
Report prepared for the Ministry of Health

Interim Report Two: Evaluation of the Adult 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 ā 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 goes to 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 significant others – be it whānau, family, carers. This adds significant value to understanding how the services are affecting patients and their whānau.

We also wish to acknowledge the time and effort of the Initiative teams and individual staff 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. This is in addition to their time for interviews with us.

This evaluation and the learning from it would not be possible without the contributions of all these people.

Thank you.

Executive summary

This is an invaluable service for patients with some room for on-going service developments

We have now interviewed 63 patients and received 124 patient surveys, as well as interviewed 132 stakeholders and 52 workforce members. Consistent with our Interim Report One, we can report that by far the majority of feedback from patients and stakeholders is exceedingly positive of the impact the Initiative has.

However, as with any new service, once implementation has occurred and a formative evaluation like this is undertaken, areas for on-going development and improvements can be seen. This is a positive outcome for patients and staff alike and the purpose of such an evaluation.

This report in context and key activity this year

This is the second Interim Findings report of the Evaluation of the Adult Cancer Psychological and Social Support Initiative (the Initiative). The final report is due early 2019. The evaluation has been commissioned by the Ministry of Health to evaluate the Initiative.

The key activity by the evaluation team this year has included on-going:

- qualitative interviews: patients, a small number of whānau, Initiative staff and a sample of stakeholders
- a survey of patients (a rolling survey) and completion of a workforce survey; and
- document reviews and analysis of service referral data.

Interim findings update

The Services are invaluable to the majority of patients we heard from, but some room for on-going service developments

Over time, as the sample size and geographic locations of those having input has significantly increased from the first Interim report (March 2018) we are starting to see some variation in feedback of what services are achieving and how they are doing this. The majority of patients feel this is an invaluable service but more are saying they would like to have had it earlier and that their whānau members should be able to access it. A concern for us is the particularly low rate of Pacific volumes we have received (noting that we are dependent on workforce members gaining interview consents for us, and distributing the survey to their patients).

Services are working in variable ways, including in how some of the criteria in the Model of Care is being interpreted

Some of the variation is appropriate to local and individual patient and whānau situations, whereas others might require on-going discussion and more national and regional developments. This is a formative evaluation therefore we are looking for opportunities for development and improvements over time.

Some workforce members have explained that the variation in how various criteria of the Model of Care are interpreted relates to what other relevant supports or services are available in the local area, so they can more appropriately refer to them and take on other patients within the Initiative. Looking at wider supports was out of scope of the evaluation so we did not observe these.

Meeting cultural needs and service development is an on-going challenge

Although some services have tried very hard, there is still a lack of strong linkages between Māori health teams and services and Pacific health teams and services, both within DHBs and external, that is in the community. This is a work in progress but needs to continue to identify and address the needs of these whānau, hapu and iwi and Pacific Island fono. These are already noted as priority cohorts in the Model of Care for the service.

There is a large variety of therapeutic and practical aspects of the service that make huge differences in people's lives

Patients reported a large range of aspects of therapeutic and practical care that made a big difference to their lives. This variety and flexibility is vital in working with people on their own needs and where they are at in their lives with cancer, and other life experiences.

There are various gaps across the service that are common including which potential referrers are educated about the service

Gaps include aspects that hadn't originally been identified as a priority such as survivorship and transitions. Having said that, some services work differently with people in these circumstances, than others. It will be important to explore these differences and national consistency to ensure equity, especially as demand increases.

Workforce can be isolated in some areas where there is only one discipline, part time

As with most health services, there are limited resources to meet emerging and growing demand. This service is no exception. The way the resource has been allocated has meant that in some smaller DHBs there are singular and part time individuals working in the service. This means there is not a joint working of psychological and social work disciplines and a major challenge to ensure coverage when people are on planned or unplanned leave. The future opportunities lend themselves to exploring models that can support a more regional or broader approach to supporting these areas.

DHB support for the Initiative, both practical and at service level, varies greatly

DHBs were required to implement and support these services and as such have a contract line item with the Ministry of Health for this. However DHBs have interpreted and enacted this quite differently across the country. Examples include some services have dedicated office and counselling rooms, some don't. Other variables include tools (lap tops, phones etc.), IT systems data support etc. Most report however they can book pool cars relatively easily.

There is a great deal of concern from most services that DHBs will quickly erode these services over time due to a variety of competing DHB demands. Our advice is that there needs to be some cost benefit analysis undertaken as it is possible there is significant cost

benefit for DHBs keeping, and even growing, these services, not just in cancer but in wider complex health issues such as high and complex, long term health needs.

Interim conclusions and recommendations

The two disciplines of psychology and social work are greatly benefiting patients, and the two are working more closely together than we observed for Interim Report One.

Following are our interim recommendations. We would appreciate discussion on these with you in preparation for completing the evaluation and furnishing our final independent report.

1. **Definitions:** clarify definition and appropriate use of ‘front of pathway’, to create an equitable service opportunity for patients. It is understood that different people will be ready for supports at varying time, but to clarify the service approach may be useful. The other key definition that has caused discussion and challenges is ‘rural’. What is rural and when does living in a town or city but being isolated count? We recommend that this merits further discussion and if possible clarification.

Importantly in clarifying definitions and service access criteria and scope is when and how whānau are supported (see below for separate recommendation). We note there has been some clarification on this but practice still varies greatly.

2. **Mix of the two disciplines:** continue with the mix of psychology and social work as reports are this is working very well. Clarify which disciplines can take on the Regional and / or National Lead roles.
3. **Māori and Pacific needs and approaches:** continue to plan for and build a holistic, inclusive and Whānau Ora approach to service delivery. This needs to include collaboration with both Māori and Pacific health teams and Iwi/ Māori health as well as Pacific providers.
4. **Equity:** consider what Recommendations 1 and 3 mean for equity of access and supports from the Initiative.¹
5. **Supporting small FTE and isolated workforce:** investigate models of how to further support those working in relative isolation and /or on their own in a DHB in the Initiative and how to support the service when that individual goes on leave (planned or unplanned)
6. **Continue to work with DHBs to access appropriate supports:** we understand the contracts between the Ministry and DHBs have just been renewed for two years and that was an opportunity to try and address some of the gaps in support needs. We recommend this is an on-going discussion and relationship with all DHBs, especially from the National and Regional Lead levels to ensure staff are supported appropriately in their roles e.g. IT, administration where needed and environment and clinical space

¹ Note: Outcomes are not being measured yet but a model is being worked on.

7. **Continue to clarify respective roles of National and Regional Leads across the Initiative:** Continue to work together to focus on service enhancements and supporting the teams
8. **Consistency of data:** Further work to improve consistency of data collection (noting this can be a challenge across DHBs), and fill gaps – suggested priorities to focus on:
 - ensuring all services collect basic demographics: age, gender, ethnicity, tumour stream
 - reason for acceptance into the service (i.e., what Initiative criteria they meet)
 - distinguishing between referrals in and acceptances (so all services can tell how many patients seen by the Initiative)
 - consistent categorisation, including of tumour stream, point in pathway and criteria met (consider drop downs)
9. **Funding and managing future demand:** The Ministry should consider retaining centralised funding of the Initiative to avoid the inherent risks of devolution of such a relatively small amount of funds to each DHB. Increasing demand is a risk as more referrers learn of the benefits for their patients. We also believe the service is so valuable and could reach many more people in the target populations that increased funding levels should be considered in the out years. This will require on-going planning and development of the right skilled workforce and potentially tighter targeting / prioritisation to manage demand.
10. **Model of care:** for various reasons outside of the Initiative’s control there was a delay in finalising and circulating a Model of Care. We note this has required the services to develop as they saw right for them. But would recommend that where ever possible for other new Initiatives in the future that a priority is to get a consistent Model of Care and National Minimum Data set established up front.
11. **Meeting unmet need in other areas:** The Ministry should consider extending this service beyond its front-of-pathway focus to other areas, in particular survivorship.

1. Objectives and goals of the evaluation

The evaluation has a wide range of objectives and goals that the Ministry and Sapere detailed and agreed in the original Evaluation Plan.

1.1 Objectives and goals have been agreed in the original Evaluation Plan

The objective of the evaluation 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; and
- identifying service improvements and recommending changes that could improve the overall outcomes of the Initiative.

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 and 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;
- 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; and
- 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 (e.g., 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; and²
- impact on the lives of people with cancer and whānau who use the service.

This is the second of three major reports in the evaluation of the Adult Cancer Psychological and Social Support Initiative. It builds on the first Interim report, dated March 2018 and focuses on the learning we have seen since then from additional interviews and receipt of surveys from staff and patients. The third and final report is due in January 2019.

Interim Report One focussed on the initiation of the initiative, interviews and interim findings to date. This report takes a more in-depth look at some of the successes and gaps we have seen, based on our next level of inputs and interim findings.

² From the Model of care: Recommendations for improving access to psychological and social care for Māori include:

- screening for need from the earliest stage of diagnosis and appropriate onward referral, with screening repeated where unmet need is suspected (noting that distress screening has not been mandated by the Ministry as part of this initiative)
- assessment of the level of whānau support from the earliest stage of diagnosis, and facilitating whānau engagement with health services
- space for the role of whānau to complement the delivery of specialist psychological and social cancer care
- use of the Māori model of health Te Whare Tapa Whā (Durie, 1982) to inform practice.

Our focus has been to ensure we are addressing the key evaluation objectives. The objective of the evaluation 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; and
- identifying service improvements and recommending changes that could improve the overall outcomes of the Initiative.

The final report due in January 2019 will also focus on the process part of the evaluation, which is how the Initiative was implemented and has been supported over time.

1.2 Key activity since December 2017

Our evaluation activities have continued in line with our evaluation plan that was agreed with the Ministry of Health. Work since our first Interim Report has involved the following.

1.2.1 Qualitative interviews

We were tasked with exploring service implementation and delivery across all 20 DHBs. One DHB area, West Coast, is covered by services based in Canterbury. This means there is a total of 19 individual services (though MidCentral operates as two distinct but linked services, as per a pre-existing arrangement and the 3DHB (Capital and Coast, Hutt and Wairarapa DHBs) services operate as a regional team).

Initially from the information in the original Request for Information documentation we expected to see one national service, however what we have discovered is 19 separate and individual services, with various nuances and practices in how they work, prioritise work and volumes and collect data.

Since our last report in March 2018, we have conducted face-to-face interviews with workforce, stakeholders and patients in Capital & Coast, Canterbury and Southern. And we have covered the following sites by phone:

- Taranaki;
- Hawke's Bay;
- Tairāwhiti;
- Hutt;
- Wairarapa;
- Nelson-Marlborough; and
- South Canterbury.

We have a few telephone interviews to conclude in some of these sites, leaving us with one more (face-to-face) site visit to complete (Bay of Plenty).

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.

1.2.2 Workforce and stakeholder interviews

As at 27 June 2018 (the cut-off date for this interim Report Two for analysis purposes), we had completed interviews with 52 workforce members and 132 stakeholders. A breakdown of the stakeholder interviews is provided in the following table. We were reliant on individual services providing us with the names and contact details of their key stakeholders.

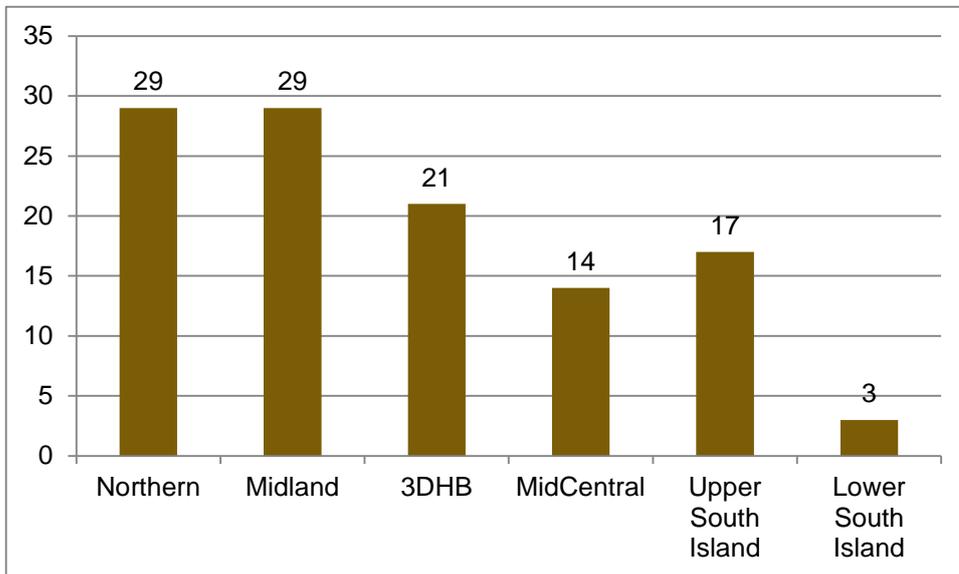
Overall, we were provided with very few Māori and Pacific stakeholders, and these from just three DHBs. They comprised:

- Māori Health Unit Director;
- Pacific Health Unit Director;
- Māori Liaison Officer;
- CNS Patient Navigator (Māori and Pacific); and
- three representatives from a community-based iwi provider.

We had also had Māori and Pacific stakeholder names from one other DHB and did not hear back from the identified stakeholders. We will continue to endeavour to achieve this. We also met with the National Maori Cancer Leadership Group, Hei Ahuru Mowai, to provide an update and seek input. This was not a formal stakeholder interview, but a part of Sapere processes in ensuring additional consultation and collaboration and a two way sharing of information. We contacted Le Va, for a Pacific voice but at this stage they felt they didn't have anything to add. We will follow up again in the next tranche of work.

A breakdown of stakeholder interviews by Initiative region is provided below.

Figure 1 Stakeholder interviews by Initiative region



Source: Sapere stakeholder interviews

1.2.3 Patient interviews

As at 28 June 2018 we had completed 63 interviews with patients (n=61) and/or whānau (n=6). Eighteen were face-to-face and 45 were telephone interviews. Nineteen (30 per cent) were conducted by a Māori interviewer (12 Māori and one Pacific patient). The following table shows the breakdown of patient characteristics. We have recorded these for patients themselves (as opposed to whānau members who spoke on their behalf), so the figures total 63. Note that two DHB have yet to provide us with any consents to speak with patients. We continue to follow up on these.

