MINISTRY OF HEALTH

IMPLEMENTING SUPPORTIVE CARE GUIDANCE PROJECT

PRIORITY AREAS RESEARCH REPORT

AUGUST 2011

FINAL

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INTRODUCTION

In March 2010, the Ministry of Health (Ministry) published the Guidance for Improving Supportive Care for Adults with Cancer in New Zealand\(^1\), herein referred to as ‘the Guidance’. The Ministry subsequently contracted Health Outcomes International (HOI) to undertake a targeted stocktake of supportive cancer care in New Zealand and to develop a prioritised Implementation Plan. The following is a report of research conducted with respect to the priority areas of the Guidance as identified by the sector.

1.1 SUPPORTIVE CARE

The Guidance defines supportive care as:

"The essential services required to meet a person’s physical, social, cultural, emotional, nutritional, information, physical, spiritual and practical needs through their experience with cancer."

The Guidance further identifies eight supportive care domains that require action in order to improve the quality of life for people affected by cancer. These care domains are:

- Coordination of care and support
- Information support
- Psychological support
- Interpersonal Communication
- Social support
- Complementary and alternative Medicine
- Support for living long-term with cancer
- Spiritual support.

For each of these domains of care, the Guidance provides definitions, discusses the relevance of that domain, and makes recommendations for care provision. The Guidance is aimed at both government and non-government organisations involved in programme development, and funding, planning, policy and delivery of cancer support services including:

- Ministry of Health (MoH)
- District Health Boards (DHBS)
- Non-government organisations (NGOs)
- Public Health organisations (PHOs)
- Māori and Pacific service providers
- General Practitioners, allied and other health professionals.

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\(^1\) Ministry of Health (2010). *Guidance for Improving Supportive Care for Adults with Cancer in New Zealand*. Wellington: Ministry of Health.
1.2 **PRIORITISING ACTION**

Whilst the overarching aim is to develop and implement actions across all of the domains of supportive care, the Guidance also notes the need to prioritise activity and allocate funds accordingly. In light of current health system funding and workforce constraints, the initial stage of the targeted stocktake of supportive cancer care was aimed at identifying the key priorities to be addressed. This was achieved through engagement with Māori and Pacific partners/stakeholders and through a series of six ‘Strategic Thinker’ workshops.

We have sought to ensure high quality engagement with Māori and Pacific peoples through engagement and participation with Māori colleagues to ensure that key Māori values and aspirations are built into the project design, approaches and methodologies. To date, partnership with Māori has been enabled through the participation of HOI’s Cultural Advisor, the Cultural Advisor on the project Implementation Working Group (IWG) and close liaison with the Inequalities Managers/Service Improvement Facilitators within the Regional Cancer Networks (RCN). These individuals have collaborated, advised and sought feedback from Māori sector participants and/or networks to ensure attendance at the workshops, contribution to the research processes and observation of cultural protocols as appropriate. To a lesser extent Pacific Communities have also been involved through the IWG Pacific Advisor and the RCN Pacific links. Our Māori colleagues, noted above, have also undertaken to support Pacific engagement in the project.

Six Strategic Thinker workshops were held in each of the cancer centres around the country in order to gather a more ‘rich and broad’ response from the sector than that which might be achieved through a survey. This approach utilised and extended existing supportive care providers and networks, and aimed to increase efficiency by ensuring engagement with representatives of the groups of people for whom the Guidance applies. The approach also aimed to reduce the burden on the supportive care workforce and recognised that time spent in workshops is time away from patients and their whānau/families. A total of 99 sector participants attended the workshops and included:

- Consumer representatives
- NGOs including the Cancer Society
- Clinical service providers (oncology specialists, surgeons, clinical nurse specialist, radiation therapists, social workers etc.)
- Māori providers (secondary care services, community service providers)
- Pacific providers (secondary care services, community service providers)
- Primary care service providers (general practitioner, hospice)
- Planning and funding representatives
- Service leaders, managers and strategic planners.

The workshops sought to answer four broad questions regarding each and every domain of the Guidance:

1. What is currently happening or is planned?
2. What are the service gaps?
3. What are the issues?
4. What are the priority areas for action?

The findings of the workshop were documented in a priority areas action report that was circulated within the sector for validation of the outcomes.

**CONSUMER PARTICIPATION**

Consumer representation in this project is through the existing consumer representative networks on the RCN forums and through the project IWG Consumer Representative position. This project is also complementary to the Cancer Control New Zealand (CCNZ) Voices of Experience research that provided in depth feedback from consumers of cancer services.
1.3 **The Priorities**

The domains of supportive care that were identified as the top three National priority areas in the Guidance include:

- care coordination
- psychosocial support – covering both psychological and social support domains
- information support.

These priority areas align well with the findings of the CCNZ Voice of Experience research, where consumers noted greatest concern with: information provision; confusing information; consideration of patients’ circumstances in treatment planning; and emotional support.

In addition, stakeholders identified a number of cross cutting themes (i.e. factors common to all of the supportive care domains) including: inequality reduction; a whānau ora approach including holistic care support for both the patient and the whānau; equity of service access; the importance of providers’ interpersonal communication skills; the need for timely support; workforce issues; and the importance of assessment of individual support needs.

1.4 **Research of the Priority Areas**

In order to sufficiently inform an Implementation Plan for supportive care, the priority areas identified above were the subject of more in-depth research. This included consulting with key stakeholders, surveying the sector and reviewing the literature. In conducting this research the other domains of supportive care in the Guidance were considered where this linked to a priority area.

Within the New Zealand context, our research of the priority areas identified evidence of well-established and high quality practice, along with significant gaps. Accordingly, the areas for implementation planning and recommended actions are focussed on what the supportive care sector needs to do broadly to improve supportive care for people affected by cancer. In doing so, it is recognised that a number of service providers are already well advanced in these actions. Those who are well advanced in the various action areas could take a leadership role in furthering this better practice nationally.

This report outlines the process for and the outcomes of the research with respect to the 3 priority areas.

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1.5 **Structure of the Report**

Table 1.1 below outlines the structure for the remainder of the report.

**Table 1.1: Report Structure**

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<td>Chapter Three</td>
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<td>Chapter Four</td>
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<td>Chapter Five</td>
<td><strong>Information support</strong> - key findings and recommendations for development of supportive care.</td>
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<td><strong>Summary</strong> - provides a summary of the key findings, a proposed framework for development of supportive care.</td>
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2 METHODOLOGY

This section outlines the methodology used to undertake research in each of the priority areas of care coordination, psychosocial support and information support. Cross cutting themes such as inequality reduction, cultural responsiveness and workforce issues were interwoven in the priority areas research. The project methodology was developed and agreed to in consultation with the Implementation Working Group and the Ministry of Health.

It is important to note that the stocktake findings are limited by the available time and resources to conduct the research and the number of individuals and agencies consulted. However, we are confident that this report fairly reflects the situation within New Zealand.

2.1 CARE COORDINATION

Three broad processes were agreed for the Care Coordination research: 1) an electronic stocktake survey; 2) interviews with key informants; and 3) reviewing publicly available documentation and literature.

The focus of the research was on:

- evidence for the benefits of cancer care coordination and the current and planned approaches to cancer care coordination
- the approaches to care coordination outside of the cancer field such as Long Term Condition Management
- establishing baseline measures of care coordination activity in New Zealand
- identifying the need for cancer care coordination and the associated issues, challenges and successes with current care coordination activity in New Zealand
- any differences in approach, challenges and success measures of Māori and Pacific models of care coordination.

ELECTRONIC STOCKTAKE SURVEY

An electronic stocktake survey (Appendix A) was administered to gather information from the sector regarding cancer care coordination. The survey ran for one month and the distribution method included emailing contacts from a range of relevant networks including:

- the four Cancer Networks
- Māori networks including the inequalities managers at the cancer networks, the IWG Māori representative, known Māori cancer care coordination services and the national Māori PHO
- Pacific networks including the IWG Pacific representative and known Pacific cancer care coordination services
- Primary care nursing networks through the New Zealand College of Primary Care Nurses website
- Palliative care network contacts.
It is estimated that the survey would have been distributed to approximately 1,500 - 2,000 recipients. There were 151 respondents to the survey, the majority of whom were nurses (n=78). These included registered nurses, clinical nurse specialists, nurse managers and nurse practitioners. Medical and social workers comprise the second and third largest group of respondents. Further information about respondents is included in Appendix B.

**Key Informant Interviews**

A total of 21 interviews were undertaken. Key informants comprised:

- six Māori providers
- a Pacific Provider
- representatives of the four Regional Cancer Networks
- representatives of the Cancer Society of NZ
- a men’s health expert at the Cancer Society of NZ
- a representatives of the Leukaemia & Blood Foundation of NZ
- clinical nurse specialists
- social workers
- hospice staff
- tumour steam staff
- personnel from the Ministry of Health, Information Technology (IT) section.

**Documentation/Literature Review**

A review of publicly available documentation and literature was undertaken that included:

- published and non-published research on cancer care coordination
- key documents from within New Zealand including relevant non-cancer care coordination documents (e.g., cancer pathway mapping reviews).

**2.2 Psychosocial Support**

Psychological and social support are discussed as separate sections in the Guidance (Sections 4 and 5 respectively). In discussion with the IWG it was agreed that for the purposes of this research, these supportive care domains would be paired as in this sector the work is often intertwined due to a lack of both psychological and social support personnel and services.

Research on psychosocial support included key informant interviews with 10 individuals representing services in each of the six cancer care regions as well as NGO representatives. Interviews focused on current psychosocial support and gaps against the Guidance as well as areas for action in relation to:

- service delivery, including screening and/or assessment of psychosocial support needs and referral processes
- workforce development, including the capacity and capability of the cancer care sector to provide psychosocial support
- research and development, including any current work being undertaken or planned to improve psychosocial support.

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3 Due to the approach of distribution through other networks, contacts, organisations and links we are unable to note the exact number of recipients of the stocktake survey.
A targeted literature review was also undertaken with the aim of gaining more in-depth understanding of the areas for action highlighted in key informant interviews. The literature review involved examination of:

- previous research on psychosocial support for individuals affected by Cancer in New Zealand to identify whether any changes in the provision of support over time
- documentation of current psychosocial support delivery models in New Zealand as well as plans for service development
- overseas models of psychosocial support in cancer care
- published research on models and evidence for screening and assessment of psychosocial support needs
- published research on health outcomes associated with provision of psychosocial support.

2.3 INFORMATION SUPPORT

Two broad processes were agreed for the Information Support research: 1) interviews with key informants and 2) reviewing publicly available documentation and literature.

The focus of the research was on:

- assessing the need for an information resource(s)
- production of information resources
- quality processes for validating resources prior to making them publicly available
- guidelines to assist patients in accessing appropriate information and/or what questions to ask the care team
- specific approaches used to ensure access to information for various cultural groups
- where appropriate, the coordination of resource development and distribution in order to avoid duplication.

KEY INFORMANT INTERVIEWS

Interviews were conducted with key personnel from:

- Cancer Society of NZ
- Leukaemia and Blood Foundation of NZ
- Various Māori specific service providers
- Cancer Society Australia
- Hepatitis Queensland (to contrast approach used by other health areas).

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4 Note that the review of service documentation included only those documents supplied by key informants and or through the request for documents that HOI made through the RCN networks. This was not an exhaustive review of all documentation related to the provision of psychosocial support in New Zealand.
DOCUMENTATION/LITERATURE REVIEW
A review of publicly available documentation and literature was undertaken that included:

- research on the information support needs of patients
- guidelines and standards for the production/publication of health information
- guidelines for health professionals on the provision of health information to patients
- certification of health information as reliable and credible
- guides as to the questions a patient should ask their doctor.
3 CARE COORDINATION

This chapter presents findings from the care coordination research stream.

3.1 INTRODUCTION

Chapter 9 of the Guidance defines care and support coordination as a ‘Comprehensive approach that seeks to achieve continuity of care and support, drawing on a variety of strategies that strive for the delivery of responsive, timely and seamless care across a person’s cancer service pathway (p. 48)’. Furthermore, the Guidance indicates that the provision of coordinated care and support for those affected by cancer requires:

- good communication between support service providers, the person affected by cancer and their carers
- a single point of contact, such as a specifically trained patient navigator, to support people to access the services they need
- linking Māori, Pacific and other cultural groups to culturally specific cancer support services
- flexibility on the part of healthcare professionals in their responses to the changing needs of people with cancer and their carers
- establishing information transfer systems to ensure that relevant information follows the person affected by cancer both within and between cancer services.

In order to address these care coordination needs, the Guidance includes the following objectives:

1. All people affected by cancer, their family and whānau have access to care and support services
2. Service providers deliver timely and seamless support to those affected by cancer
3. Services are of the highest possible quality and are appropriate to the needs of those affected by cancer, including their cultural needs (p. 48).

In addition to these objectives, the Strategic Thinkers workshops identified systems level and individual level priority issues associated with the provision of care coordination for people with cancer and their whānau:

- Systems level issues included:
  - Knowledge of available services
  - Care coordination within and between care providers (primary, secondary, tertiary and NGO sector support services)
  - Challenges associated with multiple entry points for support
  - Lack of key workers.

- Individual level issues included:
  - Care coordination assessment has the potential to be utilised as a baseline assessment for all supportive care needs
  - Effective care coordination approaches are consistent with a whānau ora approach
  - There is a need to identify where care coordination should be housed (e.g., in primary care/PHOs, in secondary care or with NGOs).
3.2 **Key Findings**

Key findings from the care coordination research stream confirmed the priorities identified in the Guidance and also showed the following.

- There are multiple models of care coordination being utilised across the country, including variations in the staffing of care coordination roles (e.g., professional versus lay staff). These models have generally developed as a result of identifying and responding to the local population and service issues and challenges.
- Communication is the single most important aspect of effective care coordination. This includes communication between patients/whānau and healthcare providers, and between healthcare providers, departments, services, organisations and DHBs. Keys to improving communication include:
  - Timely updating of primary healthcare teams regarding the patient's condition and the supportive care needs of the patient and whānau; and
  - Healthcare provider awareness of the services available to support patients, the processes of linking patients to those support services and of using current 'standalone' information management systems (including the barriers to care coordination that result from standalone systems).
- Currently there are few services that ensure a single point of contact for patients and whānau to obtain help.
- It appears there is a lack of commitment to the care coordination role. For example, stakeholders reported there is insufficient funding and infrastructure support (e.g., administrative) and information management systems are lacking or suboptimal. Additionally, reports indicate that there is insufficient acknowledgement or comprehension of the resources and time required to provide successful care coordination.
- It also appears there is a lack of flexible funding structures to: support collaboration across different sector service providers; to provide additional supports for patients experiencing financial hardship; and to address provider contracts that currently fail to reflect the level of care provided by many coordination services.
- It appears there is little consistency across the regions and across the country in regards to available services (both clinical and supportive) and available funding for support (e.g. prosthetics, travel support, parking costs, and services such as lymphoedema management). Consistency is further hampered by siloed working practices (e.g., information management systems, referral systems, assessment processes, and the services delivery mechanisms and criteria).
- Reportedly there are still gaps in the extent to which services are meeting the cultural needs of patients and whānau, and in the availability of cultural services.
- Recent evaluation of pilot research shows that cancer care coordination in New Zealand has helped to reduce inequalities in cancer service access and care, these findings are also supported through anecdotal evidence obtained in this research.
- Respondents had varying viewpoints on where care coordination services would be housed (primary secondary or both). However there was consensus on the need for communication across services irrespective of the service location.

### 3.2.1 Definition of Care Coordination from the Patient’s Perspective

In addition to the above research key findings the patient’s perspective of care coordination should be considered. The following statement has kindly been provided by a current patient within the healthcare system who is receiving treatment for a cancerous condition:

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3.2.2 Service delivery

Three key themes were identified in regards to service delivery aspects of care coordination including: 1) roles or personnel; 2) care coordination models; and 3) care coordination activity.

Select care coordination roles

Cancer navigators, cancer pathway facilitators, youth and young adult key workers and cancer treatment schedulers specifically provide care coordination services. Additionally, there are a number of other cancer specific and non-cancer specific personnel who identify care coordination as an important part of their job. The following list in Table 3.1 is not exhaustive but provides an overview of some of the roles currently in place.

Table 3.1: Selection of varying Cancer Care Coordination roles identified

<table>
<thead>
<tr>
<th>Specific Cancer Care Coordination roles</th>
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<tbody>
<tr>
<td>• Cancer Pathway Facilitators</td>
<td>• Cancer Navigators</td>
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<tr>
<td>• Cancer Treatment Schedulers</td>
<td>• Adolescent &amp; Young Adult Key Workers</td>
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<tr>
<th>Roles with aspects of cancer care coordination</th>
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<tbody>
<tr>
<td>• Radiation Therapists</td>
<td>• Cancer Specific Clinical Nurse Specialists: Colorectal, Breast, Medical Oncology</td>
</tr>
<tr>
<td>• Oncology Nurses</td>
<td>• Nurse Practitioners</td>
</tr>
<tr>
<td>• Oncology District Nurses</td>
<td>• National and Regional Supportive Care Manager (Cancer Society)</td>
</tr>
<tr>
<td></td>
<td>• Medical and Radiation Oncologists</td>
</tr>
<tr>
<td></td>
<td>• Patient Support Service (Leukaemia and Blood Foundation)</td>
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<td></td>
<td>• Oncology Social Workers</td>
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<table>
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<tr>
<th>Non-cancer specific roles with aspects of cancer care coordination</th>
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<tbody>
<tr>
<td>• District Nursing Services</td>
<td>• Service CNS (who may undertake a component of cancer care coordination) Respiratory, Elderly, Palliative Care, Gynaecology, Orthopaedic</td>
</tr>
<tr>
<td>• PHO nurses</td>
<td>• Nurses, Specialists, Allied Health, Palliative Care Coordinators and so on</td>
</tr>
<tr>
<td>• Nurse Practitioners</td>
<td>• General Practitioners</td>
</tr>
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Cancer Specific telephone support (which assists in care coordination)

- Cancer information helpline (0800 CANCER)
- Leukaemia and Blood Foundation telephone helpline

In addition to the care coordinator roles outlined above, many other cancer specific NGOs are available to increase awareness of available services and provide advocacy/support services (e.g., Prostate Foundation New Zealand, Breast Cancer Aotearoa Coalition, Sweet Louise, Melanoma Foundation, etc.).
Whilst these services provide many valuable supportive care functions, they are not however the primary coordinators of patients’ clinical and supportive care and as such are not included in the above table.

