
Report for the Ministry of Health

Interim Report One: Evaluation of the Cancer Psychological and Social Support Initiative

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Tibei mauri ora

Kei ngā maunga whakahi

kei ngā wai tapu,

kei ngā tini pepehā o te motu

E mihi ana ki ā koutou katoa.

*Mei kore ake te hunga i whai wā kia whakabaumako ai i tēnei arotakenga ki ā koutou kōrero. E
houtupu ana ā mātou mihi ki a koutou katoa.*

Behold the sneeze of life

To all the prominent mountains

to the many sacred waters

to the many identities of this land

We greet you all.

We wish to sincerely thank those who have contributed their time and stories to enrich this evaluation.

Thanks includes patients and supporting whānau, Initiative workforce members (including National and Regional Leads), and other stakeholders who participated in interviews and surveys. We have been particularly humbled by the openness and sharing of experiences by patients and their supporting whānau. This adds significant value to assessing how the services are affecting patients and their whānau.

We also wish to acknowledge the time and effort of the Initiative teams we have worked with, including their on-going support in implementing the patient survey, facilitating patient consents for interviews, responding to our requests for data and documentation, and hosting us at their sites.

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Executive summary

Introduction and methodology

This interim report provides findings from the evaluation of the Cancer Psychological and Social Support Initiative (the Initiative) from July 2016 up to December 2017. We have undertaken site visits and service data analysis of the Northern Region and site visits at Waikato, MidCentral, and Lakes services.

The service data discussed in this report relates only to the Northern region (i.e. the District Health Boards of Northland, Waitemata, Auckland, and Counties Manukau). This is because we have undertaken to present only regionally aggregated data in our reporting to the Ministry of Health,¹ and we have not yet completed another full region. However, feedback from patients, workforce, and stakeholders is from surveys and interviews in the Northern region, as well as the individual DHBs visited to date (i.e. MidCentral, Waikato, and Lakes).

We have used a mixed methods evaluation approach to gain the broadest input we can. This has included interviews and surveys, a rapid literature scan, document review, data analysis, and site visits. This is a formative evaluation, which means the findings are intended to assist with development of the services in real time and over time, and to provide transferable learnings on implementing a new service within the existing health structure.

Interim findings overwhelmingly indicate this is a highly valuable service for patients

In total at the early stage of writing this report we had interviewed 33 patients and had received patient surveys. Overwhelmingly the patients and whānau we have interviewed have commented on the positive outcomes for them from accessing this service. They highly value the professionalism of the staff and the ability to talk with someone who is neutral and non-emotive, understands the cancer journey, and knows the health and social support systems. There have been many benefits noted by patients that cover a wide spectrum of treatment and health outcomes. Also highly valued were the individually tailored psychological strategies given to patients and their whānau to help them manage their own situation, e.g. panic attacks, sleep, attending treatment, relationships, participating in family life during treatment time, etc. From a social work dimension, there is great value to patients and whānau when they are supported to access practical things they now need like income support, transport assistance etc.

Implementation

The services have evolved and continue to develop over time and from a formative evaluation this has been a desirable outcome. Implementation has had, and for some continues to have, some challenges at national, regional, and local levels. These mostly relate to lack of clarity on some aspects of the Initiative and Ministry roles, how the service fits

¹ Because this evaluation is not about assessing the performance of individual DHBs or evaluating individual services. However, we are providing DHB-level results to each service.

within a DHB, and timeliness of some aspects of national rollout, e.g. especially Model of Care and consistent data fields.

Service design varies slightly between the services we have reviewed so far. Criteria for access are broadly similar across services, and how services are designed and configured varies based on local needs and resources. Except for single discipline services all but one service reviewed so far have co-located the social work and psychology team. Services not co-located have a variety of mechanisms to promote joint working and communication.

There are various interpretations of the Model of Care and criteria may vary slightly differently. There is also some variance in how and when people are transitioned from the service, although this variance appears to be lessening over time as services evolve and embed their criteria and practice. For example, we saw some services end directly at the end of the cancer treatment, and others use clinical judgement and the relationship they have built with the patient to determine when the service will end or when the person is to be transitioned to another service. Most psychology services have an initial cap of approximately six sessions, but other clinical matters do come in to play. Social work does not appear to work on a session basis, rather working alongside the person, their whānau, or in the background to offer solutions and resolve issues they may have. This is particularly of a practical nature, e.g. income support, transport, food, amongst other things.

Many felt that stronger input and support from the Ministry around implementation, especially to DHBs, to enable implementation to be done as efficiently and consistently as possible, should have been available. There are national expectations of DHBs regarding the service description and requirements of the Initiative, which are detailed in the Crown Funding Agreement (CFA) between the Ministry and DHBs. There are variations in DHBs in meeting the requirements. Administration support has been raised as a gap, and for many this includes difficulty in accessing appropriate, or any, physical space to meet with patients and whānau.

It was reported by some that a phased rollout would have been better to avoid DHBs competing against each other to secure skilled resource, to promote learning from each other's experiences and working together earlier. Overall nationally there is a relatively small number of appropriately qualified staff for such a specialist area, and other services may also be competing for the same staff. Therefore it may have been more appropriate to work in a phased approach and more closely together.

Patient feedback

To date, we have had feedback from 65 patients and where the patient wanted, supporting whānau members, either via interviews or surveys. Stakeholders, overwhelmingly noted positive experience of the services, which when people are at high levels of distress being targeted, we believe that is a significant and of particular interest to our formative evaluation.

People reported that the service they received had enabled them to start or remain in treatment, had enabled them to cope with life (e.g., improved sleep and reduced anxiety, panic attacks etc.) and had literally been a *“life saver”*, e.g. prevention of suicide. Several people mentioned that it had *“saved my marriage”*. Many also talked about the importance of being supported to understand, navigate, and access the health and welfare systems, and the value of having money (i.e. some had to give up work, needed more food to support family

and carers, etc.), and having transport issues resolved. In addition, knowing more about their treatments and what to expect next was very important to people.

Out of the patients we have engaged with to date, 29 per cent were Māori and nine per cent Pacific.² They told us that the services they received from the Initiative, irrelevant of who the staff were, were culturally responsive, and met their needs, including their spiritual needs, as Māori or Pacific people.

Workforce feedback

Most staff felt well supported to do their work and have appropriate professional supervision as well as adequate peer support. However many felt the need for greater support and resources to do their job, such as IT (including reporting for some), administrative support, suitable rooms for seeing patients, and access to transport for home visits (pool cars and/or travel time). Some staff reported that it is a very difficult job and they would like more recognition from wider DHB management, not just their team.

Most services report that patients raise many issues and disclose a wide range of life traumas, not just the cancer diagnosis and experience. This is significant as this means the work the services do is highly complex and challenging. The staff need to be very experienced and skilled, having strong resilience and ability to cope with the huge variety of trauma, know when to refer and who to refer to for those matter out of scope of the Initiative (such as ACC sensitive claims) and other topics that are brought up during sessions. Patients also highly value cancer-specific expertise and understanding of the cancer experience. Staff felt this can be attained through prior cancer-related experience or taught on the job.

High levels of unmet need remain within and outside of the Initiative criteria

The Initiative was never intended to meet all unmet cancer related psychosocial needs and across the cancer sector. The aim of this Initiative is to improve access to psychological and social support services for adults with cancer, whose needs have not been met by existing services. This does not meet all needs of those in that particular cohort as many have these needs but don't reach the threshold. This includes patients who:

- have high and complex needs (i.e., those who have multiple stressors, unrelenting distress, or risk factors like a history of mental illness and little or no social support)
- live in communities that find it more difficult to access services (e.g., rural communities, low socioeconomic communities, Māori and Pacific communities)
- have a cancer diagnoses where there tends to be fewer supports or that are associated with greater distress (e.g. head and neck cancer).

The services we have looked at so far do not run waiting lists, but mainly manage this by not advertising their services too widely or educating all potential referrers, e.g. primary care. In general, they target clinical nurse specialists and oncology wards for their main referral sources. All said that, there is a remaining unmet need both within and outside of the Initiative criteria, and several reported that they are only able to see “*the tip of the iceberg*”. A

² This includes interviews with/surveys completed by supporting whānau members of Māori or Pacific patients.

common theme from both workforce and stakeholders was the desire to achieve greater reach to Māori patients in particular. Unmet need, or perceived unmet need, within the Initiative criteria can be evidenced by staff noting a hesitation and delay to educate and open up to all referrers, as they do not think they have the capacity to accept all people referred.

At the beginning of the evaluation, we observed one service that was not applying the criteria for access and so were seeing many other patients; however, they have now revised that and are targeting more tightly to the criteria. This, along with other variances we have observed, shows that the Initiative is still developing and will continue to evolve and mature over time, which is positive for effective service delivery.

We have no way to ascertain the levels of the wider unmet need, as not all potential referrers are educated about the service yet and there is no data recorded on gaps, at this stage.

Who receives the service in the Northern Region?

Sixty two per cent of referrals in this region are women. The average age is 55 years for women and 59 years for men. The main tumour streams the Initiative is seeing are breast, gynaecological, brain and head and neck cancers.

Eighteen per cent of referrals are Māori and nearly 11 per cent Pacifica. When compared to the cancer registry data, this is proportionately more Māori. Other cultures vary in representation in the Initiative.

Staff of the Initiative

Of those who responded to the survey to date (n=33), psychologists accounted for 44 per cent, and social workers for 39 per cent (with the remainder comprising Regional Leads, the National Lead Role, and other roles such as management and administration).³ The workforce is predominantly female and New Zealand European. Most work three to five days a week in the Initiative.

Interim conclusions

From what we have seen to date this service is highly valued by patients and helps them in their overall health and wellbeing as well as attending and remaining in treatment, as intended by the Initiative. In this regard, the Initiative is meeting its objectives of improving the experience for patients.

Staff we talked with are highly committed and skilled. Demand is managed by not advertising or educating potential referrers too widely, although activity in this area is increasing. Although there of national activity and support for services during initial implementation, staff have noted there could have been greater national leadership through the implementation phase and there still needs to be better support from most of the DHBs for administration and infrastructure. This reflects the general difficult nature of change management through implementation of a new service. On-going communication to reinforce consistent messages is key in these instances.

³ Respondents can and did select multiple roles, for instance the Regional and National Leads also undertake clinical work for the Initiative.

Delays in the development and promulgation of national guidance on fundamental matters for clinical service delivery such as the Model of Care and data reporting protocols have contributed to the variation in service design across services. Therefore individual services have spent considerable time and energy developing their own systems and protocols. To date, we have seen evidence of a regional referral processes in one of the three regions visited.

In our view, the variation of service delivery approaches, such as referral criteria and interpretations of the Model of Care, may have implications for equity of access (including for Māori, Pacific and rural patients), and be impacting on the Initiative's objective of greater national consistency in service delivery and access. We will continue to explore this as we carry out the evaluation for the remainder of 2018.

SECTION ONE: BACKGROUND AND INPUTS TO THE EVALUATION

2. Background and purpose of this report

2.1 Background to the Initiative

2.1.1 Unmet need for psychological and social supports

Emotional distress is common among people affected by cancer and can be experienced at any stage of the cancer treatment pathway. Such distress falls along a continuum, ranging from normal feelings of vulnerability, sadness and fear, to significant clinical problems such as major depression or anxiety disorder. People may also experience difficulties in their relationship, sexuality concerns, spiritual and existential concerns, neuropsychological syndromes, exacerbation of substance-related disorders, body image disturbance and the effects of chronic pain.⁴ Distress is now becoming widely recognised as the “6th vital sign”.⁵

Many people will need some form of support to help them cope with emotional, social, and economic changes. While it is estimated that around 10 per cent of people with cancer experience severe psychological distress, it is understood that psychological problems for people with cancer, as well as for the general population, are generally under-detected and undertreated.⁶

There are a number of possible reasons for this. Healthcare providers may not identify need (e.g. due to lack of consistent screening for distress) and/or the necessary services may not be available. When services are available, people may not access them for a variety of reasons such as the associated stigma,⁷ fear of the health system/hospitals, denial, and practical barriers such as inconvenient times/locations.

The extent of unmet need in terms of both psychological and social supports may be higher for people facing particular barriers to access such as geographic isolation, lack of family or friend supports or lack of cultural responsiveness of services. It is well recognised that cancer has a disproportionate impact on Māori and Pacific peoples who experience significant inequalities compared to the general population in terms of the incidence of cancer morbidity and mortality, the stage at which cancer is diagnosed, and access to services.⁸

⁴ Ministry of Health (2010) *Guidance for improving supportive care for adults with cancer in New Zealand* (Ministry of Health: Wellington, New Zealand), p.25.

⁵ The ‘vital signs’ indicate the status of the body’s vital (life-sustaining) functions. Turner et al (2011) note that in 2010 the International Psycho-Oncology Society proposed a new international quality standard endorsing distress as the Sixth Vital Sign (Jane Turner et al (2011) ‘A randomised trial of a psychosocial intervention for cancer patients integrated into routine care: the PROMPT study (promoting optimal outcomes in mood through tailored psychosocial therapies’, BMC Cancer 11:48).

⁶ Ibid, p.26.

⁷ Ibid, p.25.

⁸ Ministry of Health (2010), pp.5-9.

Drivers of the inequality of outcomes between Māori and Pacific people and the general population include:

- Socio-economic factors affecting the distribution of risk and protective factors.
- Barriers to accessing screening and timely treatment.
- Low uptake of services due to fear and/or cultural and religious beliefs.
- Culturally responsive services – for example, failure to provide opportunity for whānau input and participation, and to provide whānau with adequate support.⁹

The 2010 Guidance document discusses the aspects of culturally responsive health services for Māori, with reference to Te Whare Tapa Whā (a holistic Māori model of health) developed by Sir Mason Durie (1985) and the Whānau Ora framework in He Korowai Oranga: Māori Health Strategy (2002). Culturally responsive services may be delivered “by Māori, for Māori”, by integrating Māori expertise and advice with mainstream services, and/or be delivered within a setting of their choice. Services may include traditional healing practices.¹⁰

Work commissioned by the Ministry in 2011 identified a number of problems with the provision of psychosocial services, including:

- Regional variation in the delivery of psychosocial support, with large gaps in some areas.
- A lack of clarity around screening and assessment for psychological support, and variable awareness and understanding of services amongst healthcare providers.
- Variation in screening tools used around the country if at all, and concerns around the cultural utility of these tools.
- Under-use of multi-disciplinary teams (MDTs) to discuss patients’ psychosocial care needs.
- Lack of a skilled workforce.
- Lack of funding or siloed funding.
- Lack of clear referral pathways in many places.¹¹

A number of specific problems with the provision of social support services were identified:

- An absence of regular comprehensive social support needs assessments for people affected by cancer.
- Variable interpretations of eligibility criteria for health and disability support within and across regions.
- An absence of regionally consistent social support models.
- Fragmentation of support and rehabilitative services.
- Regional inconsistencies in the provision and availability of support services.

⁹ Ministry of Health (2010), pp.7-8.

¹⁰ Ministry of Health (2010), p.8.

¹¹ Health Outcomes International (2011) Implementing supportive care guidance project: priority areas research report August 2011 (Ministry of Health: Wellington, New Zealand), p.34.

- A lack of identification of national workforce and research requirements.
- A lack of cancer-specific Māori and Pacific services.
- Poor access to support services for those living in geographically and rurally isolated areas.¹²

2.1.2 Funding for the Initiative

In Budget 2014, the Minister of Health announced \$4.2 million per annum for improved cancer psychological and social support services across New Zealand. These services are intended to ensure the emotional and psychological needs of cancer patients are properly assessed and appropriate support is provided to patients and their whānau affected by cancer.

The Initiative provides additional full-time equivalent (FTE) positions to build on existing services in District Health Boards (DHBs) and the community to improve access to psychological and social support services for adults with cancer. This includes approximately 38 FTE cancer psychological and social support workers across the country, and six lead clinical psychologist FTEs in the six DHBs with cancer centres.

The new roles form a mixed workforce, including psychologists and social workers, and are supported by a time-limited National Clinical Lead appointed by the Ministry. The National Clinical Lead supports DHBs to implement the new roles, and provide on-going support to the workforce.

All new roles focus on delivering interventions to people whose cancer has had a large impact on their life, at the front of the cancer treatment pathway, and on improving the supportive care skills of the wider cancer team. The six lead psychologists provide leadership across their region, including developing referral pathways, alongside their clinical workload.

There was a regional planning process undertaken with all of the DHBs to identify priority groups for service and a model that is responsive to “hard to reach” groups and communities. This also included options on how to allocate the available funding to FTE in the region.

The regional plans were led by and developed by the four Regional Cancer Networks¹³ with the DHBs. Then the Ministry of Health (the Ministry) funded all 20 DHB Chief Executives according to a population-based funding model, within the allocated budget. It was up to each DHB to then decide on and appoint disciplines and FTEs. We were told this did not necessarily match the regional plan.

2.1.3 Objectives of the Initiative

Cancer is a significant health concern for Māori and has a major and disproportionate impact on Māori communities. The need to improve access to health services and equity of health outcomes for Māori is a particular focus of this Initiative.

¹² Ministry of Health (2010), pp.30, 37.

¹³ The four Regional Networks are: Northern, Midland, Central and Southern.

The objectives of the Initiative are to improve:

- The experience for patients, including their family and whānau, with cancer.
- Overall access and timeliness of access to psychological and social support services for patients with cancer.

The Initiative has been developed to achieve improvement and national consistency in terms of service delivery and access. Priority areas for the Initiative include:

- Patients and whānau with complex psychological and social issues associated with cancer.
- Groups within communities that may find it more difficult to access and utilise services, and have high needs for social and psychological supports.

Māori and Pacific communities, people with socio-economic disadvantage, remote and rural populations and people with co-existing physical, social, or mental health issues are therefore a focus.¹⁴

In addition, the new workforce will work collaboratively with other psychological and a range of social service providers such as primary care, social support agencies, and cancer non-government organisations (NGOs) to facilitate transitions between services.

¹⁴ Cancer Psychological and Social Support Initiative *Model of care for the Psychological and Social Support Initiative*, version 5.0, last updated 2017, p.5.

