CNC to proactively help them navigate the complexity of cancer services and clashing appointments at a time when they were tired, stressed, and physically and emotionally unable to cope with this additional burden.
- CNCs' internal knowledge were seen as enabling them to negotiate and facilitate patients' progress along the pathway particularly when they needed to travel across DHBs boundaries.

Last week when the hospital got the times **double booked for the same treatment**. I was going to [name] hospital but they booked me for [name] hospital. It was kind of ridiculous. **She said she would check that out**. (Pacific patient)

To have someone **checking on the patient attending appointment** and having means of transport to the same. My husband was only recently diagnosed with cancer. Both in our 80s and had very little to do with hospitals. Being given a **contact who understands our concerns and answered our questions**. (Patient)

Most CNCs and providers agreed the CNCI has contributed to improving patient experience by enabling a more coordinated cancer journey and ensuring they know the next steps in their treatment.

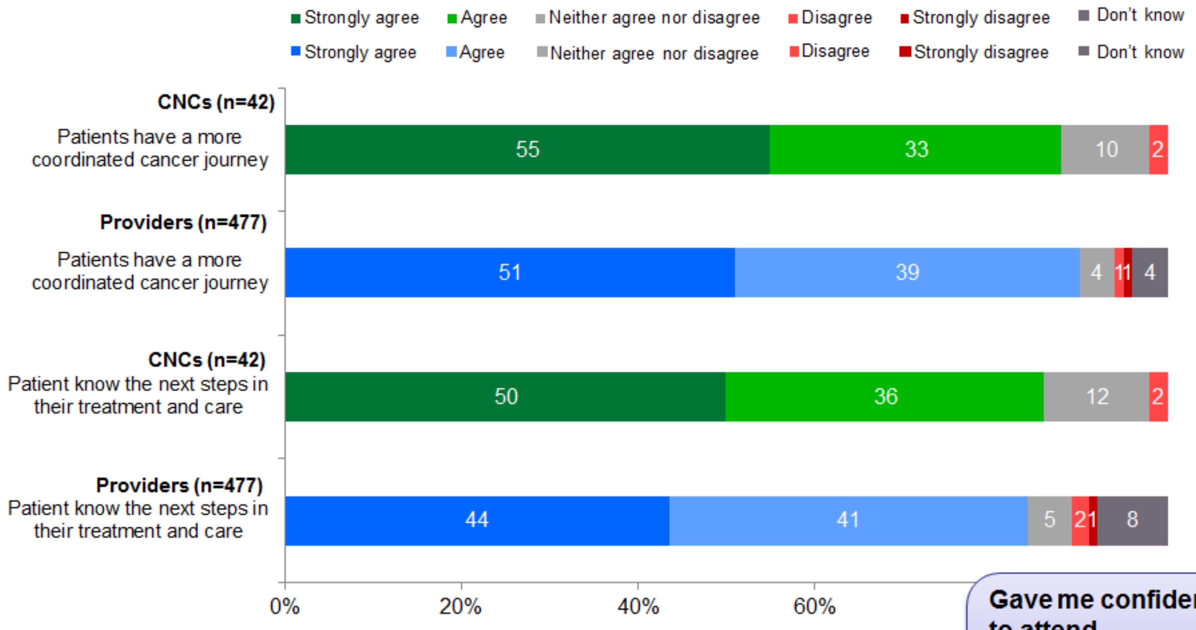
CNC the ‘go to person’ so know next steps; explained in way patients and whanau understood



Base: Patients who answered question (n=204)
Please tick if you agree or disagree that…My Cancer Nurse Coordinator…

She organises everything. With the nurses to come in and help with the dressings and that, she did that. And she helped me when I was in the hospital and would come check on me. Every time I finished an appointment she would text me or ring. It was a **good process**. I felt really comfortable with her. (Māori patient)

CNCs contribute to more coordinated patient journey



Base: CNCs and Providers who answered questions
Please tick if you agree or disagree that your Cancer Nurse Coordinator role contributes to improving the patient experience across the following areas….

Gave me confidence to attend appointments (she met us at several appointments with specialists). (Patient)

Contribution to timely diagnosis and treatment

Increased timeliness of access to diagnosis/ treatment initiation by CNCI priority groups

Agreement amongst patients, providers and CNCs the role helps to facilitate timely appointments

Currently there are no ‘hard’ measures on patients’ increased timeliness and access to diagnosis and treatment.

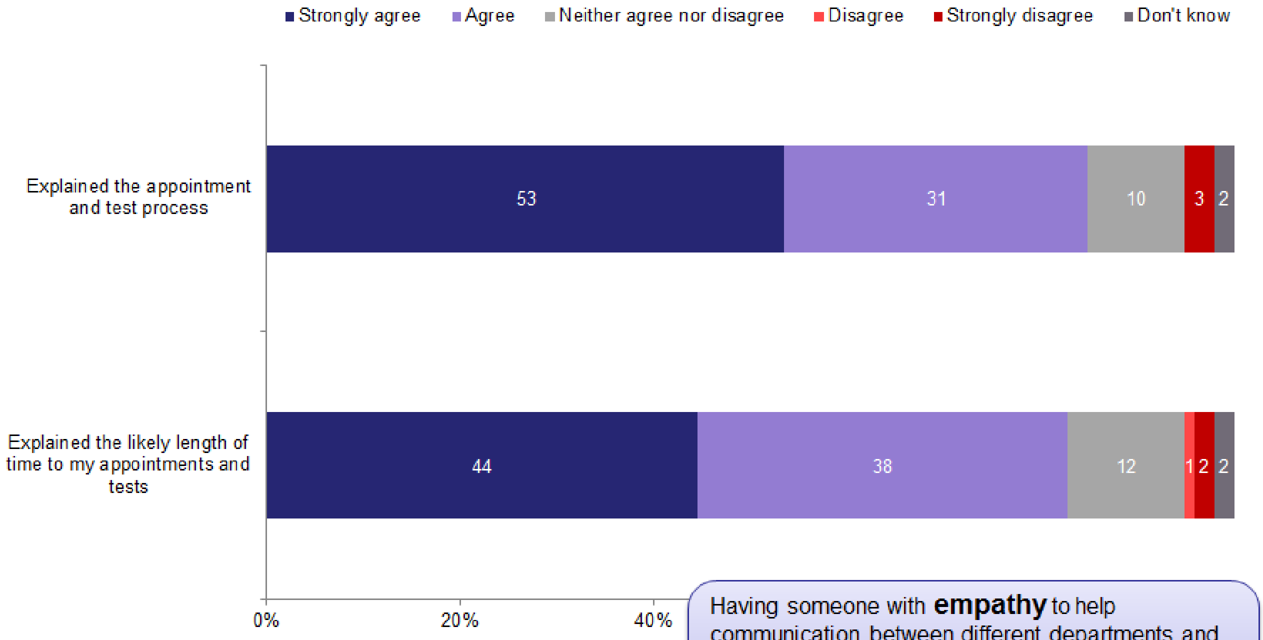
As timeliness is subjective, patients were asked whether the CNC explained the appointment process and likely timeframes – most CNCs did.