**Approaches to Care Coordination**

Different cancer care coordination service delivery approaches were noted in the stocktake. These have generally developed in response to varying gaps and identified needs across the country. For example, there are cultural cancer care navigation services in Auckland and Lakes, key worker services in Northland and MidCentral, outreach district nursing services in Southland and services utilising case management approaches throughout the country.

Assessment of the need for care coordination (for provision of services and/ or for referral to other support services) was found to be uniformly provided. Needs were either formally or informally assessed using documentation that had been developed by an individual, a service, department or hospital. In general, findings showed that assessments could be undertaken more effectively and efficiently in order to reduce duplication of information and increase information sharing among relevant parties.

Stocktake findings showed that empowerment approaches aimed at supporting and enabling patient/whānau self-management were used by all services that provided clinical care. Another theme was the importance of providing individualised care for patients/whānau, as there is no ‘one size fits all’ solution to care coordination. The level and activity of support and assistance provided varied across services and staff noted that the depth of support provided is dependent upon the patient/whānau needs identified. This approach, although informal, aligns with stepped or tiered care provision described in Section 6.

Over time, as patients become more familiar with hospital systems, services and their condition the input from professionals could be reduced. However, for a small number of patients the level of input may not reduce significantly depending upon the specifics of their cancer journey, the barriers, challenges and their social situation. The stocktake findings indicated that patients were referred to coordination support services at various points post diagnosis. Findings also indicated that there is unmet need, where conditions are not currently supported, or where patients only obtain support later in their pathway (i.e., post diagnosis but not necessarily through to survivorship stages of care).

Only one organisation reported automatic referral of patients for support at the investigation and diagnosis stages of the cancer care pathway. The option for support during this time is important, as the awaiting between investigation and diagnosis can be anxiety producing and a time when patients and their whānau have few support options available. Bowles et al (2008) noted that quality cancer care coordination is “considered to be important at every phase of the patient’s journey from suspicion of cancer to surveillance after treatment.”

The Guidance recommends that service mapping and planning activity be undertaken throughout the sector including national, regional and local levels. These approaches are generally utilised for reviewing service provision or service improvement and developing new services. Currently, there is evidence of this activity at the DHB and regional cancer network levels, as approaches to improve care coordination include support, leadership, and specific projects. Network activity has included the development of cancer care coordination forums. Generally, these forums are open to cancer and palliative care nurses or key workers/navigators in either primary care or secondary care. The main purpose is to facilitate networking, share best practice, promote service development, and provide a venue for resource sharing and accessing education.

Regardless of the specific approach taken to delivery of care coordination there are three key cross cutting themes from the stocktake: 1) a ‘one size fits all’ approach to care coordination does not exist; 2) patients need to be involved in the care coordination process at all steps along the way (including service development); and 3) communication between providers and between patients and providers is the most

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critical factor for effective care coordination. In fact, effective communication is considered more important than the healthcare provider (e.g. Navigator, Social Worker, Case Manager, etc.), or the care coordination model in use.

**Care Coordination Activity**

The stocktake showed that care coordinators engaged in multiple activities/service delivery. As shown in Figure 3.1, the top three activities were: 1) communicating with other health care providers; 2) referral to other services for transportation support; and 3) organising patient appointments.

![Figure 3.1: High level care coordination and communication activity](image)

At the systems level, care coordination included activities such as tracking and managing appointments, triage of referrals, organising extra clinics to meet demand, maintenance of clinical records or databases and attending multidisciplinary team (MDT) meetings where clinical decisions are made.

At the patient level this activity included, but was not limited to, assessment and provision of needs based services, organisation of care coordination including transportation, assistance with appointments, and assistance with childcare or other dependant relatives. Clinical management included assessment, triage of symptoms and acuity, education and provision of information and general psychosocial support.

Education of other staff (e.g., practice nurses, general practitioners, fellow staff, etc.) regarding care coordination was also reported as a core activity.

Care transfer handovers tended to occur if there was a specific critical event for a patient or a whānau member. Most teams noted that there were no services, other than GPs or hospice, to ‘hand over to’ and only one service undertook assessment of need at point of discharge (see 3.2.2 Pacific cancer coordination service provider).

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Additional care coordination activity included supporting patients/whānau with social aspects of care such as financial constraints and costs of cancer care (i.e., loss of income, increased costs such as petrol, parking and prosthetics), and support for childcare, other whānau commitments and/or transport. Stocktake findings on the barriers to care and the supports required to overcome them are consistent with findings reported in the literature.10, 11,12,13,14,15,16

Sixty-five percent of electronic survey respondents undertook care coordination activity for both the patient and their whānau, whereas the remaining 35% provided care coordination only for patients. Of those who also supported whānau the main types of support provided included information and/or educational supports. Supportive care for whānau also featured strongly in the free text responses of the survey. For example, one respondent highlighted emotional support provided… “We support with stress, grief and loss… providing a listening ear.” Other respondents indicated that they coordinate referral for cultural or spiritual support. Finally, whānau support also included coordination of tasks such as organising childcare, accommodation or transport, assistance with engaging with other services or service referral with agencies such as Work and Income and being the whānau key link or worker.

**C O M M U N I C A T I O N**

Networks, relationship building and communication were identified as core components of successful care coordination. This included, but was not limited to: attending team meetings; handover to hospice; liaison with Cancer Society regarding resources, programmes or client referrals; informal connections with other key staff; professional networking groups; referrals to other support services/providers; and communication with primary care providers.

**Coordination between and within Healthcare Teams and Patients/Whānau**

Communication between patients and healthcare providers was consistently identified as both a key component of successful care coordination and a gap in current services. The importance of communication is consistent with the findings from the literature review,17,18,19,20,21 the Priority Areas workshops and from CCNZ Voices of Experience research.22

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As shown in Figure 3.2, respondents reported high levels of communication with nursing staff, social workers, district nurses, allied health, GPs and medical staff.

However, gaps in communication between healthcare providers and patients/whānau and between and across healthcare providers were also noted. In addition to sub-optimal communication being a barrier to effective care coordination the duplication of effort by patients (who often had to retell their story to multiple providers), and by healthcare providers (repeating work already undertaken by others), was noted. The lack of systemic processes for sharing information and specifically the lack of shared electronic information capabilities were cited as reasons for duplication of effort.

Figure 3.2: Key staff included in Care Coordination communication

Note: The abbreviation NASC (Needs Assessment and Service Coordination) was not known by a small number of respondents.

Information transfer

Services noted that information transfer between healthcare providers involved duplication of effort (e.g., writing in service level records and then in the main clinical records). Primary care services were generally updated via telephone for significant events affecting the patient or whānau.

Current standalone information technology (IT) systems that do not ‘speak’ to each other are a significant barrier to timely and effective care coordination and can result in duplication of discussion, assessment and on occasions, investigations or other clinical interventions. eHealth has been identified overseas as an enabler for care coordination at an individual level, team/services level and the systems level.23

The National Health IT programme in New Zealand is developing shared platforms of care, or repositories, which will be functioning from 2014. Select information will be available across regions, and in some instances patients will be able to access components of their records. It is anticipated this will facilitate enhanced care coordination through increasing timeliness and effectiveness of information transfer.

Issues that may be considered to improve current information transfer include:

- Development of standardised documentation, such as regional needs assessment forms that can be incorporated into the clinical data repository system from 2014 onwards

Ensuring NGO organisations key to cancer care coordination are included and have access to the IT repositories (to the level required to facilitate care coordination whilst ensuring confidentiality considerations are upheld).

Confidentiality
Patient confidentiality was not noted as an issue by any care coordination service or individual. Generally policies, protocols or guidelines were in place at service, department, DHB or organisational levels where information was shared. It was reported that these were adhered to, therefore information was only shared with the patients’ consent and there were no concerns regarding confidentiality from the healthcare provider viewpoint. Other services noted that they did not share information and it was retained at the service level.

Service directories
Many individuals, departments or services have developed their own resources, networks and contacts to support them in delivery of care coordination for patients and whānau. In recognition of the duplication of effort and the need for streamlined and standardised information, the four cancer networks have recently developed supportive care directories. These directories are available electronically through the respective network websites. In addition, the Northern Cancer Network has provided this resource via HealthPoint, thus enabling patients and whānau to access this resource through an established healthcare resource tool. It is anticipated that care coordination benefits will arise from continued use of, advertisement and promotion of these resources within the sector, and where relevant to patients and whānau.

NEEDS ASSESSMENT
Mixed approaches to assessment of the need for care coordination are being undertaken across the country. Some services provide a formal assessment of patient and whānau need, whereas other services noted an informal approach, such as responding to needs as they are identified.

Assessment tools or processes
Several services or individuals noted that they had designed a specific needs assessment tool(s), for example:

- multidisciplinary team (MDT) or holistic assessment form
- service assessment form
- service level document (with triggers and assessment prompts)
- fully integrated psychosocial assessment model.

Other services or individuals reported using generic tools such as MedTec templates, nursing or Hospital Admission to Discharge Planners (or similar documentation) for this purpose.

In undertaking care coordination assessments a number of services or individuals reported utilising psychosocial screening tools including the Distress Thermometer and the MidCentral Psychosocial Assessment tool (which has been specifically adapted for the New Zealand context).

Assessments were reportedly undertaken in both secondary care and primary care settings. In general there was the sense that being able to undertake an assessment in a patient and whānau home had two key benefits: 1) both the patients and their whānau were more ‘at ease’ in their home setting; and 2) assessment in the home was more informed. For example, healthcare providers were able to note if beds, linen, heating, and so on were required, if the patient lived alone or had many whānau members living with them. The physical layout of the home and any alterations that might likely be required could also be
observed. Overseas research supports home-based assessments, and from the patient’s perspective they help providers to “…really understand my world”.

Given the complexities, barriers and challenges of cancer care coordination there may be some benefit in services sharing assessment tools and approaches, and shared approaches may also improve consistency in care coordination.

Service exit criteria

Only one service reported utilising service exit criteria. The remaining services indicated that this was either not applicable for the services they provided (as the patients directed the contact) or informal ‘criteria’ existed such as: death; becoming well and no longer having a clinical condition; or no longer needing the support of the service. Two key informants noted that they were working on developing exit criteria for cessation of service provision.

In contrast the whānau approach to care delivery provides altering levels of support, which may reduce or change over time. However the concept of ‘exit’ criteria needs to ensure that cultural processes guide the entire approach and philosophy of care.

Care coordination assessment at service exit

Only one of the services reported undertaking an assessment of care coordination needs at discharge (see Pacific service discussion Section 3.2.2). The remainder of the services either simply discharged patients, or if ‘need’ was evident the support coordination was most likely to be provided through a community social worker, a GP or hospice.

Care transition ‘handovers’ (when undertaken), were noted to be informal or needs based and again generally directed to the GP. For patients who are identified as palliative, referral to relevant palliative care services such as hospice are generally offered. Hospice was consistently noted to receive care transition ‘handover’ information.

There is a wealth of evidence to suggest that patients require additional support during the survivorship phase and that having pathways, tools and resources to support patients and whānau at this time may vastly improve patient and whānau quality of life.

Timely referrals & transfer

Earlier involvement of support services, including care coordination services, was universally identified as a gap in current services. Filling this gap will require: increased awareness by healthcare providers of all of the services available to support patients and whānau; improved communication between services; increased involvement of NGOs; and increased involvement with primary care services.

A consistent theme noted was the lack of awareness or knowledge in secondary care of the services available to support patients and whānau, and the potential beneficial impact these support services could have. A lack of timely referral to support services was a secondary theme. One of the most consistent themes noted by NGOs was the observation that patients regularly and routinely state that they would have preferred to have had access to and knowledge of their support service earlier and this is a finding that is also noted in the literature.

Developing a means for informing healthcare providers of the support services available to patients and the benefits these services can provide could potentially improve outcomes for patients and whānau. Support would be required for healthcare providers to change their practice regarding referral to additional services (e.g., through use of care coordination assessment forms, and regular discussion of care coordination needs with patients and whānau at clinic or ward visits and/or at MDTs).

Transfer and coordination of services may be improved by considering automatic referral of all patients to an organisation such as the Cancer Society, which can use its care coordination services to ensure patients reach other supports that they need: This sort of automatic referral could be phased in over time. For example, initially patients receiving chemotherapy may be referred. If it turns out to be a successful approach, then the automatic referrals could be provided to patients receiving radiotherapy and then to all patients.

**Multidisciplinary Approach**

Multidisciplinary approaches to care coordination were identified in the stocktake as:

- 'An ideal venue for team discussions of referral, assessing needs and allocation of the team member best placed to meet the patient and whānau needs';
- 'A primary method of providing care which recognises the value of the different professional disciplines. This also ensures that professional disciplines can work within their professional boundaries and competencies and therefore ensure safe/quality care'; and
- 'The Midland Cancer Network regional care coordinator framework recognises and promotes the need for strategies to support care coordination at all levels (individual, team, service and system). Potentially this includes involvement of care coordination discussions at MDT meetings'.

None of the stocktake respondents indicated that MDTs (where clinical care decisions were made) were used to discuss information about patient and whānau care coordination issues. However, support for care coordination activity within a MDT setting is well documented in the literature and in the Guidance.

**Care Coordination Clinical & Supportive Care Tasks**

As shown in Figure 3.3 below, survey respondents reported the top three care coordination clinical tasks as: 1) providing support through investigations; 2) explaining investigations; and 3) explaining treatment.

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As shown in Figure 3.4, 87% of respondents provide general psychosocial care (for example emotional, social, psychological or spiritual support), 82% provide referral to other services such as NGOs for provision of supportive care, and 66% reported assisting patients and whānau with organising care for other dependent relatives.

CULTURAL ADVISORS, GUIDES & NAVIGATORS

Cultural cancer navigation services are discussed in detail in section 3.2.2. Care coordination guides or key workers were universally identified as a current gap in services, and the requirement of the healthcare system to be responsive to the cultural needs of all patients and whānau was highlighted.

The Guidance notes that patients should have a single point of contact, such as a specifically trained patient navigator, to support them to access the services they need. Of the key informant interviews where the opinion was expressed that cancer care coordination should not be targeted, comments generally indicated that care coordination should be for all, or for those who wished it. This universal approach was also supported by 44% of respondents to the electronic survey who indicated that care coordination should not be targeted to ‘some’ people.
The majority of survey respondents (56%) indicated that additional care coordination is required by some people, including:

- the elderly
- Māori, Pacific and other ethnic minorities
- patients with low income or receiving benefits
- rurally isolated
- anyone with language or health literacy challenges
- anyone with complex conditions or existing health conditions
- patients with complex care needs
- patients with care responsibilities (young children or the elderly)
- anyone who had care in more than one DHB area
- men and young adults.

Those respondents who supported targeted care coordination services provided rationale such as:

- fiscal constraints
- social isolation
- existing co-morbidities with potential for increased complexities around treatment outcomes
- low income
- migrant populations
- Māori communities with reduced access to services
- Pacific communities with reduced access to services
- high users of services, low socioeconomic and rural patients requiring cancer services.

Some key informants expressed the opinion that community based cancer care coordination or navigation services are possibly better to provide ‘generic’ cancer support services (as opposed to tumour specific). Furthermore, some thought that ‘lay people’ should not undertake cancer care coordination. The rationale provided for this was that tumour stream centred care needs to be clinically focussed at the individual patient level and at the systems focussed and that both levels need to be addressed for successful coordination.

Due to the often highly complex needs of clinical care, a high level of knowledge and expertise on the specific tumour pathway was considered to be minimum competency for the person coordinating care. It was felt that effective cancer care coordination “needs someone who can talk patients through the pathway – demystify the journey for them manage symptoms etc” (Quote 58) and it was noted there is “some aversion by the tertiary service to support from community based nurses who are attached to primary care – chemo etc can be highly complex and subsequently a high level of knowledge and expertise is required to support someone during this time” (Quote 87).

In contrast, other key informant thought that effective cancer care coordination “Really just depends on the job description of the care coordinator and the size of the population the model serves” (Quote 88). Supporting the use of lay staff, cultural service providers discussed evidence (anecdotal and research) that care coordination for specific groups of society has better engagement and outcomes if the healthcare providers are known to, and ‘look like’ the community they serve. Nguyen and colleagues (2008) support this view noting “respect, trust and appreciation of the clients and their worldviews (is required), because knowledge of the culture alone is
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necessary but not sufficient in working with the community”. Regarding navigation programmes for underserved populations, Petereit (2008) notes “navigators can make the difference between suffering a cancer death or becoming a cancer survivor”. In summary, there is evidence that navigation works to improve care coordination for underserved populations. There is also evidence that specific care coordination interventions or services at diagnostic or treatment phases of care are also effective.