3. Evaluation purpose and objectives

3.1 Evaluation purpose

The purpose of the evaluation is to evaluate and assess the Initiative and to understand whether the service objectives are being met.

3.2 Evaluation objectives

The objective of the evaluation¹⁵ is to provide an understanding of the efficiency and effectiveness of the Initiative, including:

- Providing information to the DHBs, Regional Cancer Networks, the Ministry and the Minister as to whether the services of the Initiative are meeting population needs, including the needs of vulnerable populations.
- Determining the impact of the Initiative and the impact that the roles have on (self-reported) patient outcomes.
- Identifying whether the needs of Māori, Pacific and rural people with cancer are being met by the new roles and service.
- Identifying service improvements and recommending changes that could improve the overall outcomes of the Initiative.

3.3 Requirements of the evaluation

In order to meet these objectives, the Ministry of Health requires a process and outcome evaluation. This is not an audit, rather an independent, interactive evaluation working alongside people to learn what is happening, what works well and what might be improved over time. Sharing lessons between regions will be an important part of the evaluation as well.

The process evaluation component will determine whether implementation of the Initiative has enabled service objectives to be met. This may cover, but not be limited to:

- How did patients enter (i.e. get referred to) the services.
- The extent to which rural, low socio-economic, Māori and Pacific patients, and their whānau access the psychosocial support services (percentage of total using them – from service data).
- Whether the new roles are targeted at the appropriate point in the cancer treatment pathway.
- Whether the composition of the new roles provides the right skill mix to deliver the services to people with cancer and their whānau.

¹⁵ Source: Sapere Living Evaluation Plan as agreed with the Ministry of Health, August 2017.

- Whether there are skills that are required and not present in the new roles, and also skills that have been considered important but have not been utilised in practice.
- The level of need of patients being seen, including access and discharge criteria.
- What needs of patients and whānau are being met by the new roles and what needs are not.
- Types of services provided by the new roles (e.g. individual, group sessions, other, venue/location).
- Number of contacts with a patient and the length of time a patient accesses the new roles, and whether the mix and intensity of contacts is meeting patients' needs.
- The timeliness of service delivery (such as length of time from referral to triage and/or first contact).
- The relative value of flexibility (e.g. local tailoring of services) *vis à vis* regional consistency.
- Whether the new roles have the ability to work in collaboration with other support services outside of DHB settings (e.g. such as cancer NGOs, community i.e. home and community support, allied health, hospice and primary care).

The outcomes evaluation component will determine the impact of the Initiative for people with cancer and their whānau. This may cover but not be limited to:

- Whether services are culturally responsive and what this may look like.
- Improved knowledge of psychosocial needs and supports across cancer healthcare and supportive services.
- Impact on the lives of people with cancer and whānau who use the service.

3.4 Evaluation methodology

3.4.1 Overview

This Interim Report One is focused on the process evaluation component, in particular on the roll-out and implementation of the Initiative. It is too soon in the evaluation to be able to make firm statements on the extent to which the Initiative is meeting the needs of the target populations, and the impact of the service on patients and whānau. However we do reflect the emerging findings from the interviews and surveys of patients and whānau captured to date.

The evaluation methodology for this report, has included:

- Interviews with a sample of patients from the services we have evaluated to date, where possible ensuring a Māori evaluator and approach for Māori patients.
- Interviews one-on-one, or in focus groups, with as many Initiative staff as we can engage with (depending on their availability and scheduling).
- Interviews one-on-one, or in focus groups, with referrers or other stakeholders, e.g. Cancer Society, Clinical Nurse Specialists (CNSs), and Māori clinicians, health service managers and patient navigators. We note that at this stage CNSs appear to be the major referrers to the Initiative, followed by oncology teams.

- Discussions with the relevant Ministry of Health Staff and National and Regional Leads of the Initiative.
- Rapid literature scan on the models of care for this type of service.
- Begin surveying of patients and families.
- Begin surveying of staff.
- Document review from each service and any foundational documents we have been able to source.
- Analysis of service data.

This has been achieved via a mix of site visits, surveys (paper and electronic) and face-to-face and phone interviews. Once we have visited a site and done all the qualitative and quantitative analysis, we feed back their findings to them, so they can use the analysis for their planning. This is an aspect of the formative part of the evaluation.

To date, we have had feedback from:

- Sixty-five patients (via surveys and interviews).
- Twenty-six Initiative Staff members.
- Seventy-five stakeholders.

In total, this is input from 166 people so far. This report reflects the triangulation analysis from all methodologies and inputs.

3.4.2 Actively avoiding potential patient input bias

We are sampling patients for interviews in a purposive way to reach as many of the target populations as possible, i.e. demographics, cancer types, ethnicity etc. In addition, running the survey throughout the evaluation gives as many patients as possible the opportunity to have input, as the survey is offered to all patients.

To minimise potential bias, we gathered a larger number of consents than we required so we could purposively choose from the list. We then phoned the selected patients and gained a second consent, confirming if they were still willing to participate or not. If they were, we then arranged an agreeable time and venue. The majority to date have chosen by telephone¹⁶ (n=21 out of 33), the remaining eleven have been face-to-face either in their homes, at the service's premises, or at cafes.

3.4.3 Site visits require a lot of planning, guidance and hosting by the site staff

We first talked with the lead person of the service we were to visit (e.g. the key contact person for the local Initiative and/or the Regional Lead who may or may not be the same person). We always informed the Regional Lead prior to approaching a service in their region, and took their advice if there were any specific aspects to consider. We aim to have

¹⁶ Note: Sapere has observed over the past two or so years, for a range of assignments patients are choosing to undertake telephone interviews. Most often, they quote this as being too busy to meet or that they can then do it after they have put children to bed, etc.

two interviewers for at least the majority of patient interviews, and for some of the staff and stakeholder interviews. Contact with the appropriate people was made and site visit dates were negotiated and agreed.

Local people set up times and venues for interviews in their local district for staff and stakeholders, whilst Sapere did that for patients. Sapere generally aims for two days at each site – one day where patients can be interviewed and some staff or stakeholders as well, then a second day for the majority of staff and stakeholder interviews. In addition, at times interviews were completed by telephone before or after site visits, depending on peoples’ availability or choice.

We aim to interview the Regional Lead in each of these visits as early as possible to get an overview up front.

All interviews, whether in person or by phone are confidential to Sapere and hence, this report and future reports of this evaluation will be non-identifiable to any individual person or specific service.

3.4.4 Patient interviews required locality approvals and informed consent

Sapere initially tested the need for national health ethics approval to interview this sample of “vulnerable patients”. The National Health Ethics Committee advised that this was not needed. However, we were required to go via each DHB locality “ethics” process and committee, which took a significant amount of effort, time and follow up, and more resource than budgeted for. In some cases, it also caused planning delays.

Once locality approvals were gained, we then contacted the local Initiative teams to assist us to obtain a sample of consenting patient names and their contact details for interviews to pass to Sapere. We developed a script for staff to use when contacting patients regarding consent to help ensure consistency across sites.

Note: where quotes are used they are non-identifiable to a region or individual. Interviewees were informed that their interviews would remain non identifiable and that we may use some of their quotes where they couldn’t be identified. Interestingly some said they wouldn’t mind if they were identified, but we didn’t take that offer up. In a few instances interviewees and survey respondents asked us to give direct verbal feedback to their Initiative workforce member which we did.

3.4.5 Patient surveys will be continuing in 2018

Survey method

We have implemented a rolling patient survey (i.e. is on-going and will continue to end of September 2018, and is not a one-off point in time), initiating it in each service at the time we visit. However, for future sites we will implement the survey as soon as practicable, even in advance of visiting, to ensure the greatest reach possible.

It was initiated at the first site we visited in June 2017 and is now running in all four Northern region DHBs, and has started in Waikato, Lakes, and MidCentral.¹⁷

Recruitment for patient surveys

The survey is opt-in, with patients invited by workforce members to complete the survey confidentially. Written and verbal guidance for staff is provided from Sapere, including an information sheet to use as a guide for explaining the survey.

To help ensure that each patient completes the survey only once, we have asked that patients be offered the survey either around the time of their discharge from the Initiative or after they have received support for a period of time (long enough for them to have had sufficient experience with the Initiative that they could provide feedback on their experience to date).

We have asked workforce members to use their clinical judgment in assessing whether it would be reasonable to ask the patient to participate (e.g. in light of where they are at in their treatment, their levels of distress, health and their ability to give consent).

Consent

The information sheet explains that participation in the survey is voluntary and that their responses are confidential. It also explains how the information provided will be used. Providing patients are able to give informed consent, we have encouraged the workforce to err in favour of inviting a range of people to participate.

Survey form

Bearing in mind that services may be delivered face-to-face, over the phone or in other ways, and in a variety of settings, we have provided hard copy forms as well as self-addressed envelopes and stamps so it can be returned by post. Patients can complete the survey either on paper or online via the Sapere website. We have also given the services a half page flyer to give patients who wish to complete the on line survey, with the Sapere URL on it.

For those forms completed onsite, we have provided confidential collection boxes. Patients are asked to place their completed survey form in a sealed envelope and then into the box so their responses are anonymous. These are then gathered up quarterly (or when there are enough to send us) and returned to Sapere in courier bags we have provided.

The survey form comprises a mixture of closed (tick box) and open (free text) questions.

The patient survey will be initiated in the remaining services in the first quarter of 2018. Sites will continue to run the survey through until September 2018.

3.4.6 Staff interviews have been a mix of individual and focus groups, alongside staff surveys

Not all Initiative staff work full time for the Initiative and when they are working for the Initiative they all carry a clinical load. It is important for Sapere to work closely with the local team to make the most appropriate time for interviews. We sought local advice on

¹⁷ For social work patients only in MidCentral as the Massey psychology service undertakes its own patient satisfaction survey. We have been provided with an extract of their survey data to augment our analysis.

whether they wanted individual or focus group interviews and venues. Most have been face-to-face interviews with a small number via telephone (for reasons of clinical load or geography).

An e-survey was sent to Initiative staff across all DHBs in the Northern and Midland regions, as well as Whanganui/MidCentral DHBs. Lead contact people in each service obtained the permission of Initiative staff to supply us with their email addresses.

The survey was sent in five tranches over March-October 2017 as we progressed with our fieldwork, with reminder emails sent. As at 10 November 2017, we had a 76 per cent response rate and 65 per cent survey completion rate (five respondents chose only to complete the demographic details).

Initiative staff from all other services will be surveyed for the first time over early 2018. All staff will then also be invited to participate in a second survey later in 2018. The purpose of the second survey is to analyse and ascertain any changes. This will be reported in our final report in 2019.

3.4.7 Stakeholders have been identified by local Initiative staff, as they vary for different services

We asked local Initiative staff to identify a sample of key stakeholders, e.g. referrers, services or supports the Initiative refer to, that would then consent to be interviewed. Stakeholders were anyone who had significant contact or input to the Initiative and may vary across site. The key ones we interviewed related to referrers in to the Initiative and those receiving referrals from the Initiative. For example, there were CNSs, health professionals from Oncology Wards, the Cancer Society, colleagues such as other social work or psychology staff in DHBs. Where possible we also spoke with Māori clinicians, health service managers and patient navigators.

All interviews are confidential to Sapere.

3.4.8 Analysis and conclusions triangulate all inputs

We took comprehensive notes from all interviews. These notes, as well as the free text comments in surveys, were coded thematically and analysed inductively. We then triangulated this information with the quantitative information from the surveys and data analysis, as well as the information from the documents reviewed, to develop the findings and interim conclusions against our evaluation questions.

3.5 Purpose of this report is to reflect and comment on implementation of the Initiative to date

This Interim Report One provides findings from six DHBs and one non-DHB provider who is [part of the Initiative, which Sapere has surveyed and interviewed to date, as well as inputs from a sample of patients, whānau and stakeholders, e.g. referrers to or those receiving referrals from the Initiative. The findings relate to implementation and an operational view

of what each service is undertaking. Of even greater importance, are the findings from patients about how they have experienced and found the service and the outcomes for them, and in many cases their whānau also. That is the qualitative aspect on the outcomes of the service.

This report gives an overview of what we have found to date but Sapere reserves the right to update these findings as we research more patients and Initiative services and understand how the services have been implemented and are operating. These may vary across the country and we are aware that some have been implemented at different times than others and we will be looking to see if this has had any material impact in any aspects of the service.

4. Strategic and policy context

4.1 Strategic context

There are two key strategic documents that guide cancer work in New Zealand: the *New Zealand Cancer Plan 2015–2018* (New Zealand Cancer Plan) and the *New Zealand Health Strategy: Future Direction, 2016*.

The New Zealand Health Strategy: Future Direction has the following vision for the future health system:

*all New Zealanders live well, stay well, get well in a system that is people-powered, provides services closer to home, is designed for value and high performance, and works as one team in a smart system.*¹⁸

The guiding principles for the health system include acknowledging the special relationship between Māori and the Crown under the Treaty of Waitangi, and an improvement in health status of those currently disadvantaged. The Strategy notes that changes in behaviour are required to effect the vision, including a shift from “*a focus on the individual to a wider focus on the family and whānau*”.¹⁹

The New Zealand Cancer Plan provides a strategic framework for an on-going programme of cancer-related activities for the Ministry, DHBs and Regional Cancer Networks so that:

*all people have even more timely access to excellent cancer services that will enable them to live better and longer.*²⁰

Building on what has already been achieved, the New Zealand Cancer Plan sets out the cancer-related programmes, activities, and services that are being implemented across the country over until 2018. It also signals potential future initiatives.

The principles guiding the New Zealand Cancer Plan are to:

- Equitably, effectively and sustainably meet the future demand for cancer services.
- Maintain high quality of care and improve the quality of life for people with cancer.
- Ensure fiscal responsibility.

It has a focus on:

- Prevention and early detection.
- Diagnosis and treatment.
- Follow-up care.

The plan notes the key enablers are:

¹⁸ Ministry of Health (2016) *New Zealand Health Strategy: future direction*, p.13.

¹⁹ Ministry of Health (2016) *New Zealand Health Strategy: future direction*, p.14.

²⁰ Ministry of Health (2014) *New Zealand Cancer Plan: better, faster cancer care 2015-2018*, p.1.

- Infrastructure.
- Workforce.
- Supportive care.

The New Zealand Cancer Plan explains, “*good social and psychological support at each stage of the patient pathway improves health outcomes and quality of life*”.²¹ The outcome desired by 2018 is that “*more people will be accessing the psychological and social support they need*”.²² This will be achieved by, inter alia:

- Addressing language, culture, literacy, communication and other barriers.
- Supporting DHBs to implement a service model for psychological and social support services for those who need them.²³

The New Zealand Cancer Plan explains that an “*appropriately trained, motivated, supported and flexible workforce is essential to providing high-quality and sustainable cancer services*”.²⁴ The New Zealand Cancer Plan involves aligning professional education, training and development programmes with cancer service delivery needs, with the desired outcome by 2018 that the “*cancer workforce will have grown and will be working at the top of their scope*”.²⁵

4.2 Cancer-related programmes and services

4.2.1 Faster cancer treatment programme

The faster cancer treatment (FCT) programme aims to reduce waiting times for appointments, tests and treatment, and standardise care pathways for all cancer patients. DHBs are required to report against the 62-day target – that 90 per cent patients referred urgently with a high suspicion of cancer will receive their first cancer treatment (or other management) within 62 days, and be seen within two weeks.²⁶

Key FCT initiatives include the following:

- The development of national tumour standards for ten tumour types. These describe the level of service that a person with cancer should have access to, and are used as benchmarks for nationally coordinated and consistent levels of care across New Zealand.
- Implementing the Cancer Nurse Coordinator (CNC) initiative. CNCs aim to improve the timeliness of access to treatment services and improve the overall experience of

²¹ New Zealand Cancer Plan, p.19.

²² New Zealand Cancer Plan, p.15.

²³ New Zealand Cancer Plan, p.20.

²⁴ New Zealand Cancer Plan, p.18.

²⁵ New Zealand Cancer Plan, p.18.

²⁶ Targets do not relate to patients diagnosed through one of the screening programmes or in private settings, or when they are already in the hospital system.

patients and their whānau. CNCs provide personalised support to people help navigate the cancer pathway. Three delivery models have emerged across DHBs:

- Generalist CNCs who focus on care coordination for all cancer patients in their region.
- Population CNCs focused on reducing barriers by working with a specific population group such as Māori or Pacific patients.
- Tumour stream CNCs responsible for patients with a particular tumour type.²⁷
- Improving the coverage and functionality of multidisciplinary meetings to improve continuity of care, and so that more patients benefit from a range of expert opinion and there is less duplication of services.²⁸

4.2.2 Regional Cancer Networks

Regional Cancer Networks are formal structures designed to enhance co-operation and collaboration in service planning and delivery across DHB boundaries. There are four Regional Cancer Networks in New Zealand: Northern, Midland, Central, and Southern.²⁹ As already noted, these were the networks that developed the original Initiative plans for the Ministry of Health to consider in 2015.

4.2.3 Public health prevention and awareness programmes

The government funds a range of prevention and awareness programmes targeted at areas that can potentially be related to higher cancer rates, such as smoking cessation, prostate cancer awareness, and the human papilloma virus (HPV) immunisation programme.

4.2.4 Screening programmes

There are three national cancer-screening programmes in operation or development:

- BreastScreen Aotearoa, which provides free mammograms every two years for women aged between 45 and 69 years.
- The national cervical screening programme.
- Following a pilot programme at Waitemata DHB, a national bowel-screening programme is being rolled out nationally from July 2017.

4.2.5 Follow-up and palliative care

The New Zealand Cancer Plan describes the planned actions to enhance follow-up and palliative care. These include implementation of an integrated model of palliative care

²⁷ Saskia Booiman (undated) *Faster Cancer Treatment: The New Zealand cancer nurse coordinator initiative* (Ministry of Health).

²⁸ New Zealand Cancer Plan, p.6.