CNCs agreed they contribute to timely diagnosis and manage patients’ appointment expectations.

Providers also acknowledged the CNC role in facilitating appointments; however they are less certain about contribution to ensuring timely diagnosis. The latter may reflect there are a range of factors contributing to a timely diagnosis beyond the influence of the CNCs.

> When [CNC] called me offering **support, especially around coordination of all the specialties involved** both here or in Auckland, it was like having someone else say "hey, I can share some of that." The **everyday minutiae that sometimes overwhelms**. (Patient)

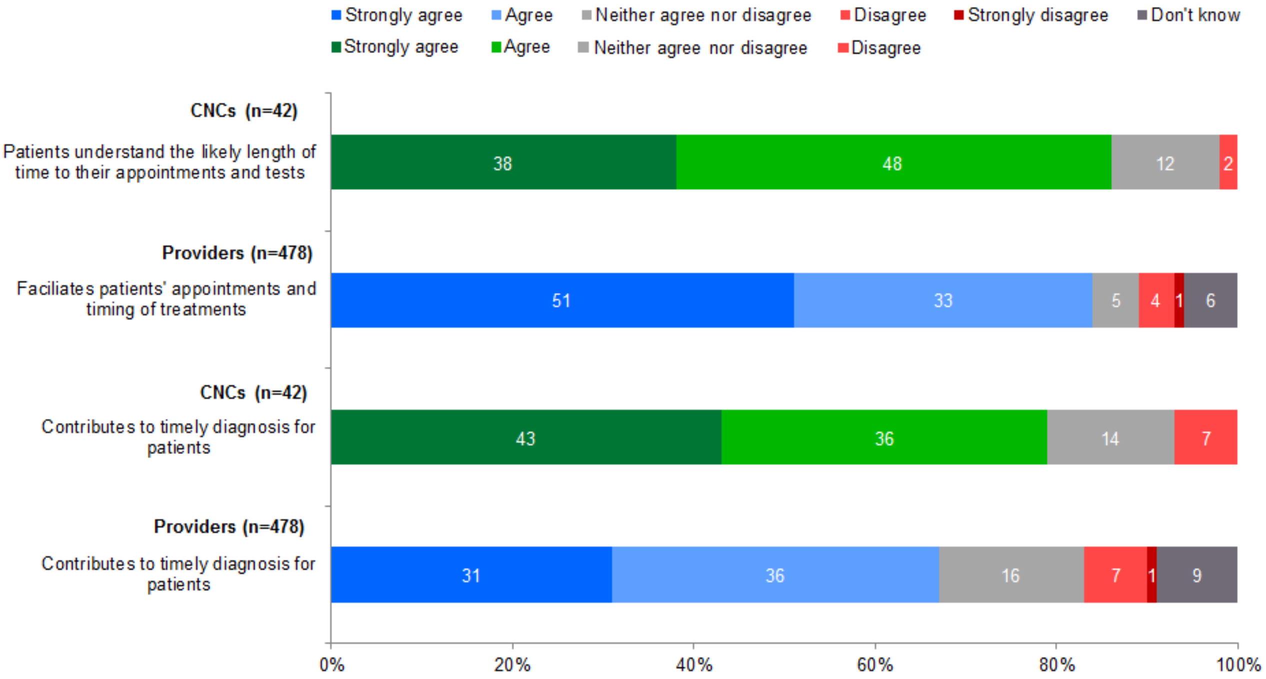
Patients aware of appointment and test process and likely timeframes



Having someone with **empathy** to help communication between different departments and me. I am under surgery clinic, cancer clinic, and health clinic, **making sure they are all on the same page is very important**. (Patient).

Base: Patients who answered question (n=204)
Please tick if you agree or disagree that...My Cancer Nurse Coordinator...

CNCs contribute to timely diagnosis and process expectations; providers acknowledge CNC role in facilitating timely process; less so timely diagnosis



Base: CNCs and Providers who answered questions
Please tick if you agree or disagree that your /the Cancer Nurse Coordinator role...
Please tick if you agree or disagree that your Cancer Nurse Coordinator role contributes to improving the patient experience

CNCs linking to other services

CNCI patients/whanau receive appropriate information / support

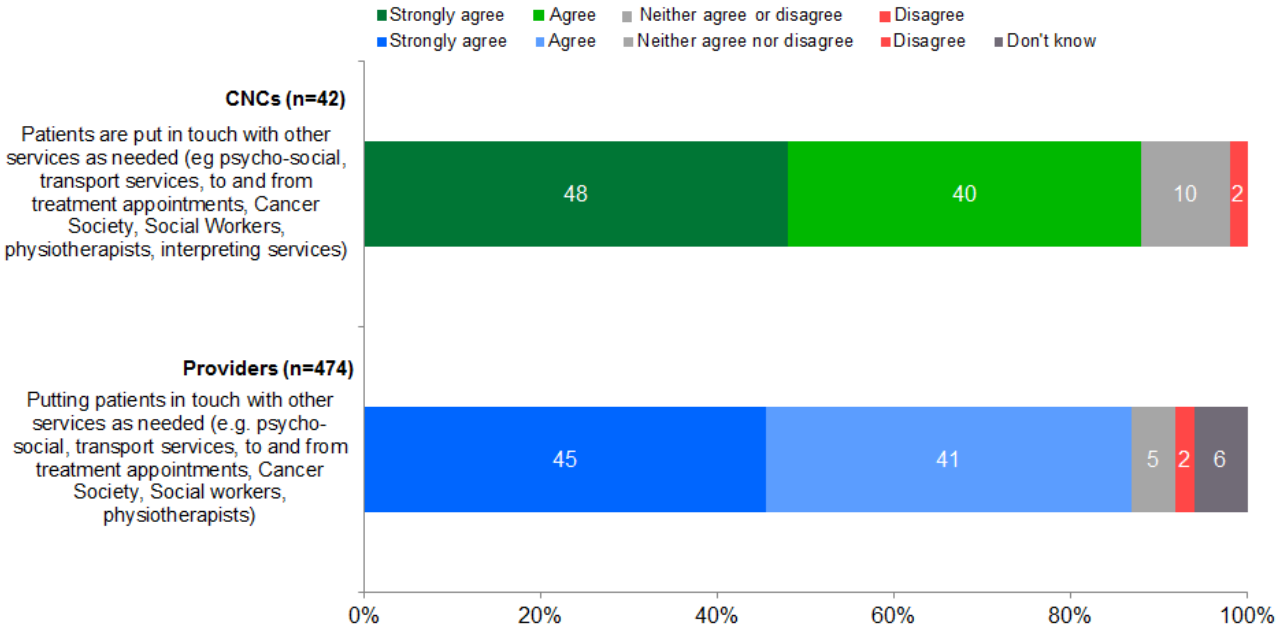
Patients are mainly getting the services they need; however a few do not