Table 1 Break down of patient interviewees

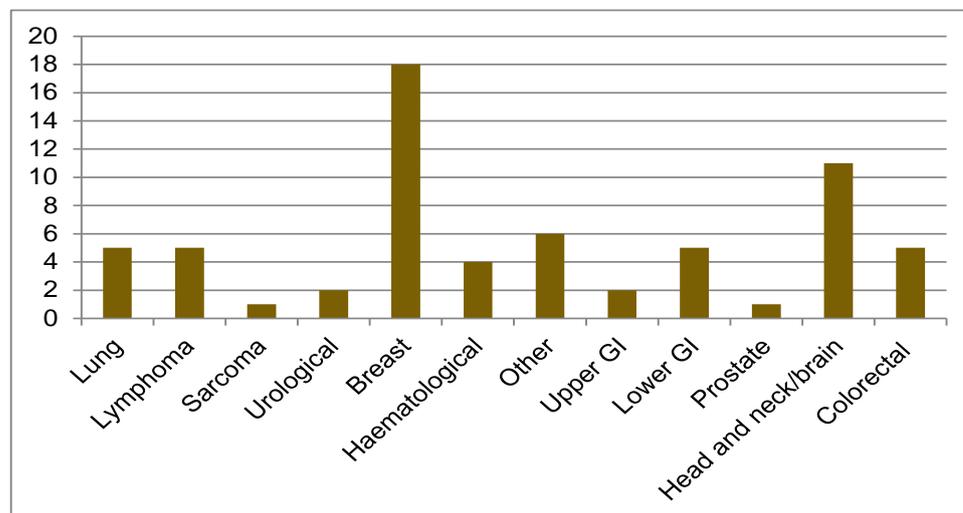
	Patient #s	Proportion of total
Māori	19	30%
Pacific	2	3%
Rural ³	26	41%
Male	21	33%
Female	42	66%
Total	63	**

**Note this column doesn't add to 100% as interviewees were recorded in multiple categories.

Source: Sapere interviews

One of the criteria for the Initiative is tumour streams that might cause greater distress than others, though there is some variable agreement on what these tumour streams are. Many staff talked to us of levels of distress being just as important as some of the tumour streams. The following table shows a breakdown of interviews by tumour streams patients were recorded as having.

Figure 2 Patient interviews by tumour stream

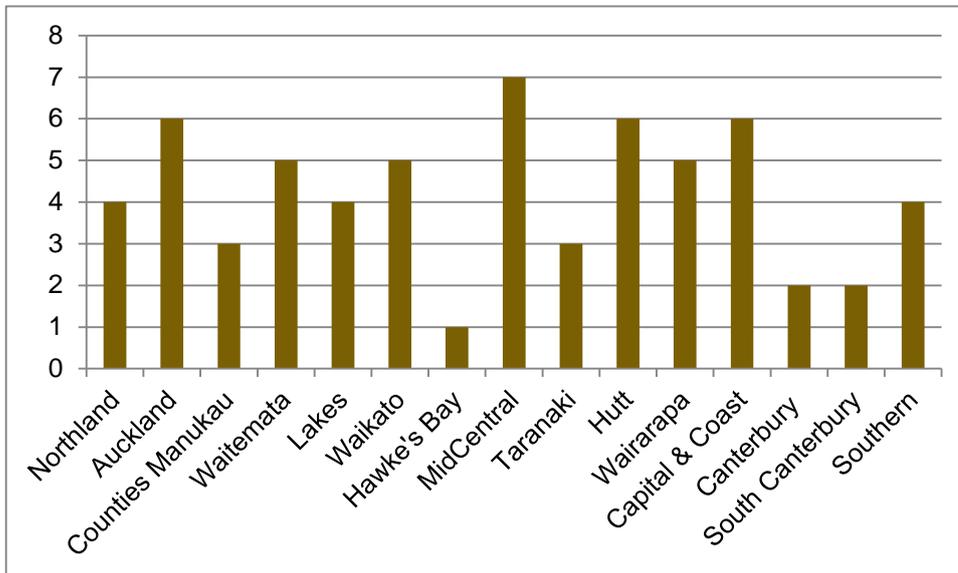


Source: Sapere patient interviews

³ There is no consistent definition of rural. So we relied on the definition being used by the staff member gaining consent.

Figure 3 shows the patient interviews by DHB district. These were a mix of face-to-face or phone depending on the patient choice.

Figure 3 Patient interviews by DHB



Source: Sapere patient interviews

1.2.4 Rolling patient survey continued

We have now provided the patient survey materials to all services. As at 2 July 2018, we have received 124 responses, with breakdowns as follows. Detailed findings from the survey are presented in Appendix 1. The survey will run till the end of September 2018 and we follow up with those Districts with current low volumes. In general the timing of the survey launch at sites was initially related to our visiting timetable however as time went on sites made their own decisions when to start surveying so we cannot determine exact dates surveys started from each area.

Table 2 Patient survey responses by region

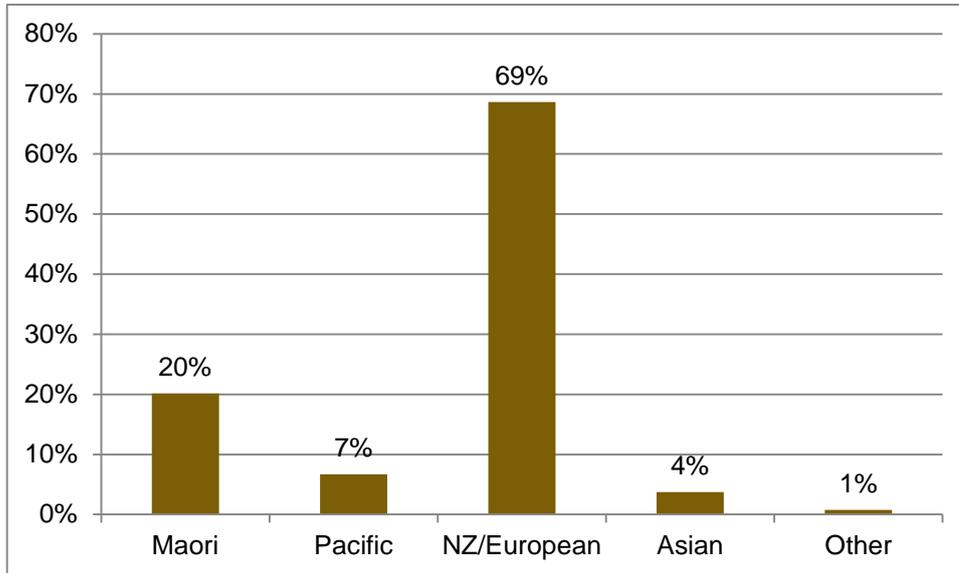
Initiative region	# responses	% responses
Northern	70	56%
Midland	17	14%
MidCentral	12	10%
3DHB	4	3%
Upper South Island	20	16%
Lower South Island	1	1%
Total	124	100%

Source: Sapere patient survey

Figure 4 Ethnicity of respondents

The ethnicity of respondents were predominantly NZ European.

Percentage of respondents (n=124)



Source: Sapere patient survey. Note respondents could select more than one ethnicity, so figures total to >100 per cent.

1.2.5 First workforce survey completed

The workforce survey was sent in seven tranches over March 2017 to March 2018 as we progressed with our field work. In our first Interim Report, we reported on the findings from the Northern region only. This second report includes the results from all sites to date. We received 48 responses in total (an 81 per cent response rate). The survey form is contained in Appendix 2 and detailed findings are presented in Appendix 3.

1.2.6 Document review and referrals data analysis

We have now received documentation from 16 services and data from all services. The detail of the quantitative analysis we were able to do with the available data is set out in Appendix 4. This includes sources and dates of referrals, some demographics and point in the treatment pathway.

2. Interim findings update

At this point in the evaluation, we feel we have a sufficient evidence base to address all the evaluation objectives and questions. In this section we summarise the evidence and discussion our conclusions and recommendations.

2.1 Although still significantly positive, some emerging mixed patient and stakeholder experiences are emerging

Overall the feedback on the Initiative is extremely highly positive, with some exceptions. We indicate that some of the exceptions are about where improvements can be made, for example referral processes and data collection, and others are about patient outcomes based on personality match or gaps in services – both the Initiative and other surrounding resources.

In summary the feedback is:

- this is a highly valuable service making significant differences to people's lives and health wellbeing
- there is not enough of it
- there are gaps, e.g. survivorship; and
- don't take it away.

2.2 National consistency has not been achieved; some of which is appropriate for local needs and some a challenge for equity

Local flexibility and some variation is appropriate, in order to meet local needs and take account of pre-existing and / or complementary or synergistic services. There is a national Model of Care document that, for various reasons, was not finalised until well into implementation and some services had already fully established themselves and there is variation in interpretation of some of the criteria and content of the service. There are various Question and Answer updates released via the National Lead and Ministry to try and clarify some of the variances and create consistency and clarity on scope of the Initiative. However what we observed is some variations in how model of care is applied in terms of:

- front of pathway: how this is interpreted and when it is applied, for example high suspicion is not included in every service

- whether and how whānau are included: either with the patient and / or on their own; also which whānau might be able to access the Initiative supports, e.g. spouse, significant other, siblings, parents, children of the person with cancer
- specifically a number of Māori and non-Māori referred to that it would have been good to have tamariki (children) able to access supports too⁴
- who are educated to be referrers: some focus on primary care and others exclude them for fear of volume explosion.
- interpretation of criteria/target populations
 - varying agreement on which tumour streams to target (sometimes related to working with willing specialities in the local area as a start), with at least one service utilising their own tumour stream definitions and not the national ones
 - no consistent definition of rural – Initiative staff have asked is ‘isolation’ actually more appropriate? For example geographic isolation being distinct from social isolation/connectedness (e.g., due to lack of transport, no knowledge or support of neighbours even in towns and cities), as rural/remote areas also have lack of support services; and
 - triage and prioritisation; and
 - definition of high distress.

2.3 Meeting cultural needs an on-going challenge

At an individual level, Māori respondents stated that they felt the service provided was meaningful to them as a Māori person. Overall, Māori patients valued the opportunity to talk and process issues related to their cancer. Many commented that it was useful to have someone outside of their immediate whānau to talk with. Māori patients felt listened to and valued. There were comments around the value of non-Māori staff using Māori words, in some instances that fact that the staff member was Māori, and in other instances incorporating acknowledgement of spirituality were noted by different patients.

It was also evident that there was variance in the inclusion of whānau or not. It was noted a number of couples were offered joint sessions. However a number of Māori patients noted that it would have been especially valuable if sessions/ support had also been offered to their tamariki (children) who they felt were equally affected by cancer.

In relation to the evaluation objectives of identifying whether the Initiative is meeting the needs of Māori, it must be noted that Māori health is not an individual issue. It is holistic and inclusive of whānau, hapu and iwi. In many instances, Māori community organisations and workers become a type of whānau, often referred to as Kaupapa whānau. Based on the evaluation at this stage, it would appear there is little engagement with both whānau and kaupapa whānau. There is a missing link which is the inclusion of Māori whānau and Māori community organisations. Many services also reported ongoing efforts and desire to achieve

⁴ Very few noted they were seeing children, and if they were it was part of a whānau model. Many said they referred children to other services, for example school councillors, where it seems there is varying success for the children.

strong relationships with local Maori groups and some have started achieving positive outcomes. Often it was reported that building these relationships can take longer than expected due to the competing demands on Maori teams in DHBs and community. Other services noted they need to make more effort in this area.

2.3.1 How, and if, whānau are included is varied

We have already noted the range of how or if whānau are included and assistance is available to them varies. It ranged from not at all, to being able to be seen on their own through to only being able to be seen with the patient as the service is about the patient. Some services will see spouses and others not. Some will see wider whānau members such as siblings, grandparents and parents and children of the person who has cancer.

There have been some reports of not wanting to include whānau due to not believing that is required in the Model of Care, for managing demand (prioritisation) and others of not having a clinical notes recording system that they can put clinical notes in to confidentially. It has tried to be clarified that whānau are part of the model of care.

2.3.2 Definition of front of pathway is varied

What services are interpreting as front of pathway criteria is also varied. The variation we have seen includes:

- only before treatment starts, including high suspicion of cancer;
- only after treatment starts;
- continue when treatment ends for some; and
- 'yes or no' at a re-diagnosis or high stress transitions.

Some consider all of the above to be appropriate depending on individual needs and / or distress levels. Others base their decisions on when they will see people on what other services and supports are available locally that they can refer to instead of needing to see them in the Initiative. This networking is important and can support people and whānau in different ways.

Some of this we believe is about managing demand and others are about interpretation of the intent of the Initiative, and / or clinical judgement based on patient needs and the importance of continuity.

We expect as the services become better known and demand increases these issues will become even more varied as increasing demand management initiatives are required to be put in place, if there are no additional funds for FTEs.

2.3.3 Access, waiting times, prioritisation and equity challenges

An observation is that access is quite varied in terms of who the services are educating to be referrers (i.e. marketing, referral criteria and referral processes) and therefore this impacts on who can access the service and when. All services appear to be working with the Cancer Clinical Nurse Specialists and / or Coordinators and oncology departments, however some are working with primary care and mental health services, and others are not.

Demand is variable in terms of meeting full availability of the Initiative yet, however all services seem very conscious that this is likely to grow. Therefore by default an ‘unconscious’ prioritisation for service may be occurring in some of the services we have seen. Some DHBs require that the service has ‘no waiting lists’ and most others say they don’t have a waiting list. At least one service stops referrals if they are too busy, and those with only one practitioner have to stop referrals if they are on leave, unwell, etc.

We are puzzled as to how this equates to the intent of the Initiative for a high distress front of pathway service and would recommend that there is national discussion on this and how it impacts on equity of access to the services.

2.3.4 Data collection is variable and in some places patchy

We expected to find a national service with a national minimum data set that we could pick up and analyse. However this has not been the case, as the development of a national dataset occurred sometime after services began implementation. As a result, each service is collecting different data. There is no single variable that all services are gathering, which has limited the extent to which we have been able to aggregate data.

2.4 Therapeutic and practical aspects of the service that make a positive difference

We asked interviewees what made the most positive difference to people that the Initiative could deliver. Although the list was long there were common themes and these are listed in the sections below. In addition we have added a few salient quotes to show the value and importance of the service to people.

‘She was genuinely interested in ME. Not just my tumour, but ME!’

‘I really don’t think [husband’s name] would be alive today without [name]. She really got him through all this.’

‘She understood cancer. It is a dedicated cancer service. She can prepare me for the next parts. She can really relate to what I am experiencing and what will come next. That is so helpful.’

‘It is a life saver. It makes me fairer on myself – which helps my wellbeing.’

‘How could you relate satisfaction to a service like this. This service is MAGIC!’

Patients and whānau that had been seen, as well as some stakeholders could clearly identify very practical and therapeutic aspects of the Initiative service that make a significant difference to how they cope and can live with, and after, their cancer and treatments. We have summarised these in to the main themes below.

2.4.1 Time and place of appointment to suit the patient is important

Many people commented on how valuable it was that the Initiative staff person could see them either at their home or in the hospital when they were having treatment. Some had to

travel to the service to their ‘clinic’ rooms and mostly people felt if that was necessary then they could do this. The option of home visits was greatly valued by all we spoke to who had had that option, particularly Māori and those living rurally.

We canvassed with some people the option of using telehealth for those who are more remote. For some they embraced the idea with enthusiasm and for others they felt it was too sensitive a topic to do over a screen and would prefer to continue having personal relationships / meetings, even if it meant less frequency. This discussion may need to take greater traction as demand grows. However home visits are very, very highly regarded by the patients and whānau where they do occur. For some who have become semi-recluse it is the only solution for them, e.g. loss of face from face and neck cancer. Extreme care must be taken when considering telehealth type options and should be on a case by case basis. For example for Māori kanohi ki te kanohi (face to face) is often of most value and important culturally.

The other most common reflection on the environment from patients was that the rooms were often too ‘clinical’ and not a relaxing environment conducive to counselling and relaxing.

‘The rooms are so cold and sterile. Even the staff don’t like working in them.’