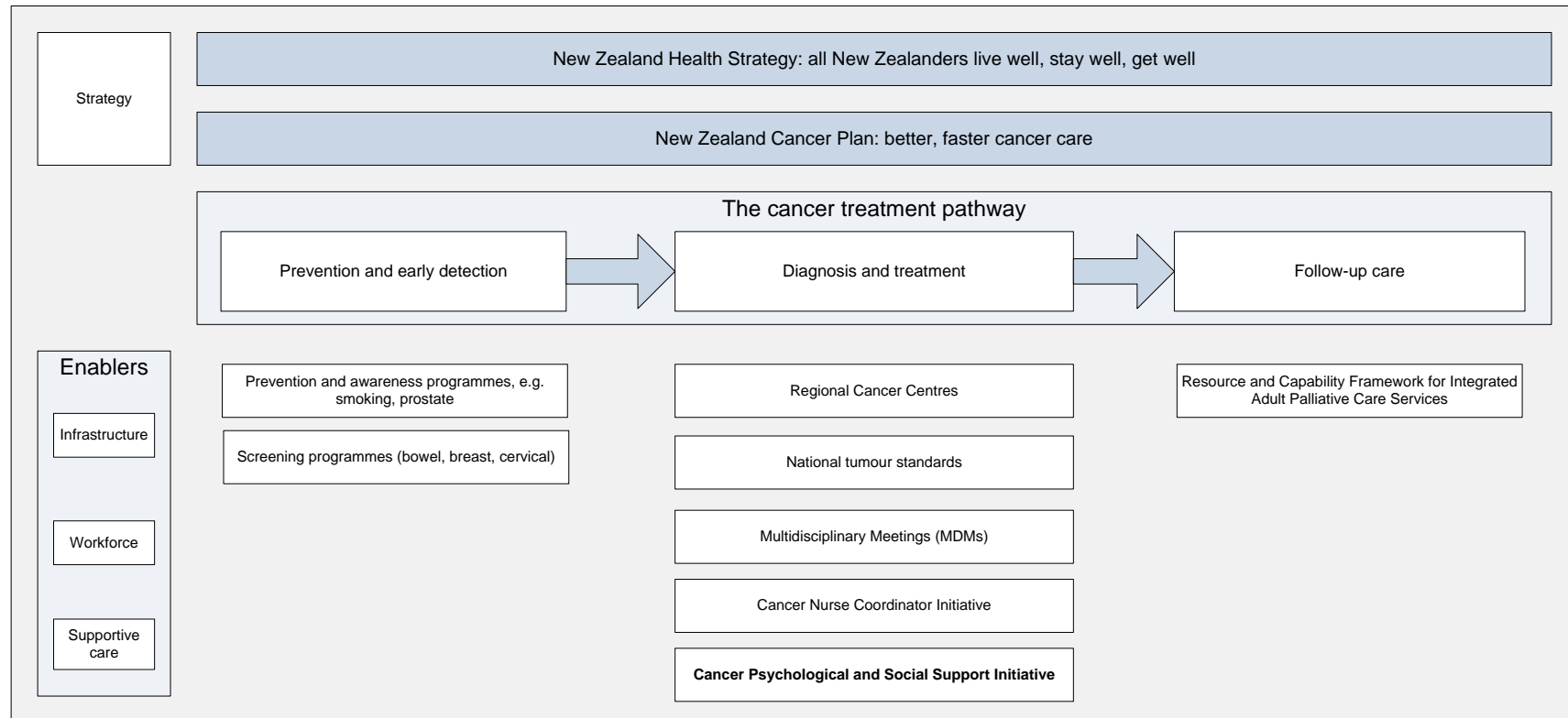
²⁹ <http://www.health.govt.nz/our-work/diseases-and-conditions/cancer-programme/regional-cancer-networks>

delivery based on the 2013 *Resource and Capability Framework for Integrated Adult Palliative Care Services in New Zealand*.

As discussed later in this report, the intersection between the Initiative and palliative care has been one of the more difficult aspects of the Model of Care raised by the workforce we have engaged with so far. This issue may well be one of the service evolution, and we note that clarifying guidance has been issued by the National Clinical Lead to help resolve it.

Challenges have been linked to the transfer of care when trust and empathy has been built with the patient and the original health professional. Many times, it was cited that it might have been better clinical practice to keep the patient with the Initiative for that final short period of time, working alongside and with Hospices.

Figure 1 Overview of key programmes and initiatives: adult cancer



Source: Sapere

5. Models of care for cancer psychosocial support – principles and guidance from the literature

5.1 Introduction and method

We undertook a rapid literature scan to identify models of care and/or clinical practice guidelines used for the provision of psychosocial support for cancer patients in other jurisdictions. The purpose of this was to identify best practice principles, which could be used to inform our evaluation of the Initiative’s implementation and effectiveness, and guide the development of any recommendation(s) for any service improvements.

5.2 Overarching themes from the literature were relatively consistent

A number of consistent themes emerged from the material we reviewed.

5.2.1 High levels of unmet need for psychological and social supports

There is evidence of high levels of unmet need for psychological and social supports, particularly for some groups such as indigenous populations and ethnic minorities, and patients in rural and remote areas. For example, it is widely recognised that patients from rural and remote areas have poorer access to treatment services and information, and experience poorer cancer outcomes.³⁰

Culture and religion can play a strong role in patients’ experiences of cancer and their psychosocial support needs, including their attitude towards their cancer and its treatment, which have implications for service delivery. For Pacific patients, a cancer diagnosis may be seen as shameful, and impact on their capacity to meet family and community obligations. In Māori and Pacific cultures, whānau have a central role in decision-making, which may not be recognised in the way treatment is delivered. The 2010 Ministry Guidance noted that:

Mainstream cancer services, including supportive care services, do not always support a whānau-based approach to cancer care.... Services are not always geared towards providing opportunities for whānau input and participation, facilitating whānau access to appropriate information, or providing whānau with adequate direction and support (Ministry of Health, 2010, p.7).

³⁰ Department of Health, State of Western Australia (2008) *Psycho-oncology model of care* (Government of Western Australia: Perth, Western Australia), p.41.

Partners and children of cancer patients are also vulnerable to distress – partners’ distress may be even higher than that of the patient – but often receive less support.³¹

Studies have identified a range of barriers to the provision and access of support, which include:

- Lack of awareness and understanding on the part of both referrers and patients regarding psychosocial services.
- Lack of integration of services into routine oncology care – including lack of routine screening and lack of profile of the services.
- Lack of coordination or leadership of psychosocial services.
- Wide variation in the provision of and access to service, including lack of workforce.
- The persistence of stigma and negative attitudes towards psychological problems and services, on the part of both clinicians and patients.
- The cost of accessing services (such as the cost of travel and childcare, particularly for patients from rural and remote areas).
- Limited availability or understanding of the need for private spaces for discussing psychosocial concerns confidentially.
- Language barriers.

5.2.2 The importance of effective communication

The literature emphasises the importance of effective, face-to-face communication between patients and clinicians, and the need for on-going education in this aspect for the workforce including referrers.

To date, too many clinicians working in the cancer field have had limited formal training in communication skills for talking to patients about their cancer, particularly regarding points of increased emotional distress... Furthermore many clinicians feel they have limited skills in managing emotional distress if it arises in the consultation (WA Department of Health, 2008, p.10).

The Australian clinical practice guidelines cite evidence that effective communication with a patient and their family can generate significant improvements in a range of areas including their psychosocial adjustment, decision-making, and satisfaction with care.³² They also note that the presence of a support person can increase positive impacts such as understanding and satisfaction with care.

The Western Australian guidance recommends that ‘*all clinicians working in the field of cancer should be encouraged to develop and practice effective communication skills and assessment for psycho-social issues*’ (WA Department of Health, 2008, p.13).

³¹ National Breast Cancer Centre and the National Cancer Control Initiative (2003) *Clinical practice guidelines for the psychosocial care of adults with cancer* (National Health & Medical Research Council: Australia), pp.14-15.

³² National Breast Cancer Centre and the National Cancer Control Initiative (2003) *Clinical practice guidelines for the psychosocial care of adults with cancer* (National Health & Medical Research Council: Australia), p.7.

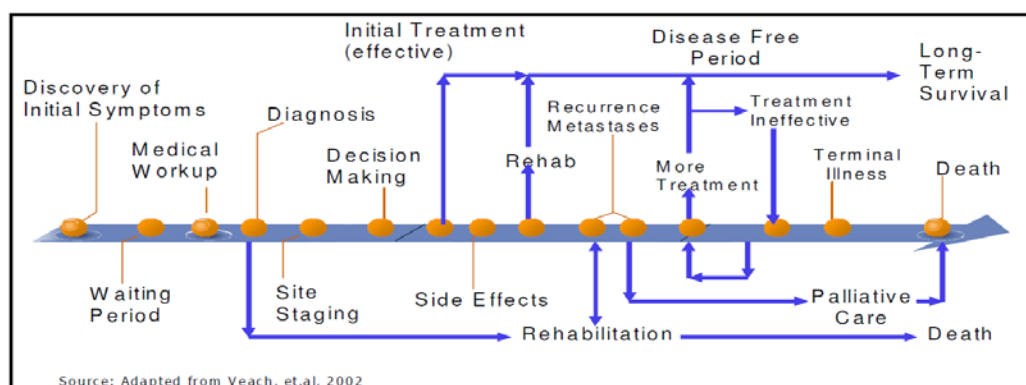
5.2.3 Regular screening and monitoring throughout the cancer pathway

The material we reviewed advocated for routine, standardised screening for distress across all cancer populations and at critical points throughout the cancer pathway (see the figure below). We note that distress screening across all patients being investigated or treated for cancer is a matter to be addressed by the wider sector as well as the Initiative. It is particularly relevant for this Initiative, as there is little point screening for distress if there are no services to refer people into. Moreover, there is a specific role for Initiative staff to be educating potential referrers (such as oncology teams) in how to screen and identify patients that may meet the criteria for the Initiative. However, it is a wider DHB and regional responsibility to educate referrers about the range of other services that may be appropriate to refer patients into (such as mental health).

The literature recognises that on-going monitoring and screening is important because patients' psychosocial needs change and evolve. Canadian guidance³³ identifies key points for assessments as including:

- Initial diagnosis.
- Start of treatment.
- Regular intervals during treatment.
- End of treatment.
- Post-treatment or at transition to survivorship.
- At recurrence or progression.
- Advanced disease.
- When dying.
- During times of personal transition or re-appraisal (e.g. in a family crisis).

Figure 2 Cancer care continuum - points of assessment



Source: Howell et al (2009), adapted from Veach, Nicholas and Barton (2002)

³³ D. Howell et al (2009) *A pan-Canadian clinical practice guideline: assessment of psychosocial health care needs of the adult cancer patient* (Toronto: Canada, Canadian Partnership Against Cancer (Cancer Journey Action Group) and Canadian Association of Psychosocial Oncology).

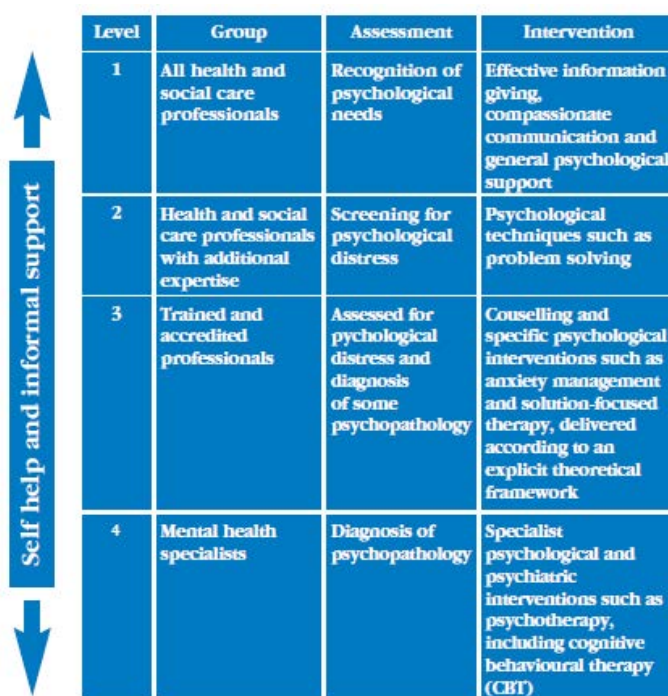
5.2.4 Comprehensive assessment

The Canadian guidelines (Howell et al) recommend that where this initial screening indicates distress, it should be followed up with comprehensive, and then focused needs assessments. By comprehensive, they mean that all domains of psychosocial healthcare needs are assessed, including physical, informational, emotional, psychological, social, spiritual, and practical.

A comprehensive assessment also takes into account the patient’s risk factors, living circumstances and life stage, and other factors such as ethnicity, gender, culture, religious beliefs, sexual orientation, mental or physical disability (Howell et al).

Focused assessments are then targeted at a specific problem to determine individual needs (e.g. dealing with changes in social roles, body image problems). The National Institute for Health and Care Excellence (NICE) guidance from the UK advocates a similar model, described as a four-tier assessment model (see Figure 3 below). The Canadian guidelines note that is ‘currently no gold standard instrument reflective of such a comprehensive approach to psychosocial health care needs screening’ (Howell et al, p.19).

Figure 3 Four-tiered model of professional psychological assessment and support



Source: NICE (2001) *Improving supportive and palliative care for adults with cancer: the manual* (NICE: UK), p.78.

5.2.5 Tailored, evidence-based interventions

The guidance and literature is clear that interventions should be evidence-based, and targeted at the specific problem. This may require referral to other disciplines outside of psychosocial oncology services, such as pastoral care services/chaplaincy, nutrition, endocrinology or relevant NGOs. The NICE guidance recommends that services are provided – to the extent possible – at the location desired by patients and carers (NICE, 2001, p.21).

5.2.6 Inter-disciplinary/inter-professional collaboration

A related theme in the literature is the need for effective inter-disciplinary/inter-professional working and the coordination of both psychosocial care and across cancer care (including services/settings such as surgery, radiology, general practice). This includes effective communication between services to ensure smooth transitions between care settings and that patients receive appropriate follow-ups and do not get 'lost' in the system (WA Department of Health, 2008, pp.37-38).

The Australian clinical practice guidelines recommend regular case conference meetings to discuss individual cases, and the development of local protocols to ensure clinicians and the GP receive adequate information (National Breast Cancer Centre and the National Cancer Control Initiative, 2003, p.79).

5.2.7 Addressing the training and support needs of the workforce

The NICE guidance recommends that additional training is provided to any member of a psychosocial support workforce who does not have specific experience in working with cancer patients (NICE, 2001, p.82).

More generally, the literature acknowledges the impact that working with cancer patients can have on the workforce, with issues including stress and burnout. There is a need for on-going professional supervision and support, such as opportunities to debrief on particular cases (WA Department of Health, 2008, p.48).

The Canadian guidelines suggest that implementation of their recommended approach may include:

- The development of a team to lead the initiative.
- Organisational support for implementation (such as workforce education sessions).
- Multi-faceted targets of intervention that addresses clinical practice change as well as policy and system-level changes.
- An emphasis on continuous quality improvement.

5.3 Implications for this evaluation

We will progressively draw on the above lessons from the literature review in our assessment of the design, implementation, and delivery of the Initiative, and in the formulation of our interim and final conclusions and recommendations.

SECTION 2: FINDINGS

6. Extent to which the Initiative is reaching the target populations

6.1 Service data analysis

The focus of our data analysis has been on exploring the extent to which the Initiative is reaching the intended populations. There is no information on the total number of patients who may have been eligible for the service. This is partly because every service and their stakeholders have different procedures and points in the process of treatment for identifying target patients. This includes different screening, referral and triage processes, thresholds for entry, and who might undertake this screening and triage.

We distinguish between distress screening (which may be population-based or targeted to individuals), referral to the Initiative (completion of referral forms, which may be general or tailored to the Initiative service), and triage by the Initiative staff once referrals are received. For example, in some places, the referrers undertake the distress-screening tool and in some, the service does; and some services are not using a formal screening tool, but instead a tailored referral form. Part of the reason for these variations in approach is the differences in pre-existing systems, individual clinician and local preferences as well as services in each locality. In addition, sites have interpreted the criteria differently, with some targeting more tightly than others.

Services have focused their education and training energy on a subset of referrers, so in some places, potential referrers are not yet aware of the services (e.g. across the spectrum of tumour streams). We have heard this is especially the case for primary care. As we see in many of our assignments, on a variety of topics, that primary care is a large and difficult to reach sector when educating on new services and creating behaviour change. This is typical, as they are already very busy.

Therefore, for data analysis and comparisons, we compared the characteristics of people receiving the Initiative to broader cancer populations as measured by DHBs as part of their FCT reporting, and as recorded in the Cancer Registry. On advice from the Ministry, we have just presented comparisons to the Cancer Registry data as it is broader and captures more people who may be eligible for the Initiative than just the FCT dataset.

We issued a data request to each of the sites visited. We sought data on the number of referrals to the Initiative, broken down by:

- Source of referral.
- Date of referral.
- Gender.
- Age.
- Ethnicity.
- Type of cancer diagnosis.
- Point in the treatment pathway.

We also asked for data on the types of Initiative services provided (i.e. whether psychology and/or social work support), time to triage and/or from referral to first session, Did Not Attend (DNAs), date of discharge, as well as any data on pre- and post-assessment/treatment scores (e.g. distress screening).

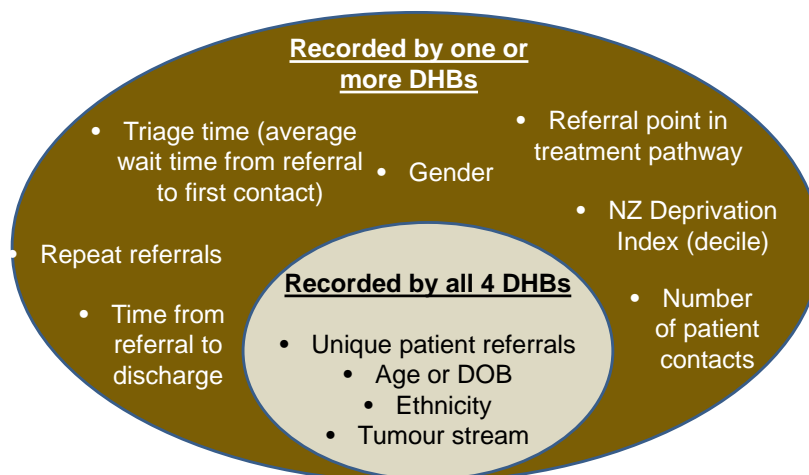
To date, we have received and analysed service data from the four Northern region DHBs and provided their own DHB-level results to each of these services.