Cancer Nurse Coordinator helped with ... Base: Patients who answered the question and said they needed the service	**Patients who did not receive help from CNC when needed**	
	Number	**%**
Services to help with my worries, fears or emotional issues (n=70)	9	13%
Services I needed, eg, nurse specialists, physios, culturally appropriate groups (n=94)	11	19%
Services about transport to and from treatment appointments (n=77)	8	12%
Services to help me with financial support (n=58)	4	5%
Written information and resources about my cancer (n=113)	5	14%

> I had to get to [name] for appointments. She made arrangements for my specialist up at [name] Hospital… I knew there was a bus but I didn’t know how to get on it. **She organised all that. If she didn’t do it then I wouldn’t know how to.**
> (Māori patient)

Qualitative feedback suggests young solo mums are not getting the support they need, particularly when they have limited family/whānau support (ie, childcare, meals).

CNCs and providers both agree that CNCI improves the patient experience by connecting them to other services as needed



Base: CNCs and Providers who answered questions
Please tick if you agree or disagree that your /the Cancer Nurse Coordinator role contributes to improving patient experience across the following areas…

Improving patient experience

Positive patient/whanau experience with cancer care pathway

Positive patient experience: CNCI valued and making a difference to patients and their family/whānau

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 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 underlie the benefits they gain from the role, by having an expert who understands what they are going through, able to explain clinical information in lay terms, knowledgeable about 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.

For patients, the CNC role is much more than an administrative navigation role. Having a CNC resulted in patients being more confident about what is happening and when, knowing more about their cancer and treatment, and having their family/whānau involved as wanted.

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.

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.

Patients surveyed were mainly happy with the role. Only two improvement areas were noted: more regular face-to-face contact and more CNCs (refer Appendix 3).

These benefits were also noted by CNCs and providers, although compared to patients and providers, CNCs are less likely to strongly agree patients are more confident about what is happening.

While overall ratings of CNCs is high, areas to strengthen going forward are respecting culture, values and beliefs, helping family/whānau, and involving patients in decisions about their cancer and treatment.

CNCI – better than before, a go-to person for whole family/whānau, emotional support, reassurance and a sense of certainty

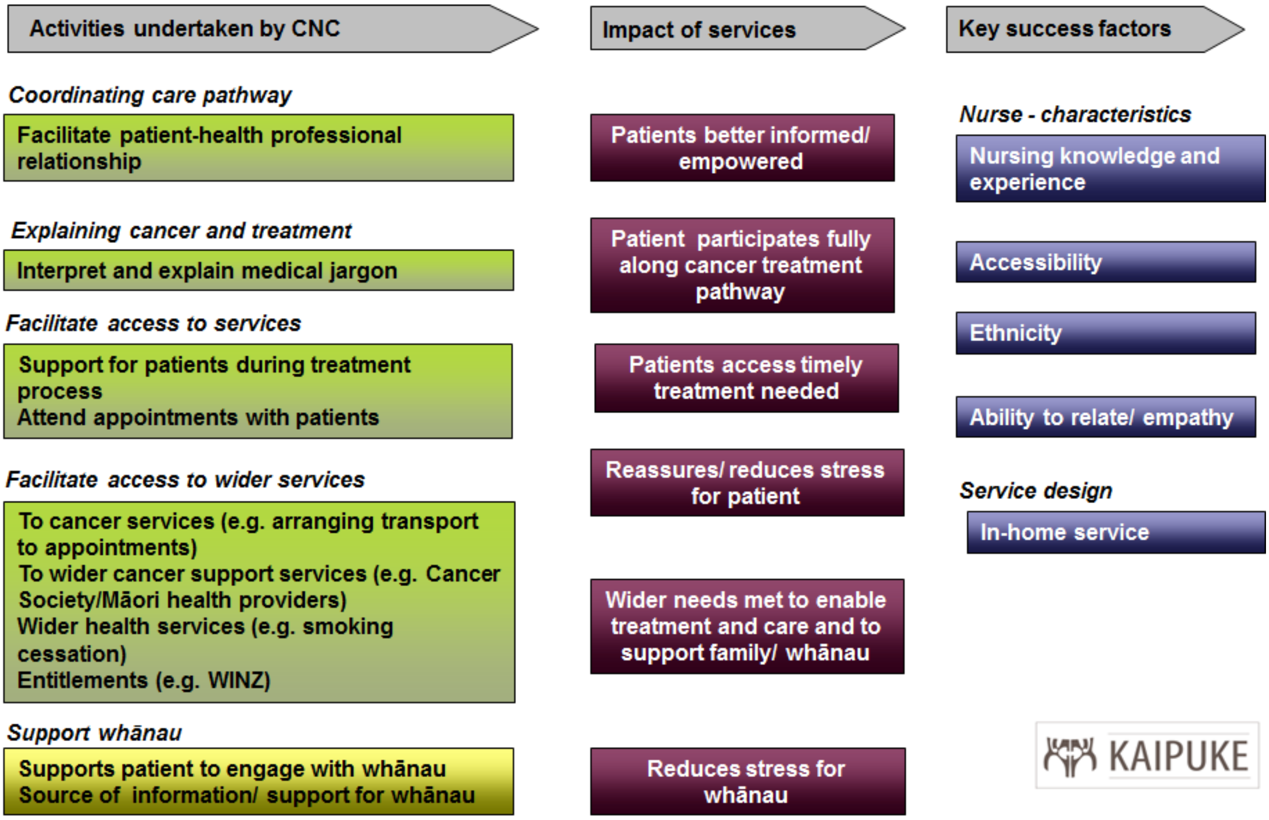
> This the **most appreciated thing I have ever** had as my husband died three years ago having cancer and had nobody to communicate with us or help us which was not good and very depressing. (Patient)

> At the beginning of the process when things are unknown and slightly scary, the coordinator provides an **incredibility valuable contact**. A friendly accessible voice that **removed an awful lot of uncertainty** and helped get me in a **positive frame of mind** to tackle what lay ahead. (Patient)