‘The room I see her in has no windows and feels like a bunker underground. Not very relaxing.’

‘They don’t have their own rooms. Every time I go there I have to find a different room. Sometimes it isn’t even at the hospital. It can be very stressful.’

‘Communicating with me about when and where she could see me was so important. That way I could fit it around appointments and family needs. She would follow up closer to the time to make sure that was still the right place and time for me – in case things had changed.’

‘Actually they need more flexible hours – evenings and weekends. I don’t mean they need to work longer or more hours, but more flexibility to fit with family life and work would be so helpful.’

Conversely there were some positive comments about the environment.

‘The room was lovely – couches, comfortable chairs, natural light. It made you feel good before you even started.’

2.4.2 On-going communication and follow up highly valued

Having one of the team follow up by text or phone just to say hello and to see how the person is doing was greatly valued. Texting to remind people of upcoming appointments was also greatly valued. People feeling that someone was there for them, like a ‘backup’, was enormous in their self-reported feelings of wellbeing and healing. People felt that not being formally ‘discharged’ meant they could ring or text at any time if they needed something or had a question. Although not many had done this, knowing there was a backup was extremely important to people. People appeared to respect how busy the staff were but their value outweighed this in knowing they could contact them if necessary.

‘Don’t let her go – having her there for follow up is invaluable.’

‘Not only follow ups but on-going open communication was so reassuring.’

'Going home after all that treatment, having all those people around, and then being on my own. It was so, so scary. I couldn't sleep for panic attacks. But follow up from [name] on a regular basis gave me reassurance over time.'

2.4.3 A range of other examples of therapeutic and practical assistance were given

There was a wide range of therapeutic and practical examples of solutions of assistance for people that were greatly appreciated and made a significant difference to their wellbeing and coping mechanisms. In no particular order these are:

- coping mechanisms and strategies: mainly these centered around reducing panic attacks, enabling people to sleep more and function in significant relationships
- starting and adhering to treatment: many people told us that they do not believe they would have had the treatment if the Initiative service wasn't there assisting them with information and support
- grief and anger: dealing with the shock, grief and anger about being told they have cancer, and foreseeing the major changes coming in their life, at least in the short to medium term
- food: food parcels, vouchers, special drinking water
- transport and accommodation assistance: when having to travel from out of town for treatment and / or specialist appointments. For some families the cost was prohibitive
- mobility cards for parking in town: helping people access the CCS Disability Action run mobility cards for disabled parking permits
- information: giving out of pamphlets, photocopied information and info direct from the internet. Having this explained and then left with people to read and re-read when they felt they could absorb it, was felt as most helpful
- housing: assisting people to find housing and / or pay for the housing especially if they have to give up employment
- Work and Income, IRD and other Government Agencies: helping people with forms, explaining what is available and how to access it. For some people the Initiative staff attending meetings or appointments e.g. at work and income, with them was invaluable
- financial assistance: from a range of sources, most frequently Work and Income but also other vouchers and other agencies, e.g. the Cancer Society
- communication and education about 'what was going on'. For example what to expect next, why this treatment came before the next one, how they worked together etc.
- advocacy, including with clinicians and government agencies such as Work and Income.
- physical and mindfulness exercises and strategies: to help people cope with whatever their fears and anxieties were. This included 'tools' and strategies, including to reduce 'rage'
- sorting legal issues: arranging 'Enduring Power of Eternity (EPA)', financial arrangements etc., 'Living Life Plans', Advanced Care Plans'
- practical reminders and support for attending treatment and other appointments: explaining what is coming next and why, text or phone reminders about the next

appointment, supporting people in person for some appointments. Also sorting other related appointments and arranging them where necessary, e.g. ophthalmology

- practical housing solutions: arranging for the NZ Fire Service to install smoke alarms, arranging for the Sustainability Trust to help with curtaining to keep the house warm
- referrals and sorting other health appointments: several people noted the importance of confidentiality and yet people in the Initiative being able to write ‘respectful’ letters to their GP to explain the circumstances’. The next most commonly reported referral was to arrange district nursing and other community based services, e.g. physiotherapy, dieticians, and occupational therapists
- “normal”: we cannot emphasise the importance people felt about this word; being told their feelings and reactions were normal, that what they were experiencing was generally part of the 5 stage Grief Process and that this will pass was so important to many, many people

‘I was told this is normal. I don’t have to be ‘perfect’ all the time. It is OK and normal to spend a day crying.’

‘I thought I was going mad; losing my mind. But then she told me that it was normal to be scared to sleep, to feel the level of fear I was experiencing. That helped me so much.’

‘I crashed and she said, “Good, this is normal and I was expecting this”. That made me feel normal and helped so much.’

- various actual practical activities like: physical exercises, mindfulness, adult colouring in books, watching YouTube clips on certain topics, being given tools to deal with ‘difficult’ people and / or situations

‘Overall she just GETS THINGS DONE. I am so grateful. It helps my wellbeing.’

But people of all cultures were clear it would have been beneficial to have the service available to their family and whānau.

‘I wanted it [the service] for my daughter as she is not coping, but they sent her to the school counsellor. That did not help at all.’

‘Would have liked the service for my spouse and the kids. They are suffering as much as I am.’

2.4.4 ‘Advertising’ and promoting the service

When asked was there anything else people wanted to say about the service, patients, whānau and stakeholders alike, most wanted the service to remain as it was so valuable, grow in size so that more people could access it. Many mentioned how important it is to advertise and promote the service more so people knew about it and more could benefit from it, e.g. GPs, self-referrals, mental health services. Notably a number of Māori patients and Māori stakeholders definitely felt promoting a higher profile of the service across a range of other services and supports was very important.

However the converse conversation we heard about promotion was mainly from many of the Initiative staff and their most frequent referrers. There were feelings that if they advertised and promoted the service more widely they would not be able to cope with the potential volumes. So our conclusion is that limited promotion and not educating certain groups of potential referrers, e.g. Māori Health Services, Pacific Health, general practice, is one way of managing volume and by default prioritising. However it does not address equity, which is a goal of the Initiative and NZ Health services per se.

We heard many reports that the Initiative may be under-servicing the target populations. One of the implications of this is that the Initiative needs more FTEs, which might be a challenge in the immediate term as the workforce needs to be grown overall. We would recommend a strategic approach to growing the desired workforce, in both type e.g. Māori and Pacific, and volume. This may also involve prioritising Māori and Pacific with a targeted approach.

In addition in some areas we also would recommend that the Initiative further targets the priority populations as noted in the contract and the Model of Care.

2.5 Gaps in the service were relatively common across the interviews

When asked what could be improved for the future, or what gaps are there in the service the most common themes were:

- survivorship: many spoke of the despair and loneliness once people go home from treatment and are dealing with survivorship. It was reported that for a lot of people that is the highest distress time as it also includes transition phases and facing what the future might be like, and how changed their life might be
- being able to work with whānau: due to the variance in how this is being done and interpreted this was seen as a major issue that needs prompt resolution. This may also require a philosophical change in perspective of service delivery whereby for Māori and Pacific, whānau is placed at the centre rather than the individual.
- second or re-diagnosis: many reported that this is one of the hardest time for people but that it is not technically ‘front of pathway’ so some services won’t pick these people up, yet others do
- links with and working with Māori Health teams and Pacific Health teams in addition to iwi and Māori in the community are a gap that most recognised should be addressed. Some services are actively trying to address this while others told us they haven’t really started yet.

2.6 Workforce

As already noted we both interviewed and surveyed the Initiative workforce. The following sections reflect the key themes we noted.

2.6.1 Size of team

We noted that for those working in relative isolation as Initiative team members, e.g. one or less FTE in a single DHB, it can be hard and isolating. Most reported having good supervision. There is also the issue of cover and continuity for patients when staff go on planned or unplanned (e.g. sick) leave.

Co-location of staff with each other is valued although not always possible due to the space the DHB has allocated the teams. Co-location relates to both Initiative team members and with other colleagues, such as members of oncology team, the Cancer Nurse Specialists or Cancer Nurse Coordinators.

'I'm working on my own and getting too many referrals. Feel under-valued and unsupported.'

'It is difficult when I go on leave as there is no cover for patients.'

2.6.2 Meeting ethnicity needs is a challenge and work in progress

As discussed above, feedback from Māori patients and stakeholders was that service delivery by Māori workforce members is valued and important, while a few others said that if the staff member was professional and highly respectful of them and their needs then ethnicity of the staff member was not deemed as important.

In some instances, Māori patients were offered the support of Māori kaiawhina roles within the hospital and this was viewed as meeting other cultural needs. At the time we conducted our workforce survey, we found that the workforce was predominantly New Zealand European/pākehā. Six respondents to our survey (13 per cent) identified as Māori, and none identified as Pacific (see Figure 12 in Appendix 3). This partly reflects the limited existing Māori and Pacific workforce – data from 2017 shows that fewer than four per cent of psychologists in New Zealand are Māori and fewer than one per cent are Pacific (we do not have commensurable data for Social Workers).⁵

Anecdotally we have heard that the Māori and Pacific workforce numbers are growing and we will re-test this before our final report in 2019. Attracting more Māori and Pacific staff is more likely to occur if Cancer Psycho-Social service delivery works in a more inclusive and holistic manner such as the Whānau Ora philosophy and practical approach that is currently being utilised in other sectors.

2.6.3 Need for greater support from DHBs

We continued to see huge variance in how DHBs support and embrace the Initiative as a service. We saw what we believe to be inefficiencies and inappropriate use of specialist clinical time where for example, there was a lack of DHB IT support, resources and tools. This included access to clinical rooms. No one reported difficulty in accessing DHB pool cars for community access or home visits.

Many staff relayed to us their fears that if the funds for the Initiative were devolved from the centralised pool at the Ministry of Health to individual DHBs, the funds would be eroded over time, and the service would not remain intact. Some felt this was because some DHB managers didn't recognise or understand the service, or the importance of the service and therefore didn't acknowledge the great value it has in people's lives.

Our assessment is that it might be useful to undertake a simple cost benefit analysis from a wider health system / DHB view, and even an economic societal view, e.g. employment rates of those who do receive psychosocial and social supports. For example we have heard a lot of anecdotal reports about the reduction in DNAs for treatment for those who receive support and services from the Initiative, and the ability to work, even part time for some.

⁵ Ethnicity of practitioners who hold a current practising certificate; data from New Zealand Psychologists Board database.

On a positive note, we heard from some stakeholder interviews, notably Cancer Teams in some DHBs, that having the Initiative available for their patients had freed them up to undertake their core cancer work. At least one DHB noted it had helped them improve their Faster Cancer Treatment (FCT) times.

2.7 Traffic light summary of interim findings based on the evaluation objectives

The following table serves to provide a quick overview of where we assess the Initiative is against the evaluation objectives set in the Evaluation Plan agreed between the Ministry and Sapere.

Table 3 Traffic light summary of interim findings based on the evaluation objectives

Evaluation objectives	Interim findings	Traffic light status for the Initiative from the evaluation observations
<p>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</p>	<p>Most services do not assess this in a formal manner. As far as we can tell two services do a pre and post distress score and two services do satisfaction surveys. Other services are waiting for the evaluation to be completed and then will start their own satisfaction surveys – they don't want to double up and make it onerous for the patients. We have gathered qualitative information on the fields required.</p>	<p>Orange</p>
<p>Determining the impact of the initiative and the impact that the roles have on (self-reported) patient outcomes</p>	<p>Overwhelmingly, with very few exceptions, self-reported feedback from those who took up the service has been extremely positive. The few instances where it has not been so positive it appears to have been personality challenges between the therapist and the patient.</p>	<p>Green</p>
<p>Identifying whether the needs of Māori, Pacific and rural people with cancer are being met by the new roles and service</p>	<p>Individual feedback from Māori patients is that the Initiative is meeting their needs. However it is highly variable across all services whether whānau are offered supports from the Initiative or not. Which does not therefore take a whānau ora approach to working with Māori.</p> <p>We received very few Māori and Pacific stakeholder names for interviewing, which we can't determine if this is due to lack of people accessing the service or declining to give consent. When we interviewed Initiative staff many felt they needed to improve their reach to Māori and Pacific communities, health services and whānau. There is a lot more work to be done regarding meeting the needs of Māori and Pacific and rural people based on the Model of Care. Some of this is well underway but takes time and many services are either making efforts or planning to, as they are aware of the gap.</p>	<p>Orange</p>

Evaluation objectives	Interim findings	Traffic light status for the Initiative from the evaluation observations
Identifying service improvements and recommending changes that could improve the overall outcomes of the Initiative	Due to the variability of the services across the DHBs there is room for improvements and increased national consistency without taking away local innovations.	Orange

Process Evaluation Questions

Process evaluation relates to: Implementation of the Initiative - did the way the Initiative was implemented enable the service objectives to be met. The following table summarises our findings.

Table 4 Process evaluation questions and interim findings

Question	Interim findings	Traffic light status from the evaluation observations
How did patients enter (i.e., get referred to) the services	<p>There are a variety of referral sources. The most common appeared to be:</p> <ul style="list-style-type: none"> • Clinical nurse specialists and nurse coordinators • Staff on oncology wards; and • The Cancer Society <p>In addition, some are educating and getting referrals from primary care and / or mental health services, and surgeons.</p>	<p>Orange</p> <p>More work to do to ensure patients can be referred at high suspicion and / or front of pathway. Also a stronger more proactive focus on Māori and Pacific potential referrers.</p>
The extent to which rural, low socio-economic and Māori and Pacific patients and their	Service data varies between services so is not directly comparable. One service is not recording ethnicity. No services are specifically recording socio-economic status or rurality. Moreover, there is no common agreement on the definition of rural – versus	<p>Red</p> <p>A lot more work to be done</p>

Question	Interim findings	Traffic light status from the evaluation observations
<p>whānau access the psychosocial support services (percentage of total using them – from service data)</p>	<p>maybe being in a town or city, but being isolated. Services are generally receiving slightly higher referral rates for Māori and Pacific patients, compared to the Cancer Registry. However due to the low volumes for these patients on the Registry, particularly for Pacific, we are unable to draw any conclusions from this. Moreover, as there were no targets for the Initiative we are unable to comment on what level of take-up might be considered appropriate, for an Initiative that is focused on reaching these groups.</p>	
<p>Whether the new roles are targeted at the appropriate point in the cancer treatment pathway</p>	<p>Patients were clear that the earlier they were referred and seen by the service, the better. However some service staff felt that patients should wait till after the “shock” of the diagnosis as they can’t take much more information in. However on balance, the patient voice was very strong that the earlier the better.</p>	<p>Orange Needs more discussion and national agreement</p>
<p>Whether the composition of the new roles provides the right skill mix to deliver the services to people with cancer and their whānau</p>	<p>By far the majority agreed the skill mix and disciplines were the right ones for the intended outcomes for these patients and whānau. Very few suggested other disciplines such as occupational therapists, but these can be accessed via DHB community services anyway. However, not all services have both disciplines. Some believe that other local services support the Initiative staff to make up a virtual team, yet many felt this was not the case and that some Initiative staff were quite isolated.</p>	<p>Green</p>
<p>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</p>	<p>As above. The staff and stakeholders interviewed generally felt that the psychological and social work discipline mix is right for the intent of the Initiative. There were some reports of initial “teething” problems but many more success stories of the disciplines working together and at times doing joint visits and assessments.</p>	<p>Green</p>