6.2 Overview of results – Northern region

In this section, we present the aggregated results for the Northern region. We found that each service collects some data in common and some uniquely (see Figure 4). We have aggregated the data that are common across DHBs, so figures are for the whole region except where indicated otherwise.

The time period covered is January 2016 – March 2017 (15 months). Over this time, there were 1,312 patient referrals. Caseload numbers were roughly evenly split between psychology as lead service (45%) and social work as lead service (55%).

Figure 4 Data collected - Northern region DHBs

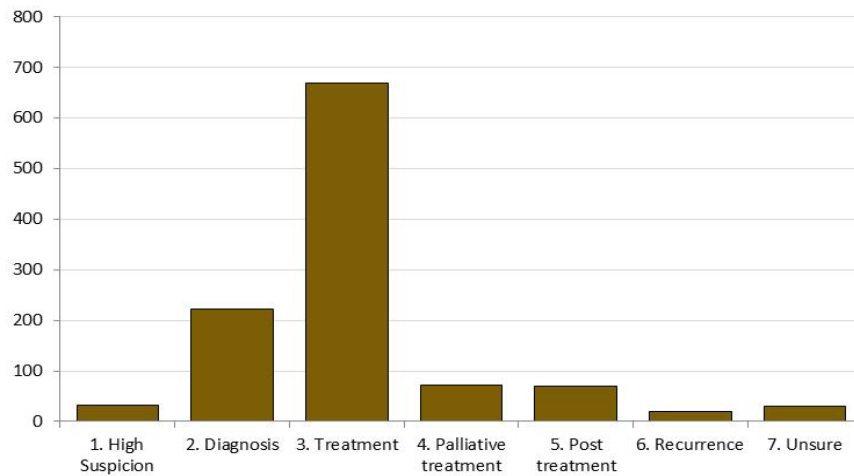


Source: Data supplied by Northern region DHBs to Sapere

6.2.1 Most patients referred at ‘treatment’ stage of the pathway

Most patients (60 per cent) were referred at the ‘treatment’ stage. Twenty-three per cent were referred at the front of pathway (‘high suspicion’ or ‘diagnosis’).

Figure 5 Number of referrals by stage of treatment



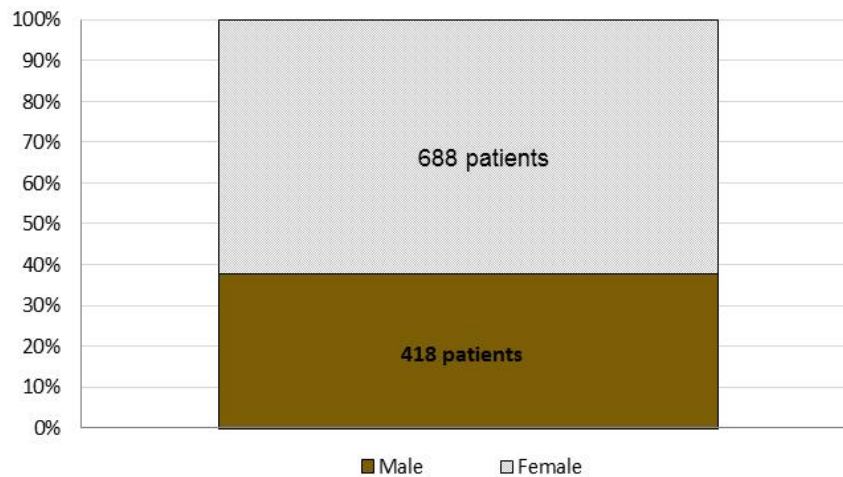
Source: Data supplied by Northern region DHBs to Sapere

Note: Covers 3 DHBs only

6.2.2 Two thirds of referrals are women

Almost two-thirds (62 per cent) of referrals were women.

Figure 6 Number of referrals by gender



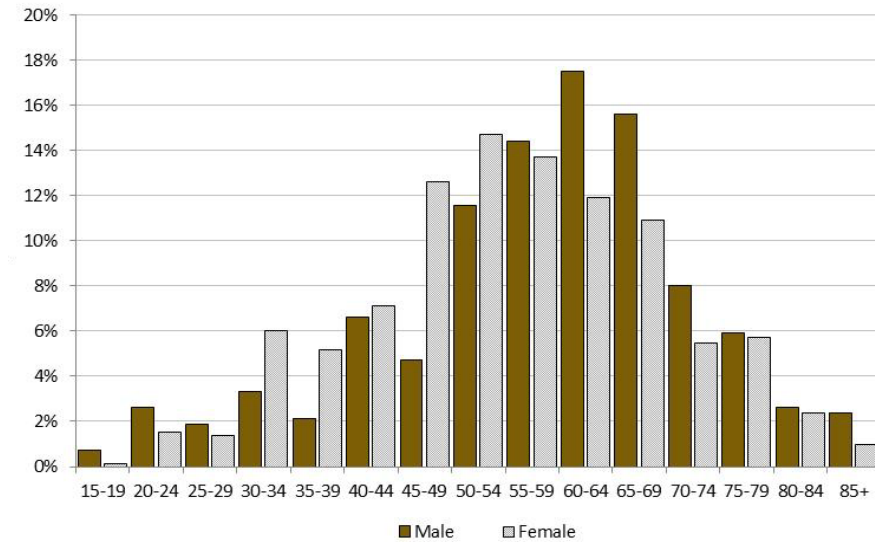
Source: Data supplied by Northern region DHBs to Sapere

Note: Covers 3 DHBs only

6.2.3 Average age of patients

The average age of women referred in to the service was 55 years and 59 years for men.

Figure 7 Percentage of referrals by age group



Source: Data supplied by Northern region DHBs to Sapere

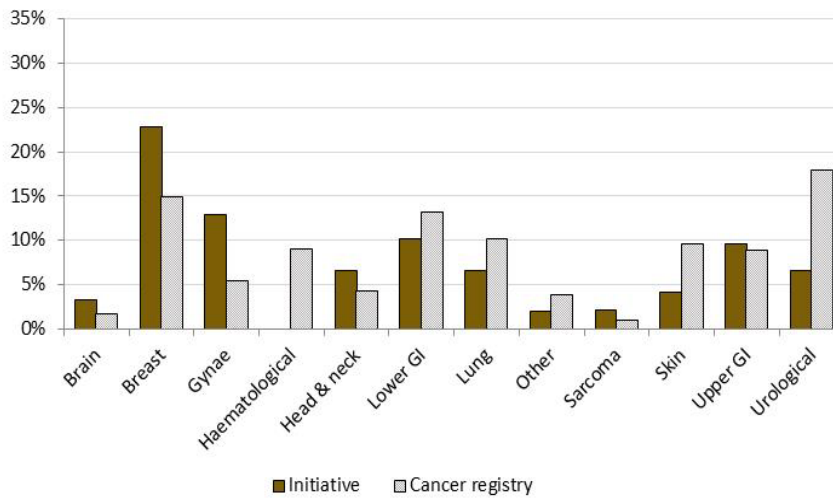
Note: Covers 3 DHBs only

6.2.4 Referrals by tumour stream

The profile of tumour streams across Northern region DHBs was broadly similar. The following two charts compare the aggregated regional figures to the Cancer Registry data. The purpose of this comparison is to compare the profile of patients seen by the Initiative with the wider population of people with cancer, to see if the services are targeting tumour streams associated with higher distress and/or fewer existing supports. The Cancer Registry data is from 2014.

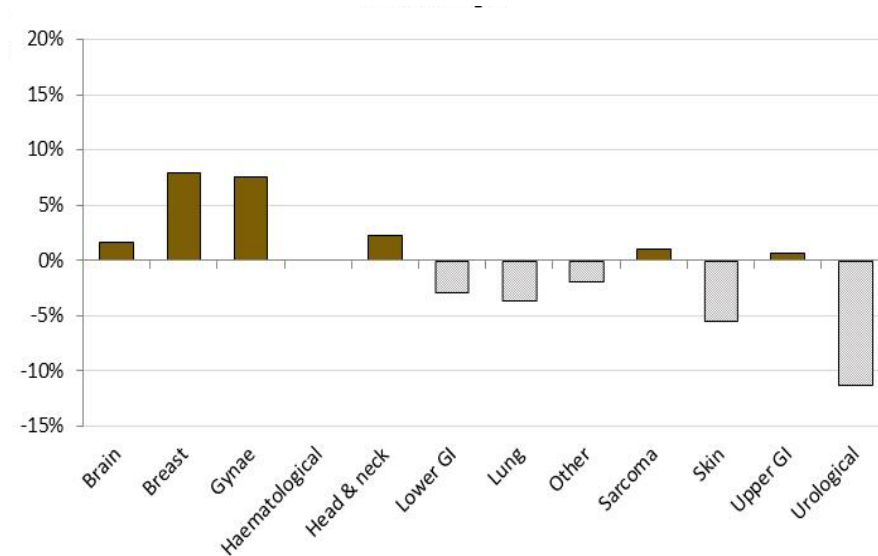
The Initiative is seeing proportionately more people with breast, gynaecological, brain and head and neck cancers.

Figure 8 Proportion of referrals by tumour stream



Source: Data supplied by Northern region DHBs to Sapere; 2014 Cancer Registry data

Figure 9 Differences in cancer types (Initiative vs. Cancer registry) – Northern Region



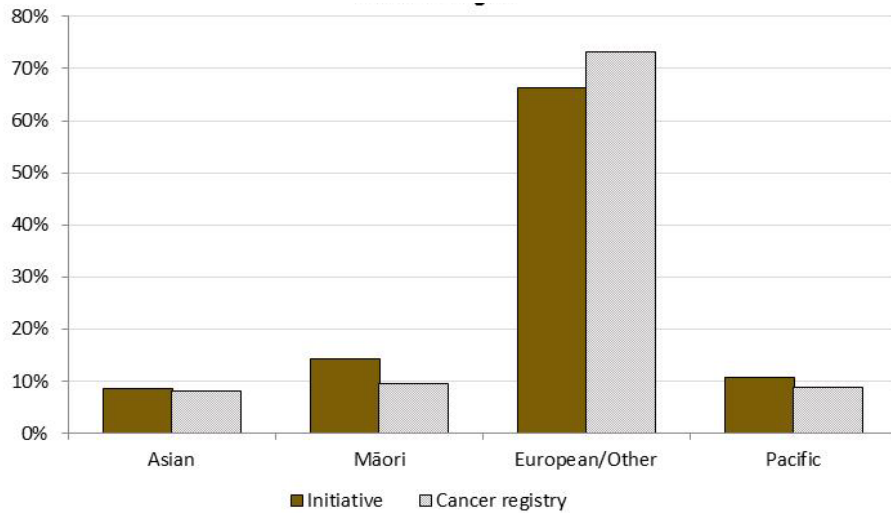
Source: Data supplied by Northern region DHBs to Sapere; 2014 Cancer Registry data

6.2.5 Initiative seeing proportionally more Māori patients

Eighteen per cent of referrals were Māori and just under eleven per cent were Pacifica people.

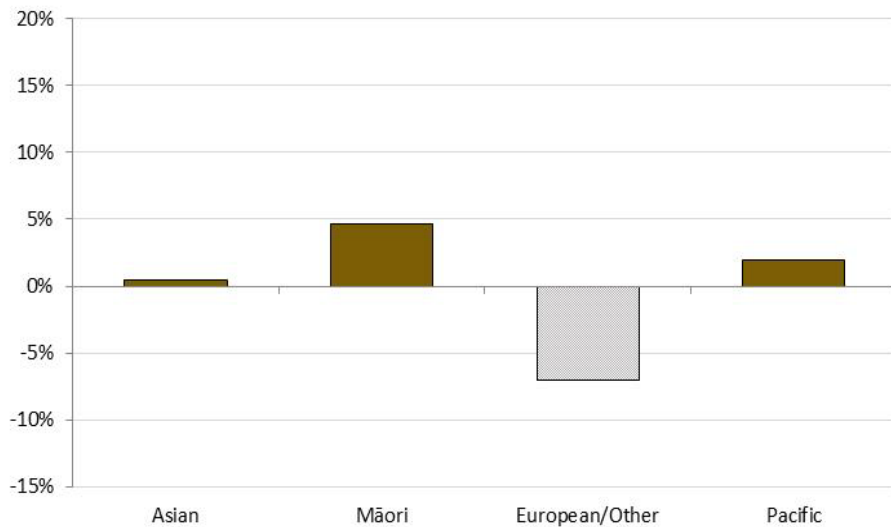
We compared the ethnicity of patients referred into the Initiative with Cancer Registry data. This showed that the Initiative is receiving proportionally slightly more Māori patients and fewer European/Other ethnicity.

Figure 10 Proportion of referrals by ethnicity



Source: Data supplied by Northern region DHBs to Sapere; 2014 Cancer Registry data

Figure 11 Difference in patient ethnicity (Initiative vs. Cancer registry) – Northern region



Source: Data supplied by Northern region DHBs to Sapere; 2014 Cancer Registry data

6.3 Service data from Northern region suggests the Initiative is focused on

front-of-pathway, and reaching Māori and Pacific patients

In terms of referral numbers, the Initiative in the Northern region appears to be broadly meeting the target populations in terms of ethnicity. This is evidenced by the slightly higher proportions of Māori and Pacific patients being reached by the Initiative, compared to the general cancer population in this region.

Most patients being seen by the Initiative are in the treatment or pre-treatment stage, which is consistent with the front-of-pathway focus. While staff expressed some concerns over this focus, the feedback from patients has overwhelmingly been supportive of the provision of the service as early as possible in the cancer journey, with many (who were already in treatment at the time of rollout) wishing it had been available earlier.

The tumour streams being reached partly reflects the nature of established relationships between Initiative staff. We were told that services are keen to continue building these relationships and extend to other tumour streams over time.

7. Implementation process

7.1 Funding allocation was via the Ministry to DHB via the PBFF model

DHBs were advised that funding would be allocated using the PBFF. As part of implementation of the Initiative the Ministry then asked DHBs to work regionally with their colleague DHBs to develop a plan around building a regional Initiative, with a strong equity focus and outline of how the needs of vulnerable populations would be met. This included ensuring that different expertise be available across the region to ensure people access the services that meet their needs. The regional planning process was instigated and led by the Ministry and developed by the four Regional Cancer Networks. The plans proposed how many FTEs each DHB would allocate according to the funding amounts, including whether the FTE would be a psychologist or social worker.

This has allowed a local variance in how FTE and disciplines are split between services and has created some significant workforce, safety (e.g. where a sole practitioner is working with little or no local supports) and quality control challenges. Initiative workforce models vary by service and there are various drivers for this variance such as size of FTE, other resources available locally, local preferences and practicalities, e.g. geography, and interpretation of the model of care (MoC). Note, the MoC was not available to planners at the regional planning stage. It came later.

The following table reflects how the budgeted FTE was originally planned to be locally split between disciplines (from the regional plans). Subsequent staffing decisions vary in places, and there have been vacancies and turnover over time.

Table 1 Initial planned FTE allocation

DHB	Social work	Psychology	Total FTE	Regional Lead
Northland	1.0	0.5	1.5	
Auckland	3.0	0.6	3.6	1.0
Waitemata	3.0	1.7	4.7	
Counties Manukau	3.0	1.0	4.0	
Bay of Plenty	1.0	0.8	1.8	
Waikato	0.4	2.2	2.6	1.0
Tairāwhiti	0.2	0.2	0.4	
Lakes	0.0	0.8	0.8	
Taranaki	0.7	0.2	0.9	
Hawke's Bay	0.5	0.5	1.0	
Whanganui	0.3	0.2	0.5	
MidCentral	2.0	0.0	2.0	1.0
3DHB	2.0	1.0	3.0	1.0

DHB	Social work	Psychology	Total FTE	Regional Lead
Nelson Marlborough	1.0	0.3	1.3	
West Coast/Canterbury	2.6	2.0	4.6	1.0
South Canterbury	0.7	0.0	0.7	
Southern	1.6	1.0	2.6	1.0

Source: Spreadsheet provided by National Clinical Lead to Sapere, February 2018

To date, we have seen a variety of workforce models, including:

- Mixed (psychology and social work) and single discipline services – including one that is social work only and one that is psychology only.
- A range of team sizes – from sole practitioners to teams comprising six or more members.
- Co-located teams and isolated workforce members – with some services co-located with oncology teams and others separately located.
- A mix of levels of experience.
- A mix of full- and part-time workforce members.

As shown in the above table, some DHBs were allocated small fragments of FTEs. Numerous interviewees told us that this made recruitment very difficult, and this was compounded by the fact that all DHBs were recruiting at the same time. Several services have recruited from overseas, as they were unable to find suitable candidates within New Zealand. In our view, it may have been better to stagger (phase) implementation across DHBs and not recruit for local positions until the Regional Lead was in place.

The way the FTE and staff allocations were made has also meant that some staff are working in isolation from other psychologists or social workers. In some sites, this was a particular concern expressed by stakeholders.

A common theme from some workforce interviews was the potential risk of staff burnout and turnover. Several staff commented that the regional forums could be more useful – e.g. having a greater focus on peer support and sharing of learnings (e.g. both in general and using case studies, exploring ways of working with different needs and levels of complexities, sharing different approaches to the service etc.), particularly for more isolated staff. The value of networking and sharing one on one experience was also noted. The extent of pre-existing unmet need for psychological and social supports is so great that the available funding is, in the words of one interviewee, “a drip in the bucket”.

There is evidence of cross-referrals and patient sharing in some mixed discipline teams. We also evidenced one example of regional teamwork underway with formal referral pathways in development. However, the existence of some single discipline teams may have implications for patient equity and the Initiative’s goal of national consistency – we will continue to explore this as our evaluation progresses.