> 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)

> Having someone from diagnosis to post op final appointment who could answer questions and **relieve anxiety and stress.** [CNC] was an **essential link between myself and the med folk** involved in my plan of action. I always had more questions following each appointment and really appreciated [CNC's] availability. She never let me down, I am grateful. (Māori patient)

Māori patients’ positive CNC experience



Activities undertaken by CNC

Coordinating care pathway

Facilitate patient-health professional relationship

Explaining cancer and treatment

Interpret and explain medical jargon

Facilitate access to services

Support for patients during treatment process
Attend appointments with patients

Facilitate access to wider services

To cancer services (e.g. arranging transport to appointments)
To wider cancer support services (e.g. Cancer Society/Māori health providers)
Wider health services (e.g. smoking cessation)
Entitlements (e.g. WINZ)

Support whānau

Supports patient to engage with whānau
Source of information/ support for whānau

Impact of services

Patients better informed/ empowered

Patient participates fully along cancer treatment pathway

Patients access timely treatment needed

Reassures/ reduces stress for patient

Wider needs met to enable treatment and care and to support family/ whānau

Reduces stress for whānau

Key success factors

Nurse - characteristics

Nursing knowledge and experience

Accessibility

Ethnicity

Ability to relate/ empathy

Service design

In-home service

Source: Qualitative interviews with Māori patients.

Māori patients’ feedback

> Now that I’ve gone through it I think people will be lost without them ay, that’s them doing their work. **A calm just came over me when she said she’s coming to my house**… To me what they do now is heaps. It’s really good… As far as I’m concerned there are none [improvements be made].

> If I have trouble she helps me. She helps explain things to me. She **breaks it down to me in words I can understand**. Like when the oncologist is talking to me and afterwards [CNC] takes time out to talk to me about it.

> **She knew what she was talking about**. I felt like I could **trust her**. And I was just so wrapt in her. Keep her keep her.

> My [son] well he is epileptic and if he needs to go to the hospital then she helps me. It costs $85 to get an ambulance. I’m by myself with him well [nurse] just says **ring me if you want help with that**.

> She **made me feel very, very comfortable and at ease**. She explained things clearly… and **she made me feel like it was up to me** because I would tell her “they said this and they said that” and she would say “it’s up to you [name], it’s not up to them, so if you don’t want to do it then you just tell them”. She just took it on board.

> **Because she’s Māori**, I said you get these people that talk all hierarchy words, you don’t understand it, you just want the basics.

Pacific patients' positive CNC experience

Activities undertaken by CNC

Coordinating care pathway

Following up appointments
Ensuring treatment appointments aligned
Supporting patient to decide whether they want to proceed with treatment
Supporting at appointments

Explaining cancer and treatment

Explaining treatment
Explaining what to expect from treatment both emotionally and physically
Providing reading material on cancer

Facilitating access to wider services

To Pacific community health services
To transport services
To home help
Note: Some patients had needed access to support for meals, heating, transport and cleaning and were not connected to these services. This may reflect they did not meet the eligibility criteria

Support whānau

Supports patient to engage with whānau

Impact of services

Patients better informed/ empowered

Patient participates fully along cancer treatment pathway

Patients access timely treatment needed

Reassures/ reduces stress for patient

Wider needs met (but not all) to enable treatment and care and to support family/ whānau

Referral process

Patients wanted to be asked whether they wanted to access a Pacific CNC or non-Pacific CNC

Key success factors

Nurse - characteristics

Nursing knowledge and experience

Accessibility

Ability to relate/ empathy

Source: Qualitative interviews with Pacific patients.

Pacific patients' feedback

> Having **someone that knows you** and you don't need to tell them over and over again about your health status and your own needs

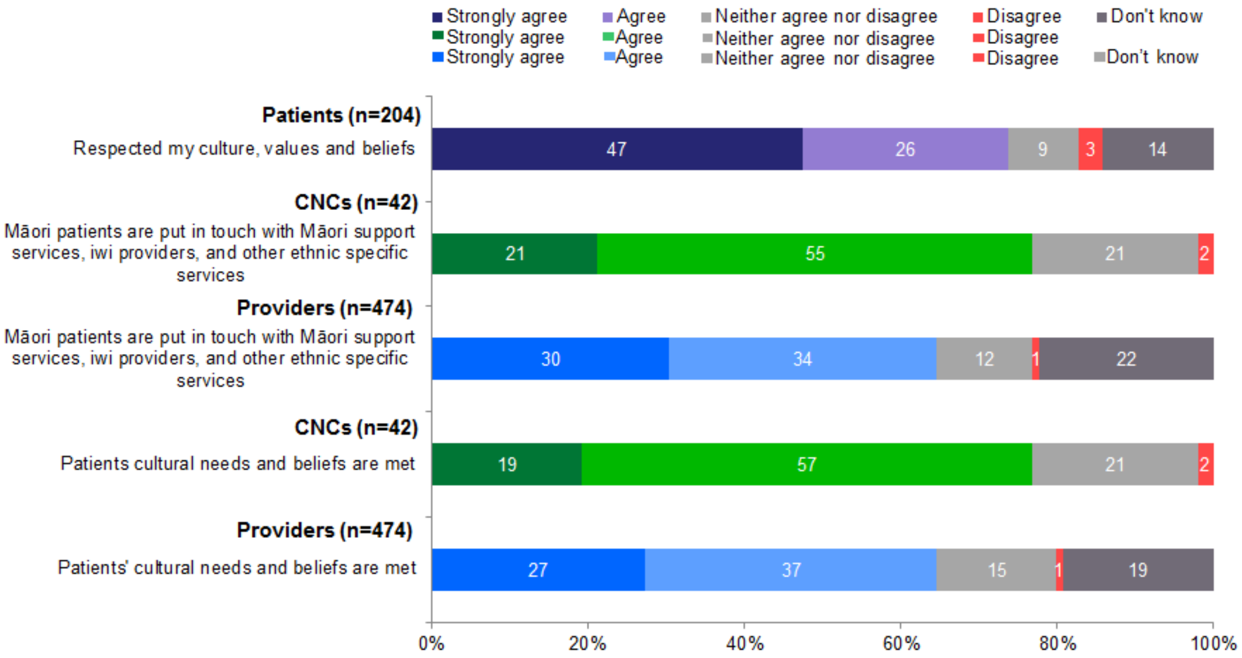
> She is lovely and **professional** in her own right and in her own job. She's **very helpful**.

> **Emotional support**. Understood what I was going through. Emotionally as well

> She does enough for me. There's nothing that I expect her to do that she hasn't done. I haven't expected her to do anything. I didn't know what to expect from her. Just **her support** and that's it.