In order to provide a single point of contact for patients and whānau, the stocktake identified the need for improved processes to link patients to the respective advisors, guides and navigators available in their area or region. In addition, there may be merit in considering a phased development of a single point of contact, such as a navigator service, commencing with populations where there is evidence of higher need (i.e., based on cancer incidence or inequitable outcomes). Over time this could be extended to ensure all patients who require or wish additional supports to coordinate their care have access to and provisions of that service.

Additional FTE may be required to fill current gaps in provision of care coordination including tumour stream staff or clinical nurse specialists, oncology social workers and travel coordinators - who all provide a coordinating role, among other functions and tasks.

Care Coordination Measurements

Cultural services in particular, but also many of the staff who currently undertake cancer care coordination functions noted that contracts, measurements, targets and reports do not fully address how the services are delivered or the type of services provided.

Due to highly individualised tracking, monitoring and reporting systems it is currently very challenging to make any comparisons between cancer care coordination services. Overall, the need for improved communication, collaboration and the development of monitoring and evaluation of practice is required to ensure that the care provided is of the highest quality and efficiency, and meets the needs of the population being served. High quality service provision may be occurring, but currently there is no means of easily measuring or determining this at regional or national levels.

Where Should Care Coordination Be Housed?

In general stocktake participants who worked in primary care expressed the view that care coordination should primarily be housed there, and those who worked in secondary care felt it was best placed there. Comment from those who believed a ‘mixed model’ was best or who felt that the model was not as important as communication, competencies and other factors are noted below:

- “It doesn’t need to stay in one place - it could be in secondary care for the duration of active treatment AS LONG AS primary care is kept informed”. (Quote 90);

- “Ideally at different places during trajectory of care as patients’ needs change significantly at different points. There is no ‘one size fits all’ as there are so many other variables to be taken into consideration”. (Quote 33);

and

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“[The] key support person needs to be closely linked to cancer service provision to maintain their competencies etc. to ensure patient safety etc. It’s difficult to get one person to have all these competencies, particularly if you’re also expected to manage large numbers of patients”. (Quote 87).

Recent research evaluating three community cancer support service pilots in New Zealand funded by the Ministry of Health has shown that a navigation model that housed cancer support workers in both a secondary and primary care setting was effective in improving communication and service delivery across service boundaries. In contrast a navigation model housed solely in an urban PHO settings suffered from competition for resources amongst other PHOs and challenges associated with networking with secondary and tertiary care while attempting to delivery patient centred care. Therefore careful consideration should be made before housing navigation services solely within PHO settings.

**GENERAL SURVEY FEEDBACK**

The final section of the electronic survey allowed free text entries regarding additional comments respondents wished to provide. Key comments are summarised below:

- **Funding** - The need for more flexibility with funding was noted. This also included the need for flexibility with discretionary spending, as often services do not have "the small sums of money necessary to ease patients’ social and transport difficulties" (Quote A2). In addition issues related to funding silos and inequalities such as the barriers to funding care provision for those less than 65 years of age, national funding variation for services such as compression garments, and oedema care and management and the resulting impact on patients and whānau were noted;
- The National Travel Assistance (NTA) scheme was reported to be too restrictive;
- Barriers to care - travel issues, including distance, cost and out of town accommodation needs for patients and whānau were consistently identified as barriers to care, and parking was also noted as an issue in some DHBs; and
- Time - a number of respondents noted patients require more time with clinicians and additional clinical FTE for care coordination activity is also required.

Many of the above issues have been identified in other New Zealand based research and are generally known to the Regional Cancer Networks, NGOs, DHBs and local service providers.

Considering the findings presented above, further work in care coordination may need to include:

- review of siloed funding practices
- increase in the flexibility of use of discretionary funding available to support patients and whānau
- review of barriers to funding related to age or diagnosis
- review of variation in service provision across the country (e.g., prosthetics and travel)
- review of FTE funding for select key services including gaps in provision (e.g., lymphoedema services, oncology social workers, travel coordinators, clinical nurse specialist)
- reduce or remove parking costs for patients receiving treatments

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• inform all patients of the NTA

• advocate for a review of the NTA criteria, amount of funding and process for reimbursement.

3.2.3 Reducing Inequalities

In order to engage successfully with Māori and Pacific peoples, the importance of the following processes were emphasised:

• face to face (kanohi-ki te-kanohi) contact
• involvement of the whānau
• listening to the primary concerns of patient and whānau and then addressing those to enable engagement, participation and completion of cancer treatment
• addressing social determinants of health (e.g., barriers such as transportation, carer responsibilities, assistance with Work and Income and Housing New Zealand, communication in first language and through use of clear and simple language).

These aspects of successful engagement with indigenous peoples have been previously researched within the context of the New Zealand healthcare system. In fact many have been well documented in key works such as Decades of Disparity, Māori Health Plan, health data and Pacific Health Plan. Despite this fact, these remain core issues for the populations being served and the cultural healthcare providers that are bridging some of the gaps. This suggests that the healthcare system requires further development in this area.

Māori Cancer Coordination Service Provision

Māori models of care coordination identified during the research phase include Te Whare Tapa Whā, a holistic approach to care incorporating; whānau (family health), hinengaro (mental and emotional health), wairua (spiritual health) and tinana (physical health), was the most commonly utilised model. One service also utilised Whakawhirinakitanga Ahua.

Across models, the provision of care for both the patient and whānau as well as identification of the key issues from the patient/whānau perspective was a recurring theme.

Māori care coordination providers reported using empowerment methods of care delivery. This approach initially supports whānau as needed, and as time goes on staff help whānau to become more self-supporting as able. Whānau hui and partnership were recurrent stocktake themes. Whānau partnership helped ensure that whānau were aware that support, advice or advocacy was always available to them and enabled the healthcare coordinator or coordination team to be aware of whānau dynamics, including identification of significant others involved in whānau care and treatment decision making processes.

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45 This approach will result in patients who are do not fit the criteria for support being informed, however no patients will ‘fall through the gaps’ and therefore potentially all patients who are entitled to support will receive it.


53 An organisational based model that incorporates a web of interconnectedness with whānau in the middle and provision for social, health and economic support.
Provision of support for complex ‘needs’ and/or support for the social components of patient/whānau wellbeing that impact upon health were identified as key components of cultural care coordination and assistance. For example, assistance and advocacy with Work and Income, Housing New Zealand, childcare or care of other dependent relatives, coordination of appointments and transportation in particular were tasks undertaken by the cultural providers.

The final theme for successful care coordination aimed at reducing inequalities was the fact that the service providers are known by and are part of the community they serve. Therefore, aspects of successful care provision for a community included being known to and part of the community served, having an ‘open door’ policy, providing a free service and engaging in whakawhanaungatanga.

In general the Māori services surveyed advocated for the main cancer coordination service providers to be situated in the community. However, the need for specific contact/s in secondary care, or partnership with secondary care, was supported in order to facilitate liaison between services (both between providers and between patients and providers) and to improve insight into patient and whānau needs in both settings.

The Māori providers interviewed used a selection of assessment methods ranging from no formal assessment to cultural assessment tools specifically developed for the provision of cancer care.

Māori providers identified several gaps in current services and identified a need for:

- Improving communication:
  - between the different healthcare providers
  - between healthcare providers and patients and whānau, incorporating
    - Cultural competence (delivery of information, tone and body language)
    - Use of clear and simple language
    - Consistency of information
  - between the whānau and the patient
  - aimed at demystifying cancer (e.g., through workshops, tools or expos).

- Working with Iwi to identify the needs of the community and develop a wraparound service to meet those needs.

- Increasing resources, such as:
  - staffing provision or full time equivalent (FTE) to provide more care coordination roles for Māori communities so that all who need or want care coordination have access to it
  - financial support to patients and whānau – for some there are huge challenges to provide food for their families, appropriate household items (bedding) transportation issues are also a very large part of the work undertaken
  - access to Kaumatua (elder advice and support) and spiritual guidance
  - more flexible funding arrangements.

- Having a key contact or person in Work & Income to assist in liaison and provision of services to patients and whānau affected by cancer.

- Contracts and measurements that reflect the work undertaken in cultural settings. A consistent theme noted in the interviews was the flexibility of service needed to provide whānau ora based care. There was acknowledgement that this work often extends to social needs and is not strictly ‘health’ related. However, without more ‘wide ranging’ supports (i.e., social support needs), the patient and whānau might be unable to attend to healthcare needs.

Further research on Māori models of care and dissemination of findings to support the sector in learning from and adopting improvements or innovation is required.

PACIFIC CANCER COORDINATION SERVICE PROVIDER
Only one Pacific cancer care coordination service provider was identified. This is a 2-year pilot service provided in West Auckland. As with the Māori cancer care coordination services, provision of care is patient centred, and the supports provided are based on needs identified from the patient and family perspective. A strength based model of care provision is also utilised to support and enable patient and family self-management.

This service utilises both a cultural assessment tool on admission and appears to be the only coordination service currently undertaking a discharge assessment. In addition the service conducts quarterly assessments of acuity related to identification of needs with goal setting involving the patient and family. The review of progress and achievement of goals results in identification of new goals, as appropriate, and resetting of acuity status. Finally, the service also undertakes an exit evaluation of the service itself, aimed at reviewing the patient experience, service provision and improvement opportunities.

Communication challenges were reported to be impacting on the delivery of culturally appropriate services (e.g., lack of face-to-face communication and mispronunciation of patients’ names by healthcare providers). Communication issues between healthcare providers, as discussed earlier were also identified. The expense of language translation services and services available for the number of Pacific languages was also highlighted as a barrier to culturally responsive care. Additionally it was reported that patients were not being referred to or made aware of the Pacific care coordination service.

As with the Māori service providers, the need for additional resourcing (for FTE) was identified by stocktake participants.

Further research on Pacific models of care and dissemination of findings to support the sector in learning from and adopting improvements or innovation is required.

3.2.4 WORKFORCE DEVELOPMENT

Three key themes related to workforce development identified in the stocktake included: 1) communication; 2) cultural awareness; and 3) awareness of the services available and training/education programs for Navigators. These themes are discussed below.

COMMUNICATION

Communication was the core theme identified in the stocktake and issues with communication were noted at several levels: between healthcare providers and patients and whānau; between healthcare providers within and across organisations, within and across regions, and nationally. Other aspects of communication considered included verbal tone, cultural awareness and sensitivity, and written and electronic notes. Additional communication issues included sharing patient notes in real time and medication reconciliation across secondary care, primary care and providing select information to relevant NGOs – clearly in adherence with patient confidentiality.

Communication training for all working in the oncology sphere was identified as key to improving communication processes across service boundaries and within different modes of communication. Additionally, greater systematisation of referral and service coordination processes may improve some forms of communication (e.g., patient note sharing).

CULTURAL AWARENESS/COMPETENCIES

Several of the DHBs and a number of NGOs provide cultural awareness training to assist staff in provision of culturally appropriate care. However, as previously noted, both Māori and Pacific providers indicated that patients consistently report a lack of cultural competencies among staff. Cultural awareness/competency training has been delivered in various ways for a number of years in DHB settings; however evaluation of these types of training and the subsequent impact upon working practices is an unknown quantity. In order to know more about this, work would need to be done in determining a set of criteria for measuring effective cultural awareness and competency training and to document successful cases where this has resulted in improved practice.
Key to patient and whānau accessing support is receipt of information about services and resources available to them. This is contingent on healthcare providers’ knowledge and awareness of the care coordination and support services available and of the beneficial impact that those services can make for patients’ and whānau.

NGOs reported that they are often ‘left out of the loop’, and that there is an apparent gap in awareness of their role and how they can support those affected by cancer. Secondary care services were identified as being highly ‘event’ or admission focussed, and whilst they generally provided excellent care, there was a gap in the lack of oversight or ability to view the patient within their wider context of a life, family, community and so on. Some of this is due to hospital staff having high workloads, the evolution of silo based care, funding constraints and on occasions a general lack of insight into patients’ life outside of the hospital setting. Developing new networks, relationships and an understanding of patient and whānau health needs outside of the hospital was advocated for all healthcare providers.

**Training or Professional Development Programme for Navigators**

Findings indicate that navigators (or key workers, community support workers and so on) need a baseline level of clinical competencies regarding their knowledge of disease, treatment process, and they also need to have a broad view of the cancer pathway and care systems. Critically, they also require extensive networks in health and social care services, which enables them to undertake their role effectively.

Specific concerns were raised during the key informant interviews regarding the lack of sufficient navigator FTE, the differences in navigation services and their access to education and support services.

Support for the development of competencies for cancer support workers such as navigators could assist both patients and whānau to receive the highest standard of care and could assist navigators to provide patients and whānau with the resources, competencies and the skills to undertake their role as effectively and efficiently as possible. The requirement for basic competencies could also improve the credibility of care coordination services and increase inward referrals. Needs assessment and processes for tracking delivery of supports should have some degree of standardisation to enable a comparison of services, tracking of outcomes and subsequent dissemination of better practice and effective models. Any standardised measures should allow some flexibility of local adaptation based on cultural/social or other context.

Supporting networking between navigation services may also assist to prevent duplication or reduction of effort. For example navigation services could share learning’s with each other regarding developing patient diaries, education programmes and the tools, such as the leaflets and posters used to promote their services.

### 3.2.5 Research & Evaluation

As discussed below, three key themes identified in the stocktake regarding research and evaluation included: 1) support for measuring patient experiences of care and cancer care coordination; 2) support for measuring outcomes of cancer care coordination; and 3) listening to healthcare provider staff regarding their experiences and improvement suggestions.

**Patient Experiences**

Universally, all key informant interviewees identified the most important component of care coordination that should be evaluated was the patients’ experience of care. This aligns with findings and recommendations from CCNZ’s *Voices of Experience Research*. Some stocktake participants also discussed utilisation of co-design methodology as a valuable approach to service development. Co-design is an experienced based design approach where patients, whānau and healthcare providers work together in equal partnership to identify issues and improvement opportunities.

**Measurements of Cancer Care Coordination**

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As noted previously, cultural services in particular, but also many of the staff who currently undertake cancer care coordination functions indicated that contracts and measurements, targets or reports do not fully address the services delivered and how these services are provided by them. Currently, measurements, when undertaken are generally linked to service level reports or aligned to contract or Ministerial reporting requirements such as referral times. In addition services are reporting on outdated or inaccurate formats that fail to document the social aspects of care that are needed and met through coordination services. Therefore business information, review and planning opportunities are missed.

Currently, it is very challenging to make any comparisons across cancer care coordination services in their data collection and transfer processes due to their highly individualised tracking, monitoring and reporting systems. Overall the need for improved communication, collaboration and the development of monitoring and evaluation of practice is required to ensure that the care provided is of the highest quality and efficiency and meets the needs of the population being served. High quality service provision may be occurring, but currently there is no means of easily measuring or determining this.

There are potential planning, monitoring and reporting advantages to developing baseline measurements (e.g., needs assessments) that all cancer care coordination services can record. In addition measurements that accurately enable the recording of the work/mahi undertaken in cancer care coordination are essential.

**Staff Experiences and Thoughts on Service Improvement**

Some key informants proposed that working with frontline staff to identify appropriate evaluation measures including successes and improvement opportunities would be beneficial. Valuing the input of these staff members and the positive contributions that can be made to patients and whānau was also felt to be positive and affirming for the staff.

Interestingly only three stocktake participants, all cultural service providers, reported involvement in research activity regarding the model of care coordination they deliver. One respondent noted that she had participated in action research. Action research is a style of qualitative research typically utilising interviews and observation and critically, involves participants in the process, rather than just conducting research ‘on them’. Meyer (2000) notes that action research is “particularly suited to identifying problems in clinical practice and helping develop potential solutions in order to improve practice” (p. 178). Two other services had been developed through specific research and one staff member who participated in the research was now, five years later, involved in delivering the care coordination service.

**3.3 Implications for a Supportive Care Implementation Plan**

There is no ‘one size fits all’ approach to care coordination. To meet the care coordination needs of patients and whānau, healthcare providers need to deliver individualised care within the context of the local services available and the model that they work under. Additional key findings are noted below.

**Communication**

Communication was the primary issue raised in the stocktake and the key to effective and successful cancer care coordination. Improved communication between patients/whānau and healthcare providers and between and across healthcare provider departments, services and organisations cannot be stressed highly enough.

**Culturally Responsive System**

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Meeting the cultural needs of patients and whānau was identified as one for the main ways for ensuring cancer inequality reduction. As previously identified this included improved communication, increased FTE of Māori, Pacific and other cultural workers, for example “I am not aware of services for Asian or refugee communities. We are increasingly seeing our refugee communities now on a cancer journey” (Quote 37). Increased flexibility in systems, such as appointment systems, transportation support, parking allowances and so on was also consistently identified as key areas for improvement. In particular to provide culturally responsive care, there is a need for healthcare providers to be cognisant of Māori worldviews, diverse Māori realities and effective strategies for engaging with Māori and the impact of these on healthcare choices and decisions.