7.2 Lack of timely national guidance

One of the most common themes from the workforce survey and interviews was the lack of timely national guidance and, therefore, service development consistency during the implementation process. For example, the development of the Model of Care and the protocols for data recording. As a result, each service has developed their own protocols and processes, which has led to variation in referral and triage criteria and processes, and data recording. Resources were expended on developing services and work was duplicated. It may have been both more efficient and more effective to stagger implementation – with recruitment occurring after fundamental service design work had been completed nationally. This does not negate the ability of local services to respond to local need and have flexibility to do so. Having said that with the Initiative only given three years to establish, a key question is, with such a specialised service was this realistic?

The variation in the criteria for referring and accepting patients into the Initiative may have implications for patient equity. Services we have seen to date vary in terms of their focus on front of pathway (including at what point patients are discharged) and what and how they use the distress screening tool. It is clear to us that there is not widespread consensus across the Initiative workforce on either the use or design of the distress screening tool. This is evidenced in the literature as well.

7.3 Implementing the Initiative in existing organisations or services

7.3.1 Scarce workforce

Psychology and social work is a relatively scarce health workforce across the entire health system, and even more so when considering a subset of expertise in working with people with this level of high distress regarding their cancer diagnosis and treatment.

Trying to implement the Initiative at the same time across all of New Zealand meant at times, services were competing with each other for resources. We were told this, compounded by the partial FTE allocated to some areas, made it very difficult to recruit and that this continues to be so in some places. We note there are other factors that can also contribute to recruitment difficulties, such as geographical location. We will continue to explore this issue through the rest of the evaluation.

7.3.2 Various organisational structures and rules make for some challenges for some Initiative Services

Even when co-locating the two disciplines in to one team, we saw evidence of various complicated reporting lines, accountability regimes, and supervision structures. The type and level of paperwork required also varies as do policies, procedures, and rules about working in different DHBs, even when their own patients may be receiving treatment in another DHB.

Examples included:

- Dual reporting and accountability lines for some staff, i.e. to both the Initiative and to their own DHB based and/or national based professional bodies, e.g. for training and other requirements. This can make for complicated and unclear processes for example for leave applications. Conversely, we have seen examples of where services have streamlined this and successfully made it clear for staff.
- Differing training allocations between the two disciplines, e.g. professional body expectations of employers (e.g. DHBs) for psychologists and not for social workers, so the Initiative funding has to cover training for the social workers.
- Differing policies and procedures, and in some cases IT systems, in the wider organisation for psychology and social work as well as additional ones for the Initiative.

Much of this is reported to cause frustration, confusion for some, is time consuming, and is not patient-centred. For example, the ability to see their patient in another DHB (if they are receiving their treatment there) can be an issue – as not all hospitals/DHBs allow this. This is a concern for Initiative staff, particularly in terms of their ability to maintain rapport and relationships with their patients while they are receiving treatment.

In addition, some services reported having to do “work arounds” to circumvent their DHB’s standard processes, as the mainstream organisation system and procedures did not suit their needs. Many examples were about how to record data when having for example, psychology in a physical health system. The same was said about where to record whānau records if they were working with whānau and their own needs. Some services had a system and others were doing work arounds.

A key challenge for some services is how and if their DHB, supports the service. This related from recognition through to a lack of administration report, and especially physical infrastructure for some. Repeated examples given were:

- Lack of office space.
- No clinical space that is private and appropriate. One service we met has to use other organisation’s rooms on a regular basis.
- Availability of technology, e.g. phones, computers, laptops.
- Variable IT support.
- Many do not have a reception or other administration functions to rely on. They feel they “beg” from other services to assist (usually other cancer services).
- Varying rules around what training funds can be used on.
- Who and in what division in the DHB holds and manages the contract for the Initiative.

7.4 What changes and impacts have been seen where similar existing services were in place before the Initiative

We have observed two services where a very similar service was already in place before the Initiative, albeit with various differences, e.g. different referral criteria. Where this is the case, examples of changes that the Initiative has presented have been:

- Differentiating between Initiative patients and others – this can be very difficult as there are many overlaps and similarities.
- Adopting the Initiative Model of Care.
- Newly agreed consistent data collection items.
- Addition of social work to the total local service.
- Broadening of outreach options for patients by clinicians being able to travel to do regular rural clinics, reducing travel barriers for patients and whānau.
- Beginning of formalising a regional referral pathway to a regional cancer centre based Initiative service.
- Broadening of referral and acceptance criteria to ensure the target populations of the Initiative are being accepted.
- Increased volume of people able to access psychology and social work services related to their cancer and distress.

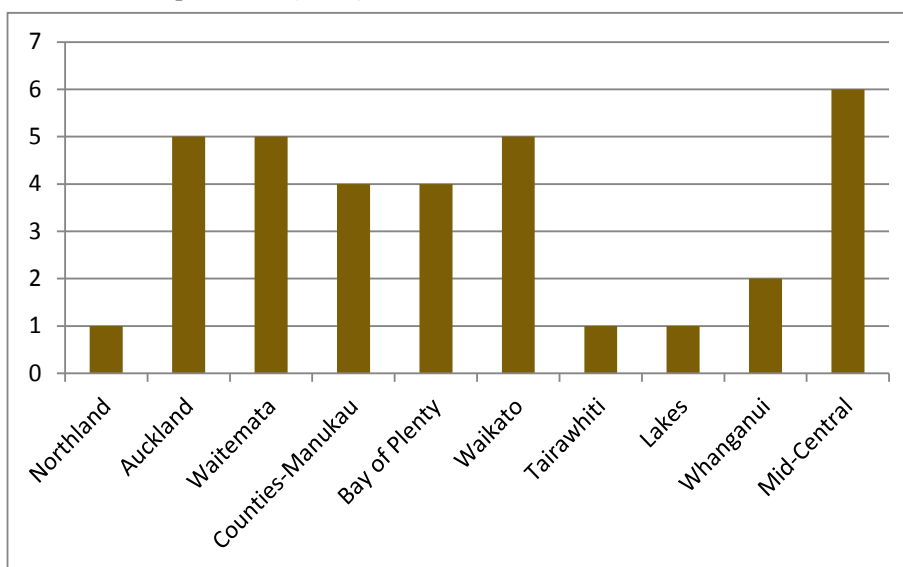
8. Workforce: interview and survey findings

8.1 Survey respondents

The following two charts show the regional and professional make-up of respondents. Note the variation in FTE per area is reflected in the number of respondents.

Figure 12 Respondents by DHB

Number of respondents (n=33)



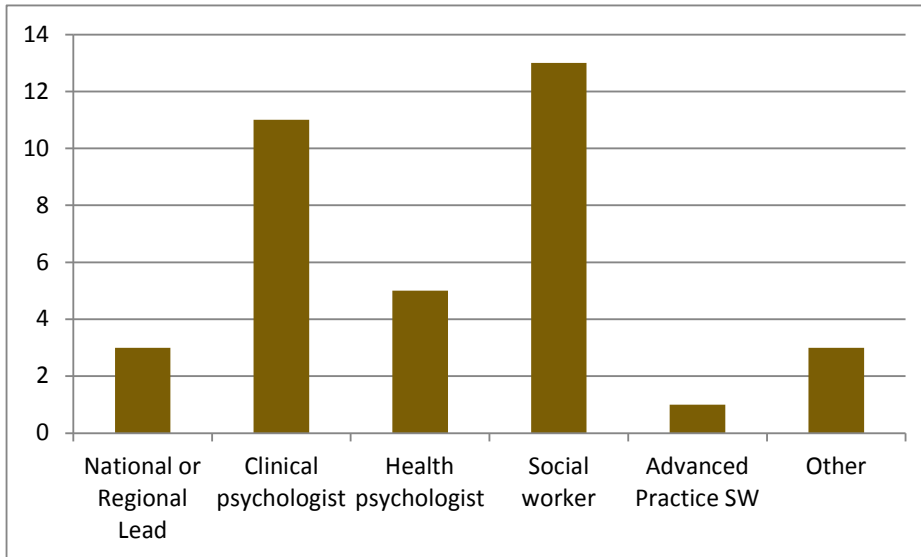
Source: Sapere workforce survey

Note: Respondents could (and did) select multiple categories if they work across DHB boundaries.

Psychologists accounted for 44 per cent of respondents and social workers for 39 per cent. The National and three Regional Leads are either clinical or health psychologists. ‘Other’ roles included service administrator and analyst, which are not funded directly by the Initiative, though the CFA expect that a level of administration support is to be provided by DHBs. What we have seen so far is that this is hugely variable by DHB varying from excellent administration support to virtually nil support. This is the same challenge for physical office and clinical space too, as well as resources, e.g. IT support, technology tools.

Figure 13 Initiative role

Number of respondents (n=33)



Source: Sapere workforce survey

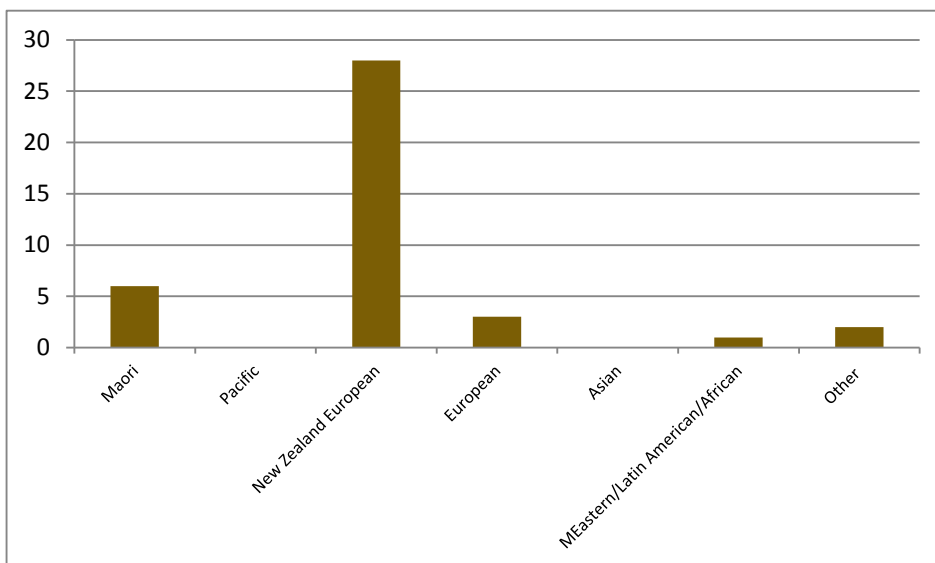
Note: Respondents could (and did) select multiple categories

8.2 Workforce predominantly female and NZ European

Ninety per cent of respondents were female, and most, 85 per cent were New Zealand European (Figure 14). Six respondents (18 per cent) identified as Māori.

Figure 14 Ethnicity of respondents

Number of respondents (n=33)



Source: Sapere workforce survey

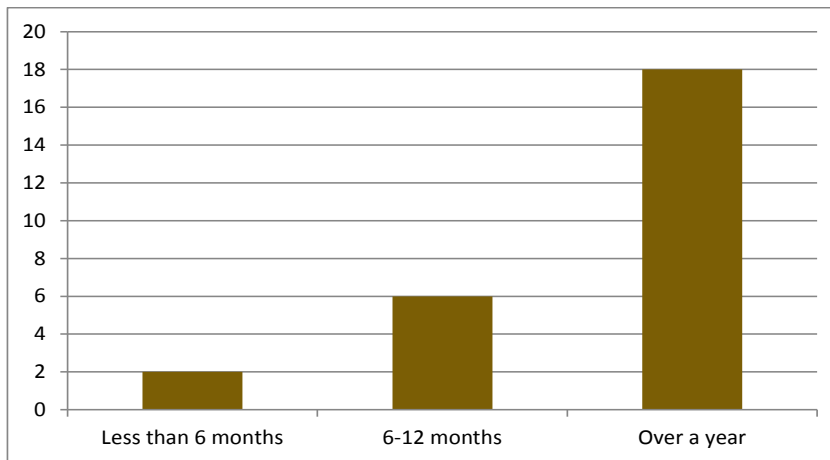
Note: Respondents could (and did) select multiple categories

8.3 Comparatively well-established

The tenure of the workforce reflects the relative maturity of the sites surveyed to date, with over two thirds of respondents having worked for the Initiative for over a year (Figure 15).

Figure 15 Tenure in Initiative

Number of respondents (n=28)

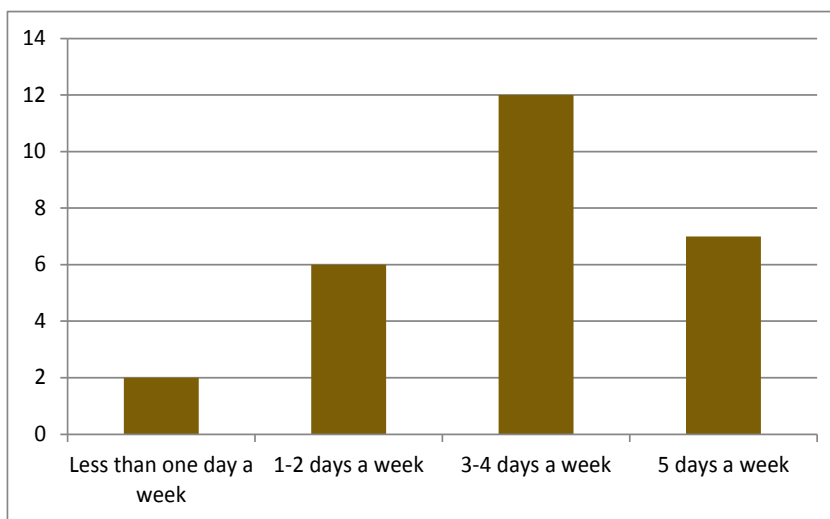


Source: Sapere workforce survey

Respondents span a mix of part and full-time roles, with most working three or more days a week for the Initiative (Figure 16).

Figure 16 Weekly time spent working in Initiative

Number of respondents (n=28)



Source: Sapere workforce survey

8.4 Support delivered in a variety of ways

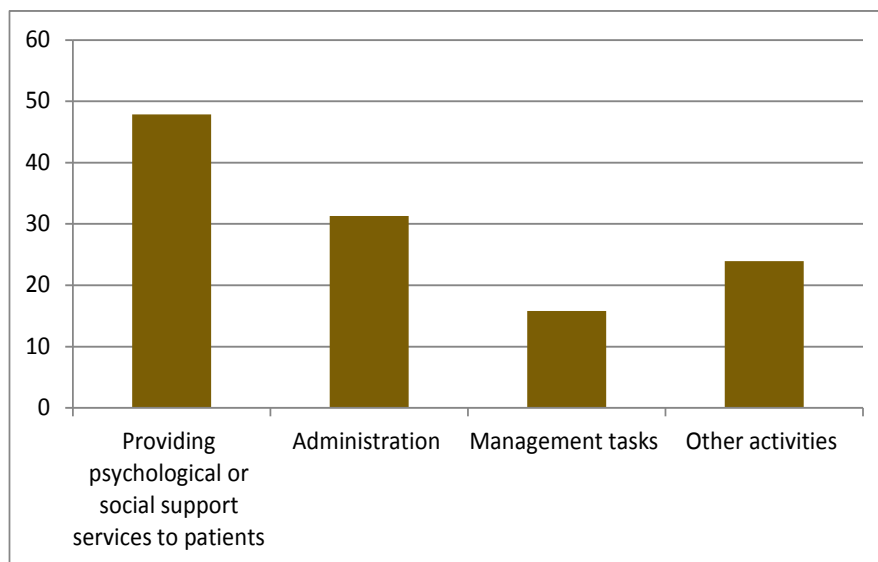
Overall, psychologists tend to deliver support to patients mostly face-to-face. Social workers tend to provide a mixture of face-to-face and telephone support. Other patient-focused tasks include clinical notes, triaging referrals, scheduling appointments and travelling to home visits.

On average, respondents spend around half of their time (48 per cent) directly providing support to patients. The remainder of their time is spent on administrative, management, and other tasks. ‘Other’ activities include:

- Service design and improvement.
- Supporting and/or supervising other staff.
- Providing training/education for other health professionals.
- Statistics.
- Team meetings.
- Journal club.
- Research.
- Professional training and development.

Figure 17 Proportion of time by activity

Percentage of time spent working in Initiative (n=28)



Source: Sapere workforce survey

8.5 Workload is currently manageable for most

Most respondents (87 per cent) reported that their Initiative caseload is currently manageable. One felt it is currently unmanageable and commented that:

We are feeling too busy currently. As a team, we feel we will be unable to continue working at this level of complex case work.

Some other workforce members raised concerns, both in the survey and in interviews, that their workload could become unsustainable in the future due to staff turnover, the intensity and complexity of cases, or if referrals increase significantly.

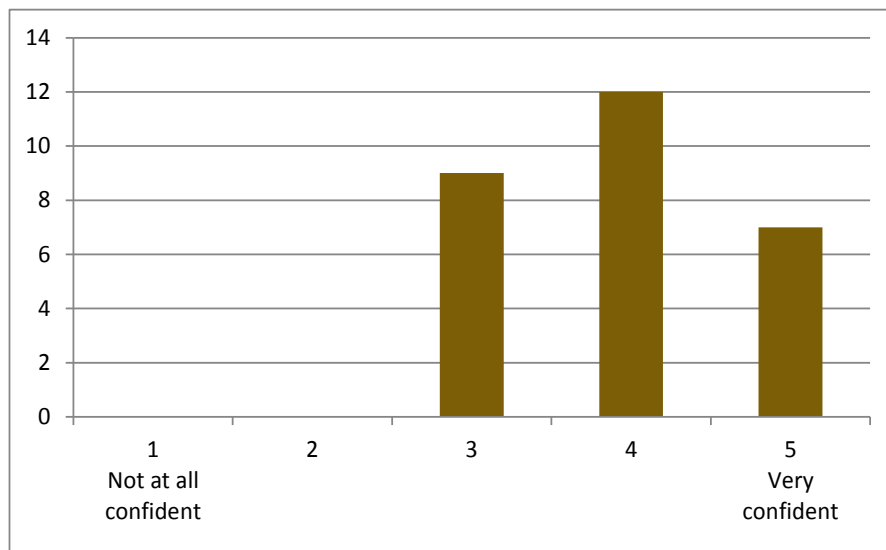
8.6 A moderate level of confidence in delivering to target populations

Respondents were asked to rate how confident they feel about delivering services to the Initiative's target populations (those with high and complex needs, and hard to reach groups such as Māori, Pacific and rural), with one being not at all confident and five being very confident. All respondents scored 3 or above, and the weighted average score was 3.9 out of 5.