> **Being available with the right advice** and knowing what to say and when to say it makes a big difference.

Meeting patients' cultural and belief needs; not rated as highly as other attributes; room to improve linking to other services for Māori patients

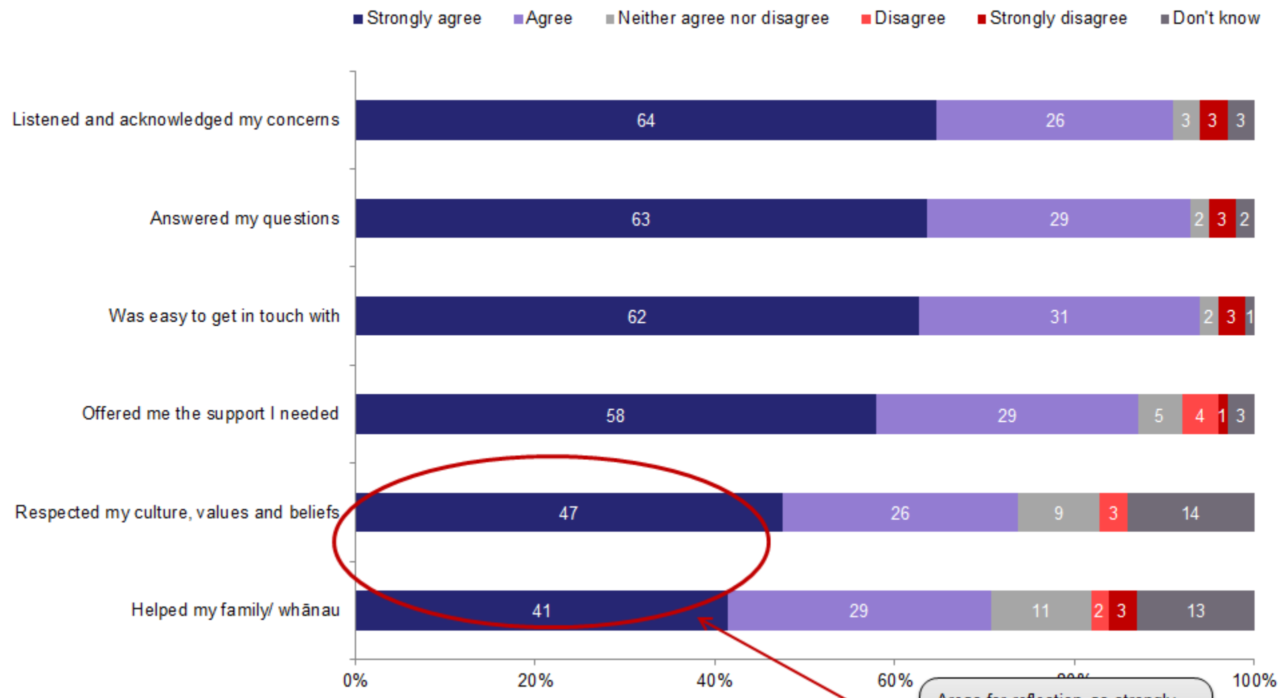


Base: CNCs, Patients and Providers who answered questions
Please tick if you agree or disagree that...My Cancer Nurse Coordinator...
Please click if you agree or disagree that the Cancer Nurse Coordinator contributes to improving the patient experience across t

Referral to Māori support services the key activity used by CNCs to improve the experience of Māori patients and their whanau in the cancer pathway

What are the two most important activities you undertake in your Cancer Nurse Coordinator role to improve the experience of Māori patients and their whānau in the cancer pathway? Base: number of CNC who answered question; multiple response	**n=42** **%**
Referral to Māori support services	57%
Cultural awareness and acknowledgement, if appropriate	21%
Explaining and mapping patient cancer pathway	19%
Ensuring timely and accessible contact and communication	19%
Inclusion of whānau	17%
Coordination of care/transport/appointments	17%
Identification of barriers	10%
Education (non-specific)	7%

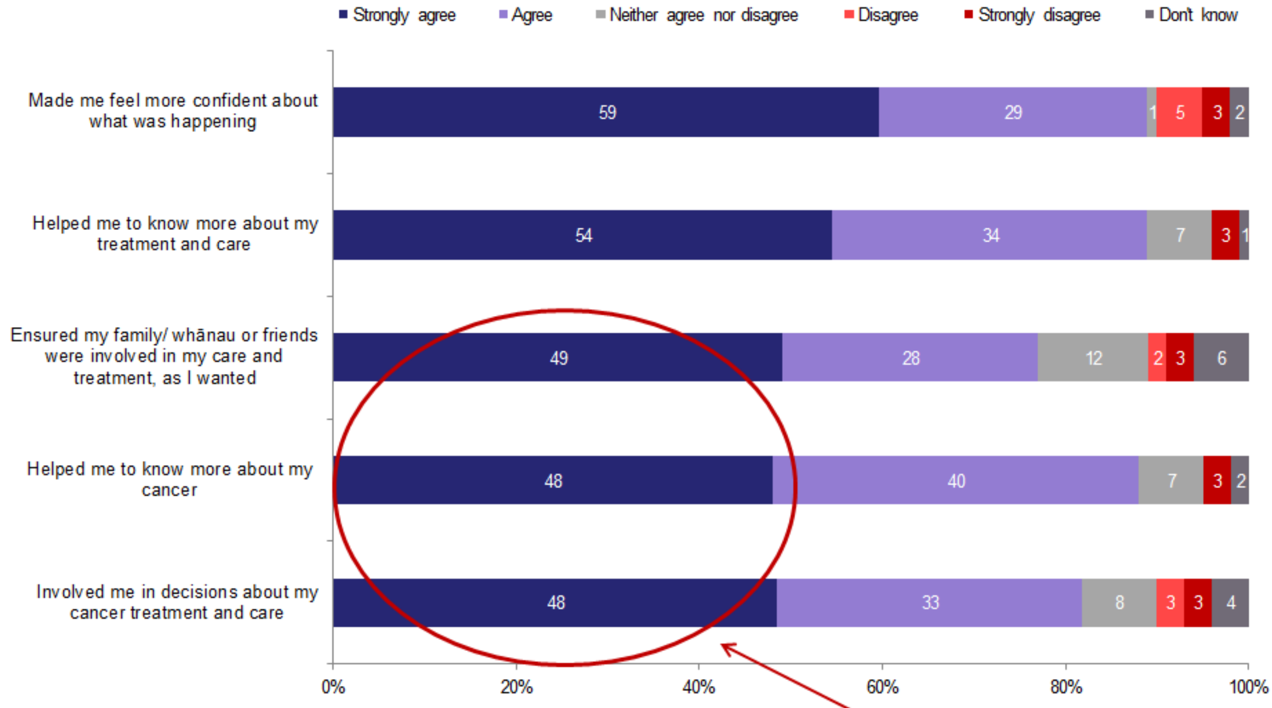
Strong agreement by patients that CNCs listen, answer questions, are accessible and offer support



Areas for reflection as strongly agree not as high as other attributes; no difference in ratings by Māori patients.