**Model of Care Coordination**

It is proposed that care coordination should be part of a tiered model of support, in which increasing supports and interventions, dependent upon the individualised needs of patients and whānau are provided (see Section 5). The Guidance (p. 50) notes that the Ministry and the Networks are working to develop an optimal care coordination matrix and patient management frameworks for each of the major tumour streams. The matrix and framework developed by the State Government of Victoria’s Department of Human Services in Australia is the reference point for this work. Utilising the proposed model in this document alongside a care coordination matrix, and alongside a more general model of tiered supportive care, patient management frameworks and other relevant literature for care coordination, the Networks can develop regional care coordination models that meet the needs of the populations being served. Some additional considerations for developing those models include:

- patients and whānau need to know what is happening next and who to contact should they have any supportive care needs. For some patients this can be achieved by providing a telephone number, for others this may require access to evidence based website resources, and for others still this may require having an identified key worker or navigator to support them on their pathway

- key workers should be available to all patients who wish to access and utilise their support. As noted, key workers can currently be found through various models: Navigators, Community Health Workers, Clinical Nurse Specialist, Tumour Stream Nurses, and Social Workers etc.

- no one role is suggested, as the key worker needs to be the right person with the right skills at the right time for the patient and whānau needs. However a baseline set of competencies are recommended and as previously stated the supportive care stepped model can be utilised as a framework to develop and provide care coordination services

- the role of primary care in providing supportive care is consistently identified by primary, secondary and NGO sector representatives as being critical in the coordination of effective cancer care. Real time access to current clinical records and medications (for medication reconciliation purposes) are essential to primary care providers’ effective delivery of supportive care

- methods of collaboration between the public healthcare system and NGOs and other voluntary organisations to support and coordinate care for patients and whānau should be explored

- each DHB and representatives from across the sector should also be involved in the development of a regional model of care coordination. The Networks could also use a regional workshop as an opportunity to engage in partnership with patients regarding the development of a care coordination model.

**More Flexible System Required**

It was generally acknowledged that the way that healthcare systems are currently funded and delivered does not always enable meeting patient and whānau supportive care needs. Rather than try and ‘fit’

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patients into existing services, it was recommended that service flexibility be improved to respond to patient and whānau needs.

Flexible funding models were also advocated for to enable support of social needs that currently act as barriers to accessing and benefiting from healthcare services. As previously discussed, developing service measures that account for the social support activities involved in cancer care coordination was recommended.

**Consistency**

Consistency of services needs to be improved to reduce regional disparity in:

- service provision (e.g., access to services such as travel coordinators, lymphoedema management services, clinical nurse specialist, navigators and cultural support workers); and

- funding (e.g., prosthetics, travel support and parking costs).

Additionally, processes such as standardised care coordination assessment systems, baseline measurements and tracking, information provision across service providers and a general reduction in the provision of siloed working practices would improve consistency of care both within and across regions.

With these key findings in mind, the following table presents areas for action in care coordination specified by the Guidance and links these to key areas for development as identified through the stocktake, as well as recommended actions for developing care coordination. Responsibility for carrying out each recommended actions is designated at the service, regional and/ or national levels and for each action the requirement regarding one-off (O), short term (ST), or sustained funding/ development (S) is specified. Where the action is a component of regular business activity, this is noted as business as usual (BAU).

<table>
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<tr>
<th>Action Area from Guidance</th>
<th>Areas for Implementation Planning</th>
<th>Recommended Actions</th>
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<tr>
<td>Service Delivery</td>
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| 36. Develop co-ordinating cancer care and support service models to ensure a seamless interface between hospital and community-based support service settings for people affected by cancer. | As part of the framework for supportive care; nationally the definition of cancer care coordination should be agreed, a model of care coordination service delivery developed and a minimum data set for activity reporting developed | • At a national level, review the definition of cancer care coordination including principles of care, key functions and tasks (for example, see the Northern Cancer Network care coordination project). (O)  
• Nationally, develop a model for care coordination, specifying the minimum standards for: service delivery, cultural service provision, assessment, documentation and minimum training requirements. (O)  
• At the service level and regionally, local adaptation of the care coordination model should include development of a systemic process for formal, regular, prioritised and culturally appropriate assessments and processes to ensure that patients have an identified point of contact. (O) and then BAU.  
• At service, regional and national levels, develop minimum data set to inform service contracting & funding decisions. (ST)  
• Develop communication processes/systems for providing coordination of care for those affected by cancer along the continuum of care  
• Develop a national information sheet template (for adoption at the local level) that refers those affected by cancer to the key support services available (e.g. GP, tumour stream nurse, social worker, key NGOs, cultural support, information resources, Cancer information helpline). (O) then BAU |
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<tr>
<th>Action Area from Guidance</th>
<th>Areas for Implementation Planning</th>
<th>Recommended Actions</th>
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<tr>
<td></td>
<td>Pathways, protocols and policies are developed locally to support staff in systemic assessment, provision and referral of patient and whānau for their cancer care coordination needs. (O) and then BAU</td>
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<td></td>
<td>Staff receive appropriate training to utilise assessment and communication tools, and supportive care IT, paper and web based resources to assist them in care coordination tasks. (ST) and then BAU</td>
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<td></td>
<td>Nationally, work with the National Health Board IT team to ensure cancer care coordination is included in eHealth developments (i.e. develop paper-based systems with a view to being adapted to electronic data management by 2014). (ST) and then BAU</td>
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<tr>
<td>Reduce disparity in core support services including service provision (prosthetics, oncology social workers, navigators, travel coordinators etc.) through more flexible funding, and improved coordination/referral processes.</td>
<td>Based on the national minimum service standards, identify regional level service gaps. (ST) and then BAU</td>
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<td></td>
<td>Address identified and prioritised service gaps at the national and regional levels. (O)</td>
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<td>37. Develop culturally appropriate co-ordinating cancer care and support models to improve access to support services for Māori and Pacific peoples affected by cancer.</td>
<td>Service providers undertake audits, surveys and service improvement initiatives to establish service delivery appropriateness for Māori and others. (O) and then BAU</td>
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<td></td>
<td>Use a consumer co-design approach when developing and implementing services. (ST) and then BAU</td>
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<td></td>
<td>Nationally/regionally document, evaluate and disseminate successful Whānau Ora approaches to care coordination through the information network (ST) and then. (BAU)</td>
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<td></td>
<td>Ensure an adequate range of support is provided for whānau who are providing the care coordination within the whānau (training, assessment)</td>
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<td>Ensure that all service providers are delivering culturally competent care for Māori and others</td>
<td>Based on the national minimum service standards, identify regional level gaps in culturally appropriate services. (ST) and then BAU</td>
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<td></td>
<td>Address service gaps at national and regional levels in accordance with agreed models of supportive care. (O)</td>
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<tr>
<td>Ensure sustainable funding for culturally appropriate services (including Māori and Pacific services) as required to support local populations</td>
<td>Develop culturally appropriate needs assessment tools utilising a co-design approach(O)</td>
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<td></td>
<td>Where assessment tools exist (and where relevant), these should be shared for use by other appropriate service providers. (O) and then BAU</td>
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<td></td>
<td>Ensure the involvement of whānau (O) and then BAU</td>
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<td>Ensure needs assessments are culturally appropriate for the target population and are conducted across multiple points along the continuum by appropriately trained staff</td>
<td>Ensure the range of cultural specific services is included in National and Regional service directories and patient information sheets. (BAU)</td>
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<td></td>
<td>At the regional level, develop and implement locally appropriate mechanisms for enhancing patients’ whānau awareness of cultural specific and mainstream supportive care services that are available. (BAU)</td>
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<tr>
<td>Increase service provider and patient/whānau awareness of cultural specific services (e.g. direct them to the relevant supportive care directories and/or provide direct links)</td>
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<td>Action Area from Guidance</td>
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<tr>
<td>Workforce development</td>
<td>Increase sector awareness of the benefit of care coordination and of supportive care services available in each area or region.</td>
<td>• Locally, where they exist, Māori specific service providers should promote their services and collaborate/liaise with general service providers. (BAU)</td>
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<tr>
<td></td>
<td>Identify education and resource supports required by cancer care coordinators (including those who have care coordination as a large part of their role) to undertake their role</td>
<td>• At the service level and regionally, document and disseminate successful care coordination practice (inclusive of cultural specific examples) including findings for the benefits of care coordination on patient outcomes. (ST) and then BAU</td>
</tr>
<tr>
<td></td>
<td>Provide support for and resourcing of Māori workforce development initiatives</td>
<td>• Ensure the benefits of care coordination are included in the orientation/induction of staff working in the cancer sector, including adherence to tikanga best practice. (ST) and then BAU</td>
</tr>
<tr>
<td></td>
<td>Develop systems for monitoring, tracking and evaluating care coordination outcomes</td>
<td>• Nationally and regionally, increase awareness of the regional supportive care service directories. (BAU)</td>
</tr>
<tr>
<td>Research and Evaluation</td>
<td>Build plans for monitoring and evaluation, including targets for change into service development plans, as well as to the [national strategy for a framework of supportive care.</td>
<td>• Nationally, agree baseline competencies for all staff in regards to their role in the coordination of care for those affected by cancer. (O) and then BAU</td>
</tr>
<tr>
<td></td>
<td>Support the dissemination of best practice service improvement approaches, research and evaluation activity</td>
<td>• Nationally, agree baseline competencies (including cultural competencies) required for ‘care coordinators’ roles (e.g. navigators, and others who have coordination as a significant portion of their role). (O)</td>
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<td>• Nationally, ensure that cultural knowledge is included as part of the baseline competencies required of all staff. (S)</td>
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<td>• Explore the possibility of using one-off funding schemes to up-skill and develop the Māori workforce in care coordination tasks (e.g. see the Whanganui inequalities pilots). (ST)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Provide bi-cultural training and education around cancer supportive care for Māori / whānau to align tikanga best practice/ Māori models of care and assessment</td>
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<td></td>
<td>• All levels, collect and analyse data on the efficacy/ effectiveness of care coordination services on improving patient outcomes, including Māori and others facing inequalities (e.g. reducing unmet supportive care needs, lowering distress), while conducting evaluations of service processes. (S)</td>
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<td>• At the service level and regionally, use the supportive care rubrics to assess the extent and quality of cancer care coordination. (ST) and then BAU</td>
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<tr>
<td></td>
<td></td>
<td>• Nationally, ensure that systems for monitoring and tracking supportive care data (e.g. service utilisation, patient distress data) are built into service agreements. (O)</td>
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<tr>
<td></td>
<td></td>
<td>• Use the Network websites to disseminate models of care coordination and the care coordination outcomes for all those affected by cancer but also specifically for Māori and others facing inequalities. (BAU)</td>
</tr>
<tr>
<td>Action Area from Guidance</td>
<td>Areas for Implementation Planning</td>
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<tr>
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<td></td>
<td>At the National and regional level, develop and implement appropriate mechanisms for reviewing, discussing and disseminating best practice service improvement, research and evaluation practice. (BAU)</td>
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Psychosocial Support

During the Strategic Thinkers workshops with the sector, both psychological and social support needs were identified as priority areas. Given their close ranking in the prioritisation process and because of the frequent pairing of these support domains in the research literature, a decision was made with the IWG to conduct research on and make recommendations for the development of psychosocial support in New Zealand, rather than to review the two areas separately. This chapter presents a report on findings from the Psychosocial Support research stream.

4.1 Introduction

The psychological impacts of cancer and its treatment can lead to significant distress, including anxiety and depression, as well as other adjustment disorders.\(^\text{57}\) This reactive distress may compound any existing psychological concerns. Pre-existing social care needs may also be compounded by a cancer diagnosis, and barriers to cancer service access and care such as financial issues can make progress along the cancer care continuum even more difficult.\(^\text{58}\) Unmet psychosocial support needs are related to poorer patient outcomes such as lower quality of life, lower satisfaction with treatment, and poorer adherence to treatment advice.\(^\text{59}\) There is mixed evidence for the link between increased distress and reduced survival.\(^\text{63,64}\)

In chapters 4 & 5, the Guidance recognises the importance of attending to the psychological and social support needs of cancer patients by outlining key objectives for delivering support including:

1. The mental health and wellbeing of people with cancer and their carers is considered at all stages of the cancer pathway
2. Those affected by cancer have access to mental health services appropriate to their needs, and those experiencing significant distress or disturbance are referred to health practitioners with the requisite specialist skills

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3. The work-related mental health needs of staff caring for such people are acknowledged and managed.

4. The social support needs of those affected by cancer are routinely assessed and addressed by the relevant health and social support agencies working collaboratively with people with cancer, their families and whānau and those affected by cancer.

5. Timely and acceptable practical and financial support are available to those affected by cancer.

6. People with cancer and their carers experience an integrated and coordinated system of continued social support, overseen by trained health professionals, to ease the social consequences arising from their experience with cancer and to enhance their quality of life.

In addition to these objectives, stakeholders in the Strategic Thinkers Workshops identified a number of concerns related to psychosocial service provision in New Zealand, such as:

- Regional variation in the delivery of psychosocial support, with large gaps in some areas.
- Clarity needed around issues of screening and assessment of psychological support, including how, by whom, and when.
- Awareness of variation in screening tools being used around the country if it all, and concern for cultural utility of these tools.
- A desire to explore the workforce training needs to ensure that the cancer care workforce understands what psychological support is and how it can be implemented.
- The under-use of multi-disciplinary teams (MDTs) to discuss patients’ psychosocial care needs.
- Lack of a skilled workforce.
- Lack of funding or siloed funding hampering access to psychosocial support by those affected by cancer.

Chapters 4 & 5 of the Guidance show that a number of the components of a ‘high quality’ service are the same for both psychological and social support. For example in both chapters, the need for systematic assessment of support needs, development and maintenance of service directories and access to health professionals and community providers that have up-to-date knowledge of local support services are outlined, as well as the need for integrated and coordinated care. However, it should be noted that during stocktake consultations some stakeholders expressed concerns that these two areas were being combined given that psychological support and social support are distinct disciplines with different training and credentialing processes. Although, the section on Care Coordination (Section 2) identifies the social needs of cancer patients and their whānau and presents models for the provision of care including social support, it may be that more research is needed to inform the implementation plan with regard to social support.

The following sections present findings from key informant interviews and a targeted literature review, which aimed to assess the extent to which sector service delivery, workforce development and research and evaluation activities were meeting the Guidance’s objectives and action areas for psychological and social support.
4.2 **Key Findings**

Increasingly and around the globe, biopsychosocial models of cancer care are being recognised as key to improving and maintaining the wellbeing of those affected by cancer and research and that through appropriate psychosocial support health care costs can be reduced via fewer unnecessary medical visits and procedures and reduced hospital admissions.\(^{46}\) Although, there are differences in models of care and mixed evidence for how screening for psychosocial distress should be undertaken, there is a move to recognise distress as the 6th vital sign (alongside body temperature, pulse, blood pressure, respiratory rate, and pain in the case of cancer care). Moreover, programmes are being implemented overseas to develop/adapt triaged models of cancer care to incorporate psychosocial support into the local context.\(^{66}\)

Findings from the targeted stocktake suggest that currently, assessment of the need for and provision of psychosocial support for those affected by cancer is inconsistent across the country and even across DHBs within cancer treatment centres. Supportive care service referrals and coordination processes appear to be better in larger cancer centres/urban centres, but apart from the workings of a few exemplary services, most of these processes are informal and rely on relationships between staff across service boundaries. Importantly, very few services were found to be collecting data on referrals and patient outcomes. Therefore there is little data on the extent of need for psychosocial support or uptake of support services, and little data on the outcomes of supportive care for those who take it up. This complicates the funding and resourcing of services. Although there is no quantitative data on the matter, stocktake findings indicate that psychosocial services in New Zealand are under-resourced, and this is reported to contribute to service gaps, and inconsistencies in supportive care.

Despite these challenges, there is evidence that some of the cancer treatment centres are working well to triage and provide support for psychosocial needs, and smaller, locally specific initiatives across the country are being implemented to improve services along the continuum. Moreover, there seems to be a general appreciation amongst care providers of the importance of attending to the psychosocial needs of those affected by cancer. Concern mostly centred on how services should best be provided in light of current constraints on service delivery.

A national approach to the provision of psychosocial care would help to provide direction to individuals working in cancer care in how best to assess and triage support needs. Research from overseas indicates that guidelines and care models may help provide cancer sector staff with a framework for integrating psychosocial care into cancer treatment. National guidance combined with workforce training on tiered approaches to care, along with systemised referral systems will help realise the objectives and action areas of the Guidance. Importantly, once more systematised processes are in place, service data and patient outcome data (e.g., pre and post service distress scores) can inform further development of supportive care services.

### 4.2.1 Service Delivery

**Integrated Service Delivery**

The Guidance recognises the various ways that psychological support can be made available to those affected by cancer (e.g., liaison service, PHO-based), but notes that an integrated service delivery model is preferable to enable establishment of local expertise within services and facilitate uniform national service provision.

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Results of the stocktake indicate that few of the cancer treatment centres have dedicated FTE for the provision of psychological support. As such, there is variation in the staffing and support available across the treatment centres, as follows:

- **Auckland**: There is one dedicated FTE health psychologist with a second position being created; both funded by the DHB, as well as health psychology roles funded by the local Cancer Society.
- **Waikato**: There is no psychologist attached to the regional cancer centre and there is no DHB funding for psycho-oncology services.
- **Palmerston North**: MidCentral DHB contract a psycho-oncology service through Massey University, comprised of 3 FTE, which includes clinical psychologists. This contract is not guaranteed (i.e., it is up for renewal every 1-3 years).
- **Wellington**: There are no specialist psychology services within the DHB. Patients get referred through threshold criteria and services are provided through IDF payment.
- **Canterbury**: There is no specialist psycho-oncology service but there is 0.5 FTE provided by a clinical psychologist for patients in Haematology. There is limited access to general psychological support through mental health services for those patients who are deemed to need it.
- **Dunedin**: There is 1.25 FTE position (currently vacant) for dedicated psychological support providers. At the time of this stocktake, recruitment was underway to fill these positions.