Several respondents noted that their ability to deliver to these target populations depends on being able to access them, which is highly dependent on referrer practices. A number noted that their service is striving to achieve better reach into these communities, including by continuing to educate and build relationships with referrers.

Figure 18 Confidence in delivering services to target populations

Number of respondents (n=28)



Source: Sapere workforce survey

8.7 Most feel well supported in their role

Respondents were also asked to rate the extent to which their clinical supervision, professional training and development, and peer support needs are being met. The weighted average was 4.4 out of 5 for clinical supervision, 4.3 for professional training and development and 4.4 for peer support. Two respondents (from different DHBs) commented that their professional supervisors are not oncology specialists.

One respondent asked whether there could be discussion about priority professional development topics that apply across the disciplines, which could be rolled out nationally.

Teams are supporting each other, particular those that are co-located: the *‘environment is supportive and one does not hesitate to pick up the phone and consult with somebody for assistance’*. However, some other staff feel isolated, and would value more Initiative FTE being collocated with them, or having access to local group meetings and workshops.

One commented on the difficulty accessing external cultural supervision: *‘great Social Work peer supports within the initiative but just needing cultural peer supports’*.

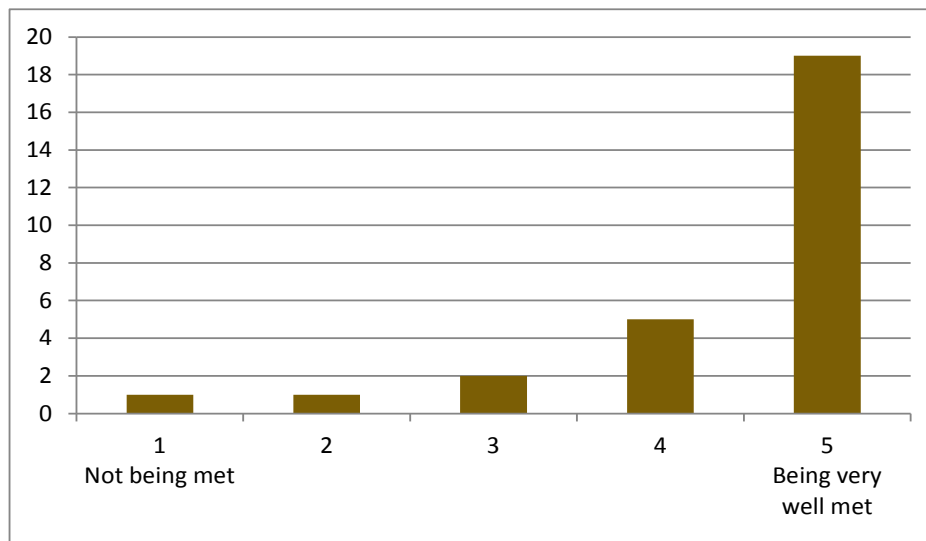
Two respondents mentioned the risk of burnout and staff turnover due to the stress of dealing with such high complexity and distressed patients:

One concern I have is the complexity of cases and emotional toll this job carries. I think the Initiative will struggle with staff turnover and burnout.

Two respondents commented that they would like more peer support and sharing, e.g. through a forum or peer network.

Figure 19 Extent to which clinical supervision needs are being met

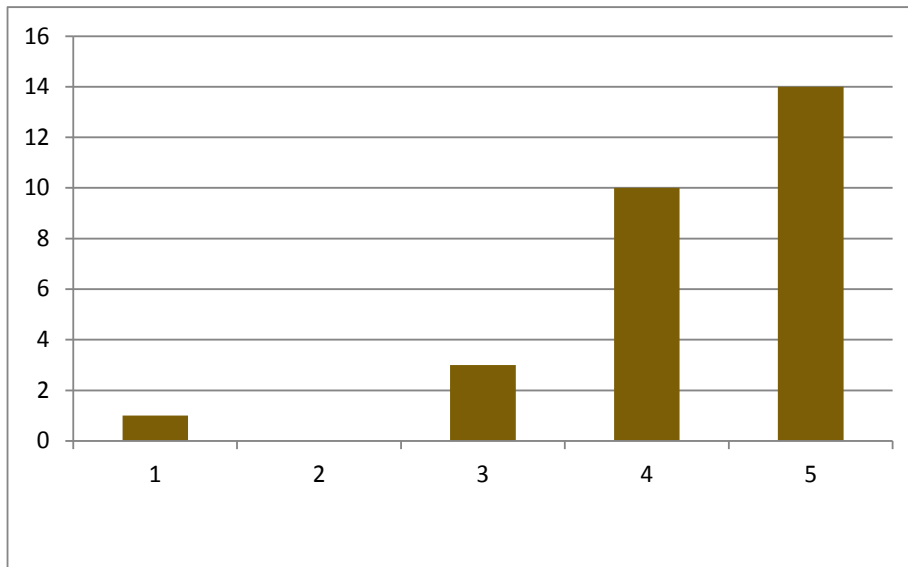
Number of respondents (n=28)



Source: Sapere workforce survey

Figure 20 Extent to which professional training and development needs are being met

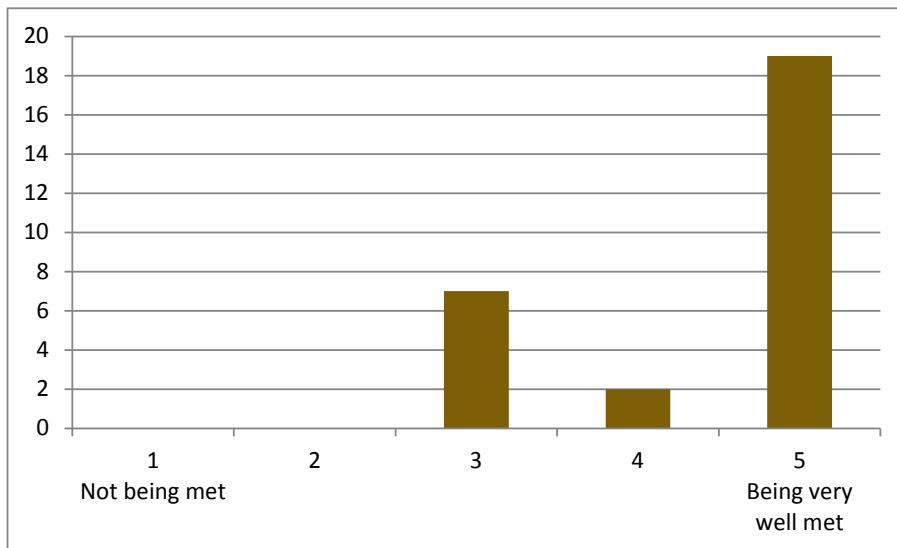
Number of respondents (n=28)



Source: Sapere workforce survey

Figure 21 Extent to which peer support needs are being met

Number of respondents (n=28)



Source: Sapere workforce survey

8.8 Supporting resources needed

The survey asked whether respondents have all the necessary tools and resources to do their job for the Initiative (e.g. policies and procedures, data collection, referral pathways). The weighted average was 3.9 out of 5.

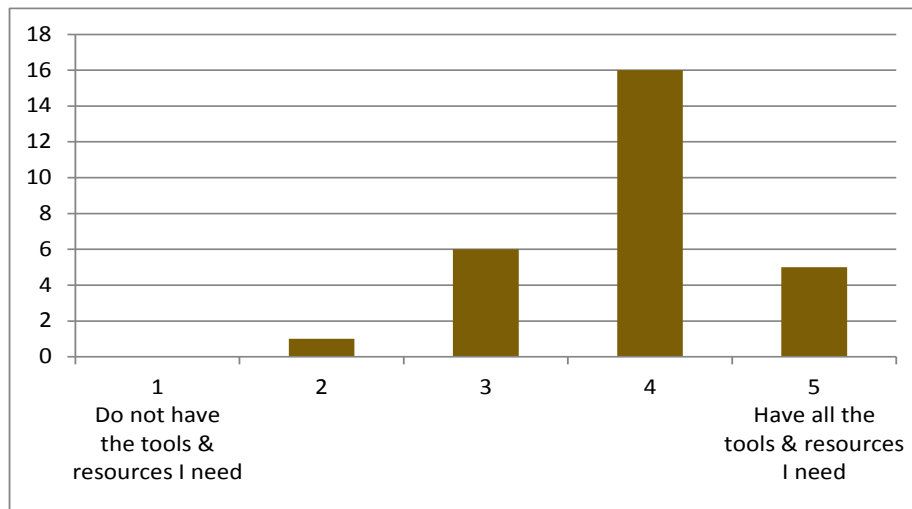
Resources needed include supporting systems, such as IT and administrative support. Transport was cited as a particular challenge – both in terms of access to pool cars and travel time:

[I] do not have time available to travel to rural areas.

It can be challenging allocating the time resource to reach very rural and difficult-to-engage patients.

Figure 22 Tools and resource to do the job

Number of respondents (n=28)



Source: Sapere workforce survey

8.9 Issues raised

Respondents were asked what could be done to meet their work, support and development needs, and also invited to make any other comments. Specific issues mentioned included:

- The challenge in finding suitable clinical space for seeing patients.
- The amount of work involved in establishing the service and the lack of timely national direction and guidance, e.g. around the model of care and data collection protocols.

Setting up the service has been a long and extended process. I did not realise it can take this long to get things sorted, especially relating to technical aspects. This had been frustrating... One such frustration is that the data needs to be collected but we had to wait a very long time to get the criteria from National office.

It created some challenges in the development of our service not having a national model of care.

- A desire for clarity around providing support for whānau.

I would like to see a clear discussion around whānau support. This was identified as a key part of the initiative early on and it feels like the 'whānau' part has been dropped off.

The initiative talks a lot about whānau support but in reality this does not work and it not practical in our DHB setting – I would like this to be acknowledged and explored more.

As in the interviews, a couple of survey respondents were concerned about what will happen to the Initiative after the “current funding agreements end” in 2018. We note however that the Ministry has confirmed that the funding will not end; it is on-going, but currently in discussions about how the funding will be managed going forward (for example via the Ministry or devolved out to DHBs).

I would like to see the initiative to continue to have it protected by the MOH for another 3 years to ensure it has a chance to develop and consolidate as business as usual within oncology.

Still wondering about the future of the initiative and the gains being made and the integration and on-going future of such a wonderful initiative.

More broadly, respondents also raised concerns about gaps in other supports for patients, including practical (such as access to transport) and psychosocial (such as support post-treatment/survivorship).

Travel and transport related issues with cancer patients remains the big challenge, it is hard to help patients access support in this regard if there are not resources for which a lot of people may qualify for, or the resources are limited, or patients do not meet criteria for support.

8.10 Workforce interviews

8.10.1 Implementation processes and funding

Implementation of the Initiative was challenging for DHBs, staff and services. There have been mixed reports on the understanding of the role of the National Clinical Lead at the time of implementation, and some are still not clear what the National and/or Regional roles functions are, despite more recent communication in the FAQ sheets. Interpretation is key. There remains room to improve role clarity of the National Lead, Regional Leads and for the Ministry. Overall, the feedback has been that there would have been great benefit in having more national leadership especially from the Ministry, e.g. for consistency, reduction of duplication in developing resources, etc. Whether that is the Ministry’s role or the National Lead role is irrelevant for the purposes of this section, as we are reporting what people have actually said would have been useful to them locally. We note that there was a gap of six months in having a national clinical lead, and this would have made a difference.

Expenditure to date has been lower (unspent funding) than available funding. The allocated budget is \$4.2 million per annum. So far this year there has been expenditure of \$3,410,841, creating a one-off underspend of \$789,159 (as unspent funds are not rolled over/carried forward). This has been largely due to the services’ inability to recruit staff upfront and the need to develop the service locally. Therefore it might have been possible to use some of the unspent funds up front to assist with service development (and reduce duplication of effort) such as consistent resource development, additional up front training, additional education, national forums and networking/peer support, etc.

As noted, the Ministry of Health funding is on-going. Currently, the funding is received via a CFA variation. CFA variations are usually used in the initial phase of an initiative to support monitoring of implementation. The expectation is that at some point (either at the conclusion of the initial 3-year CFA or after a subsequent period) the funding and service requirements will be devolved to DHBs.

The services interviewed to date are highly concerned that if the funding does not remain ring-fenced for this particular service, either at a national or DHB level, then it will be lost, or used for other purposes, like deficits, in the DHBs and the Initiative will not remain intact. We believe this requires serious consideration in the national discussions.

8.10.2 Mix of disciplines in the teams

The service is comprised of psychologists and social workers. All but one service seen to date have the teams co-located. Some reported that at first there were some difficulties working as a team with the two disciplines; however, mostly this has been resolved now. There were some reports of joint working and allocating to the most appropriate person for the patient, irrelevant of profession. Some areas are so small there is not an Initiative team, rather an individual, working in various levels of professional isolation, at times. As noted above, this was a particular concern expressed by stakeholders in some sites. In our view, this is more an issue with the total level of funding allocated to the Initiative than the regional allocations, and is a learning point for consideration in the design of potential future health workforce initiatives.

8.10.3 Referral pathways clear but need on-going education of referrers

Referral pathways and processes are clear. However, there needs to be on-going education to current and new referrers about the services and what it can achieve for patients and their whānau.

As already noted, at this stage there are very few referrals from primary care. Services are generally concerned that if they open up referrals to primary care they may be swamped and have to prioritise differently or have waiting lists. Overall, they feel that for people in high distress (i.e. the access criteria) it is not appropriate to have waiting lists. Current service gaps by volume cannot be quantified.

Services say that they can continue to improve in targeting specific parts of the population; for example, specifically Māori and Pacifica peoples have been mentioned to the evaluators.

8.10.4 Supervision and training needs mainly being met

There were only two reports of professional supervision being a challenge. Mostly staff feel highly supported and that they get sufficient and excellent supervision. Supervision comes from a wide range of internal DHB and external resources.

As the services are relatively new, training needs have overall yet to be tested. However, what we did hear is that psychologists get an annual allocation of training time and funds as part of their profession, whereas social workers do not. This can at times cause some tensions in the team and feelings of discrepancies and unfairness.

9. Patients: interview and survey findings

9.1 Rolling patient survey

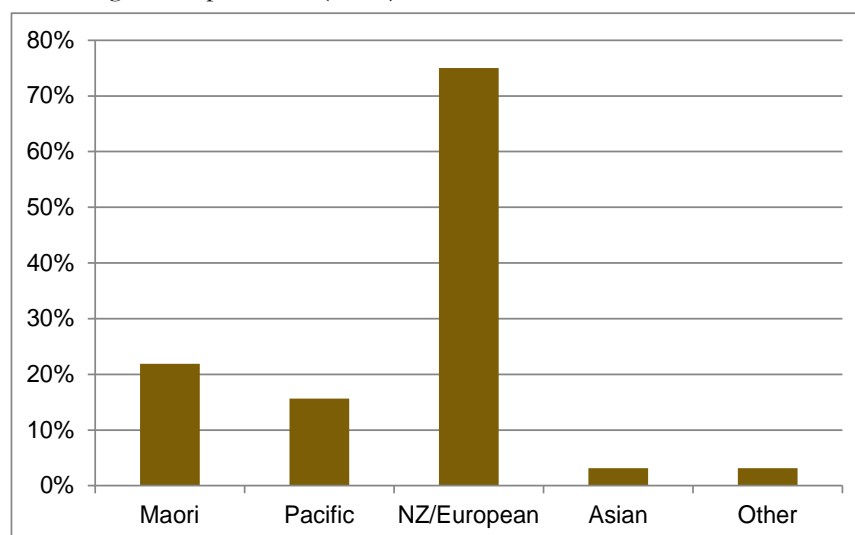
9.1.1 Overview of responses to date

As at 21 November 2017, we have received 32 completed survey forms (31 hard copy, one online). These are all from the Northern region.

The majority of respondents (84 per cent) were female. Seventy-five per cent were New Zealand European/European, 22 per cent Māori and 16 per cent Pacifica (see Figure 23).

Figure 23 Ethnicity of respondents

Percentage of respondents (n=32)



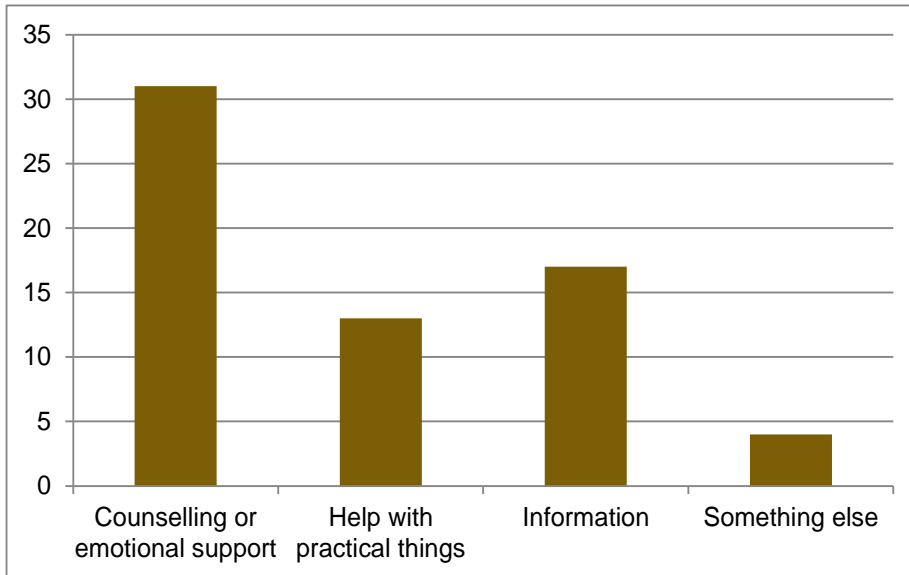
Source: Sapere patient survey

9.1.2 Types of support received

The most common type of support (received by all but one respondent) was reported as 'counselling', which may have been provided by either a psychologist or a social worker. Over half of respondents reported that they received more than one type of support. Other types of support mentioned included petrol vouchers, and on-referral to other services.