Base: Patients who answered question (n=204)
Please tick if you agree or disagree that…My Cancer Nurse Coordinator…

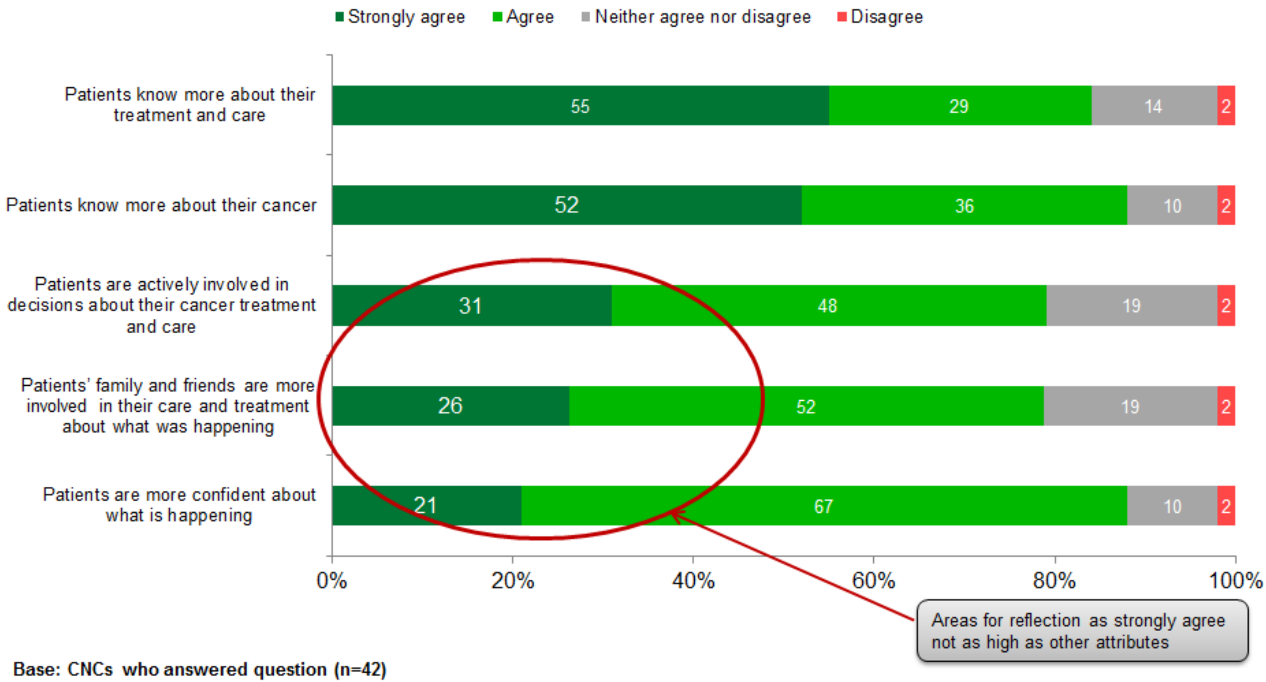
Patients agree CNCs make them feel confident about what is happening and to know more about their treatment and care



Areas for reflection as strongly agree not as high as other attributes

Base: Patients who answered question (n=204)
Please tick if you agree or disagree that…My Cancer Nurse Coordinator…

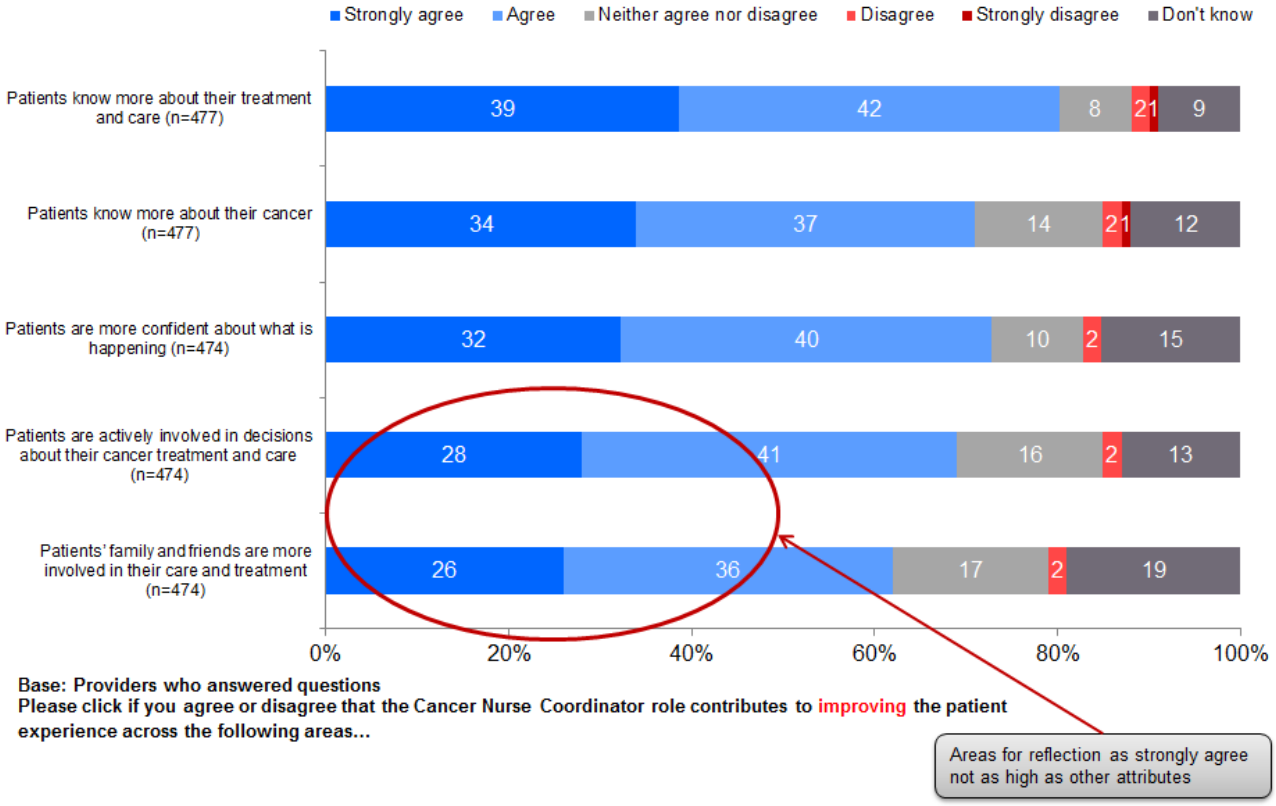
CNCs perceive patients know more about treatment, care and cancer, but not so confident and not involved in decision-making