A stocktake of psycho-oncology services across the cancer treatment regions was first undertaken in 2009. The current findings show that there has been little change since then in the basic structure of psycho-oncology services at the larger centres apart from an additional FTE funded by ADHB. Thus, the ‘ideal’ model for integrated support outlined in the Guidance is not being realised in all regions. Importantly, even in cancer centres where there are integrated services, these services may not apply across the whole cancer continuum. For example, in Dunedin, dedicated psychological support is available through the Regional Blood and Cancer Service. However, supports and funding are different for patients receiving surgical treatment, leading to disconnection among available services and lack of service continuity.

Service integration is also affected by funding silos for psychological support in tertiary and secondary services. For example, in Palmerston North, MidCentral funds access to psychological support for patients domiciled in its DHB and historically for patients from other DHBs receiving treatment at the regional cancer treatment service. However, in recent times referring DHBs have been asked to fund their own patient’s access to this service. Prior to treatment and once patients are discharged to follow up care, issues of funding become more complex, as it is not clear who should fund pre and post treatment supports. Similar issues are seen across the treatment centres where different DHBs are funding different types of psychological support services and some are not funding any. Different levels of service integration are also apparent across NGO services, with specialist psycho-oncology counselling services available through some Cancer Society sites, and funded liaison services available in others.

Limited stocktake findings for current provision of social support around the country are similar to those of psychological support --- there is wide variation in services across the cancer networks. For example, dedicated social workers in oncology in the Central Region perform psychosocial assessments of cancer patients and liaise with other services to address supportive care needs. In contrast, Waikato is without a community or hospital based social worker and other health/community professionals have to take up this function. Lack of funding and a skilled workforce are cited as key contributors to gaps in services that contribute to patients having to wait for supports and to staff taking on extra role functions.

As noted in the Priority Areas Report, there was concern amongst stakeholders that access to psychosocial support is dependent in part upon the cancer region in which those affected by cancer live. Stocktake findings regarding staffed positions for psychosocial support in each of the cancer treatment centres validate this concern. In addition to staffing issues, geography affects delivery of supportive care, and people living in rural areas face challenges in access to integrated psychosocial support available from larger cancer treatment centres. However, as documented in the evaluation of the community cancer care services pilots, there are models of care that can work to ensure that individuals located in rural areas, and
also working to systematise referral processes through a new IT system, in order to support a triaged and tiered formal support of the next level of care. Different care givers listed in the database, would help to inform decisions about models and development of more significant distress. This is important that there is availability of and access to a range of psychosocial interventions.

The Guidance states that triaged and tiered supports should be developed and implemented in each of the cancer treatment centres, and as part of this tiered approach, general support for emotional stress should be the responsibility of all staff in all cancer centres. Thus at a basic level, the Guidance indicates that all staff who provide cancer care should be able to undertake preliminary enquiries or screening for distress and to make referrals to the next level care. At the next level it is expected that a range of health and social care practitioners are available to provide more formal support, and finally, for those experiencing more significant distress, assessment and treatment services should be provided by specialist mental health services. As discussed in a subsequent section, clear referral pathways for this tiered approach are also recommended.

Stocktake findings show that there is some evidence of tiered support services across regions. For example, representatives from each cancer treatment centre indicated that informal 'distress' assessments are undertaken by all staff, and that patients identified as experiencing distress are referred to appropriate psychosocial services as needed. However, apart from a few services, the connections between different tiers of service providers are not well described. In many cases, there are no clear referral pathways --- they tend to be informal and are not systematically recorded. MidCentral offers an exception to this with clearer pathways, and Dunedin is also working to systematise referral processes through a new IT system and a mandate for psychosocial support staff to include referral data in patients’ notes. Additionally, in some centres, assessment and referral pathways for social support are clearly described (e.g., Wellington). Also, at a very general level of support, there has been some work to improve patient access to information about supports through the development of supportive care service directories by the Regional Cancer Networks.

As part of the tiered approach to support, the Guidance also indicates that psychological supports should be set up in a way that is shown to improve patient outcomes. Certainly, at higher rungs of service provision, a skilled specialist workforce is employing evidenced based treatments for treating psychological distress. However the extent to which supports at both the lower and higher rungs are helping to effect positive change for those affected by cancer is unclear. Results of the stocktake showed that through Massey University, MidCentral DHB is collecting patient outcome data (i.e., pre and post intervention distress scores). Otherwise, collection of outcomes data is scant. However, there is opportunity to collect data that will inform service development and delivery. For example, monitoring of the use of the Regional Cancer Networks' supportive care directories, including frequency of access to the sites and subsequent contact with agencies listed in the database, would help to inform decisions about

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whether efforts would be needed to improve dissemination of the website address and to encourage service users to take up available services if needed. At more ‘supportive’ levels of care, data collection should be undertaken to help identify whether supportive care interventions are having the desired effects on patient outcomes (e.g., distress reduction).

Informal supportive care processes may work well in smaller cancer centres and where staff turnover is not an issue. However, with increasing demand for psychosocial support services as well as increasing numbers of cancer patients and survivors there will be a need to provide more systematic and consistent support across the country. Results of the stocktake suggest that a national model for supportive care is needed in New Zealand to help improve consistency of service development and delivery. A review of overseas research in the area of triaged support may help inform development of such a model.

More formalised approaches for guiding services in the provision of supportive care have been adopted in the US, Australia, and Canada, among others.\(^{70,71,72}\) For example, in Victoria, a tiered approach to cancer care was developed by Fitch (2000) has been adopted in different service delivery contexts (see Figure 4.1).\(^{73}\) This model specifies four levels of supportive care that move from the more general needs associated with cancer diagnosis and treatment and which are applicable to all patients to the more complex needs of a few patients who require specialist care. Another model outlined by Hutchison and colleagues\(^{74}\) describes five levels of care including:

1. Universal care for people with mild to minimal distress
2. Supportive care for mild to moderate distress
3. Extended care for moderate distress
4. Specialist care for moderate to severe distress
5. Acute care for severe distress.

At each level of care, recommendations for specific types of interventions and service providers are made. For example, in the Hutchison model, Level 1 care would include general information about treatment and specific common problems, and support would be provided through primary care teams, and tele-based cancer help lines, as well as print media. At Level 5, patients would receive therapy to manage multiple complex problems and treatment would be provided by mental health teams, psychologists or similar.

These examples show that there are variations in approach to framing the delivery of supportive care in other countries. Despite variation, these approaches provide a general framework for the provision of supportive care that may be modified to support development of a systematic approach to assessment and delivery of supportive care in New Zealand. Cultural variations across and within countries as well as different policy and health contexts mean that direct application of a tiered model from one context to another is not always possible.\(^{75}\) However, local adaptation of a general model of triaged and tiered care, outlining screening and referral processes (see following sections) could facilitate provision of supportive care by providers and improve access to supportive care by patients. Importantly, more formalised approaches may help overcome barriers to supportive care access such as: poor promotion of

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psychosocial services and support; stigma associated with accessing services; and challenges of discussing psychosocial concerns with patients and/ or suggesting referrals.  

Figure 4.1: Fitch’s (2000) Model of Tiered Support

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<thead>
<tr>
<th>General needs</th>
<th>Screening for need and information provision</th>
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<tr>
<td>All patients</td>
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<tr>
<td>Many patients</td>
<td>Further referral for assessment and intervention</td>
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<tr>
<td>Some patients</td>
<td>Early intervention tailored to need</td>
</tr>
<tr>
<td>Few patients</td>
<td>Referral for specialised services and programs (for example, psycho-oncology)</td>
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<tr>
<td>Complex needs</td>
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Development of a systematic model of tiered support in New Zealand will require action in regards to development of supportive care service delivery processes (including decisions on methods for identifying distress and referral pathways), workforce, and research and evaluation. The model will specify activities and supports that may be provided at each level of care. Once the model is developed, actions to improve supportive care may be ‘stepped up’ to ensure that different levels/aspects of the tiered approach are targeted first, and within existing resources for improving supportive care (i.e., the model provides a vision of supportive care that may be realised over time). For example, at Level 1, improvements/greater funding may go towards servicing the Cancer Society’s information hotline (for e.g., see Hutchison77), and disseminating information about the regional cancer supportive service directories to both patients and care providers. At the same time processes for up-skilling the workforce to assess and triage patients according to their psychosocial needs could be undertaken. Over time and with improved monitoring of service access, use and patient outcome data, more long term goals of developing and funding a skilled workforce and developing more integrated cancer centres could be realised. See further discussion on developing a model for psychosocial support in the section on ‘screening’ below and in Section 6.

Screening

Distress is defined as an unpleasant experience of a psychological, social, and/ or spiritual nature, which extends along a continuum from normal feelings of vulnerability, sadness and fear, to disabling problems such as depression, anxiety, social isolation, and spiritual crisis.78 Left untreated distress may lead to

significant declines in quality of life, including poorer mental and physical health outcomes and reduced role functioning, and symptoms of distress may escalate over time.79

As highlighted in the Guidance, about a third of cancer patients experience distress associated with diagnosis and treatment and this is recognised as a normal response to the challenges associated with the disease. Reportedly, the majority of cases are likely to abate over time. However, even people experiencing ‘normal reactive distress’ may need support and in some cases, distress does not abate. Indeed research has shown many patients have unmet supportive care needs and that many of these are not realised until patients reach the survivorship stages of care.80,81,82 The need for support does not end with treatment completion, as individuals may need support for issues such as return to work, fears of recurrence, lingering side effects of treatment, or the challenges associated with extended adjuvant treatment in the outpatient setting.83,84,85

During the Strategic Thinker workshops, the issue of detection and management of distress amongst those affected by cancer was noted. In particular, stakeholders suggested that the cancer care sector does a good job of detecting significant distress and following protocols for referral and treatment for this. However, there was a sense that distress in some patients, even though not identified as clinically significant may still cause significant problems, and that distress is under-recognised and undertreated in a significant proportion of patients. Importantly, research has also shown that health professionals are not doing a good job of addressing distress among cancer patients, and that unaddressed symptoms may increase the number of visits patients make to health care providers, creating extra burden on the health system.86

Screening for distress has been identified as a way of identifying different levels of need and triaging supportive care needs. However, the Guidance is not very clear about what cancer care services should be doing in this regard. On the one hand, the Guidance advises that screening should take place, and on the other it talks about the challenges that distress screening can pose (e.g., false positives). At the same time, the Guidance recommends that a number of factors should inform decisions about referral to psychosocial support, but does not identify what those factors are. Although there is reference to the need to make assessments so that people can receive appropriate specialist care as needed. The Guidance also indicates that all cancer care staff should be able to make preliminary enquiries or screen for significant problems and be able to make referrals as appropriate. Thus, the Guidance on screening seems somewhat vague and inconsistent.

The results of the stocktake show that screening for distress in cancer centres around the county is also inconsistent. Specifically, results indicated that:

there are differences both within and across centres in the practice of distress screening. As such, it is likely that there are variations in the assessments and subsequent supports that patients are provided

few services are using formal distress screening tools. Many refer to the use of clinical judgement to make decisions about psychosocial support needs. Services that are using tools, tend to report using the Distress Thermometer or a screening tool developed by the service

in MidCentral, research was conducted to compare the use of a screening tool for all patients with ‘standard care’ (informal distress assessment). The trial found that the former led to twice as many appropriate referrals to psychosocial support, and increased referrals for Māori patients by 4%

with informal methods for screening, individuals experiencing more significant distress are more likely to get noticed and triaged to appropriate care, whereas those with milder forms of distress are less likely to receive support even though their quality of life is affected

there appears to be a general consensus (among those interviewed) that it is important to assess patients’ distress levels as part of care

however, there are differences of opinion as to whether universal screening for distress should be part of care.

A number of barriers to or issues associated with screening were raised during the stocktake – some of which were mentioned in the Guidance. For example, screening cancer patients for distress may result in a number of false positives, which may mean that patients are referred to support that they do not really need, therefore contributing to patient treatment burden as well as health system burden. In one cancer centre, an active choice had been made not to use a validated distress screener because of concerns of false positive screens and worries that current departmental resources and staffing levels would be insufficient to manage the numbers of patients who would be identified as ‘distressed’. A feeling of being underprepared to manage patient distress was also cited as a barrier to screening.

With regard to social support service delivery, the guidance indicates that MDTs should develop, establish and use social support needs assessment tools for all people with cancer at each critical stage along the cancer pathway and specify the supportive care needs that should be covered. Findings from the current project show that there is no consistent approach across cancer treatment regions/cancer networks to assess the social support needs of patients, though there is evidence of this in isolated services. For example, services adopting the care coordinator model (see Section 3) typically use new patient assessments that help to guide planning and delivery of support. In other settings, social workers may use assessment tools and share their findings with other members of the MDT (e.g., social workers in Wellington). One stakeholder suggested that the best way to ensure that psychosocial support is provided ‘to the right people at the right time’ is to ensure that psychology and social work specialists are included as part of the clinical team. This would facilitate discussion of individual cases, as well as up-skilling of other team members in distress/needs assessment.

The inconsistent presentation of screening in the Guidance and findings for inconsistent use of screening around the country, seem to reflect mixed evidence for universal screening found in the literature. Advocates of universal screening programmes cite the importance of psychosocial distress in impacting negatively on patient outcomes and the need for equitable and systematic approaches to assessing and providing support for those in need. 87 Cautions against this approach are raised by researchers who cite a lack of sufficient evidence for improved outcomes for patients who are screened for distress compared with patients who are not, along with concerns about issues such as over/under diagnosis, resource use and lack of staff time. 88


88 Mitchell, A.J. (2007). Pooled Results From 38 Analyses of the Accuracy of Distress Thermometer and Other Ultra-Short
For example, in one recent study, results showed that just one question asked by a health professional was as effective as the use of screening tools, in identifying patient distress and in effecting positive outcomes for patients.\textsuperscript{89} Reviewers of this article suggest that, rather than using the additional staffing and resources that would need to be deployed for universal screening, the energy could be used in increasing patient staff communication, so that staff need simply ask if patients would like to discuss any psychosocial concerns.\textsuperscript{90} Presumably, this charge for improved communication should not be left to one health professional along the cancer care continuum, as distress levels and supportive care needs often change along the way.

Although there are differences in approach by proponents of universal screening compared with those who advocate for less resource intensive processes, they share common ground in acknowledging the importance of identifying and managing distress in cancer patients. Thus the debate on the best approach continues, as part of the problem in assessing the importance of the effectiveness of screening programmes relates to methodological differences across studies, including differences in screening tools, patient populations, and outcomes assessed. Therefore, it is difficult to make definitive statements about the benefits of screening programmes. However, many factors can contribute to lack of outcomes for patients, such as: poor referral processes once distress is identified; lack of effective intervention by services to which patients are referred; and/or lack of patient uptake of psychosocial support. With regard to this latter point, one study found that only 25\% of patients who were referred to psychosocial support following a positive distress screen took up support services.\textsuperscript{91} Additionally, stigma associated with use of psychosocial services prevents access, and some other practical barriers such as transport may also prevent psychosocial support access. However, research has shown that the screening process itself may help patients to feel more comfortable to discuss their supportive care needs.\textsuperscript{92,93}

As a result of conflicting evidence for the effectiveness of screening, calls have been made for randomised studies that examine the comparative validity of different screening approaches and to evaluate the benefits linked with associated treatment. Specifically, it has been proposed that trials need to include distress as a patient outcome, include theory based distress management plans, provide staff training, and monitor patient uptake of interventions.\textsuperscript{94}

Despite mixed evidence, some countries have developed guidelines for distress screening. For example, according to the National Cancer Comprehensive Network, distress should be recognised, monitored and treated promptly at all stages of disease.\textsuperscript{95} The National Institute for Clinical Excellence (NICE) has also recommended screening for distress in cancer patients.\textsuperscript{96} With these recommendations, countries around the globe are working to establish policy on distress screening in cancer patients, in some cases, to lay the
groundwork for national initiatives. For example, a Distress Screening Programme in Ambulatory Care has been trialled in Japan with the use of a screening tool called the Distress Thermometer.97

Research on the programme found that there were challenges to uptake of services once referrals were made. However, of those that did take up support, a significant proportion required treatment for major depression, suggesting that screening was effective in identifying those in need of support.98

A report on the Canadian model for ‘Screening for Distress’ provides advice regarding programme development and implementation procedures that may help inform any initiatives in developing national screening processes for psychosocial distress. The report indicates that establishing a national approach to screening is feasible and beneficial and that a coordinated approach goes beyond the walls of any particular centre. It also provides the opportunity for all patients to be provided with person centred care.99 Importantly, a slow/staged implementation process is recommended to facilitate change processes. Similarly, Victoria has planned staged targets for screening for distress in cancer patients.100

A review of research indicates that there is overlap between barriers to screening cited by stakeholders in the current stocktake and in the literature. For example, the literature commonly reports barriers such as time constraints, inconsistent use of screening instruments, lack of buy in to screening programmes, and lack of resources to follow up.101,102 However, results from the implementation of a Screening for Distress programme in Canada showed that these barriers could be overcome through: 1) support from the Administration; 2) acknowledging the resistance of front line staff and actively listening to their concerns; 3) showing interest in and understanding the culture of the organisation; 4) having open communication with implementation teams and working together to overcome situations perceived as barriers; 5) taking extra time for field consultation; and 6) tailoring training material according to the scope of practice of each professional group.