Figure 24 Types of support received

Number of respondents (n=32)



Source: Sapere patient survey. **Note:** Respondents could select multiple categories

9.1.3 Satisfaction with the service

All respondents were satisfied or very satisfied with the help they received from the service (Figure 25). And all but one respondent thought the service met their needs quite well or very well, and one said it met ‘some but not all’ of their needs (Figure 26). Twelve respondents mentioned in the free text comments that the service was ‘great’ or ‘much appreciated’.

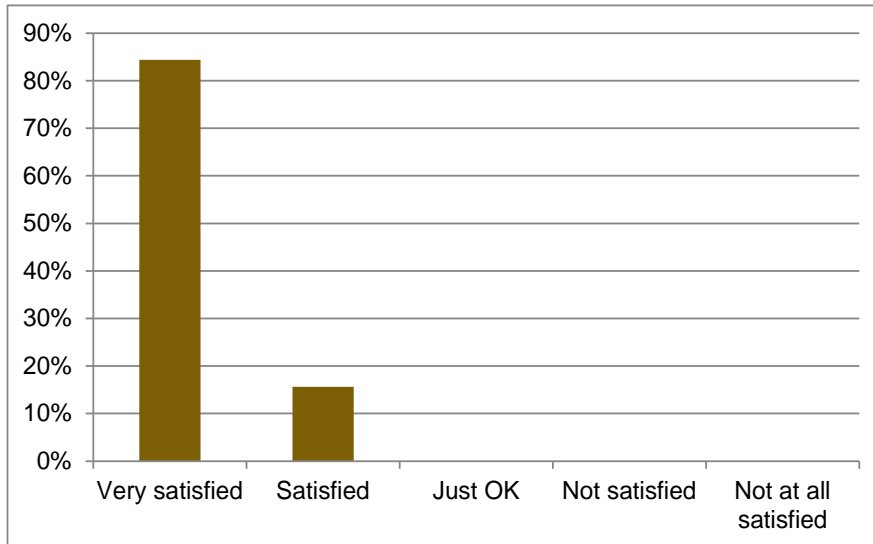
This service is great and very needed.

Your thorough, knowledgeable and caring support has been much appreciated.

Many thanks for providing this service. It was invaluable and much appreciated.

Figure 25 Satisfaction with the support provided

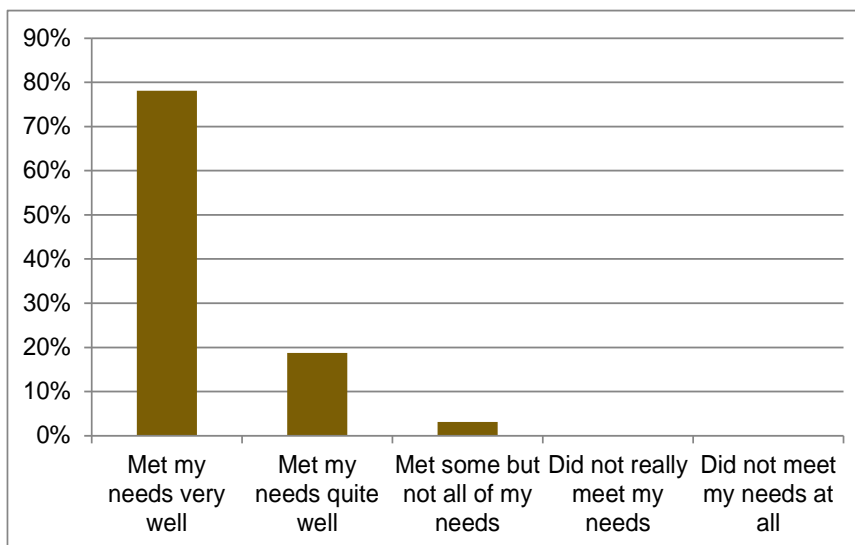
Proportion of respondents (n=32)



Source: Sapere patient survey

Figure 26 Extent to which the service met their needs

Proportion of respondents (n=32)



Source: Sapere patient survey

9.1.4 Aspects of the service that are valued

Respondents were asked whether there was anything particularly good about the service, that they liked the most. The most common response was the kindness, compassion, and understanding of the staff member.

Consistently available and high standard of info and compassion maintained.

Another common theme was the confidentiality of the service:

The aroba-love. Safe to speak. The humbleness.

Several respondents also mentioned the follow-up (staff checking in to see how they are going) as being invaluable:

Follow up phone calls to see if everything was ok or if I need anything.

Respondents were asked whether there was anything particularly good about the service, that valued the knowledge that there was someone there they could call on if needed.

The fact that the service was there on call made a big difference - my own situation in many ways is 'isolated' and in some ways 'socially unsupported' so it was good to have someone to call if my situation broke down.

The specialist oncology knowledge was also valued:

I really appreciate being able to receive counselling particularly targeted to cancer and cancer recovery. It's been such a positive thing for me to do.

Thank you [name] for your encouragement. But most of all thank you for being a friend who understood my situation. You have been such a great help, through the 6 months I have known you.

Psychologists 'specialising' in oncology patients and their carers.

Another common theme was the flexibility and convenience of the service – including the capacity for home visits.

It is a great service. And I am very happy that it was able to be provided locally. Travelling can be an issue for patients and this is a plus. I think going out into the regions is very important and makes people feel that they are not alone.

Other aspects mentioned include:

- The professionalism and knowledge of the staff member.
- The fact that the staff member was a 'great listener'.
- The friendliness and warmth.
- Having someone to talk to.
- Communication with doctors and staff.
- That the staff member would research information specifically for them and their situation.

I liked the way the psychologist validated my feelings and completely understood how I was feeling at a time when few others could. I felt I was not alone during a terrible time.

Just to say having an independent person to share and understand what I was going through, helped me to cope a lot better.

Being able to talk to someone is a great help.

9.1.5 Impact of the service

Respondents also described the impact of the service, with several saying it helped them/made them feel supported, and helped them deal with stress and/or depression. Two respondents said the service was ‘invaluable’.

The social worker related culturally appropriate[ly]. We were very lucky to have who we had. We are so blessed with the outcome. Our Baby [name] loves her. Enjoys her.

Thank you for this service, it has been at least as much help as the medical treatments.

It was very supportive. The care and advice have really helped me to cope and I’ve been able to have a much more positive outlook on life in general.

I would like to commend all the staff for their help and support during my treatment. They are all very caring and helpful and feel very privileged to have had such amazing support from them all. It has helped my state of mind and my recovery.

The level of professionalism and quality of advice has been enormously helpful.

The service and social worker [name] was helped us successfully applied our first accommodation from Housing NZ, which we greatly appreciate.

I think the service provided for dealing with cancer that helps them to deal with the mental challenge is so important and it should never be lost. Myself and my family are so grateful to have been provided with this valuable opportunity.

I couldn’t have got through without the strong psychological assistance I am receiving. Thank you to the psychologists who have helped me deal with a radically different psychological landscape - then, now and for the future. I don’t have words to express how deep my gratitude is.

9.1.6 Suggestions for ways in which the service could be improved

Four respondents made suggestions for ways in which the service could be improved. These suggestions were:

- A more consistent room.
- Provide simple, easy to understand notes on subjects that were covered in the sessions.
- Available earlier in the pathway – ‘it would have been good if someone was present when being told bad news. Someone to talk to after’.
- To offer the service more widely.

One respondent commented that there was ‘too much at once at the beginning, social workers and phone calls’.

9.2 Patient interviews

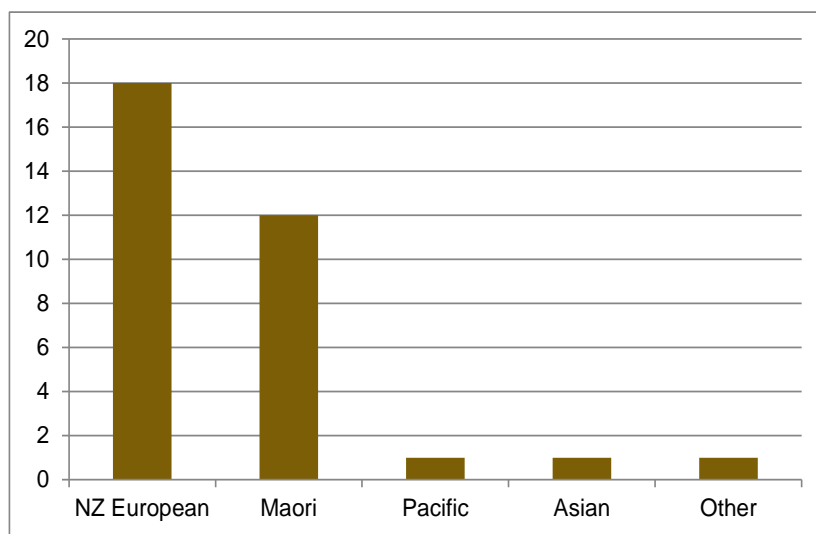
To date, we have conducted 33 interviews with patients. Patients were welcome to have supporting whānau members present if they wished, and some chose to do so. Two thirds of

these patients (n=22) were female, one third (n=11) were male. As noted already in this report, we employed a purposive sampling methodology focusing on patients from the Initiative’s target groups, particularly Māori and Pacific people, those living rurally, and those with high and complex psychological and social support needs (including people from socioeconomically deprived situations, with cancer diagnoses associated with higher distress, and/or with multiple and complex needs such as pre-existing disabilities).

Eighteen patients (58 per cent) were New Zealand European and twelve (36 per cent) were Māori. The remainder were Pacific, Asian or other ethnicity (Figure 27).

Figure 27 Ethnicity of patient interviewees

Number of interviewees



Source: Sapere interviews

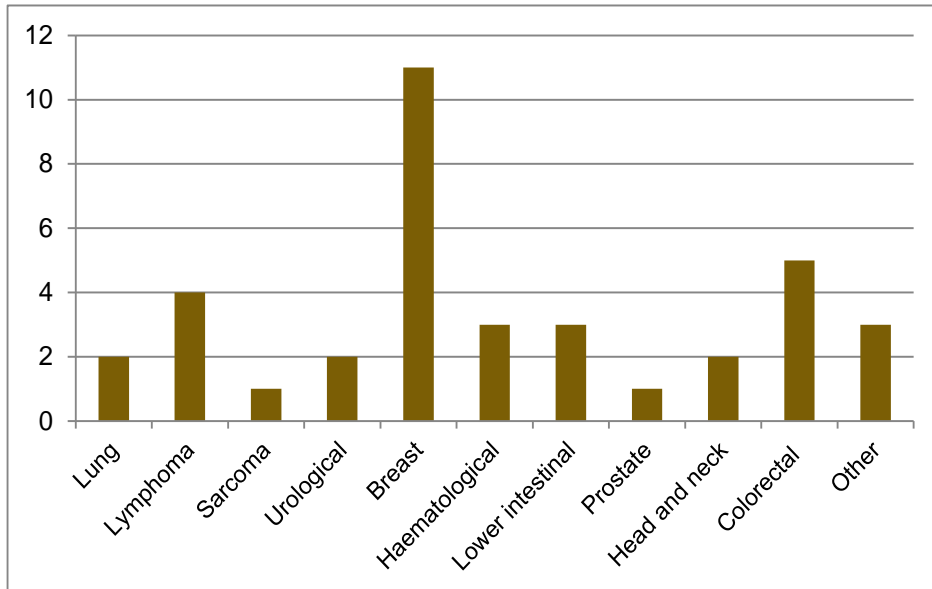
Most interviewees (n=16, or 48 per cent) were aged 25-60, ten (30 per cent) were aged over 60 and the remaining two (six per cent) were aged 18-23.

Over half of interviewees (n=18, or 55 per cent) live rurally, the remainder live in urban areas.

The following chart shows patients’ cancer type, as reported by the interviewee. Note these categories do not align with the Ministry’s classification system, as we are reliant on the information provided by patients, reflecting their understanding of their own diagnosis. The most common categories were breast cancer (n=11) colorectal (n=5) and lymphoma (n=4).

Figure 28 Patients' self-reported cancer type

Number of interviewees



Source: Sapere interviews

9.2.1 Overwhelmingly, patients are highly satisfied with the service

Overwhelmingly, people have been more than satisfied with the service.

The service was great, was the biggest response.

Followed by: *When she told me my behaviour or feelings were normal, that made all the difference.*

I didn't know that chemo gave you brain fog. I thought I was dying. It was so good to hear that was normal.

Our conclusion to date is that this is an essential service that makes a significant positive difference to individuals' and whānau lived experience. However, the scope, reach and intention of the Initiative does not meet the demand that is there. From what we have heard in interviews and surveys, from both a variety of patients, stakeholders and Initiative staff, there is a gap for others who could greatly benefit from this service, but do not meet the target criteria. Staff find this challenging as they can see the potential benefits for these patients and whānau. In addition with the variation in interpretation of how whānau can be involved in the Initiative, some areas are more inclusive of whānau than others based on their interpretation of the Model of Care and/or difficulty in recording whānau notes privately within their DHB system.

Most patients said they were very satisfied with being offered the service in the first instance of diagnosis. Only a few (fewer than five) said they thought it was offered too soon. We believe this reflects the individual nature of distress and ability to receive information at any specific time, and individual circumstances.

9.2.2 Referrals are from targeted areas with no waiting lists

Referrals are mainly from oncology or radiology services, especially the Clinical Nurse Specialists. Some are also from the Cancer Society or surgeons. Very few reported that GPs refer. As noted already, mainly the services visited have not targeted GPs for referrals due to time and resource constraints and also hesitancy in creating demand they cannot cope with.

At this stage, we have had no reports of waiting lists. However, this does not mean that priorities of needs are being met as intended, as some people who may be eligible may not be being referred.

9.2.3 Outcomes, as self-reported, for patients are very, very positive overall

We have heard a series of comments on outcomes for people. Only one person reported not having had an amazing experience with the service. Overwhelmingly the positive themes relate to the following:

- Service was so much appreciated and made such a positive difference for them.
- Enabled people to start and/or continue with treatment (i.e. reduced DNAs as self-reported by patients and some whānau members).
- People found it highly professional, accessible, and convenient.
- An invaluable service – could not have survived (i.e. received the treatment and/or maintained their marriage) without it.
- Gave them the will to live and/or that they may have committed suicide without the help of this service (n=4).

Other key themes about why it was found so valuable were:

- Flexibility (time, location (i.e. at home, in hospital or another clinic, etc.).
- The individual person (therapist) was so easy to build rapport and trust with. Trust was especially important and related mostly to the therapist being non-judgemental and confidential.
- Independence from family and friends so an “*independent non-emotional ear*” (Note: this was a strong theme).
- Checking in (i.e. a phone call every now and then, so people did not think they were “lost in the health system”. “*It was good to know I wasn’t lost in to a black hole*”.); and
- Sorting out money – i.e. Work & Income, transport, groceries (Note: we had a lot of people talk about having to give up employment to have treatment, to have to shift towns while having treatment and having additional whānau staying, and so therefore income/money was a big issue).

We provide a range of direct quotes as examples as these best reflect the stories and themes we have heard.

What I learnt was that I was worth something. And even though I was going to die soon, I knew for the first time in my life I had mana.

Having the knowledge of cancer...and being able to anticipate what might be next for me was so valuable.

She was so flexible and approachable. That was so important.

Sorting out Work and Income. I never had to go there before. It was great having someone help me through that.

My dad wouldn't have been alive now without that service.

She was an excellent person. Didn't judge us, and just was there for us.

It was a confidential service. I could say what I liked to.

It was so valuable having an independent ear. Not an emotional family member. Someone who would just listen and be there.

9.2.4 Session numbers and times are about right

People said the session numbers they had “*were about right*”, and that this was discussed and negotiated with them in advance. Only one person said it was not right – they wanted more. In general, psychology sessions are numbered to six, but can be extended if need be. However, services are clear this is a short to medium term service not a long-term service. They will refer to other longer-term services if they are needed.

On average, psychology session times are about an hour. Most people felt this was about right for them.

The key issue in terms of sessions and times is that the majority of patients disclose other trauma (pre-cancer trauma, e.g. sexual abuse, relationship and whānau issues, etc.) and so the services have to be disciplined in what their scope is and when they need to refer for other supports, counselling or services. Scope of the model of care can be challenging for staff.

The Model of Care in place for this Initiative has scope and boundary issues that some staff find very difficult. The key ones are:

- End of treatment. For some people end of treatment, going home, loneliness and even survivorship is the hardest times for them.
- Transition points, e.g. from hospital or home to hospice.
- Working with whānau if the person is not there – often it is the family carers who have the most distress.

9.2.5 Staff empathy and professionalism is highly valued

Feedback from patients is that staff empathy and most of all professionalism and independence is most valued.

She was amazing. Someone to talk to who had no emotion about my cancer.

She was so professional – I really valued that.

She checked in on a regular basis – I felt she was always there if I needed her.

10. Findings: stakeholder interviews

10.1 Stakeholders impressed with the services

Most stakeholders we spoke to were highly impressed with the services and the staff who worked with in them. They noted the major benefits to their patients. Stakeholders included local DHB oncology wards, referrers to the service and other support groups, e.g. the Cancer Society.

The most common benefits stakeholders reported included:

- Reduction in anxiety, stress and panic attacks – which improves health and wellbeing overall, as well as healing.
- Support of whānau and ability to access money, transport, and food.
- Beginning and adherence to treatment.
- Ability for the patient to sleep.
- Referral to other supports, for either the patient and/or whānau, e.g. relationship counselling, or Cancer Society group sessions, etc.
- Highly skilled and approachable staff.