Areas for reflection as strongly agree not as high as other attributes

Base: CNCs who answered question (n=42)
Please tick if you agree or disagree that your Cancer Nurse Coordinator role contributes to improving the patient experience across the following areas…

Providers agree CNCs improve patients' knowledge about their treatment, care and cancer, and are more confident about what is happening



Base: Providers who answered questions
Please click if you agree or disagree that the Cancer Nurse Coordinator role contributes to improving the patient experience across the following areas…

Areas for reflection as strongly agree not as high as other attributes

Conclusions

Conclusions against success criteria

Implementation status

Providers have an improved understanding of CNC role.

CNCs have an effective working relationship other health professionals; CNCs recognise more work to do in ensuring wider understanding and more clarity about role and its boundaries.

CNC is a key and very valued contact for patients and family/whānau.

Success criteria

Indicative evidence suggests CNCI delivering against purpose; not known if this is consistent across all DHBs:

- targeting Māori and those with complex needs (extent across DHBs not known) ; not known if Pacific people with cancer are accessing CNCI
- positive patient experience
- perceived by providers surveyed as contributing to improved access and timeliness of access; patients feel care is coordinated
- system issues are being identified and acted on in some DHBs (not known for seven DHBs). Not known if system change actions will have positive impact on patients.

Areas to focus

- Patient access to support services.
- Ensuring patients’ cultural needs met and linked to appropriate services.
- Facilitating patients’ involvement in their treatment and care decisions.

Evaluation reflections

CNCI database

- Review to enhance useability, particularly the category that identifies if patients experience issues with travel.
- Discussion with DHBs who did not complete or provide data solutions to ensure data for future reports.

Patient survey

- Determine the inclusion of high suspicion patients; will require patient questionnaire to be revised.
- Review distribution method and frequency (ie, point in time or ongoing).

Provider survey

- Review distribution and responses from providers interfacing with multiple CNCs across DHBs.
- Agree distribution time.

DHB level report

- Litmus to prepare 15 DHB dashboard reports (5 DHBs have no or insufficient data to develop a dashboard report).

Appendices

Appendix 1: CNC survey profile

Profile Base: answered CNC survey		**Number** **n=43**	**%** **n=43**
Years qualified as a nurse	5–10 years	5	12%
	11–15 years	9	21%
	16–20 years	7	16%
	Greater than 20 years	22	51%
Highest nursing qualification	Registered Nurse	4	9%
	Bachelors Degree	8	19%
	Postgraduate Certificate	15	35%
	Postgraduate Diploma	10	23%
	Masters Degree	6	14%
Professional groups (multiple choice questions; adds to more than 100%)	NZNO	38	88%
	NZNO Cancer Nurses Section	28	65%
	NZNO College of Practice Nurses	3	7%
	Cancer Nursing Society of Australia	2	5%
	Oncology Nursing Society	4	9%
	Other	9	21%
Ethnicity	Māori	2	5%
	New Zealand European	35	81%
	Other	6	14%

CNC survey profile

Profile Base: answered CNC survey		Number n=43	% n=43
Length of time in role	Less than 3 months	2	5%
	More than 3 months and less than 6 months	1	2%
	More than 6 months and less than 12 months	15	35%
	More than 12 months and less than 24 months	21	49%
	More than 24 months	4	9%
Permanent or fixed term	Fixed term	3	7%
	Permanent	40	93%
FTE	0.1	1	2%
	0.2	0	0%
	0.3	2	5%
	0.4	1	2%
	0.5	4	9%
	0.6	5	12%
	0.7	3	7%
	0.8	2	5%
	0.9	9	21%
	1	16	37%
Nursing position in same DHB	Yes	8	19%
	No	35	81%

Provider sample profile

Positions Base: Answered Provider survey	Number n=485	% n=485
Administration support	47	10%
Allied health and NGOs	30	6%
Māori/Pacific/Asian providers	18	4%
Primary care	38	8%
Secondary care nurses	139	29%
Senior medical officers	163	34%
System support/management	31	6%
Blank/refused	19	4%

Provider sample profile

Provider DHB locations Base: Answered Provider survey	**Number** **n=485**	**%** **n=485**
Auckland	19	4%
Bay of Plenty	27	6%
Canterbury	104	21%
Capital & Coast	4	1%
Counties Manukau	35	7%
Hawke’s Bay	8	2%
Hutt Valley	5	1%
Lakes	3	1%
Mid-Central	2	0%
Nelson-Marlborough	25	5%
Northland	10	2%
South Canterbury	10	2%
Southern	57	12%
Tairawhiti	41	8%
Taranaki	37	8%
Waikato	38	8%
Wairarapa	13	3%
Waitemata	19	4%
West Coast	8	2%
Whanganui	3	1%
Blank	17	4%

Provider sample profile

DHB locations of provider	DHB locations of CNCs	Number n=485	% n=485
Auckland	Auckland	10	2%
	Counties-Manukau	1	0%
	Northland	4	1%
	Waitemata	4	1%
Bay of Plenty	Bay of Plenty	25	5%
	Lakes	1	0%
	Waikato	1	0%
Canterbury	Canterbury	36	21%
	Southern	1	0%
	West Coast	1	0%
Capital & Coast	Capital & Coast	1	0%
	Hutt Valley	1	0%
	Don’t know	2	0%
Counties-Manukau	Counties-Manukau	35	7%
Hawke’s Bay	Hawke’s Bay	8	2%
Hutt Valley	Hutt Valley	5	1%
Lakes	Lakes	1	0%
	Southern	1	0%
	Waikato	1	0%
MidCentral	Hawke’s Bay	1	0%
	MidCentral	1	0%
Nelson-Marlborough	Nelson-Marlborough	25	5%
Northland	Northland	10	2%
South Canterbury	South Canterbury	10	2%
Southern	Southern	57	12%
Tairawhiti	Tairawhiti	40	8%
	Waikato	1	0%
Taranaki	Taranaki	37	8%
Waikato	Tairawhiti	3	1%
	Waikato	35	7%
Wairarapa	Wairarapa	13	3%
Waitemata	Waitemata	19	4%
West Coast	West Coast	8	2%
Whanganui	Northland	1	0%
	Whanganui	2	0%
Did not answer	Did not answer	17	4%