Concerns about limited resources are typically raised as another barrier to screening. Bultz and colleagues suggest that this can be overcome by: ensuring that the scope of practice is understood; by working with professionals to determine how to handle various concerns; and to remind staff that screening is not creating any new concerns – it merely helps to standardise processes for the identification of concerns.103 Additionally, there is a documented reduction in unnecessary health care system use when appropriate psychosocial supports are identified and provided. Thus, working to identify patients’ psychosocial needs in the short term may have important downstream effects that relate to increased healthcare cost savings over time.104 It is important to disseminate information to cancer sector staff on the benefits that psychosocial support has for both the patient and the wider health care system in order to help overcome negative perceptions of the processes involved in the provision of support.

Based on the above findings, it appears that triaged and tiered psychosocial support services could be developed/improved through:

- a Ministry led debate on distress screening (i.e., convene a committee, including Māori, Pacific, Consumer, and service provider representatives, as well as programme developers and funders to review issues associated with screening). On the basis that screening is considered to be a routine part of care, issues to be considered are:
  - Development of national standards and guidelines for screening for distress
  - Introduction of a more formalised/consistent approach to screening, which uses validated tools so that distress can be graded to facilitate tiered and triaged care
  - Input of specialist Māori advice into any screening tools used/developed Māori advice to ensure that cultural assessments are appropriately designed and implemented
  - Identification of factors (in addition to screening scores) that may help triage supportive care, while reducing the number of false positives (e.g., patient preference/perceived need for support)
  - Development of strategies for overcoming common barriers to the implementation of screening programmes (e.g., fears of ‘opening the floodgates’ can be overcome by educating staff about appropriate referrals sources and processes)
  - Guidelines for processes involved in monitoring distress along the continuum of care, as individuals’ supportive care needs may change along the way
  - Electronic documentation of any significant patient distress and the service/s to which the patient was referred
  - A staged process to the implementation of a national approach to screening with timed and realistic goals
  - Funding available to support these activities

- processes to raise awareness of distress as the 6th vital sign and to teach health professionals about the negative impacts of untreated distress. CME may help this. Additionally, the Ministry may wish to consider processes for accreditation of services based on screening and referral processes, as exemplified in Canada

- if a formal screening programme is not implemented a systematic basis for identifying people with significant distress and offering prompt referral to specialist psychology services should be developed. Systemised processes would be especially helpful for cancer care staff who do not specialise in the delivery of psychosocial support

- engagement with patients around their psychosocial support needs, such that all patients should be asked whether they are receiving and/or would like to receive psychosocial support and then receive appropriate referrals along the care continuum (i.e., the decision to obtain psychosocial support should be like any other treatment decision)

- raising awareness of support services with patients once they are discharged from treatment and ensuring that screening for psychosocial distress is undertaken at any follow up appointments.

**Referral, Coordination of Support and Service Access**

The Guidance on psychological support indicates that there should be clear referral pathways across the ‘tiers’ of supportive care and that information about the range of psychological support services available and how to access these should be provided to patients as they move along the cancer continuum. Similarly, the Guidance on social support emphasises coordination of services both within and across hospital boundaries and the importance of agreement among relevant agencies in regards to specific assessments, referral procedures, and information sharing.

According to stocktake findings, referrals within and across services are not working as well as they could because of issues such as:
lack of appropriate screening/assessment methods
lack of staff knowledge of how and when to make a referral
lack of available to refer out to once supportive care needs are identified
IT systems specific to individual services that make transfer of information across service boundaries difficult
different funding streams for mental health support depending on patient age (e.g., those over 65 years are not eligible for hospital funds)
siloed services
informal referral pathways, which are reliant on staff relationships and vulnerable to staff turnover.

Although these issues exist, there are some programmes currently underway to improve referrals across hospital and community boundaries and some services have very clear referral processes in place. For example, in Palmerston North, the Cancer Society has provided radiology staff with ‘tear away’ referral pads, which include contact details for key cancer support providers in the community. In Otago, a survivorship support programme is being trialled in which cancer patients meet with a MDT comprised of key support providers (e.g., occupational therapists, physiotherapists, nutritionists etc.). Each member of the team is introduced to the patient and his or her whānau and the available supports are described prior to patient discharge from treatment. In MidCentral, a formal screening tool is used to assess distress and staff are provided with a psychosocial referral decision tree to help inform their decisions about how to manage patients who are identified as needing support. Similar processes are used by specialist social workers in Wellington. In Auckland, specialist staff are working informally to educate cancer care teams on how and when to make referrals to psychosocial support.

Stocktake findings also suggest that referral and service coordination processes are smoothed by basing NGO services within the hospital setting or vice versa. For example, in Christchurch, recent events have caused a change in location of the Cancer Society offices into the oncology wing of the hospital. As a result of the relationships being formed through close proximity, the Cancer Society is reporting an increase in referrals from the oncology team. In Auckland, a model where hospital services are delivered in the community has resulted in increased uptake of supportive care services. Specifically, a liaison nurse located in the Cancer Society is providing new patients with ‘chemotherapy education sessions’. In this way, patients and their whānau can obtain information about their upcoming treatment and at the same time become familiar with the supportive care services that the Cancer Society provides as well as the staff who provide them.

These examples provide evidence for the effectiveness of bridging services and ways that relationships can be formed both between patients and providers and between providers from different services. Indeed, a number of stakeholders highlighted the importance of good relationships in facilitating referral processes - services need to be known and trusted before referrals will be provided. Although informal referral and service coordination processes may work well in some instances described above, it would seem that more work is needed to systematise these processes, as relatively few services have formal referral decision trees to help inform referral processes and there is indication that some patients have been referred to more than one support provider at the same time, thus causing service double up in a system that is already under-resourced. Without documentation and follow up on referral processes, data on the need for and uptake of services cannot be collected and tracking of patient outcomes becomes more difficult.

Given these stocktake findings and goals for referral and coordination outlined in the Guidance, it seems important that:

hospital based cancer care providers are made aware of the community based supports that are available (including those such as Māori or Pacific specific services that provide culturally appropriate support) and to which staff can refer patients and their whānau
• electronic systems for tracking patient referrals be developed to improve care coordination and enable monitoring of service use
• patient referrals to hospital based psychosocial support services are discussed at MDTs
• issues related to ‘who’ is funding psychosocial support services are worked out.

Additionally, addressing professional (lack of networking across cancer providers), organisational (inability to share information with other services) and funding silos will improve service referral and coordination.

**SERVICE ACCESS & RESPONSIVENESS**

The Guidance indicates that all cancer care providers should be able to refer people in distress to the appropriate services for support, and highlights the role of psychosocial services in reducing barriers to access, such as those associated with ethnicity, geography and stigma. As discussed in the previous section, there are initiatives within different cancer treatment centres to improve service access by educating care providers and patients about available psychosocial supports. However:

• it is not clear whether appropriate referrals are being made and whether these referrals are leading to patient uptake of services, as this information is not tracked. Anecdotal evidence indicates that awareness of services and referrals could be improved
• supportive care access issues are affected by funding issues. As previously mentioned, DHB service specifications are unclear and need to be revisited, as at the moment there is no clear agreement on whether individual DHBs or tertiary centres should pay for psychosocial services
• there is a lack of appropriate services for different cultural groups and in particular, there is a need to build capacity and ensure that Māori psychologists are supported to provide Māori specific services
• services are available to support patients and their whānau however, there may be lack of awareness about these services, or patient/whānau access to these services may be poorly coordinated.

It is important that patients and their whānau are empowered to access supports on their own and to engage in self-management activities. Some services attend to these issues in an active way and were set up to do so (e.g., the community cancer care evaluation pilots). Others work on this in a more implicit or passive way by giving patients information on available supports and services. However, it appears that more work could be done to raise awareness among people affected by cancer about the importance of attending to psychosocial concerns alongside cancer treatment and to reduce stigma associated with asking for help.

Based on findings, some areas for consideration in regards to service access and responsiveness are:

• the need to reduce stigma associated with access to psychosocial services through awareness raising campaigns such as those undertaken through the NZ National Depression Initiative and improved dissemination of information about available psychosocial support services
• the need to support patients/whānau to overcome practical barriers that may impede access to psychosocial support (e.g., through care coordination)
• the need to coordinate service provision and raise patient/whānau awareness of available services (see section on care coordination)

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ensure that there is appropriate and early sector engagement with Māori, Pacific and other groups facing inequalities in cancer support service access and ensure their contribution to the development of a model of triaged and tiered supportive care

improve service referral processes (see previous section)

the need to develop workforce (see below) to ensure that there are key workers and specialists available who can provide culturally appropriate psychosocial support to patients and their whānau

address the need for culturally relevant information supports (see section on information support).

4.2.2 WORKFORCE DEVELOPMENT

CAPACITY & CAPABILITY

The Guidance states that there are insufficient numbers of registered health practitioners qualified to offer specialised forms of assessment and treatment required for those with significant psychological distress. Results of the stocktake affirm this position, and as discussed in section 4.2.1, there is regional variation in integrated psychosocial service delivery, with funding of specialised service providers dependent upon funding in individual DHBs. Although the Guidance talks about active recruitment of specialist providers of psychosocial support services there is no clear indication that this is being undertaken or of how this should be undertaken and by whom. Additionally, the system is also experiencing funding constraints.

With regard to the capability of workforce, the Guidance states that staff providing mental health, primary care and psychological services should be adequately trained to work within the scope and competencies of their respective disciplines. Stocktake findings suggest that staff employed in the upper tiers of psychosocial support delivery are indeed working within their scope. However, there is a reported lack of support for continuing education of these positions compared with other health professionals/ cancer care providers. For example, continuing professional education resources are not built into DHB psychologists' employment contracts, effectively requiring them to seek external funding grants for professional development.

There also does not appear to be a consistent approach to training staff working in the 'lower tiers' of psychosocial support and the need for this is not reflected in the Guidance. It is important that institutions and individual professionals commit to proper training of staff working in oncology so that they may provide and triage appropriate psychosocial support.106 The Guidance recognises that workforce development should be promoted and supported, but does not indicate how or by whom.

In other countries, policy has been developed outlining the importance of training the cancer care workforce to be able to recognise distress and understand survivorship concerns. For example in Victoria, one of the supportive care targets is to provide evidence of training among the cancer workforce in issues related to psychosocial support by 2012.107 It may be that similar strategies and aims in workforce development may be adopted in New Zealand in order to:

• raise the profile of psychosocial support needs as part of cancer patients’ treatment plans

• make it clear that screening for and triaging psychosocial support needs is part of the role of all staff

• train staff in how to identify psychosocial support needs, preferably mandating a consistent approach across services, and train staff about what to do if patients test positively for distress


in order to increase staff understanding of supportive care processes and to increase their confidence in engaging them

- ensure that patients psychosocial support needs are acknowledged at MDTs.

Support for the workforce to manage its own psychosocial care needs is also acknowledged in the Guidance. Stocktake findings suggest that in larger treatment centres, supervision and support for staff is available. However, these supports are not taken up as much as they could be, presumably because staff do not perceive a need, they are too busy or because they take up supports off site.

To improve the capacity and capability of staff to provide psychosocial support, that the Ministry/ cancer care sector may want to consider:

- training and CME for cancer care staff in regards to understanding the importance of psychosocial care needs, and screening and triaging distress be provided to all staff in cancer care.
- providing access to continuing education for health psychologists and other specialists working to provide support in cancer care at a level akin to that which their medically trained peers have built into their contracts
- ensuring that supervision and support are available to all staff working in cancer care and clear pathways and processes are articulated for staff to obtain this support within different service settings
- developing a strategy at the Ministerial level for recruiting more appropriately skilled staff to work in the area of psychosocial support
- working at the National level to develop minimum supportive care training standards for staff working in oncology care
- making funding decisions regarding who should fund training and support of staff and make sure that funding is available to do this.

4.2.3 RESEARCH & EVALUATION

The Guidance stresses the importance of research and evaluation to determine the efficacy and effectiveness of psychological services for people with cancer and makes research and evaluation a primary action area. These issues have already been discussed in relation to referral and screening processes. To reiterate, in order to determine the efficacy and effectiveness of services it is important that:

- referral processes are systemised and tracked in order to assess need for services
- uptake and use of psychosocial support services are tracked
- pre and post service patient outcomes are measured (e.g., change in distress scores; reductions in unmet need)

Data collection in these areas is essential for research into psychosocial support in New Zealand and for establishing baseline data on the need for services, service use, service user outcomes, the cost effectiveness of services and for ensuring that services are accountable for the support they provide to those affected by cancer.

Findings from the stocktake showed that there are isolated examples of Ministry, DHB or other service (e.g., NGO) funded research and evaluation of supportive care projects. As discussed in the section on Care Coordination, the Ministry funded evaluation of three community cancer care pilot projects, which included elements of psychosocial support as an integral part of cancer navigators’ roles. The Cancer Society has been monitoring and measuring use of services such as the Cancer Support Hotline and has evaluated pilot Living Well programmes that are now being rolled out Nationally and adapted for use in Māori services. Various DHB programmes are being researched, such as referral rates to MidCentral’s
Health Outcomes International

psycho-oncology service and subsequent patient outcomes, and the processes and impacts of Dunedin’s pilot survivorship programme are also being assessed.

Although there is research underway, more attention needs to be paid to the sustainability of services should evaluations show that they are effective in obtaining their aims of improved support and outcomes for those affected by cancer. Issues of service sustainability need to be considered as part of service/project development. Additionally, greater information sharing of effective programmes/services is needed to improve efficiency of service development and delivery. It may be that development of an information clearing house or information network (see Section 5), may help to alleviate this problem. Finally, linking cancer services with academic or other research institutions can facilitate programme evaluation and research on the effectiveness of support programmes. For example, in Palmerston North, the DHB contracts Massey University to provide psycho-oncology services to cancer patients. At the same time, Massey is tracking referral data as well as patient outcome data (i.e., change in distress thermometer scores).

4.3 IMPLICATIONS FOR A SUPPORTIVE CARE IMPLEMENTATION PLAN

The results of the stocktake suggest that there is work to be done at the service, regional and Ministry level to develop a consistent, tiered and integrated approach to psychosocial support for those affected by cancer. This section presents areas for service development and plans for the development of psychosocial support. Current limitations in workforce and funding have been considered while developing these plans. At the same time, stocktake findings have shown that the area of psychosocial support for those affected by cancer is one that is under-resourced and under-recognised for its importance in influencing health outcomes and healthcare use. Internationally, psychosocial support for cancer patients is recognised as a priority area. In fact, distress has been deemed the 6th vital sign, and integrated services that provide biopsychosocial models of care are needed to support patients along the continuum of cancer care. Based on the findings of the stocktake including a targeted review of the literature, it is recommended that a model for psychosocial support be developed in New Zealand in order to ensure:

- **Consistency** between regions in regard to a minimal standard of care (e.g., that people are assessed, and that pathways of psychosocial support in each cancer treatment region are developed)

- **Basic systemic promotion/education** for the general cancer workforce about psychological distress and the negative impacts it can have on health and wellbeing. Education should help staff to make psychosocial support more integral to their role (while acknowledging that not all staff need to engage in psychosocial interventions), and help them develop some basic skills and confidence in applying any model of psychosocial support that is developed. It may be that the cancer networks work with workforce development teams to create CME modules for staff

- **Support for providers at the lower tiers of supportive care** should enable more general staff to assess and triage distress among those affected by cancer. Support should include education on the importance of managing distress including appropriate referral pathways, and education may be facilitated by specialist psychosocial service providers (to help improve links)

- **Capacity at the upper tiers of supportive care** so that appropriately skilled psychosocial support providers (e.g., psychologists, social workers, psychotherapists) are available to provide support for people experiencing significant distress. Capacity should include clinics and outreach models to help reduce inequalities in service access and care. More specialist staff are required to meet demand as there are currently few psychologists/social workers in the country who specialise in supportive care. Improved capacity at this level will require dedicated funding and long term planning

- **Referral mechanisms & coordination between services are systematised** within DHB services (e.g., between general surgery and cancer and blood services), between DHB and

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community/primary care services, and between tertiary centres and patients’ local DHB/psychological services

- **Clearly articulated funding systems.** For example the Ministry should develop specific guidelines about whether the responsibility for funding psychosocial support lies with the tertiary centre or to individual DHBs, and work to develop a business case to improve capacity and increase workforce should be undertaken by the Ministry in collaboration with the Regional Cancer Networks

- **A uniform policy** on an approach for screening for distress is developed as part of a model of tiered support. The Ministry needs to lead the debate on screening and come to some sort of conclusion about this, ensuring that the sector has been involved in deciding upon a base level of assessment and who should be involved in screening activities (including referral if distress is identified).

With these components of a model of supportive care in mind, the following table presents areas for action in psychosocial support, specified by the Guidance and links these to key areas for development as identified through the stocktake, as well as recommended actions for developing psychosocial support services. Responsibility for carrying out each recommended actions is designated at the service, regional and/ or national levels and for each action the requirement regarding one-off (O), short term (ST), or sustained funding/development (S) is specified. Where the action is a component of regular business activity, this is noted as business as usual (BAU).