As an example the roles of stakeholders includes:

- CNCs and CNSs
- Maori CNS / patient navigator
- Maori Health Services
- Oncology staff
- DHB Planning and Funding staff
- Service managers
- Allied Health Directors / staff
- Cancer society

11. Interim conclusions and recommendations

Caveat: these conclusions and recommendations are interim only and are based on sites evaluated to date; therefore, findings may change. Recommendations we offer at this stage are focused on implementation processes, and roles of National and Regional leads and the Ministry. This includes communication to the wider Initiative workforce. They are lessons learned from implementation and operationalising the service to date.

11.1 Conclusions

Overall, the services are highly functioning and delivering a great and significantly valued service to patients and whānau that we have heard from. However, this can be despite a lack of infrastructure support from some local DHBs. We believe the Ministry has a role in requiring and supporting DHBs to provide more appropriate supports, including administration and necessary tools, to the services.

The Initiative services are highly valued and make a great difference to people's lives. Many say that it enabled them to start and continue with their cancer treatment and to cope with day-to-day life. Patients report that the staff are highly professional and they value their knowledge and skills. The front of pathway felt entirely appropriate for patients however some staff felt it was too early. Several patients said they wished they had access to the service earlier than they did.

There is a need for on-going new and repeated referrer education. Services should work at least regionally, if not nationally, to discuss and figure out if demand exceeds availability in the future and how will triaging, on referrals and/or waiting lists be managed fairly and consistently. This requires careful consideration for people with very high needs who are in distress and have cancer.

Transitions out of the service have been reported by both patients and staff as a difficult process and time. Some felt that transitions for some people were poor clinical practice and that they should stay on the Initiative books if it is likely to be only for short term. There was general agreement that support or counselling for other major traumas and for long-term issues, including survivorship, need other appropriate services i.e. referred on.

11.1.1 National guidance and timeliness of resources are seen as important

There are lessons observed regarding implementing this new service. These relate to role clarity (e.g. the Ministry, National and Regional Leads) and service detail for national guidance.

It would have been better to have more timely guidance on data protocols so everyone started collecting the same data for comparability reasons. We note that for some services the way their DHB data systems work makes this more difficult than for others.

The agreement on and circulation of the MoC was not seen as timely either. This means the service is being delivered somewhat (but not significantly) differently in different places. While there is a balancing act between national consistency and local flexibility (including meeting differing local needs and needs to be based also on availability of other local resources), there are some questions regarding outcomes from an equity of access perspective across the country. This is not a clinical evaluation therefore we cannot comment on any variation, or not, in clinical practice.

It may also have been better for rollout across the country to be phased, in order to support recruitment, and promote collaborative working and sharing of learnings.

11.1.2 There are many aspects that are working well for patients

The service has been invaluable for, by far, the majority of patients we have interviewed or surveyed. What is most highly valued by patients are:

- Workforce traits such as the kindness, professionalism, empathy, trust, confidentiality, and non-emotive nature of the staff.³⁴
- Options for where sessions take place, e.g. at home, in the community (e.g. Cancer Society), on the Ward, while outpatient treatment is occurring, separate clinical rooms.
- Follow up calls and know staff are available.
- Dealing with the whole person and their needs, not just the cancer aspects.
- Culturally appropriate (as reported by patients).
- Staff knowing the “systems”. The most commonly cited were wider health systems, the DHB systems and processes and Work & Income.
- When transitions work well this involves good planning and effective handovers. Patients talked about “good handovers” or transitions being when the Initiative staff introduced them to the new person early and, where possible, there was at least one joint session. Building trust was the most difficult thing to do again.

11.1.3 What is working well for staff and services

There were some services that reported aspects that worked well for them, that other services found a challenge. Once again, this appears to be DHB dependent on how the services have been implemented and are supported locally, or not.

Overall what has been reported as working well is:

- Referral pathways are in place and continue to evolve e.g. regional pathways.
- Focus on front of pathway, level of distress and while patient is in treatment, but varying uses and interpretations of the distress-screening tool.
- Increasing volumes of the target tumour streams as referrers are educated and re-educated, and services develop.

³⁴ Language as used by patients.

- The role of the Regional Lead can be pivotal in supporting the services with local challenges, especially with DHBs.
- Where there is a dedicated manager to the service (as all or part of their role), staff report this as being a valuable role that makes service development and delivery easier.
- Co-location of teams (where there are teams and not sole practitioners) has been successful. Two particularly noted are having social work and psychology together and the other is one where the CNS's and the Initiative team are co-located. We note that at this stage CNSs appear to be the major referrers to the Initiative, followed by oncology teams. The CNSs and the two teams have many patients in common to discuss.

11.1.4 Challenges for service delivery remain in some areas

There are some challenges in on-going service delivery especially for some services. Typically, these are the converse of above and specifically include:

- Small fragments of FTEs in some services and resulting isolation or a non-available/flexible service (e.g. if a staff member is only one day a week).
- Lack of administration and DHB physical space support, as well as other resources and tools such as IT and electronic tools, (e.g. phones, iPads, or laptops for home visits and community work) and lack of clinical rooms for undertaking the work in private.
- Challenges with feeling that there have been delays in national guidance, pre- and post-implementation (noting our evaluation interviews mainly concluded before the current new national lead was appointed) and therefore replication of effort for resources and planning, e.g. changes to the distress screening tool, development of culturally appropriate resources.
- Fear that if this service's money does not remain ring-fenced, it will be absorbed by other services in the DHBs.³⁵

11.2 Theory of service implementation for new services

For successful and efficient implementation of services, based on inputs Sapere has gleaned from many assignments we have undertaken and informed by various literature searches for those assignments, the following are possible dimensions for design and planning of a new service implementation to create the greatest opportunity for a seamless and successful implementation. In essence, they are core factors of effective change management theory.

11.2.1 Vision and objectives

Have a strong process for developing an agreed vision and objectives with current and potential future stakeholders including workforce, planners, national and local representation, and patients.

³⁵ Note: some commented that they felt the amount of available funding for this service was not enough as there is much unmet need.

Communicate the vision and objectives widely and frequently to ensure they are understood and front of mind for services and planners.

11.2.2 Planning

Plan in detail for implementation and consider what will be the major success factors and challenges or barriers and how to overcome these. It is at this planning stage risks and mitigation factors should be identified and scored for potential impact.

A project plan, agreed by stakeholders, no matter how brief should inform the implementation and roll out in terms of phasing, timeframes and resources needed. A communication plan should be parallel to this to keep everyone informed and know whom to contact if they have any queries.

11.2.3 Policies and procedures

Policies and procedures, guidelines or systems developments etc. are an important part of implementation. There will be some that should be national to give guidance and consistency, whilst allowing for local variation where necessary and within scope.

11.2.4 Workforce

Details and scope of the workforce that will be required should be carefully mapped out. Consideration of availability of such a workforce is vital in informing the implementation planning. For a national new service, it may not be helpful to have multiple services and geographic regions all vying for a limited and too small pool of staff at the same time. In addition, acting in a supportive and non-competitive manner between geographic regions is desirable.

11.2.5 Systems and Infrastructure

The systems, tools, and infrastructure to support and help develop the staff and service need to be in place early and not replicated where this is not necessary.

Examples may include (depending on the service in play):

- Administration and reception (meet and greet) support.
- Appropriate space and environment for the type of service.
- Technology tools.
- Training.
- Anything else that has been identified for that specific service being implemented.

11.3 Interim recommendations

Once again, we use the caveat that these are interim recommendations only as this is the first part of the evaluation.

In summary, the recommendations we make are:

1. The National Lead to continue to facilitate process to build towards agreement across the workforce on design and use of (e.g. who, where, when) the distress screening tool, explicitly considering and taking advice on the criteria for Māori and Pacific patients,
2. In addition, the Ministry of Health, advised by the National Lead, provide on-going leadership and review of data fields for collection and supporting services within the DHBs they are located in to work towards national equity of access and the monitoring and reporting of this.
3. National and Regional Leads to consider how they refresh the format and agenda-setting for national and regional forums, to continually better meet the evolving and changing needs and the priorities of the workforce, for example sharing experiences and case studies to learn from each other, especially of sensitive or difficult situations that need a lot of discussion.
4. Work with all DHBs to ensure the services are supported with the required resources and tools including appropriate administration support and where required, reception functions, clinical space etc.
5. The Initiative to discuss experiences and clarify the process for and ability to see and/or work with whānau. This includes can whānau be seen on their own without the patient (note there appears to be varying views if this can, or even should be undertaken, based on the interpretation of the criteria and/or business of the service) and how to record whānau notes safely and securely. This includes for clinical safety.
6. The Ministry to provide support required to DHBs to ensure the Initiative is fully embedded and integrated into DHB services before it is devolved, and to ensure there is clear communication and understanding of use of funding expectations to DHBs.

Note: there is a belief by many interviewed that if the funds are not ring fenced, they will be used to bulk up traditional psychology and/or social work services within DHBs, and the Initiative will struggle and potentially be stopped

Appendix 1 References

Canadian Association of Psychosocial Oncology (2010) *Standards of psychosocial health services for persons with cancer and their families*.

Department of Health, State of Western Australia (2008) *Psycho-oncology model of care* (Government of Western Australia: Perth, Western Australia).

Howell, D., et al (2009) *A pan-Canadian clinical practice guideline: assessment of psychosocial health care needs of the adult cancer patient* (Toronto, Canada: Canadian Partnership Against Cancer (Cancer Journey Action Group) and Canadian Association of Psychosocial Oncology).

Luxford, Karen and Jane Fletcher (2006) 'Leading the way – best practice in psychosocial care for cancer patients', *Psycho-oncology* 34(1), March 2006.

National Breast Cancer Centre and the National Cancer Control Initiative (2003) *Clinical practice guidelines for the psychosocial care of adults with cancer* (National Health & Medical Research Council: Australia).

National Institute for Clinical Excellence (2001) *Improving supportive and palliative care for adults with cancer – the manual* (NICE: UK).

Neumann, Melanie et al (2009) 'Barriers to using psycho-oncology services: a qualitative research into the perspectives of users, their relatives, non-users, physicians, and nurses', *Supportive Care in Cancer* April 2011.

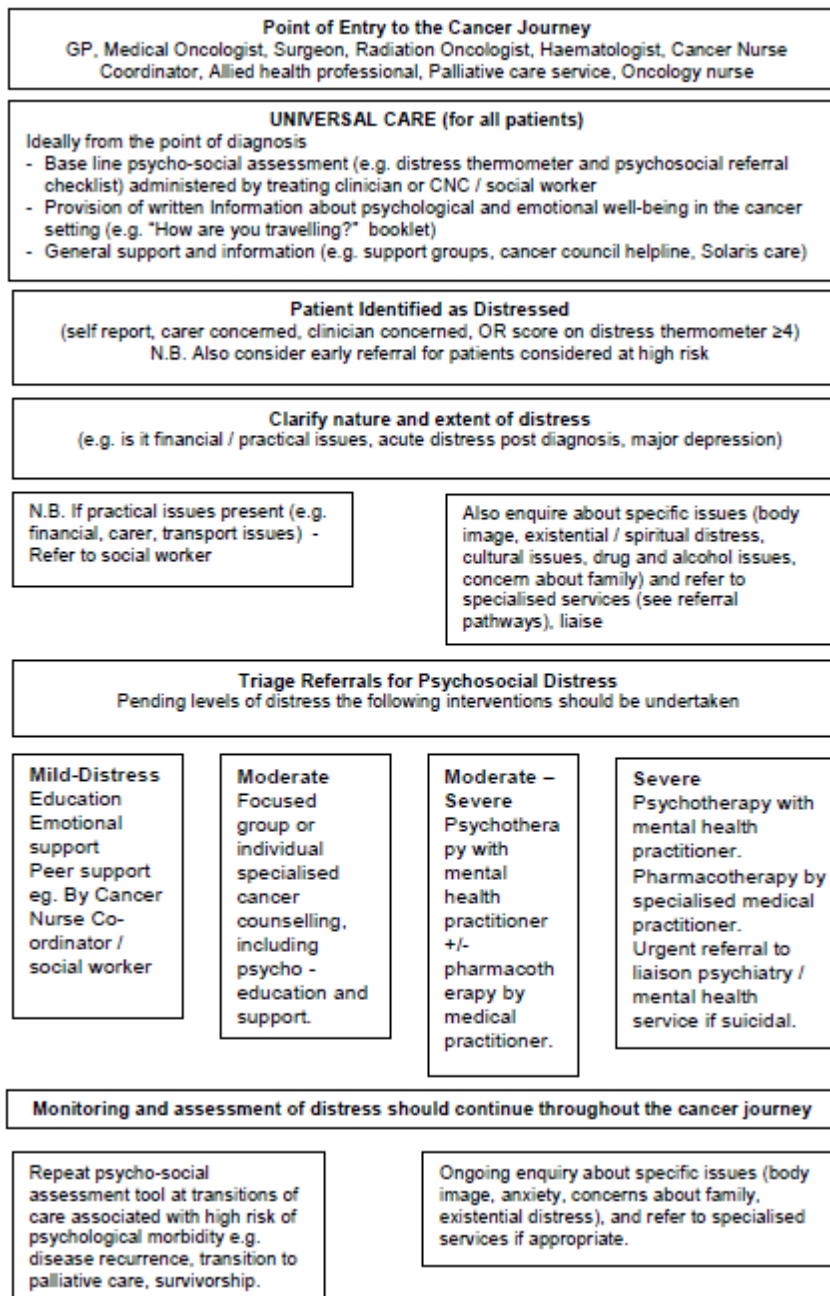
Rankin, Nicole M. et al (2011) 'Psychosocial oncology services in New South Wales', *Australian Health Review* 35 (156-63), 2011.

Shepherd, Louise et al (2008) 'Enhancing psychosocial care for people with cancer in rural communities: what can remote counselling offer?' *Australian Health Review* 32(3) August 2008.

Williams, Lauren K. and G. Bruce Mann (2009) 'The breast service psychosocial model of care project', *Australian Health Review* 33(4), November 2009.

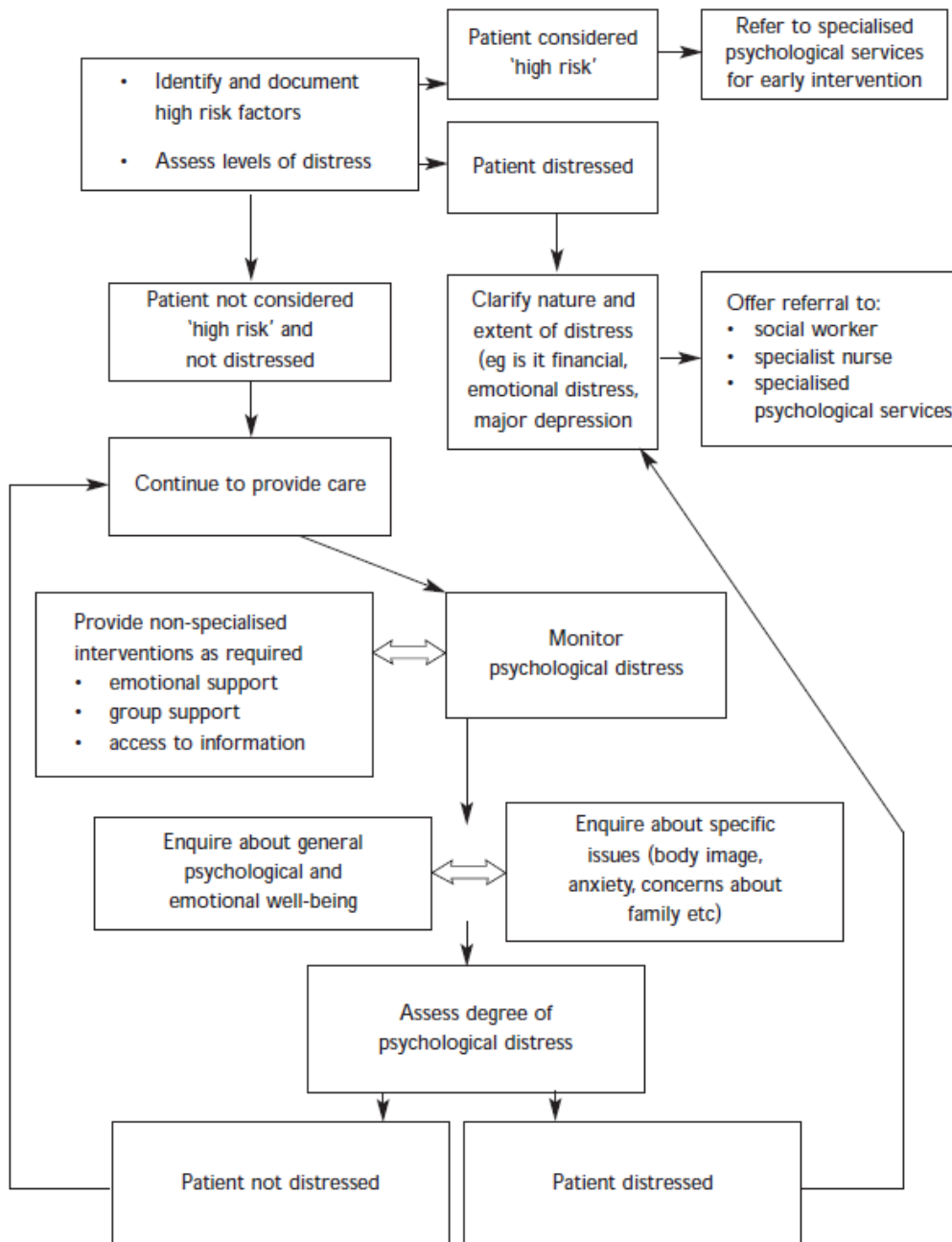
Appendix 2 Examples of patient referral pathways

Figure 29 Proposed patient pathway - Western Australia



Source: Department of Health, State of Western Australia (2008) *Psycho-oncology model of care* (Government of Western Australia: Perth, Western Australia). Adapted from Hutchison and Dunn (2006) and MBCC and NCCI (2003)

Figure 30 Summary of care and referral to psychological care



Source: National Breast Cancer Centre and the National Cancer Control Initiative (2003) *Clinical practice guidelines for the psychosocial care of adults with cancer* (National Health & Medical Research Council: Australia).