Patient sample profile

Profile Base: Answered Patient survey		**Number** **n=204**	**%** **n=204**
Ethnicity	Māori	26	13%
	Pacific	3	1%
	New Zealand European	160	78%
	Other	13	6%
	Refused	2	1%
Gender	Female	105	51%
	Male	96	47%
	Refused	3	1%
Age	20–29	3	1%
	30–39	9	4%
	40–49	16	8%
	50–59	38	19%
	60–69	49	24%
	70–79	65	32%
	80 years or older	22	11%
	Refused	2	1%
DHB locations	Bay of Plenty	6	3%
	Canterbury	40	20%
	Hutt Valley	2	1%
	Lakes	12	6%
	Nelson-Marlborough	1	0%
	Northland	14	7%
	Southern	18	9%
	Tairawhiti	20	10%
	Taranaki	17	8%
	Waikato	37	18%
	Waitemata	6	3%
	West Coast	27	13%
	Whanganui	4	2%

Appendix 2: CNC training needs

What other training would be the most useful in your Cancer Nurse Coordinator role? Base: Number of CNC who answered question	**%** **n=27**
Excel	22%
Postgraduate papers	19%
Project management	15%
Process Mapping	11%
Change management	11%
Supervision	11%
Computer skills (general)	11%
Tumour specific study days and meetings	7%
Cultural training	7%
PowerPoint	4%
Quality improvement training	4%
Psycho social	4%
Other	33%

Appendix 3: Patients' best things and improvements

For patients CNCs' availability, oversight and support are key, while improving communications and follow-up as well as more resources are the key improvements

Best things for patients about having CNC Base: Number of patients who answered question	**%** **n=179**
Availability and ease of contact for questions/results	30%
Alleviated stress/more confident as someone has dedicated oversight and indepth understanding	22%
Overall support for patient and family/whānau	22%
Provided information and educated patient on treatment process/cancer/services using layman terms	20%
Approachable 'go-to' person for patient and family/whānau	19%
Coordination of appointments, meetings and travel/ensuring timeliness of referrals	16%
Single point of contact for patient/ identifiable contact person for queries	12%
Regular contact and communication	10%

Improvements to CNC role Base: Number of patients who answered question	**%** **n=109**
More regular communication and improve follow up procedures/ more hands-on contact and less phone calls to support patient and family/whānau	17%
More CNCs/more resources and supports for CNCs (IT resources, leave cover, training and information resources)	12%
Better information sharing about patient's progress on cancer pathway with other health professionals	6%

Appendix 4: CNCs' successes and challenges

For CNCs building relationships with other health professionals and facilitating system change both a success and challenge

What are the biggest successes in this role to date? Base: Number of CNCs who answered question	**%** **n=41**
Building relationships with other health professionals/ being part of a team/increased awareness and use of role by other health professionals	41%
Identification of system barriers/ Facilitating system enhancements such implementation of tumour stream standards, establishment of patient tracking database and implementation of clinics, and improving cancer pathway for Māori	35%
Being 'go-to' person for patients/supporting patients	27%
Improved patient care coordination/referral process	27%
Patient satisfaction	24%
Improved timeliness (non-specific)	24%
Input at MDMs/ presenting reviews and reports	24%
Educating patients	12%

What are the biggest challenges to date in this role? Base: Number of CNCs who answered question	**%** **n=41**
Educating other health care professionals about role/ negative perceptions of role from other health care professionals	44%
Managing intersection of management duties with other role components/workload of administration and reporting duties/unclear role description	29%
Facilitating system change/changing ingrained attitudes about process (advocating patient-centred approach)	27%
Not enough FTE/lack of funding/resource	22%
Coordination of patients through patient cancer pathway/ensuring timeliness of process	22%
Lack of patient database/IT resources/tracking patients between DHBs	10%
Identification of eligible patients	12%

Appendix 5: Providers' best things and improvements

For providers key strengths of CNCI are having a single point of contact for patient information, improved coordination and improved communication

Best thing about the Cancer Nurse Coordinator role Base: Number of providers who answered question	**%** **n=408**
Dedicated person tasked with patient oversight/single point of contact for information on patient	28%
Improved coordination of patient cancer pathway and treatment process	19%
Facilitates improved communication and relationships with other health care professionals/ ensures smoother interaction and transfer of patients from different DHBs/support for and alleviates workload for other health care professionals	17%
Provides patients with information and education on cancer, treatment process, services available; patients less confused about process	13%
Patient has a 'go to' person for queries and advice	13%
Facilitates system enhancements/addressing barriers and gaps in service delivery	11%
Provides overall support for patients and family/whānau from diagnosis/reduces patient stress	10%
Improved timeliness (non-specific and referral/treatment process)	9%
Good link between patients and secondary care; makes referrals to primary care services	4%
Patients' cultural needs met (Māori/Pacific/Asian), links to Māori services and providers are good	1%

For providers key improvements are increasing number of CNC roles, clearer definition of CNC and interface with other health professionals

Improvements to the CNC role Base: Number of providers who answered question	**%** **n=303**
Increase FTE/ CNC roles	23%
Clarification of criteria for CNC role/ better definition of role specification	12%
Better clarification of role boundaries in patient cancer pathway/ better communication and relationships with other health care professionals	10%
Increase awareness and understanding of CNC role with other health care professionals/ better clarification of cancer patient criteria for CNC service	10%
CNC role still evolving and will develop with time/ has made little/no impact	6%
Timely and appropriate handover of services and less duplication of roles	6%
Ongoing and increased education for CNCs	5%
More cultural literacy (Māori/Pacific/Asian) and better links with Māori support services and providers/dedicated CNCs for different ethnic groups	4%
Creation of a user-friendly IT systems in the form of an electronic database, accessible to all relevant staff for information sharing and tracking patients across different DHBs	4%
Have dedicated CNCs for tumour streams	4%
Ensure timely and streamlined coordination of services for patient by following up delays and addressing gaps in system, having authority to order tests/make referrals	3%
Increase visibility of role/make CNC more accessible and easily contactable to wider range of patients	3%
Patient-centric focus resulting in greater communication and psychosocial and social work support for patients	2%
Greater admin support for CNC role	2%
More MDMs and case conferencing with greater involvement and coordination by CNCs and increased frequency of MDMs and meetings between CNCs	2%
Establishment of nurse-led follow up clinics	1%

Draft: Triage and management of referrals to Cancer Nurse Coordinator

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	
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	
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	
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, eg, GP, MDM Update patient records as required Maintain data	