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<th>Action Area from Guidance</th>
<th>Areas for Implementation Planning</th>
<th>Recommended Actions</th>
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| 10. Ensure that psychological support and services are available as part of an integrated cancer service | As part of the framework for supportive care, nationally the definition of psychosocial support should be agreed, a model of psychosocial support developed that includes baseline standards for the delivery of psychosocial support | - At a national level, review the definition of psychosocial support including principles of care, key functions and tasks, approaches to screening, assessment and referral etc. (O)  
- Nationally, develop a model of psychosocial support, specifying the minimum standards for: service delivery, cultural service provision, screening, assessment, referral, documentation and minimum training requirements. (O)  
- At the service level and regionally, local adaptation and implementation of the psychosocial support model should undertaken. (O) and then BAU.  
- At the service, regional and national levels, develop minimum data set to inform service contracting & funding decisions. (ST)  
- Electronically track & use psychosocial service data to inform funding for incorporating psychosocial services within cancer services  
- Promote patient and practitioner awareness of psychosocial services and available support services across the continuum of care  
- Ensure clearly articulated responsibilities for funding psychosocial support services  
- Nationally, specify baseline training/ CME for all staff in cancer care on the importance of psychosocial issues in influencing patient quality of life as well as health outcomes & training to conduct basic distress screening & make appropriate referrals. (O)  
- Nationally, articulate funding responsibilities for psychosocial supportive care across DHB boundaries (i.e. should the tertiary centre fund care or should it be up to each DHB?). (O) |
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| 11. Offer prompt referral for psychological assessment to people affected by cancer who have significant levels of psychological distress to determine the need for treatment and management | As part of developing and implementing models for psychosocial support, ensure that referral trees for decisions about psychosocial support are developed for each cancer treatment centre, and satellite service centres | • Nationally, ensure referral processes for providing psychosocial support are included as part of service specifications. (O)  
• At the service level, systems are implemented to ensure that at patient entry and at key points along the continuum of care, all patients are screened for psychosocial support needs & referred as appropriate. (S) |
|                           | Link referral processes to work in information management so that referral processes are systematised and so that referral and uptake data may be tracked | • Nationally, work with the National Health Board IT team to ensure that psychosocial support is included in eHealth developments (i.e. develop paper-based systems with a view to being adapted to electronic data management by 2014. (O) |
|                           | Utilise service data to identify staffing levels required to provide psychosocial support | • Nationally and regionally, develop minimum data set to identify need for different levels of psychosocial support and ensure that there are appropriate staffing levels (FTE) to meet per capita need. (S) |
| 12. Ensure that staff providing mental health services are qualified to do so, and work within the scope and competencies of their respective disciplines | Raise awareness of distress as the 6th vital sign and educate health professionals about the negative impacts of untreated distress. | • Include training in conducting basic distress screening & making appropriate referrals a component of National baseline training/CME for all staff in cancer care. (O) |
|                           | Develop workforce to ensure that there are key workers and specialists available who can provide culturally appropriate psychosocial support to patients and their whānau | • Nationally and regionally, specify the specialist FTE required to deliver psychosocial support as part of integrated cancer care. (S) |
|                           | Ensure that staff are appropriately supported to manage their own psychosocial support needs | • At the service level, ensure that there are clear pathways within the cancer care sector for staff to obtain supervision and support. (BAU) |
|                           | Support the training and development of staff in psychosocial support across the continuum of cancer care | • Nationally, and regionally, identify staff training and support needs (S) and then (BAU) |
| 13 & 21. Determine the efficacy and effectiveness of psychosocial support for those affected by cancer | Develop systems for monitoring, tracking and evaluating outcomes of psychosocial support | • Nationally, prioritise research funding for studies on the efficacy of supportive care services (including the provision of psychosocial support). (O)  
• All levels collect and analyse data on the efficacy/ effectiveness of psychosocial support services on improving patient outcomes (e.g. reducing unmet supportive care needs, lowering distress), while conducting evaluations of service processes. (S) |
<table>
<thead>
<tr>
<th>Action Area from Guidance</th>
<th>Areas for Implementation Planning</th>
<th>Recommended Actions</th>
</tr>
</thead>
<tbody>
<tr>
<td>14. Accompany the development of psychological services with systematic evaluation</td>
<td>In light of funding and workforce constraints, developments in the psychosocial support model of care should be introduced incrementally (e.g. target development of one ‘tier’ of the model at a time) and evaluated to demonstrate the requisite benefits</td>
<td>• Regionally and nationally, pilot key actions to improve psychosocial support, evaluate service effectiveness, including cost effectiveness and ‘step up’ project/action reach based on findings. (ST)</td>
</tr>
<tr>
<td></td>
<td>Develop plans for monitoring and evaluation, including targets for change, into service development plans, as well as to the national model for psychosocial support</td>
<td>• Nationally, ensure that systems for monitoring and tracking psychosocial support data (e.g. service utilisation, patient distress data) are built into service agreements. (O)</td>
</tr>
<tr>
<td></td>
<td>Develop a model of psychosocial support that accounts for those who face greatest inequalities (e.g. Māori &amp; Pacific; individuals living in rural areas) through co-design and by detailing appropriate psychosocial screening, assessment and referral processes that are flexible for local adaptation</td>
<td>• Refer to recommendations in action area 10.</td>
</tr>
<tr>
<td>15. Continue to improve equitable access to social support services</td>
<td>Reduce stigma associated with use of psychosocial support services</td>
<td>• Regionally and nationally, identify strategies to reduce stigma associated with access to psychosocial services through awareness raising campaigns such as those undertaken through NZ National Depression Initiative. (ST)</td>
</tr>
<tr>
<td></td>
<td>Reduce practical barriers to psychosocial support</td>
<td>• Assess patients’ practical barriers to accessing psychosocial supports and ensure appropriate referrals to care coordinators and/or social workers. (S)</td>
</tr>
<tr>
<td>16. Develop and disseminate regional support service directories</td>
<td>Ensure that all staff working in cancer care are aware of available support services</td>
<td>• Regionally, regularly update the regional support service directories. (BAU)</td>
</tr>
<tr>
<td></td>
<td>Ensure that all patients are aware of the supportive care service directories</td>
<td>• Nationally, ensure that CME and training for health professionals and other cancer care providers includes information about the regional supportive care directories and of the importance of directing people affected by cancer to these directories. (ST to BAU)</td>
</tr>
<tr>
<td>17. Develop and use social support needs assessment tools</td>
<td>• Refer to recommendations in action area #10</td>
<td></td>
</tr>
<tr>
<td>18. Build a seamless interface between hospital and community based social support services</td>
<td>Build on existing programmes that link hospital and community based referrals through documentation, evaluation and dissemination of effective models</td>
<td>• Use information network and regional service directory websites to disseminate information on models of supportive care that help bridge service boundaries. (S)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Ensure psychosocial support is linked to developments in care coordination. (S)</td>
</tr>
<tr>
<td>Action Area from Guidance</td>
<td>Areas for Implementation Planning</td>
<td>Recommended Actions</td>
</tr>
<tr>
<td>---------------------------</td>
<td>----------------------------------</td>
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</tr>
<tr>
<td>19. Ensure people affected by cancer are able to access financial and social support</td>
<td>Refer to recommendations in action areas #11, 13, 21</td>
<td></td>
</tr>
<tr>
<td>20. Establish systems to assess the training needs of hospital and community based social support provider</td>
<td>Refer to recommendations in action areas #10, 12</td>
<td></td>
</tr>
</tbody>
</table>
This chapter presents a report on findings from the Information Support research stream.

5.1 INTRODUCTION

The Guidance cites research suggesting that people affected by cancer will need information that enables them to:

- understand what is wrong
- gain a realistic idea of their prognosis
- make the most of consultation
- understand the processes and likely outcomes of possible tests and treatments
- provide or assist with their own self-care
- learn about the services and other sources of help available to them
- help others to understand their condition and needs
- legitimise their help-seeking and concerns
- learn how to minimise the risk of further illness
- find additional supportive care information and self-help groups
- identify the best and most appropriate health care providers.

In order to address these information needs, the Guidance has established the following objectives for providing information support:

1. All people affected by cancer have access to high-quality information resources when they need them, in a form that is evidenced-based, regularly updated, culturally sensitive and available in various formats and languages

2. Cancer information resources are relevant to the needs of Māori, Pacific peoples and other ethnic groups resident in New Zealand

3. Involvement of consumer representatives is actively sought for the design, development and evaluation of cancer information resources

4. Health professionals familiarise themselves with the information resources available.

5. Health professionals ensure that those affected by cancer understand the information provided, or refer them on to suitably qualified service providers/advisors who can interpret the information for them where necessary (p.14).

Priority issues associated with the provision of information to people with cancer and their whānau were identified in the Strategic Thinker workshops as:

- a lack of coordination regarding resource development and provision resulting in duplication of effort and information gaps. The establishment of an information Clearing House was proposed as a ‘solution’ to this issue
patients and whānau were often provided with information that was a combination of ‘too much, too little, and too late’. For example, research indicates that:

- patients and whānau are generally overloaded with information at the beginning of the cancer pathway
- language/health literacy is an issue, and the sector needs to pay greater attention to checking patient and whānau understanding of the information provided

significant information gaps identified include a lack of culturally responsive resources, as well as a lack of resources for the survivorship phases of care

concerns regarding patients and whānau utilising the Internet for advice with no or limited understanding of the credibility or reliability of the information.

5.2 Key Findings

It must be acknowledged from the outset that a significant and comprehensive body of work (funded by the Ministry of Health) was undertaken by the Cancer Society of New Zealand (CSNZ) in 2006 to stocktake and review a selection of consumer cancer information resources. Many of the findings of that review informed the Information Support section of the Guidance and the key issues identified at the time accord with many of the priority issues identified in the Strategic Thinker workshops.

On this basis our research has aimed to broadly revisit the issues identified in the CSNZ stocktake and review, to consider additional findings from the Strategic Thinker workshops and to report on any ‘new’ initiatives concerning information provision that should be considered within the New Zealand context.

The following section reports the findings of the research against the best practice components of the Guidance pertaining to: consumer information principles; resource design and development; information dissemination and delivery; workforce development; and inequality reduction.

5.2.1 Consumer Information Principles

The Guidance notes a range of consumer information principles that were largely developed through the CSNZ stocktake and review. Through the stocktake project, an extensive review of the literature was undertaken in order to identify any standards for consumer information, however, a minimal number were identified. The most relevant, although not a perfect fit for the New Zealand context was the NICE (2004) guidance on cancer services; “Improving supportive and palliative care for adults with cancer”.

Subsequently, the project advisory group developed a set of consumer information principles that form the basis of those contained within the Guidance. These consumer information principles underpin the remaining best practice components of the Guidance for Information Support.

In the current project, a further review of the literature was undertaken to identify whether any additional work has been completed in relation to consumer information principles. Whilst a large number of service provider organisations have developed and publicly documented their principles and processes for developing quality consumer health information, we were unable to identify any further ‘Standards’. Additionally, we were unable to identify any principle that is not covered by the existing Consumer Information Principles in the Guidance.

However, through the research, we identified two areas that may be of interest in respect to the provision of consumer health information: Principles for ensuring quality consumer health information; and guidelines for developing consumer information pertaining to complementary and alternative medicine (CAM).

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The Centre for Health Information Quality (CHIQ)\(^{110}\) promote three simple principles for ensuring development of quality consumer health information: 1) Relevant; 2) Accurate; and 3) Clear.

- If it is to be **relevant**: involve members of the target audience
- If it is to be **accurate**: involve experts in the subject area
- If it is to be **clear**: involve an appropriately experienced/qualified health communicator

Consumer health information that meets these principles is ‘accredited’ as symbolised below.

The simplicity of this accreditation process may offer some benefits for a nation-wide promotion of best practice in developing consumer health information resources in New Zealand. Additionally, any national approach (to be discussed further) to ‘accrediting’ consumer information produced may be able to adapt this concept to the New Zealand context, obviously taking into account any copyright issues that may exist.

This might also further enable the key recommendation of the CSNZ stocktake and review 2006 that: ‘The cancer information principles developed by the advisory group should be used by organisations producing consumer cancer and health information’.\(^{111}\)

**WHO Guidelines on Developing Consumer Information on Proper Use of Traditional, Complementary and Alternative Medicine (CAM)**

The World Health Organisation (WHO)\(^{112}\) has produced guidelines to provide governments and other stakeholders with an overview of the general principles and activities necessary for the development of reliable consumer information. The document can also be used as a reference to consumers in guiding them on the information they need to have in order to choose a traditional medicine/complementary and alternative therapy that is safe and effective. While outlining some key principles, the Guidelines strongly emphasise the need to take into account the local context of: culture; health systems; existing practices; and regulations.

In addressing the issue of providing information to patients and their whānau regarding the use of CAM in New Zealand, there would be benefit in referencing this document to ensure key principles have been addressed.

### 5.2.2 Resource Design & Development

The literature review, undertaken as part of the CSNZ stocktake and review (2006), comprehensively researched the aspect of designing and developing resources with reference to the consumer information principles.

Our research of the literature and interviews with key informants regarding the approaches organisations are taking in relation to producing consumer information, indicate that steps to ensure relevancy, accuracy

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\(^{110}\) It is our understanding that CHIQ was part of the British NHS, however, our current research is unable to identify their current status.


\(^{112}\) Retrieved 10th of June 2011 from [http://apps.who.int/medicinedocs/pdf/s5525e/s5525e.pdf](http://apps.who.int/medicinedocs/pdf/s5525e/s5525e.pdf)
and clarity are the standard in New Zealand. Additionally, the processes used are in keeping with the National Guideline for Health Education Resource Development in NZ.\textsuperscript{113}

The key points in the process include:

- consumers determine the need for a resource either directly or through health professionals
- the type of resource to meet the need is established (print, electronic, web, etc.)
- research is undertaken to identify what already exists
- consumers are engaged to assist in design and development of the resource
- the quality of information is checked using evidence, technical experts, consumers and quality tools (e.g. Discern, EQIP, HON code, quality frameworks)
- simplicity of language is checked using consumer input and tools (e.g. FLESCH)
- cultural needs are addressed throughout each of the above steps.

Whilst the significant providers of cancer related consumer health information in New Zealand address most of the above steps (and hence the consumer information principles), there remain some key issues that have been identified by both the CSNZ stocktake and review, and the recent Strategic Thinker workshops. These include, consumer involvement in resource design/development and guidance concerning the use of web based information.

**Consumer Involvement**

Whilst there is evidence of consumers being involved in the development and design of consumer health information, this is not as proactive and consistent as it could be. The trend towards experienced based design as promoted by the NHS Institute for Innovation and Improvement\textsuperscript{114} or the New Zealand based health co-design\textsuperscript{115} offer a model for improving consumer involvement.

The model promotes consumers and staff coming together to share the role of improving care and re-designing services (including information provision). The focus is on using patients’ and/or carers’ **experience** not just their views and opinions. Through a co-design process, a number of the consumer information principles issues can be more effectively addressed including:

- establishing the need for a resource – identifying gaps
- identifying what type(s) of resource should be developed and how it should be disseminated
- ensuring the information provided is the information required
- deciding how much information should be included
- simplifying the language – accounting for health literacy
- ensuring cultural appropriateness through co-design with the relevant cultural representatives.

Key service providers should be encouraged to take a co-design approach not only to service design but also to the provision of health information.

**Web-based Information**

The Internet presents a conundrum for health service providers. On one hand, it is seen as highly advantageous as consumers, carers and family can: access the information at the time they consider to be appropriate and convenient; ‘take on’ as much or as little as suits them; do this relatively cheaply; and for the most part, have access to high quality information.


\textsuperscript{114} Retrieved 10th of June 2011 from \url{http://www.institute.nhs.uk/quality_and_value/introduction/experience_based_design.html}

\textsuperscript{115} Retrieved 10th of June 2011 from \url{http://www.healthcodesign.org.nz/index.html}
On the other hand: some consumers do not have ready access to the internet; there are numerous sites
with poor quality information many of which are simply attempting to promote a ‘cure’ of some
description; and there is sufficient information for consumers to (inappropriately) attempt self-diagnosis.

Health insurance provider Bupa found from a global survey of 12,000 people that 47% per cent accessed
the Internet to make a self-diagnosis. Bupa's research summarised the issue well noting that depending
on what website you look at, the physical symptoms of pins and needles could be a vitamin B12
deficiency, sciatica or multiple sclerosis. Stomach cramps could be indigestion, appendicitis or heart
disease, while an earache could be the result of a common cold, ear infection or brain abscess.

To counteract this latter issue a number of approaches have been taken internationally and within New
Zealand to ensure the reliability and credibility of health information websites for consumers including:
the development of the Health on the Net Code; quality frameworks; and consumer guides to health-
based information.

Health on the Net (HON) Code

HON was founded to encourage the dissemination of quality health information for patients and
professionals and the general public, and to facilitate access to the latest and most relevant medical data
through the use of the Internet. HONcode certification is an ethical standard aimed at offering quality
health information, and for organisations that are ‘direct’ providers of health information (i.e., producers
and disseminators of health information through the web), HONcode certification or similar is desirable.
A code of ethics guides site managers in setting up a minimum set of mechanisms to provide quality,
objective and transparent medical information tailored to the needs of the audience. This code of conduct
is currently being used in over 72 countries, and 5533 sites including Internet search engines such as
PubMed, Medline and WebMD. The HONcode Principles are listed in Table 5.1 below.