Question	Interim findings	Traffic light status from the evaluation observations
The level of need of patients being seen including access and discharge criteria	This appears to be somewhat subjective, as are a lot of decisions in health. Various individuals within each service and various services have different criteria for acceptance of people. What is common is the term “high level of distress”. Discharge criteria can be a challenge for some due to clinical and ethical relational reasons. However this is getting clearer over time especially with hospice and palliative care services.	Orange Needs more discussion and national agreement
What needs of patients and whānau are being met by the new roles and what needs are not	By way and far of the majority of patients who take up the service say their needs are being met or exceeded. However due to the variance in opinion as to whether whānau needs can be addressed via this service is still highly variable and at times at odds with each other. There was a relatively low number of Māori patients compared to the volume of non-Māori patient names to interview. We also noted a low number of survey responses from Māori. However, most concerning was the very low rate of Pacific Island patient names provided to us for consenting interviews. Sampling was purposive, focusing on the Initiative’s target groups, as per the agreed Evaluation Plan. More broadly, we heard from workforce and stakeholders that there is a high level of need the Initiative is unable to meet within its current resourcing and scope.	Green for patients who have the opportunity to take up the service. Orange Needs more discussion and national approaches, emphasis and agreement
Types of services provided by the new roles (e.g., individual, group sessions, other, venue / location	This depends on the need of the person, but qualitatively we see the majority of services are one on one – either face to face or by phone once the relationship has been built. Venue and location is variable. Patients, especially Māori and those living out of town, significantly value home visits and visits to the Ward when they are receiving treatment. However clinic rooms leave a lot to be desired, where a service even has any. This is dependent on the DHB and some do not enable dedicated clinic space for the Initiative to use.	Green for patients. Orange Needs more discussion and national agreement

Question	Interim findings	Traffic light status from the evaluation observations
<p>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</p>	<p>The number of 'sessions' varies in theory by each service. Some psychology services are limited to six and then the therapist has to get approval for more. Whilst others don't have a limit and it is based on clinical discretion. For social work it also depends on need and there can be a lot of time spent that is not face to face with the patient, but work being done in the background.</p>	<p>Green for patients.</p>
<p>The timeliness of service delivery (such as length of time from referral to triage and/or first contact</p>	<p>Most reported a very short waiting time, e.g. 5 to 9 days. A number of patients said it would have been better to be referred earlier. This was especially for those who had had a second or re-diagnosis of cancer and had had no access to an Initiative type service previously.</p> <p>Each service said it has "no waiting list". However we are aware of at least one service that when it gets busy stops accepting referrals so there is no record of a waiting list, yet people are not able to access the service at all – at that time or later. Single staff services may cease during staff absences.</p>	<p>Orange</p> <p>Needs more discussion and national agreement, especially once demand and volumes increase</p>
<p>The relative value of flexibility (e.g., local tailoring of services) vis à vis regional consistency</p>	<p>Flexibility is valued by both patients and staff. Yet some staff are concerned about a lack of clarity on some criteria and lack of national consistency, and therefore equity of access for people with like needs.</p>	<p>Orange</p> <p>Needs more discussion and national agreement</p>
<p>Whether the new roles have the ability to work in collaboration with other support services outside of DHB settings (e.g. such as cancer support organisations in the community, (e.g. the Cancer Society)</p>	<p>Yes the services do work with other outside roles. Most notably:</p> <ul style="list-style-type: none"> • The Cancer Society • Cancer Nurse Coordinators • Oncology Teams / Wards • Community Health Services • Hospices 	<p>Orange</p> <p>Although it is orange it could benefit from continued development for example primary care and Māori and Pacific Health Services</p>

Question	Interim findings	Traffic light status from the evaluation observations
<p>community services, (e.g., home and community support, allied health, hospice and primary care. In addition Māori health services, Iwi providers and Whānau Ora services.</p>	<p>We saw very little established relationships with Māori or Pacific Health Services within DHBs and/ or in the community. Services have been busy establishing a lot of features and the service themselves but it is now time to enhance services with improved relationships with wider Māori and Pacific networks.</p>	

Outcomes evaluation questions

The following table details our interim findings based on the outcomes questions in the evaluation plan.

Table 5 Outcomes evaluation questions interim findings

Outcomes question	Interim Findings	Traffic light status from the evaluation observations
Whether services are culturally responsive and what this may look like	From the 19 Māori interviews conducted to date, the majority of respondents felt that the service provided to them was meaningful to them as a Māori person. It is unclear as to whether this equates to being culturally responsive in the wider Whānau Ora context. In addition, it would appear that there was variance across the nation as to the inclusion of whānau, or not, to the service. From a te ao Maori lens which is an inclusive holistic perspective, this would suggest this area is a priority for ongoing development and will require prioritisation of collaborative relationships with Māori and Pacific stakeholders and whānau in addition to an exploration of how Whānau Ora and Te Whare Tapa Wha can be meaningfully applied within the Cancer psychological and support arena. We noted the relatively low numbers of Māori and Pacific patient interview consents we were provided by the workforce.	Orange
Improved knowledge of psychosocial needs and supports across cancer healthcare and supportive services	Various services have focussed on different healthcare and supportive services in terms of education and promoting referrals.	Orange Needs more discussion and national agreement
Impact on the lives of people with cancer and whānau who use the service	Interview findings with patients indicated high satisfaction levels and qualitative reports of significant positive impact on both their psychological and social wellbeing factors. People are anxious to have their say to tell us to make sure the service is not taken away as it is so valuable. There were only a few interviews and surveys that were not positive and based on this we can observe that the Initiative	Orange

Outcomes question	Interim Findings	Traffic light status from the evaluation observations
	is meeting individual needs. However, we are unable to comment on a more strategic broader Whānau Ora or Pacific approach or outcomes as we didn't see this or hear about it.	

3. Interim conclusions and recommendations

3.1 Front-of-pathway focus is appropriate and especially supported by patients

Interestingly some of the Initiative staff and other stakeholders interviewed felt that seeing people right at the point of diagnosis is too early as the ‘shock’ factor has just set in. However the ‘sooner the better’ was reported as important and valuable by patients.

‘I wish I had known about this service earlier. It has helped me so much. For a start I just didn’t know what to do or expect, till I saw [name].’

‘My cancer has come back. I have been in remission for three years and this re-diagnosis is far, far worse than the original one. I wish I had had this service back then. It has made such a difference to both me and my wife. Having them in my life so early after this new diagnosis is fantastic. It has helped me cope and plan, and even keep working part time.’

In addition the need can arise at any time throughout the cancer journey so referrals shouldn’t be limited to front of pathway, but to the level of distress that can occur at various transitions, changes in treatments, survivorship, etc. We observed a clear unmet need for this service across many areas, and in particular survivorship.

3.2 Discipline mix appears beneficial

There was a reported clear need for both disciplines – and where possible for both to be based in all services. The mix of disciplines of psychology and social work was seen as being very important and complementary. There is a need for both sets of skills and more staff reported working in teams across the disciplines than in Interim Report One. This is for both triage and for working with patients on-going.

Both disciplines reported referring to other services, some within DHBs and others in the community.

One query that was raised by some is why is there a restriction of regional lead roles to psychologists, and not enabling social workers to take that role, if appropriate. We did hear one anecdotal report that one person thought originally there was a social worker in a regional role but they weren’t sure.

There was mixed opinions and views on what the respective roles of the Regional Leads and National lead are. However we understand work is underway on clarifying and building on this as the National Lead is working closely with the services and we will look with interest at this for our final report in 2019.

3.3 More to do on meeting Māori and Pacific needs

As mentioned throughout the report staff in the Initiative, as well as other stakeholders, identified the need to improve linkages and working relationships with Māori and Pacific Health teams and other Iwi and Māori health providers. We were provided with very few Maori or Pacific stakeholders to interview. As noted, the number of Pacific patient and stakeholders names was exceptionally low. We acknowledge that most teams noted it was a work in progress and that some teams had made very good in roads. However from a national strategic level, further prioritisation of this is required. The Initiative needs to be a holistic and inclusive service of whānau and Kaupapa whānau.

There are examples within other sectors, of successful incorporation of a Whānau Ora philosophy being actualised and incorporated into service delivery. It involves service collaboration and integration in conjunction with placing the whānau at the centre and allowing and supporting the whānau to determine their own pathways and aspirations in relation to their well-being. It is unclear whether the Initiative in its inception, whilst wanting to target Māori and Pacific, have been able to consider service delivery from this perspective yet. Some Māori stakeholders voiced the need for 'for Māori by Māori.' The minimal and relatively 'ad hoc' inclusion of Māori stakeholders into much of the Initiative is a clear reflection of a missing link in the equation of meeting the needs of Māori and Pacific people in many geographic areas.

3.4 Combined with lack of consistency on some criteria, gaps in meeting Māori and Pacific needs poses equity concerns

Work commissioned by the Ministry in 2011 identified a number of problems with the provision of psychological and social support 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; and
- lack of clear referral pathways in many places.⁶

⁶ Health Outcomes International (2011) *Implementing supportive care guidance project: priority areas research report August 2011* (Ministry of Health: Wellington, New Zealand), p.34.

The Initiative has made progress towards addressing some of these challenges, such as the lack of funding and skilled workforce, and the under-use of MDT. However the lack of consistency across various aspects of services means a number of questions still remain. This includes local and regional variation in service delivery and variation in the use of screening tools (with some services not using them at all).

Stakeholders in a number of services also described a lack of clarity and transparency around referral pathways/criteria, with some believing that is a deliberate strategy to keep volumes in check. As discussed above, the criteria and focus areas of the Initiative are being interpreted by services differently across the country. While in some cases this reflects appropriate local tailoring to take account of pre-existing services, it does mean that both access to the Initiative and the nature/extent of support provided is variable – i.e., where patients are referred from, what a patient is offered/receives may depend on where they live. Some of this is just practical about what is available in local, especially smaller communities, to refer to and tap in to.

In some locations, the Initiative has augmented existing supports; in others – particularly more rural and geographically isolated areas with large gaps in pre-existing services, it is felt by some interviewees that it is a small contribution to filling pre-existing gaps, without other supports in the community.

In our view, this combination of factors may be working against the equity objectives of the Initiative – by exacerbating rather than reducing inequities.

3.5 Supporting small and isolated FTE

We heard a mix of challenges with small FTEs in any one location and heard of some relatively isolated Initiative staff. Some felt they were supported by other colleagues in the local DHB, whilst others felt relatively isolated. Now that the first sweep of service implementation has occurred there is an opportunity to build on this and consider how to develop the service with more of a national and regional focus and potentially support staff more that are working alone and / or are more isolated. Although we do understand this can be a challenge across DHB boundaries, but innovative solutions could be sought.

An article by Dr Carol Atmore⁷ notes there are various success factors and barriers to consider when trying addressing some of this health professional isolation. She cites things such as connectivity using various IT tools, building trusting relationships, growing clinical governance and ensuring two-way traffic between DHBs.

3.6 Need for greater support from DHBs

Earlier in the report we noted the varying levels of support and tools and resources allocated by DHBs in supporting the Initiative.. Access to administration, IT support and data collection and processing, as well as access to appropriate rooms (offices and therapeutic

⁷ Atmore, C. Dr. The Transalpine Health Service Model – A New Zealand Approach to achieving sustainable hospital services in a small district general hospital. *Future Health Care J.* Vol 2, No. 2, pp117-120. 2015

rooms) were the biggest challenges. The majority of services had no issues accessing DHB pool cars and felt supported via professional and peer supervision.

There is significant amount of cynicism and fear that if the Initiative funds are devolved to individual DHBs in the future then there will be even less supports from some individual DHBs and some services may cease to exist over time (e.g. sinking lid policy).

3.7 Case for on-going and greater funding

The evaluation has highlighted an extent of unmet need – as well as other gaps including for survivorship challenges and other long-term chronic conditions. We were frequently asked why patients with cancer get this great service opportunity when others, who may have the same or greater levels of distress don't, e.g. those living with multiple long term chronic conditions. Many services are not working with whānau in a whānau ora model, and this includes children of parents with cancer, as well as significant others. As noted, there is variable engagement with Māori and Pacific health teams as well as building of connections with Iwi and Māori health providers outside of the DHB. We note there are a multiple of reasons for this and that some teams are making some advancement on this. There was no evidence of engagement with Pacific organisations outside of the DHB that we were made aware of.

We believe that the service is providing such great individual (patient) and other health level service gains, e.g. the FCT targets, reduced DNAs, that there could be significant more investment to get even greater longer term health system, individual and whānau gains. Further work in the future could measure this and apply a cost benefit model to this.

3.8 Interim recommendations

Following are our interim recommendations. We do acknowledge that these topics have been discussed before but our observations are that they remain somewhat variable, for a variety of local and individual reasons.

1. **Definitions:** clarify definition and appropriate use of 'front of pathway', to create an equitable service opportunity for patients. It is understood that different people will be ready for supports at varying time, but to clarify the service approach may be useful. The other key definition that has caused discussion and challenges is 'rural'. What is rural and when does living in a town or city but being isolated count? We recommend that this merits further discussion and if possible clarification.

Importantly in clarifying definitions and service access criteria and scope is when and how whānau are supported (see below for separate recommendation). We note there has been some clarification on this but practice still varies greatly.

2. **Mix of the two disciplines:** continue with the mix of psychology and social work as reports are this is working very well. Clarify which disciplines can take on the Regional and / or National Lead roles.
3. **Māori and Pacific needs and approaches:** continue to plan for and build a holistic, inclusive and Whānau Ora approach to service delivery. This needs to include

collaboration with both Māori and Pacific health teams and Iwi/ Māori health as well as Pacific providers.

4. **Equity:** consider what Recommendations 1 and 3 mean for equity of access and supports from the Initiative.⁸
5. **Supporting small FTE and isolated workforce:** investigate models of how to further support those working in relative isolation and /or on their own in a DHB in the Initiative and how to support the service when that individual goes on leave (planned or unplanned)
6. **Continue to work with DHBs to access appropriate supports:** we understand the contracts between the Ministry and DHBs have just been renewed for two years and that was an opportunity to try and address some of the gaps in support needs. We recommend this is an on-going discussion and relationship with all DHBs, especially from the National and Regional Lead levels to ensure staff are supported appropriately in their roles e.g. IT, administration where needed and environment and clinical space
7. **Continue to clarify respective roles of National and Regional Leads across the Initiative:** Continue to work together to focus on service enhancements and supporting the teams
8. **Consistency of data:** Further work to improve consistency of data collection (noting this can be a challenge across DHBs), and fill gaps – suggested priorities to focus on:
 - ensuring all services collect basic demographics: age, gender, ethnicity, tumour stream
 - reason for acceptance into the service (i.e., what Initiative criteria they meet)
 - distinguishing between referrals in and acceptances (so all services can tell how many patients seen by the Initiative)
 - consistent categorisation, including of tumour stream, point in pathway and criteria met (consider drop downs)
9. **Funding and managing future demand:** The Ministry should consider retaining centralised funding of the Initiative to avoid the inherent risks of devolution of such a relatively small amount of funds to each DHB. Increasing demand is a risk as more referrers learn of the benefits for their patients. We also believe the service is so valuable and could reach many more people in the target populations that increased funding levels should be considered in the out years. This will require on-going planning and development of the right skilled workforce and potentially tighter targeting / prioritisation to manage demand.
10. **Model of care:** for various reasons outside of the Initiative’s control there was a delay in finalising and circulating a Model of Care. We note this has required the services to develop as they saw right for them. But would recommend that where ever possible for other new Initiatives in the future that a priority is to get a consistent Model of Care and National Minimum Data set established up front.

⁸ Note: Outcomes are not being measured yet but a model is being worked on.

11. **Meeting unmet need in other areas:** The Ministry should consider extending this service beyond its front-of-pathway focus to other areas, in particular survivorship.

Appendix 1: Rolling patient survey

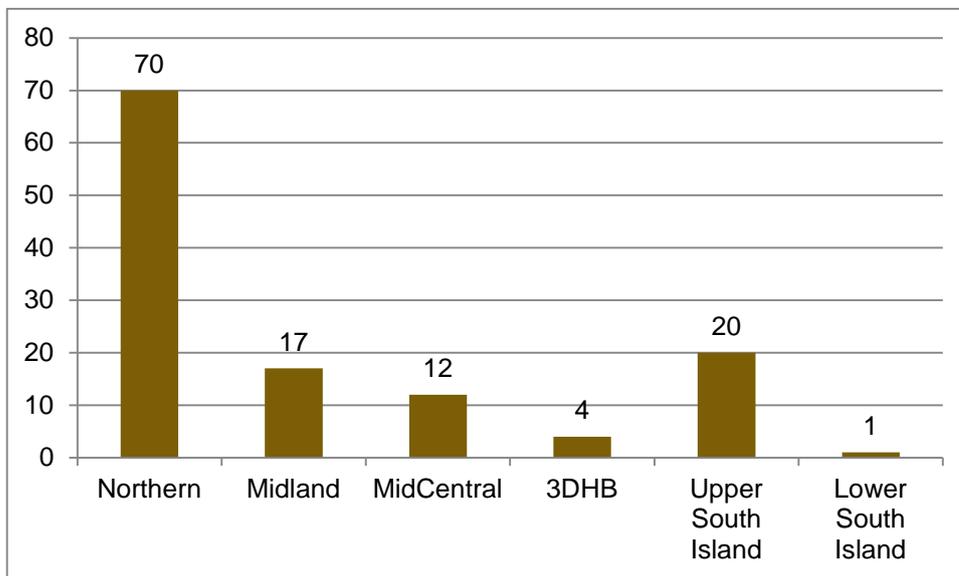
Overview of responses to date

The patient survey materials have now been distributed to all DHB sites.

As at 2 July 2018, we had received 124 completed survey forms (116 hard copy, eight online). Responses have so far been received from 15 DHB areas. The distribution of responses by Initiative region is shown in Figure 5, below.

Figure 5 Respondents by Initiative region

Number of respondents (n=124)

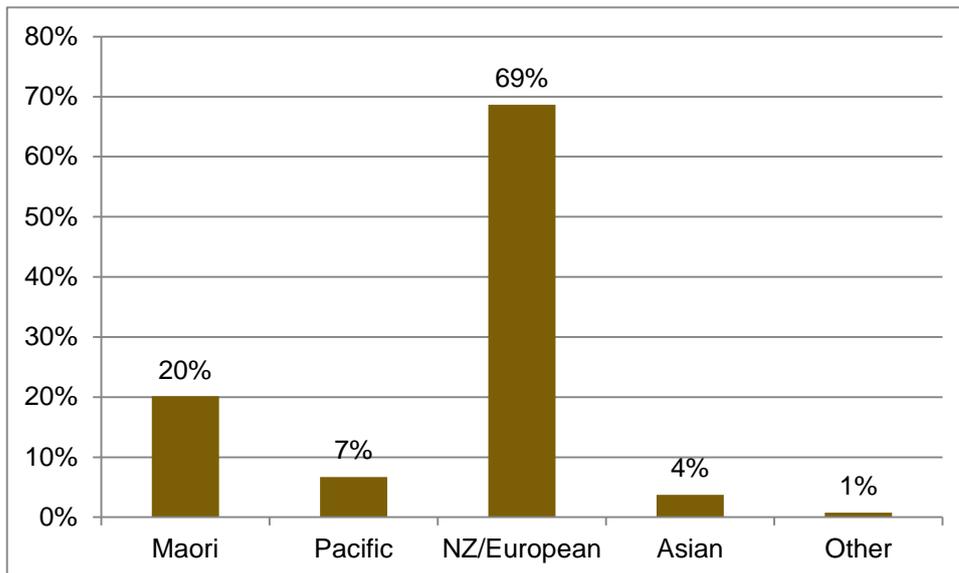


Source: Sapere patient survey

Two thirds of respondents (65 per cent) were female. Sixty-nine per cent were New Zealand European/European, 20 per cent Māori and seven per cent Pacific Islanders (see Figure 6).

Figure 6 Ethnicity of respondents

Percentage of respondents (n=124)



Source: Sapere patient survey. Note respondents could select more than one ethnicity, so figures total to >100 per cent.

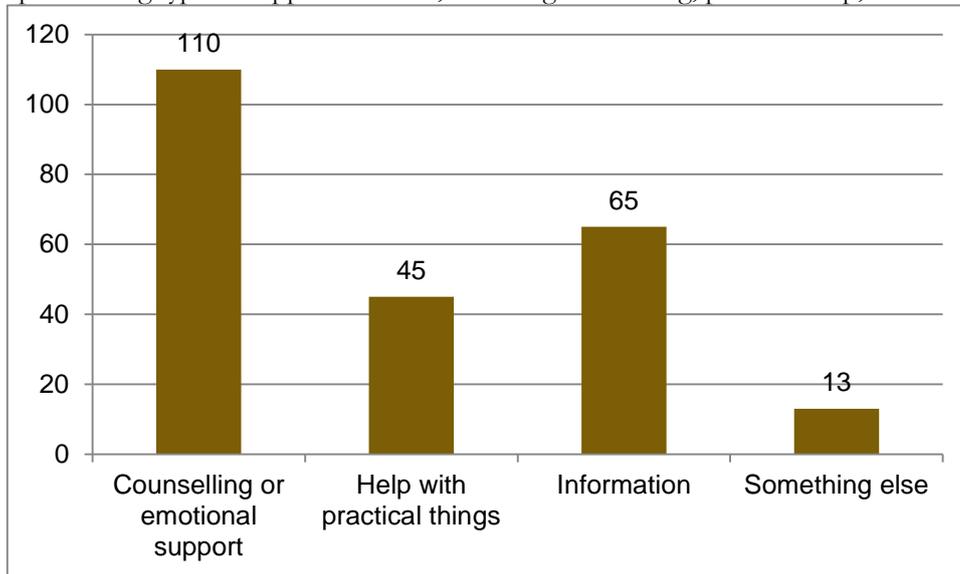
Types of support received

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 (56 per cent) reported that they received more than one type of support. Other types of support mentioned included petrol vouchers, accommodation and on-referral to other services.

Figure 7 Types of support received

Number of respondents (n=124)

Graph showing type of support received, including counselling, practical help, information



or

Source: Sapere patient survey

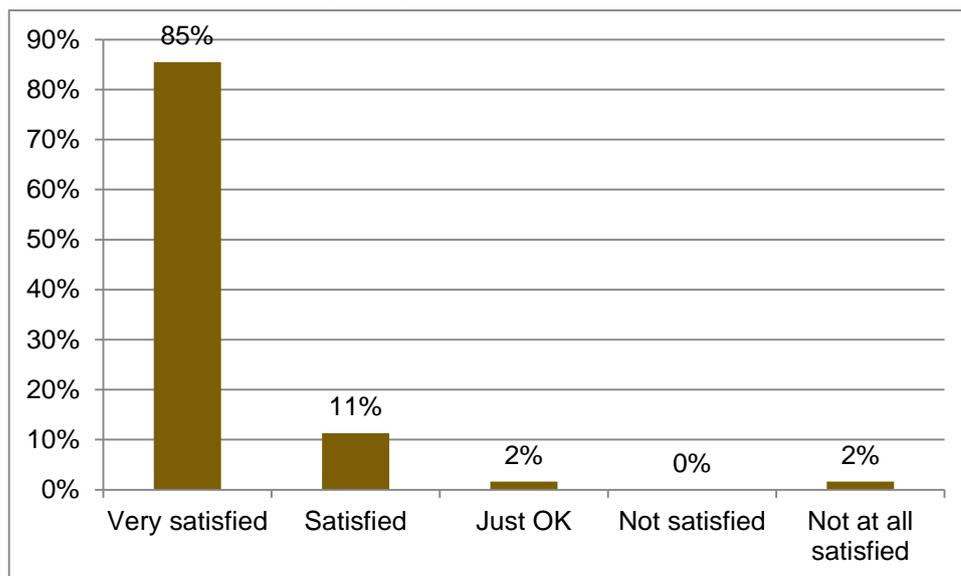
Note: Respondents could select multiple categories

Satisfaction with the service

Ninety-seven per cent of respondents were either satisfied or very satisfied with the service (Figure 8).

Figure 8 Satisfaction with the support provided

Proportion of respondents (n=124)

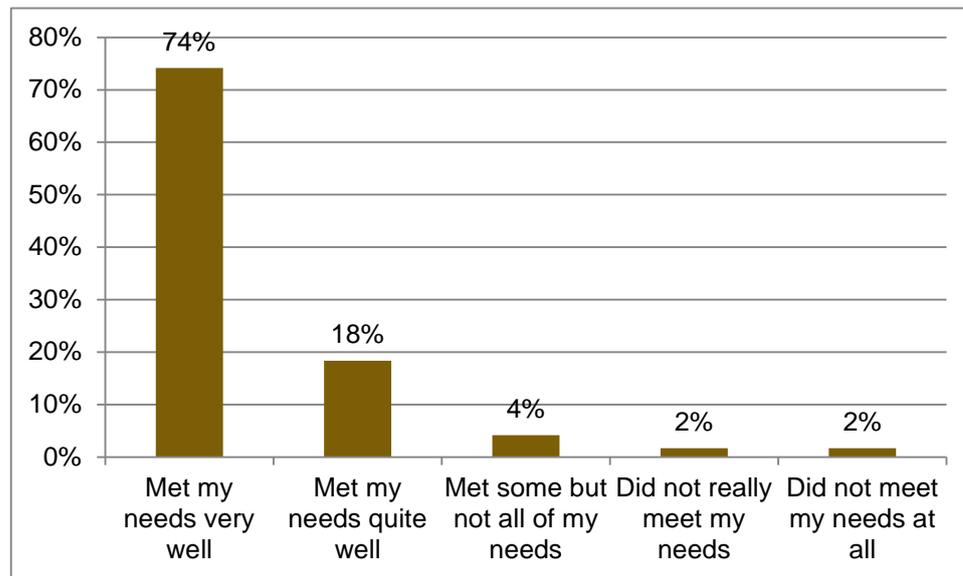


Source: Sapere patient survey

Similarly, the majority of respondents (93 per cent) thought the service met their needs quite well or very well (Figure 9).

Figure 9 Extent to which the service met their needs

Proportion of respondents (n=120)



Source: Sapere patient survey

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 comment was ‘thank you’.

In terms of specific aspects of the service, common themes were the kindness, friendliness and compassion of the workforce, and the ability to speak freely/be listened to in a confidential manner:

Confidential and kind.

Private and personal.

Sensitive, caring and supportive.

Her approach towards me was caring and very supportive. The tone in her voice made me warm towards what she was saying.

Consistently treated with respect which meant a lot to me personally. A safe place to listen.

[Worker] listened very well, was approachable, non-judgemental.

My wife and I were both supported and listened to. There was great understanding of our needs. I could talk openly about my cancer.

Other aspects frequently mentioned included:

- the professionalism of the workforce – ‘totally professional advice and empathy’;

- being able to speak to someone impartial – ‘it is a great help mentally to have people who are not family or friends to guide you’;
- the flexibility and accessibility (including ability to do home visits) – ‘Counsellor came to my house, easily contactable by text and calling when needed’;
- the ability to be seen together with family members – ‘I felt the inclusion of both my wife and I (along with other family members if they wished to attend) very advantageous to the overall process’;
- regular follow-up/keeping in touch – ‘regular contacts by phone and knowing that support is there’; and
- that fact that the service exists – ‘that it was actually offered’.

Impact of the service

Respondents also described the impact of the service. A common theme was the ability to cope, and deal with the emotional aspects of diagnosis and treatment.

Helped us both understand and how to cope with things.

It enabled me to navigate the emotional minefield at a time when I did not know what the future held and if I would make it or cope with the road ahead.

I just want to thank you for your service and what a great job you’re doing. It’s been a sudden diagnosis and a very scary and lonely journey for us, but having someone to come and talk to me helping me how to deal with my emotions and thoughts has helped me tremendously.

I was stuck in fear. I am still fearful but have been able to move on in part and that is all down to the service.

I have been in some dark places and without this help I know I would not have seen my way through this. Words really cannot describe how valuable this is.

Another common comment was around advocacy and support in navigating the health and social welfare systems

I was amazed that my counsellor could empower me to become a strong proactive patient rather than an anxious, passive victim.

Provided helpful advice and advocacy throughout my WINZ application.

The support person was amazing and gave me support when I met with the oncologist. She justified my feelings.

Suggestions for ways in which the service could be improved

Many respondents said there was nothing that could have been improved or done differently about the service. Of those that did make suggestions for improvement, the most common comment was for a better physical environment for sessions, both in terms of privacy and comfort – ‘a dedicated room for counselling – environment not calming’.

A couple of respondents also thought it would have been helpful to have been told about the service earlier – *‘maybe could have been informed sooner so less stress for everyone’*; and a couple wondered whether the service is being widely advertised enough – *‘I wonder how others would know about this service and I wonder how known it is.’*

Appendix 2: Workforce survey form

About the evaluation

Sapere Research Group (Sapere) has been commissioned by the Ministry of Health to undertake an independent evaluation of the adult cancer psychological and social support initiative (the Initiative). The purpose of the evaluation is to evaluate and assess the Initiative and to understand whether the service objectives are being met. The evaluation will also identify enablers and barriers to success so that the Initiative can learn from these factors.

Sapere is undertaking a process and outcomes 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 evaluation runs from 1 July 2016 to 31 January 2019.

An important part of this evaluation is seeking the input and views of workforce members such as yourself, via this survey and also through face-to-face/telephone interviews. You will have a further opportunity to input towards the end of the evaluation when we run a final survey.

We invite you to fill this survey, which will take up to 20 minutes.

Your answers are confidential

Your answers to these questions will be completely confidential to the evaluation team. We will write a report for the Ministry of Health that summarises the themes from what people have told us. The information will not be able to be identified to individuals. The report will include what works well, what doesn't work so well and things we heard about what might be good ideas for any future changes to the way services and supports are run.

We will store your survey form securely in our computer system, accessible only by the evaluation team.

Who to contact

If you have any questions, concerns or complaints about the evaluation at any stage, you can contact:

Jo Esplin, Principal, Sapere Research Group

Cellphone: 027 233 4010

Email jesplin@srgexpert.com

Please tell us a bit about yourself

1. What is your professional title?
 - National or Regional Lead
 - Clinical Psychologist
 - Health Psychologist
 - Social worker
 - Advanced Practice Social Worker
 - Manager
 - Other (please state)
2. What DHB region do you work in? (Tick ALL that apply)
 - Northland
 - Auckland
 - Waitemata
 - Counties-Manukau
 - Bay of Plenty
 - Waikato
 - Tairāwhiti
 - Lakes
 - Taranaki
 - Hawke's Bay
 - Whanganui
 - Mid-Central
 - Capital & Coast
 - Hutt
 - Wairarapa
 - Nelson Marlborough
 - West Coast
 - Canterbury
 - South Canterbury
 - Southern
3. What gender are you?
 - Male
 - Female
 - Gender diverse
4. What is your age?

- 17-25
 - 25-34
 - 35-44
 - 45-54
 - 55-64
 - 65 and over
5. What is your ethnicity?
- Māori
 - Pacific
 - European/New Zealand European
 - Asian
 - Middle Eastern/Latin American/African
 - Other

Working in the service

6. How long have you worked for the Initiative?
- Less than 6 months
 - 6-12 months
 - Over a year
7. On average, what proportion of your time is allocated to the Initiative?
- Less than one day a week
 - 1-2 days a week
 - 3-4 days a week
 - 5 days a week
 - Other (please state)
8. On average, roughly what proportion of your time do you spend on the following activities? Please write your answers as the percentage of your time working within the Initiative – for example if you work for the Initiative 2 days a week and spend 1 of these days (50%) doing admin tasks, please state ‘50’ for Administration.
- Providing psychological or social support services to patients (% of time)
 - Administration (% of time)
 - Management tasks (% of time)
 - Other activities (please elaborate)
9. Is the support you provide for the Initiative mostly.
- Face-to-face
 - Over the phone

- A mixture
 - Other (please specify)
10. Do you think your Initiative caseload is manageable?
- Yes
 - No
 - Unsure
 - Comment (free text)
11. If not, can you tell us why not, and what could be done to make it more manageable?
(free text)
12. What do you understand to be the roles of:
- The National Clinical Lead (free text)
 - The Regional Leads (free text)
 - Your local workforce (free text)

The Initiative is targeting patients with complex and high needs of social and psychological support, and “hard to reach” groups such as Māori and Pacific communities and / or those who may be living in rural areas.

13. How confident do you feel about delivering services to these patients?
(number line 1-5 not at all confident to very confident, with free text comment, e.g. why?)

Support, training and development

14. In relation to your work for the Initiative, to what extent do you feel your clinical supervision needs are being met?
(number line from 1 to 5, not being met to being well met, with optional free text comment)
15. In relation to your work for the Initiative, to what extent do you feel your peer support needs are being met?
(number line from 1 to 5, not being met to being well met, with optional free text comment)
16. In relation to your work for the Initiative, to what extent do you feel your professional training and development needs are being met?
(number line from 1 to 5, not being met to being well met, with optional free text comment)
17. To what extent do you have the necessary tools and resources to do your job for this Initiative (e.g., policies and procedures, data collection, referral pathways)?
(number line from 1 to 5, not being met to being well met, with optional free text comment)
18. If you answered 3 or lower on any of these questions, then what could be done to better meet your work, support and development needs?
(free text)

Anything else

19. Is there anything else you'd like to share with the evaluation team about: (free text)

- The concept of the Initiative
- The implementation of the Initiative
- The supports you get – locally, regionally and / or nationally
- The future of the Initiative?
- Anything else?

Appendix 3: Workforce survey

Survey method

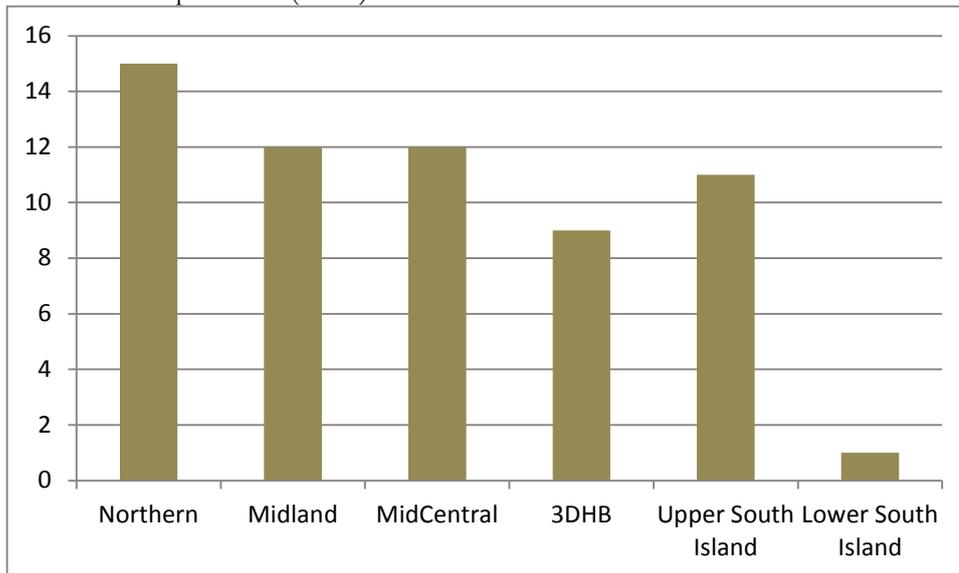
The survey was sent in seven tranches over March 2017 to March 2018 as we progressed with our field work. As at 6 April 2018, we had received 48 responses (81 per cent response rate).

The survey form is attached in Appendix 2

The following two charts show the regional and professional make-up of respondents.

Figure 10 Respondents by region

Number of respondents (n=48)



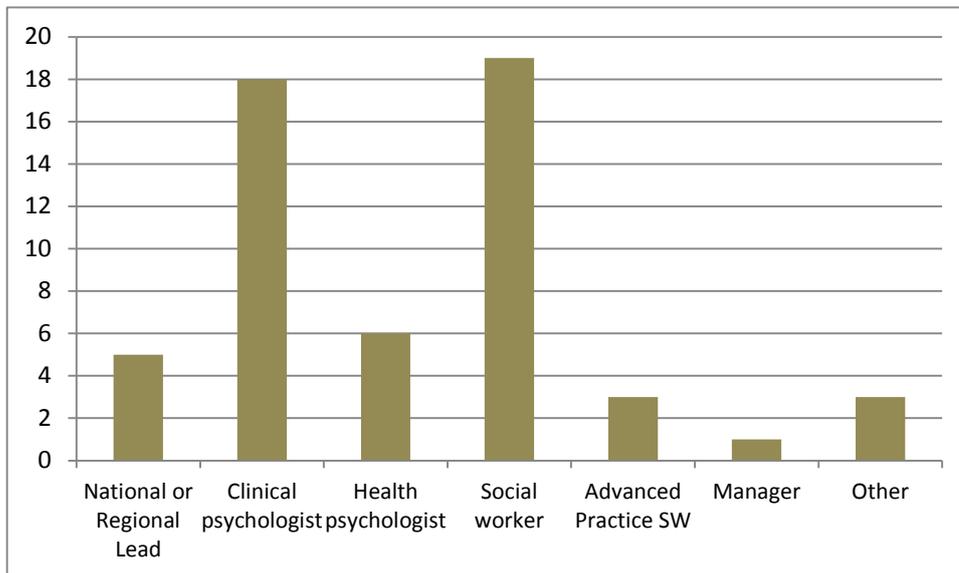
Source: Sapere workforce survey

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

Psychologists accounted for 50 per cent of respondents, including the regional and national leads who are either clinical or health psychologists. Social workers account for 46 per cent. 'Other' roles included service administrator and analyst, which are not funded by the Initiative.

Figure 11 Initiative role

Number of respondents (n=48)



Source: Sapere workforce survey

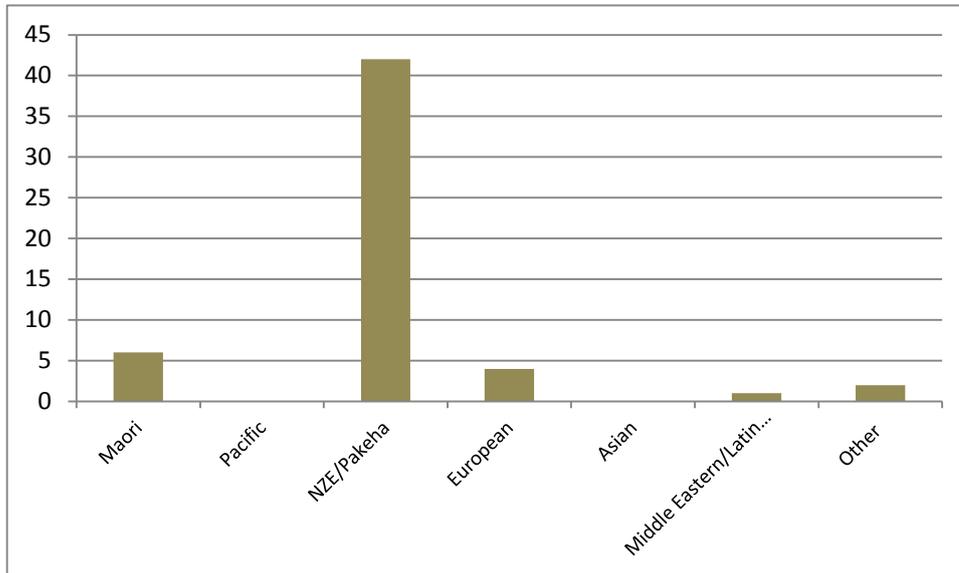
Note: Respondents could (and did) select multiple categories

Workforce predominantly female and NZ European/pākehā

Eighty-five per cent of respondents were female, and most (88 per cent) were New Zealand European/pākehā (Figure 12). Six respondents (13 per cent) identified as Māori.

Figure 12 Ethnicity of respondents

Number of respondents (n=48)



Source: Sapere workforce survey

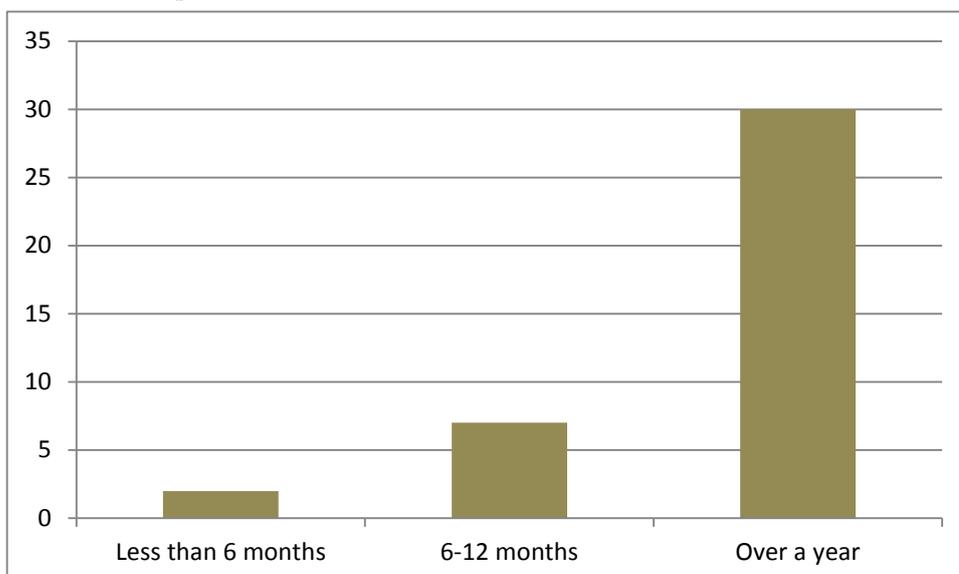
Note: Respondents could (and did) select multiple categories

Comparatively well-established

Despite some turnover in staff, seventy per cent of respondents have worked for the Initiative for over a year (Figure 13). This may reflect the fixed-term nature of contracting for the Initiative.

Figure 13 Tenure in Initiative

Number of respondents (n=43)

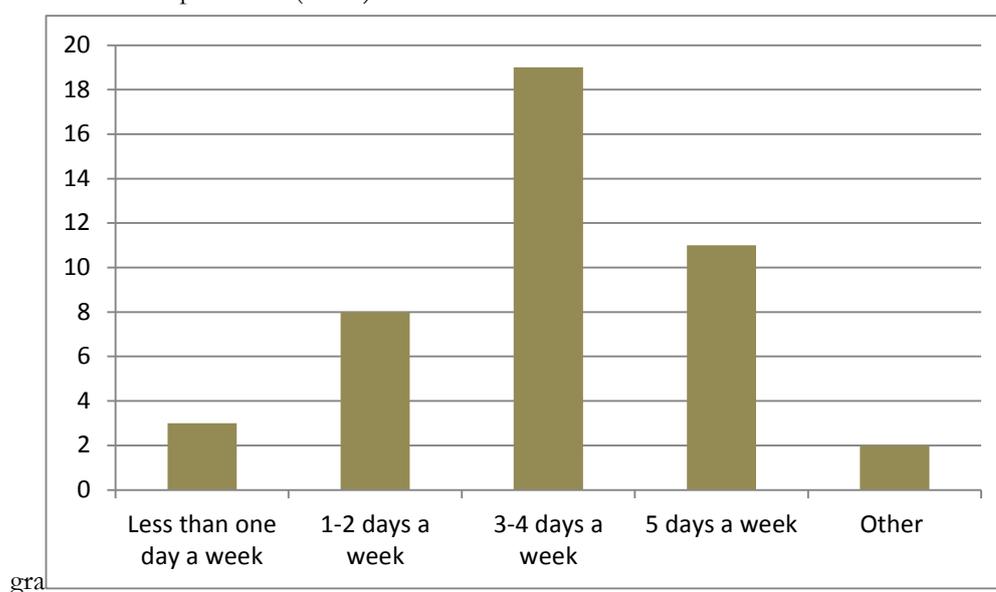


Source: Sapere workforce survey

Respondents span a mix of part and full-time roles, with most working three or more days a week for the Initiative (Figure 14).

Figure 14 Weekly time spent working in Initiative

Number of respondents (n=43)



Source: Sapere workforce survey

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 directly providing support to patients. The remainder of their time is spent on administrative, management and other tasks⁹. 'Other' activities include:

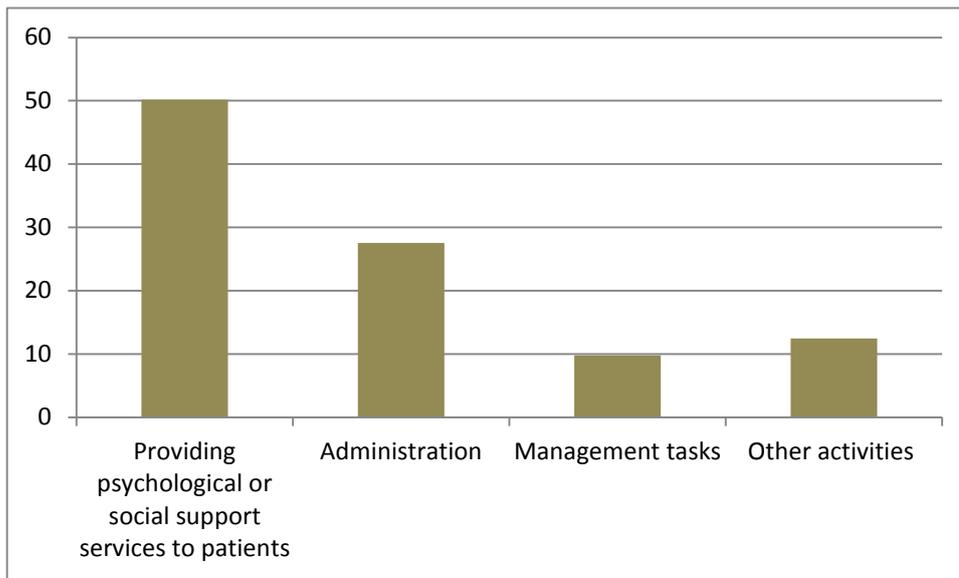
- service design and improvement;
- providing training/education for other health professionals;
- supporting and/or supervising other staff;
- networking and relationship building;
- statistics;
- community liaison;
- team meetings;

⁹ Note in the body of the report we have observed that some of this time could be better spent undertaking clinical work, being supported by other roles.

- journal club;
- research; and
- professional training and development.

Figure 15 Proportion of time by activity

Percentage of time spent working in Initiative (n=43)



Source: Sapere workforce survey

Workload an issue, particularly for part-time and isolated staff

In our initial survey analysis (presented in our first Interim Report), most respondents (87 per cent) reported that their workload was manageable. This was based on responses from workforce members in the Northern and Midland regions, as well as MidCentral DHB.

This complete survey analysis includes responses from across New Zealand. Analysis of responses from across all regions shows that the proportion of the workforce who report their Initiative workload is manageable is just sixty per cent. Staff outside the large, metropolitan-based teams, and with part-time staff or single-person services are more likely to be struggling to manage their workload.

Factors that impact on workload include time spent travelling to patients (particularly in rural and remote areas) and gaps due to staff turnover.

‘[Travel time] cuts down on my available clinical time and requires considerable juggling.’

Varied understandings of National and Regional Lead roles

Respondents' had varied understanding of the respective roles of the Regional and National Leads. The following table sets out the range of responses. In addition to the diversity of perceived roles, there are also areas of functional overlap, such as initiative development.

Table 6 Roles of National and Regional Leads

National Lead	Regional Leads
<ul style="list-style-type: none"> • Liaison/representation with the Ministry of Health • National oversight/governance and direction • Strategic direction/leadership • Support to regional leads • Initiative development • Implementation guidance • Quality improvement • Guidance on issues • Coordination of service delivery • National consistency • Communication with regional leads • National-level communication and advice • Advocacy • Managing issues at a national level 	<ul style="list-style-type: none"> • Ensure regional collaboration and consistency • Regional oversight of service delivery • Regional leadership and support (incl. for isolated staff) • Initiative development • Feedback to/from regions and the national lead • Regional communication • Linkages/communications with stakeholders • Advocacy for staff • Managing issues/trouble-shooting at a regional level • Monitor progress • Sharing resources

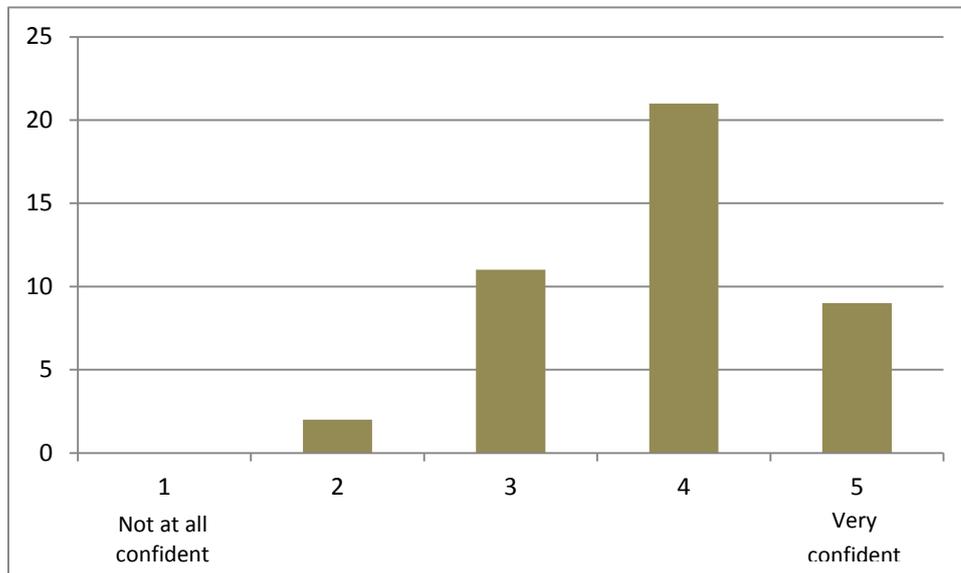
Source: Sapere workforce survey

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 1 being not at all confident and 5 being very confident. The weighted average score was 3.9 out of 5.

Figure 16 Confidence in delivering services to target populations

Number of respondents (n=43)



Source: Sapere workforce survey

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 4.0 for peer support. The result for peer support was lower than the 4.4 score from the interim survey results, suggesting that staff outside the Northern and Midland regions are feeling less well supported.

The need for more funding for training was raised as a particular issue, as was the challenge of obtaining cover for staff with a small Initiative FTE to attend training. The latter issue was also raised in workforce interviews, with some staff reporting a lack of DHB support to attend regional and national fora.

We do not have enough funding available to attend appropriate training.

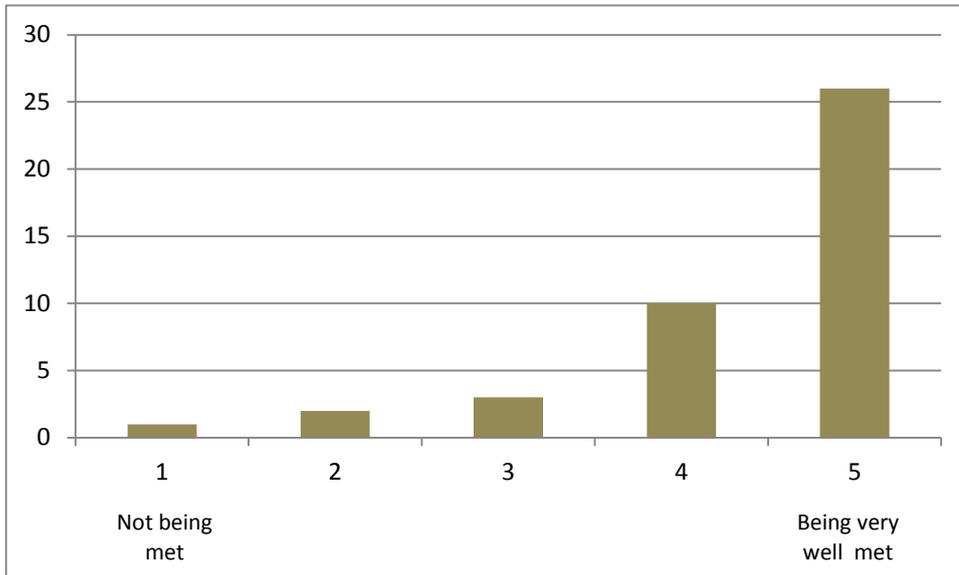
Funding for training is limited.

It is not always easy to find the time to do this [attend education and training sessions], as the FTE is small and it's not always possible for other staff to cover.

I just require more support and guidance with my role.

Figure 17 Extent to which clinical supervision needs are being met

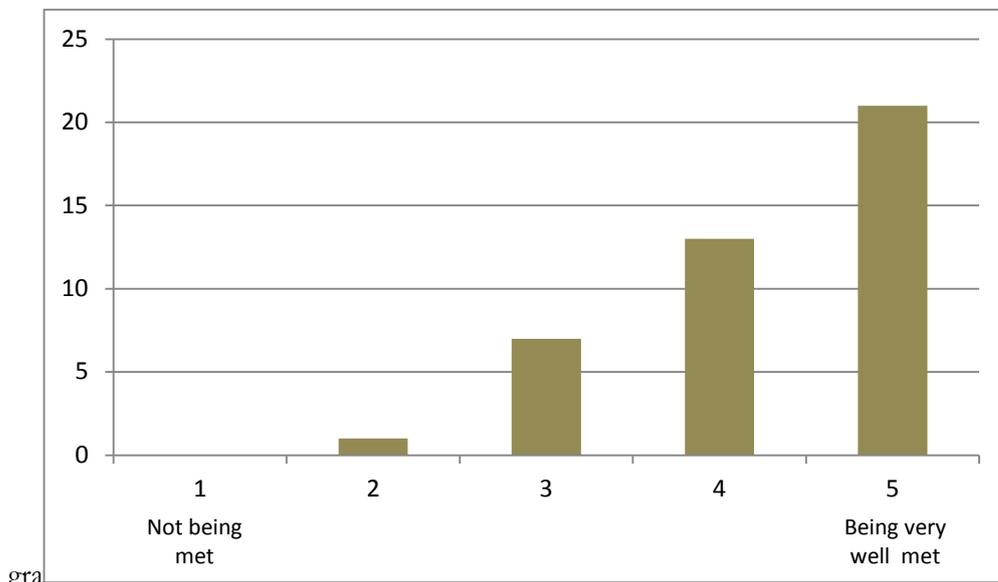
Number of respondents (n=42)



Source: Sapere workforce survey

Figure 18 Extent to which professional training and development needs are being met

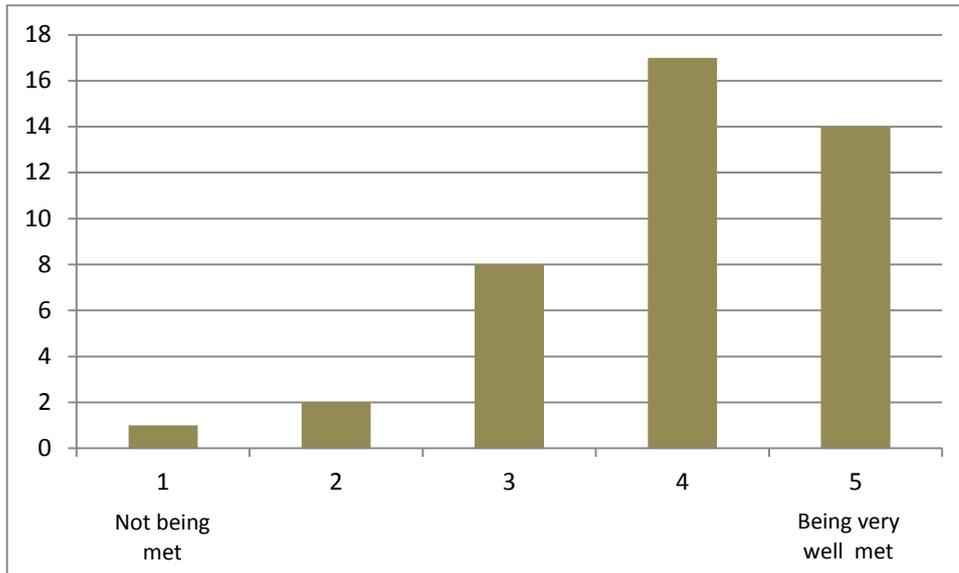
Number of respondents (n=42)



Source: Sapere workforce survey

Figure 19 Extent to which peer support needs are being met

Number of respondents (n=42)



Source: Sapere workforce survey

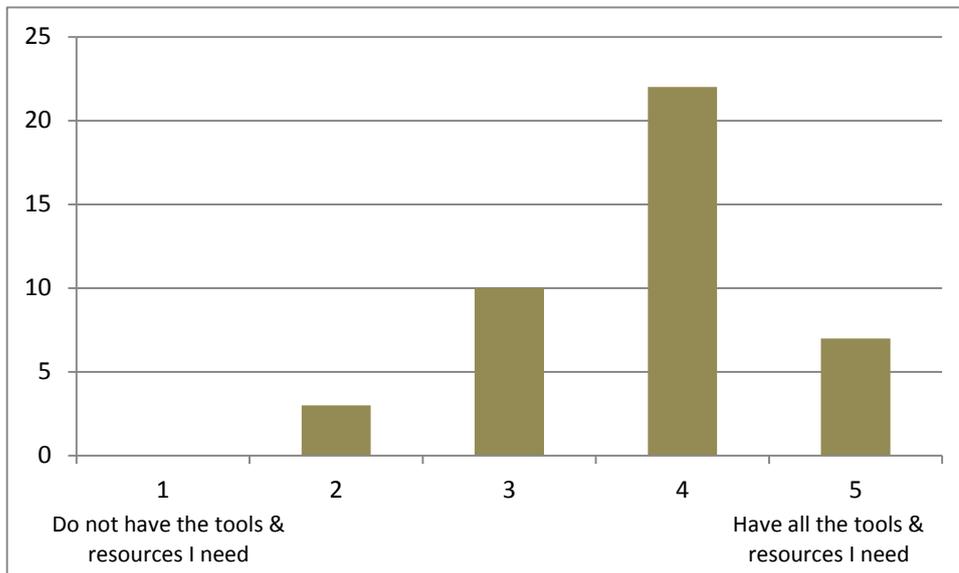
Supporting resources needed

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 3.8.

Specific issues raised were the need for administrative support, support from the DHB for home visits (including the travel time needed, particularly in rural areas), and the challenges posed by DHBs' IT systems.

Figure 20 Tools and resource to do the job

Number of respondents (n=42)



Source: Sapere workforce survey

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. Issues noted from the interim survey results in our first report included the challenge in finding suitable clinical space, the amount of work involved in establishing the new service, uncertainty and concerns around on-going funding for the Initiative, and concerns around gaps in other supports for patients including access to transport and survivorship services.

Gaps in support

Subsequent survey responses also highlight the gap in survivorship supports, and this was a strong theme in our stakeholder interviews. Other gaps for patients include support for long-term conditions.

More work to do to reach Māori and Pacific patients

Concern about the effectiveness of the Initiative in reaching Māori and Pacific patients is a strong and recurrent theme from both the survey and from our interviews with workforce and stakeholders. Many staff have told us this is a ‘work in progress’ for their service.

We are great at targeting rural people but there is still a chasm in terms of helping Māori and Pacific people.

There is more we could be doing to meet the needs of some of these groups (e.g. Māori/Pacific).

Uncertainty regarding future funding

Staff continue to be concerned about the future of the Initiative, including the implications of devolving funding to DHBs.

Ongoing prevarication on the part of MoH as to whether or not the initiative is to be fully deployed into the DHBs vs kept under their oversight for a further period of time remains a key threat to successful execution. Uncertainty as to how the initiative is to be deployed... will impact the ability to retain staff, and thus the sustainability of the service.

These concerns, including the implications for staff retention, were echoed in our workforce interviews. We acknowledge that the Ministry has recently indicated a further two years of funding will be provided to DHBs, before the service is devolved. However the lack of certainty regarding the future of individual services remains.

Concerns around national consistency and coordination

The interim survey responses expressed concern around the lack of timely implementation guidance, and the impact this had on teams as they undertook service development ‘from scratch’. In the absence of national guidance, the service criteria and model of care have been interpreted and implemented differently in every area. One respondent described the resulting lack of consistency:

I appreciate that a national initiative is going to take time to be in place across the country. However for me it has been patchy, inconsistent and at times lacking a clear and coordinated direction.

Another respondent noted that such service development is outside the skill sets of clinicians:

... as the only resource available at the outset of the initiative to those recruited was a document outlining high-level strategic intent, the team members have had to ‘fill in the gaps’ between strategic intent and service delivery. This requires skillsets beyond those of a purely clinical/professional nature.

Views on the referral criteria varied, from a few saying it was too rigid, to just unclear:

I feel that the implementation of the initiative has been too rigid and as such there has been no room to move or provide local flavour or meet the actual needs of our population.

I am not clear on referral pathways and if these people are being identified effectively.

Are the clients being seen for psychology actually ‘psychologically complex’? – and what does this mean, as compared to specialist mental health services.

Too psychology-focused?

Some stakeholders and workforce have queried and commented on the psychology focus of the Initiative, remarking that the Regional Leads are all psychologists. One survey respondent also commented on the under-representation of social work:

There is a glaring issue in the way social work concepts and theories are presented and represented at governance level. While the Regional leads do their best to represent all initiative staff, there are all psychologists and there is no space for social work theories, models and world views. This is a great omission from the development of the programme and I believe is detrimental to its overall success.

Risk of burnout

We have heard in our interviews how emotionally demanding this work can be on staff, and the valuable role of collegial support. One respondent suggested that these peer support processes need to be more formalised:

I would like there to be a national conversation and processes established for taking care of staff and emotional wellbeing in the workplace. I think the initiative needs to be future proofed and that there is a need for explicitly processes for managing and preventing staff burnout.

Appendix 4: Quantitative analysis of referrals to the Initiative

Purpose of service data analysis

We undertook analysis of data on referrals to the Initiative, in order to help address the following evaluation questions:

- the extent to which rural, low socio-economic and Māori and Pacific patients and their whānau access the psychosocial support services;
- number of contacts with a patient and the length of time a patient accesses the new roles; and
- the timeliness of service delivery (such as length of time from referral to triage and/or first contact).

Approach

Data received for all 19 services

We issued a data request to all services. We sought data on the number of referrals to the Initiative, broken down by:

- source of referral;
- date of referral;
- gender;
- age;
- ethnicity;
- tumour stream; and
- point in the treatment pathway.

We also asked for data on the types of services provided (i.e., whether psychology and/or social work support), time to triage and/or from referral to first session, DNAs, date of discharge, as well as any data on pre- and post-assessment/treatment scores (e.g., distress screening).

We have received data for all 19 services. We have provided site-level feedback to each service, but present regionally aggregated data in our reports so as not to identify individual DHBs' results (the exception being Lower South Island which has just one DHB).

Comparisons to Cancer Registry data

Where possible, we compared the characteristics of patients referred to the Initiative referrals to broader cancer populations as recorded in the Cancer Registry. We did this for ethnicity and tumour stream, at the level of individual DHBs and regionally. The hypothesis being that if the Initiative is effectively filling gaps by reaching more Māori and Pacific patients,

and those with cancer diagnoses associated with higher levels of distress/lower existing supports, then we should see higher proportions of these groups in the Initiative as compared to the Cancer Registry data, for their DHB.

We are aware that the comparisons with Cancer Registry data are imperfect, as the two data sets are different in terms of (*inter alia*) scope and timing. We are therefore limited in what we can interpret from the comparisons.

Limits of the available data

The Initiative data provided to us was extremely variable, in terms of the variables collected, the categorisations used and the quality of data. here is no single variable that all services are gathering. Specific examples include:

- services are using different categorisation systems for tumour stream – some are using the Ministry’s typology, some are using their own system, and others are using free text fields;
- one service is not recording tumour stream at all, one is not recording patient gender, and two are not recording patient age/date of birth;
- only three services are recording the reason for referral to the Initiative (i.e., which Initiative criteria are met);
- several services are not recording the time to triage or first contact, or fields that would enable this to be calculated; similarly, a couple are not recording information that enables calculation of time spent in the service;
- not all services are recording the point in the treatment pathway at which the patient is referred to their service;
- several services are not recording the number of patient contacts;
- most services are not recording NZ Deprivation Index (NZDep) of the patient’s domicile (which would assist analysis of the socio-economic status of patients), though most are recording postcode, which can facilitate conversion to NZDep;
- no services are specifically recording rurality, though collection of postcode could facilitate analysis of this.

We also note that at least one service is maintaining a paper-based data recording system, which made the data extract more difficult and time-consuming for them.

The variations in recording mean we cannot robustly aggregate referrals data to say how many patients in total have been offered and accessed the Initiative. This is because each service is set up differently, meaning declines can occur at different points in the pathway – for instance some services require patient consent from referrers before they are referred in to the Initiative, but declines are not recorded. And once a referral is received, services vary as to whether they record the outcomes of their triage and whether the patient is declined (either by the service or by the patient themselves).

As a result of the data collection and recording limitations by the various services, and the caveats around comparisons with the Cancer Registry data, we are unable to complete in a quantitative way what we normally would achieve, including for several of our evaluation questions. Therefore, to draw strong conclusions we have drawn on the qualitative

information from our interviews, as well as the quantitative information from our workforce survey, to help fulfil our brief.

Overview of results

Most patients referred at diagnosis or treatment stage of pathway

Most patients are referred to the Initiative at the point of diagnosis or during the treatment stage. Services vary in the extent to which they are receiving referrals at the point of high suspicion. With its front-of-pathway focus, we might have expected proportionally more patients to be entering the service before treatment commences.

Tumour streams

Services vary in the profile of their patients by tumour stream. As a referral-driven service, this reflects the nature of their relationships with referrers, which are affected by:

- the structure and location of teams (including whether co-located with referrers);
- the strength of pre-existing relationships between staff; and
- tumour streams/oncology teams they have focused on in during the establishment and early implementation phases of the Initiative.

Some common trends are:

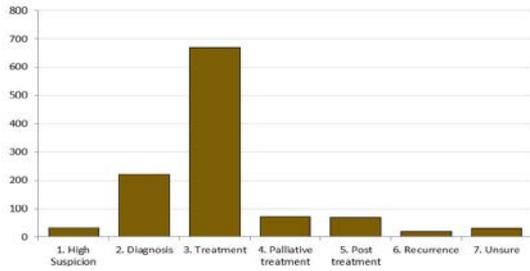
- generally, a large proportion of referrals for breast cancer and lower GI cancers (both as a proportion of referrals and compared to the Cancer Registry); and
- proportionately low referrals for brain, skin and urological cancers.

Ethnicity of referrals

Services are generally receiving slightly higher referral rates for Māori and Pacific patients, compared to the Cancer Registry. While this is a promising start, the question is how much higher should these proportions be? In the absence of baseline data on unmet need for psychological and social support services, and of quantitative targets for the Initiative, we cannot say. Furthermore, in addition to the caveats with the data explained above, we also note that the figures for both Pacific and Asian patients are very small, so we should be wary of drawing strong interpretations from these results.

Table 7 Referrals by point in treatment pathway

Northern*

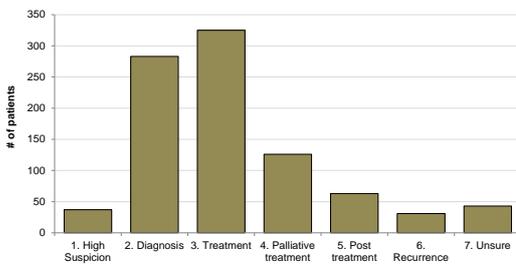


Midland

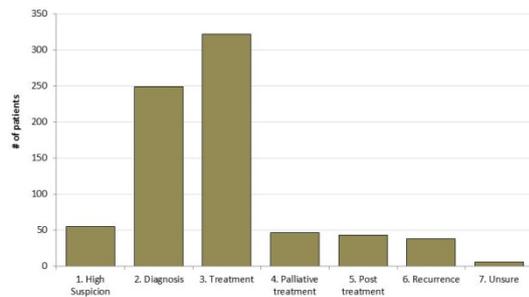
[only 2 out of 4 DHBs collect]

*3 out of 4 DHBs only

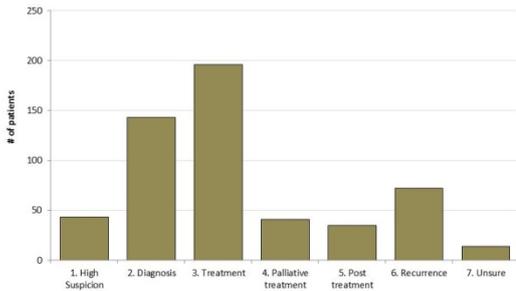
MidCentral



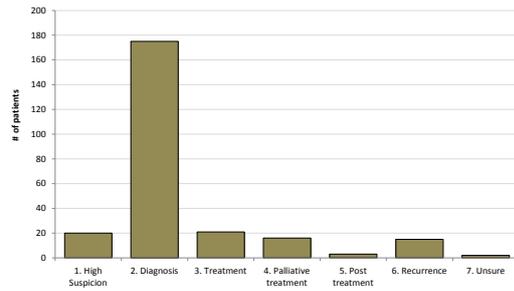
3DHB



Upper South Island



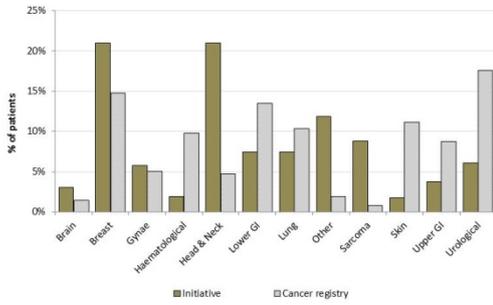
Lower South Island



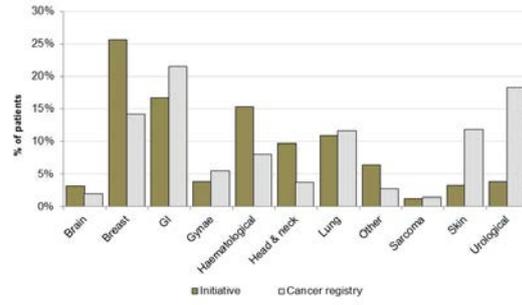
Source: Data supplied by individual services, Sapere analysis

Table 8 Referrals by tumour stream: Initiative vs Cancer Registry

Northern*



Midland*



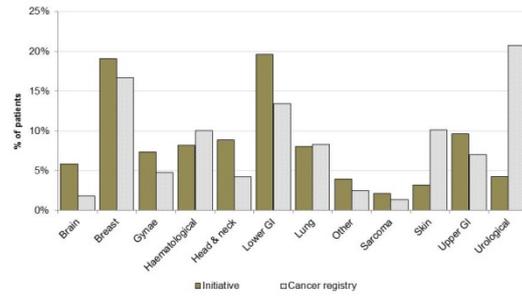
*3 out of 4 DHBs only

*3 out of 4 DHBs only

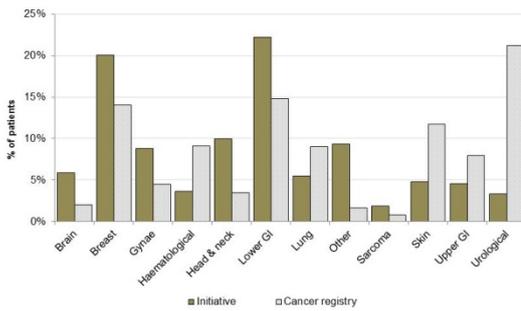
MidCentral

[only 2 out of 4 DHBs collect]

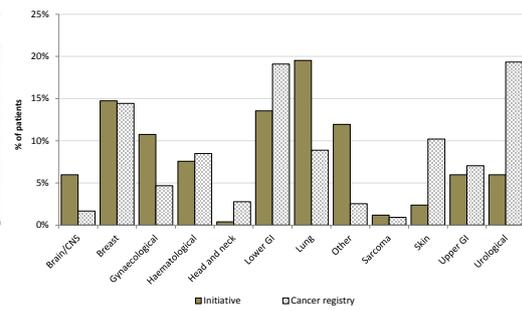
3DHB



Upper South Island



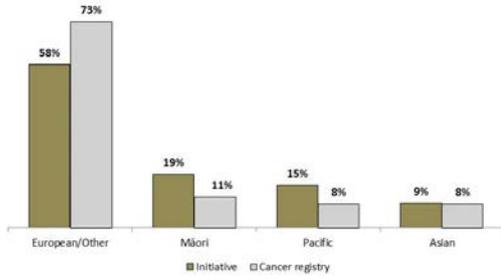
Lower South Island



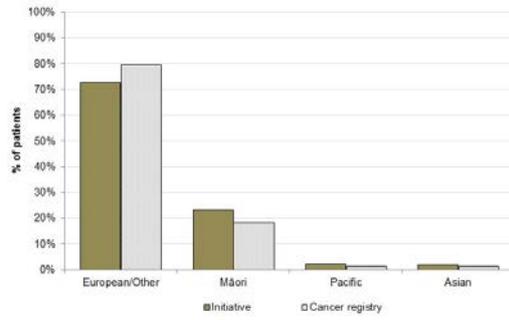
Source: Initiative data supplied by individual services, Cancer Registry data provided by the Ministry of Health and is for 2015; Sapere analysis

Table 9 Referrals by ethnicity

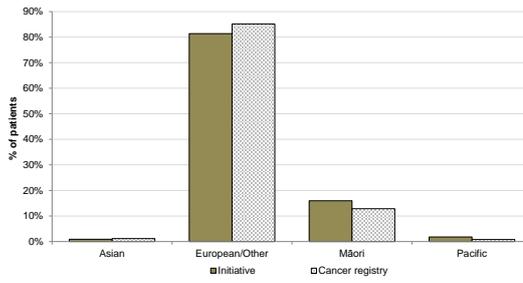
Northern



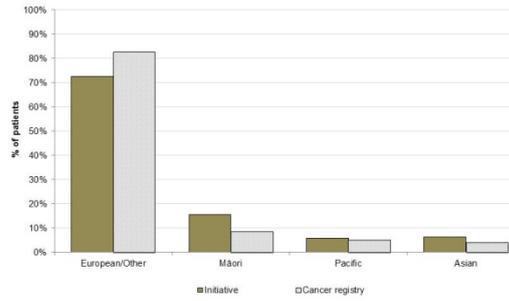
Midland



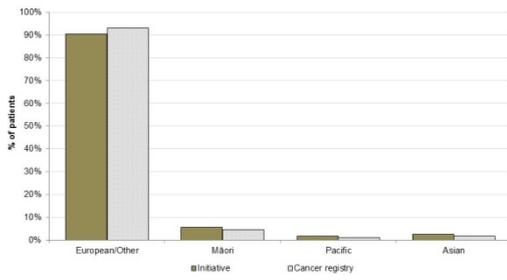
MidCentral



3DHB



Upper South Island



Lower South Island