<table>
<thead>
<tr>
<th>Principle</th>
<th>Criterion</th>
</tr>
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<tbody>
<tr>
<td>Authority:</td>
<td>List qualifications of authors</td>
</tr>
<tr>
<td>Complementarity:</td>
<td>Information to support, not replace</td>
</tr>
<tr>
<td>Confidentiality:</td>
<td>Respect the privacy of site users</td>
</tr>
<tr>
<td>Attribution:</td>
<td>Cite the sources and dates of medical information</td>
</tr>
<tr>
<td>Justifiability:</td>
<td>Justification of claims / balanced and objective claims</td>
</tr>
<tr>
<td>Transparency:</td>
<td>Accessibility, provide valid author contact details</td>
</tr>
<tr>
<td>Financial disclosure:</td>
<td>Provide details of funding</td>
</tr>
<tr>
<td>Advertising:</td>
<td>Clearly distinguish advertising from editorial content</td>
</tr>
</tbody>
</table>

http://www.bupa.com/mediacentre/healthpulse

Quality Frameworks/ Standards/ Assessment

A process for ensuring the credibility and reliability of information for people affected by cancer is also critical for organisations that provide health information ‘indirectly’, (i.e., they facilitate access or links to information provided by other organisations). Indirect information provision is predominantly managed through the development of publishing standards against which an assessment of the information is undertaken, usually by an editorial team.

An example of minimum publishing standards applied by HealthInsite (one of the biggest information databases available for health information in Australia) and Health Navigator NZ (provider of independent, reliable health information and self-help resources) is provided in Table 5.2 below. Many of the consumer information principles of the Guidance are represented in these standards with some more specific criteria for a web-based service.

The key differences between the two sites are:

- Health Navigator proactively adds information and websites that they consider to be relevant, whereas
- HealthInsite works on the basis of partner organisations making application for their information or website to be added to the HealthInsite website.

These different approaches are reflected through some variation in the stated minimum standards of information provided by each organisation.

**Table 5.2: Minimum Standards for Resources / Websites**

<table>
<thead>
<tr>
<th>Health Navigator NZ</th>
<th>HealthInsite</th>
</tr>
</thead>
<tbody>
<tr>
<td>Responsible partnering – trustworthy individual or organization</td>
<td>Includes a process to ensure maintenance of metadata for resources accessed through HealthInsite</td>
</tr>
<tr>
<td>Content accurate and reliable</td>
<td>Includes a policy that each resource is authored by a person or group with appropriate qualifications/ experience</td>
</tr>
<tr>
<td>Balanced &amp; unbiased</td>
<td>Includes a procedure for appropriate attribution of resources</td>
</tr>
<tr>
<td>Evidence-based or supports current best practice when guidelines do not exist</td>
<td>Details the final approval process (including responsibility/ qualifications)</td>
</tr>
<tr>
<td>Content – appropriate &amp; relevant for the intended audience</td>
<td>Includes a process for consumer consultation and/or audience testing</td>
</tr>
<tr>
<td>Current – considered up to date, preferably reviewed or updated within last two years</td>
<td>Includes a process for review (with capacity for review prior to initial placement onto the site and at appropriate intervals to ensure currency). Needs to cite positions/ qualifications / names of who reviews</td>
</tr>
<tr>
<td>Responsible advertising – no drug advertising and minimal commercial/ product advertising</td>
<td>Includes a policy on advertising</td>
</tr>
<tr>
<td>Independent of drug companies (resources developed by independent groups may be sponsored by unrestricted drug grant)</td>
<td>Addresses conflict of interest</td>
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</tbody>
</table>
Key providers of cancer consumer health information in New Zealand should be encouraged to develop, document and make explicit their policies and procedures for ensuring that the information they provide or ‘promote’ meet the types of minimum standards illustrated above.

**Consumer Guides to Web-based Health Information**

Another strategy for assisting consumers to assess the quality of a website is the provision of consumer guides. A number of health service providers have developed simple guides that can assist consumers to assess the quality of health websites, including looking for certification such as the HONcode. CSNZ have produced such a guide and this should be promoted for use amongst all service providers.

**Summary**

Many consumers use the Internet to obtain health information despite the risks associated with its use. Moreover, the Internet has proven to be a very efficient and effective medium for helping service providers to deliver high quality consumer health information. Therefore, service providers need to: capitalise on the opportunity to disseminate quality information through the Internet; and concurrently instigate a range of processes to minimise the risks for consumers.

The Ministry of Health can contribute to development of appropriate web-based supports through the promotion of each of the three strategies discussed above (HONcode, Quality standards & Consumer guides) among the funded service providers. Access to reliable and credible consumer health information in New Zealand could further be enabled through a nationally coordinated approach, as discussed below.

**National Coordination**

Significant concern has been raised both through the CSNZ stocktake and review and the Strategic Thinker Workshops with respect to duplication of effort in the development of consumer information resources. The development of an Information Clearing House to overcome duplication and enhance coordination has been proposed as the ‘solution’ to this issue.

A key impediment to implementing a Clearing House in the short to medium term is the resource implications of such an option. Current economic conditions in New Zealand have led to restraint in public sector expenditure and thus it is unlikely that the Ministry will have the discretionary funds for such an initiative at least in the medium term (3-5 years).

Whilst noting that a Clearing House is more likely to be a longer-term solution, alternative approaches to enhance the coordination of resource development have been identified. For example, Hepatitis Australia and its State and Territory counterparts (independently incorporated bodies such as Hepatitis Queensland), offer a potential model for coordination of information in the New Zealand context.

**An Information Network - A model for enhancing coordination of resource development**

- The model is based on an ‘Information Network’ facilitated by the peak body, Hepatitis Australia. Members of the network are the State/Territory based affiliate organisations.
- Personnel responsible for producing consumer information participate in the network.
- The network meets face-to-face for 1-2 days once a year to plan and distribute activities for the ensuing twelve months and to review existing work-in-progress. They teleconference three times per year to discuss progress, identify issues etc.
- Information is produced in accordance with agreed standards and undergoes quality assessment in a manner similar to that described above.
- Hepatitis Australia hosts the information on their website, although the State/Territory bodies may elect to do so similarly. For example, adaption of a ‘standard’ resource to suit the local State/Territory is common and subsequently is hosted on the local site.

The advantages of this model are that:

- it provides a coordinated and prioritised approach to resource development, significantly reducing the potential for duplication
- the resource development workload and cost is largely shared amongst ‘members’
• it ensures consumer health information developed meet the three critical criteria of relevance, clarity, and accuracy
• it sets the foundations in place for shifting to a full Clearing House model - processes and standards are already set in place
• the approach is very similar to that which the CSNZ (the predominant provider of consumer cancer information in New Zealand) currently uses within its own organisation.

This model presents an opportunity for service providers in New Zealand to address the issue of duplicative effort in a cost efficient way and concurrently set the policy and processes in place for moving to an information Clearing House should funding become available.

Within this approach, consideration would need to be given to how the information needs of the various cultures within New Zealand are addressed. This could include: ensuring appropriate levels of cultural representation on the information network; an additional network for specific population groups; or specific sub-groups of the main network.

The CSNZ would seem to be the best placed organisation for taking the overall coordination role for such a network. Their existing processes for needs analysis and quality assessment in particular could simply be expanded to include other organisations. The CSNZ would of course need some funding to deliver on this requirement.

5.2.3 INFORMATION DISSEMINATION & DELIVERY

The predominant issue relating to the dissemination and delivery of information resources are associated with those resources being easily accessible. Again, the notion of an information Clearing House has been proposed as the ideal way to address this issue and this approach and alternatives to it have been discussed above.

Additionally, dissemination and delivery of appropriate resources is dependent on the workforce being aware of the range of appropriate resources they can distribute or recommend. This is discussed briefly in the Workforce Development section below.

5.2.4 WORKFORCE DEVELOPMENT

As noted in the Guidance, it is critical that the workforce is cognisant of the information resources that are available for use with people affected by cancer and their whānau. Cancer service providers should continue to ensure that their staff and in particular new recruits are aware of the range of resources available and where they can be accessed. Service providers should develop a basic directory of information available within their organisation for use with patients and whānau and trusted websites that they can recommend to those affected by cancer.

A list of trusted websites, associated with a guide for patients in assessing the quality of websites could be addressed as part of the nationally coordinated approach discussed above.

5.2.5 INEQUALITY REDUCTION

Inequality reduction in the area of Information Support is best addressed by ensuring a range of information resources is available, appropriate and accessible. Two key strategies (discussed above) are proposed for addressing inequality:

• co-design with a range of consumers ensuring:
  o Prioritised gaps in information are addressed
  o The form of the information resource is the most appropriate (print, media, web etc.)
  o Health literacy is taken into account
  o Cultural aspects are considered including concept design, use of Māori images and Māori language, and strategies for effective delivery of messages in a range of Māori contexts
• an ‘information network’ (if pursued) that is configured and has the appropriate membership to ‘speak to’ inequality reduction.
5.3 **Implications for a Supportive Care Implementation Plan**

The results of the stocktake suggest that there is work to be done at the service, regional and Ministry level to develop an appropriate system of information support for both consumers and service providers in cancer care. Some of the key areas to be addressed in a supportive care implementation plan include:

**Consumer Information Principles.** While consumer information principles have been clearly documented in the Guidance, a system for ensuring their application has not been developed. This could be aided by a centralised system for ‘accrediting’ consumer health information in New Zealand against the three simple consumer information principles of Accuracy, Clarity and Relevance.

**Resource Design and Development.** Whilst generally, the consumer information principles are being addressed (albeit not in a formal process) in the design and development of consumer information resources, two specific areas would benefit from further action; consumer involvement and guidance with respect to using the web. The first issue can be addressed through taking a co-design approach to the development and provision of consumer information. The latter issue of ensuring consumers have access to relevant and quality web-based information would be enabled by encouraging NZ cancer information providers to develop a set of quality standards against which their website can be assessed, seeking the international HONcode classification and producing and disseminating consumer guides on accessing the web for health information.

**National Coordination.** The Guidance points to the development of an information clearing house as an effective means for reducing the current duplication of effort and resources in developing cancer consumer information. Whilst this is the ideal, it is likely that limited resources will limit the opportunity to meet this goal in the short-term. The introduction of an information network, where a shared approach to the development and production of (relevant, accurate and clear) information is taken, overseen by a national body may be an appropriate intermediate step. One of the major advantages of such an approach is that it sets the foundations in place for shifting to a full Clearing House model through having a range of processes and standards set in place. The information network would also aid in the efficient dissemination of information resources.

**Workforce Development.** It is critical that the workforce is cognisant of the information resources that are available for use with people affected by cancer and their whānau. Cancer service providers should continue to ensure that their staff and in particular new recruits are aware of the range of resources available and where they can be accessed. Service providers should develop a basic directory of information available within their organisation for use with patients and whānau and trusted websites that they can recommend to those affected by cancer. A list of trusted websites, associated with a guide for patients in assessing the quality of websites could be addressed as part of the nationally coordinated approach discussed above.

**Inequality Reduction.** Inequality reduction in the area of Information Support is best addressed by ensuring a range of information resources is available, appropriate and accessible. Two key strategies (discussed above) are proposed for addressing inequality: A co-design approach with an appropriate range of consumers is undertaken; and an information network (if pursued) is configured with the appropriate membership to ‘speak to’ inequality reduction.

With these information support issues in mind, the following table presents areas for action in information support linked to the action areas of the Guidance. Responsibility for carrying out each recommended actions is designated at the service, regional and/or national levels and for each action the requirement regarding one-off (O), short term (ST), or sustained funding/development (S) is specified. Where the action is a component of regular business activity, this is noted as business as usual (BAU).
### Table 5.3: Avenues for Developing Information Support

<table>
<thead>
<tr>
<th>Action Area from Guidance</th>
<th>Areas for Implementation Planning</th>
<th>Recommended Actions</th>
</tr>
</thead>
</table>
| 1. Ensure people affected by cancer have ready access to a wide range of high-quality resources | The consumer information principles documented in the guidance are addressed in the development of ALL cancer consumer information (print, media, web) | • Nationally, promote the ‘three principles’ for Quality Consumer Information: relevancy, accuracy, & clarity. (ST)  
• Nationally, develop and promote the adoption of minimum standards for the provision of web-based information (e.g. Health Navigator NZ and HealthInsight). (ST)  
• Nationally, encourage web-based information providers to achieve HONcode or similar certification. (ST) and then BAU  
• Investigate and implement if appropriate an information accreditation process (ST)  
• Develop, promote and maintain a national web-based information directory (ST) and then BAU  
• Nationally (and for local adaptation), develop and promote the dissemination of consumer guides to accessing the internet for information. (ST) and then BAU  
• Nationally (and for local adaptation), develop consumer guidelines for accessing TM/CAM services. (O) |
| 2. Ensure consumer cancer information is culturally appropriate | A range of appropriate resources should be developed to meet the needs of Māori, Pacific and other cultural groups in NZ | • Nationally, regionally and locally, a consumer co-design approach involving consumers with a range of cultural backgrounds should be implemented in the design, development and dissemination of consumer Cancer information. (ST) and then BAU  
• The information network (if established) should develop a range of culturally appropriate information. (ST) and then BAU |
| 3. Ensure consumer representatives are involved throughout the design, development and evaluation phases of information resource production | Cancer information should be designed, developed and disseminated utilising a consumer co-design approach | • Nationally, regionally and locally, a consumer co-design approach should be implemented in the design, development and dissemination of consumer Cancer information. (ST) and then BAU |
| 4. Ensure staff are familiar with the available consumer cancer information | Ensure the workforce can easily facilitate consumer access to appropriate information | • All cancer service providers should develop a directory for staff of internal and trusted external information resources that can be provided to patients and whānau. (O) and then BAU |
| 5. Establish a national information resource clearing house | Develop the foundations for a future information resource clearing house. | • Establish a National Information Network as a precursor to the development of a national information resource clearing house. (ST)  
• The Ministry should determine the appropriate agency for leading the development of the information network and support its establishment. (ST) and then BAU |
SUMMARY AND A PROPOSED MODEL FOR SUPPORTIVE CARE

This chapter presents a summary of the key findings from each of the priority areas and proposes a model for the development of cancer supportive care in New Zealand.

6.1 KEY FINDINGS

Overall, findings from the targeted stocktake of the three priority areas (i.e., care coordination, psychosocial support & information support) showed that there were consistent themes regarding needs for improvement that transcended any particular supportive care domain, which included:

- **A need for greater consistency in service provision:** Although the need for service flexibility and for local adaptation of services is important, a baseline level of service delivery within and across regions and nationally is required to ensure that patients and their whānau as well as cancer sector staff have access to similar sorts of supports/services. This includes baseline competencies of staff, baseline levels of distress assessment and referral process and baseline measures for reviewing and accrediting information support.

- **A need to review funding issues:** Clearer and more flexible funding structures will support improvements in supportive care service delivery. For example, identification of responsibility for funding supportive care access within cancer treatment regions, will help to ensure that DHB boundaries do not impede service access, and more flexible funding will reduce regional variations in available supports (e.g., provision of prosthetics) and increase the reach of supportive services (e.g., remove age restrictions on supportive care practice).

- **A need for improved communication:** Whether expressed as a need for improved access to information about available services or improved communication among service providers and patients, gaps were noted in communication systems. It appears that electronic systems (i.e., information clearing house and patient information management systems) are key to improving and monitoring communication processes.

- **A need to facilitate access to information:** Improved dissemination of information about available supportive care services to both patients/whānau and service providers may help to improve referral to and subsequent patient access to supportive care.

- **A need to improve cultural responsiveness:** There are still gaps in the extent to which services are meeting the cultural needs of patients and whānau, and in the availability of cultural services.

- **A need for taking a co-design approach to supportive care:** There are opportunities for improving a patients experience of supportive care and as a consequence their outcomes through adopting co-design approaches within supportive care.

- **A need for improved monitoring processes:** Monitoring of service data such as patient assessments, referrals, and patient outcomes post intervention is critical to understanding service use and uptake issues as well as to evaluating and disseminating information about effective services. Monitoring processes are hampered in part by service sector boundaries, patient information systems and siloed care and on balance there are few examples of systematic approaches to assessing service delivery and outcomes.
In addition to these main themes, there were key findings specific to each of the three priority areas.

Key findings from the stocktake of **care coordination** were that:

- There are multiple models of care coordination being utilised across the country, including variations in the staffing of care coordination roles (e.g., professional versus lay staff & care coordination specialists versus staff that have care coordination as a component of their role)
- Contrary to recommendations by the Guidance, there are few services that ensure a single point of contact (e.g., a key worker) for patients and whānau to obtain help
- Respondents had varying viewpoints on where care coordination services would be housed (primary secondary or both). However there was consensus on the need for communication across services irrespective of the service location.

Key findings from the stocktake of **psychosocial services** were that:

- Distress is increasingly being recognised as the 6th vital sign (alongside body temperature, pulse, blood pressure, respiratory rate, and pain in the case of cancer care) and appropriate distress management is an important part of ensuring the wellbeing of those affected by cancer
- Psychosocial support service referrals and coordination processes appear to be better in larger cancer centres/urban centres, but with only a few exceptions, these processes are mostly informal and rely on relationships between staff across service boundaries
- There is evidence that some of the cancer treatment centres are working well to triage and provide support for psychosocial needs, and smaller locally specific initiatives across the country are being implemented to improve services along the continuum
- Psychosocial services in New Zealand are under-resourced, and this is contributing to service gaps and contrary to recommendations in the Guidance, there are few ‘fully integrated’ psychosocial support services
- There is little data on the extent of need for psychosocial support or uptake of support services, and little data on patient outcomes. Therefore the effectiveness of psychosocial support services is largely unknown
- Overseas, programmes are being implemented to develop/adapt triaged models of cancer care to incorporate psychosocial support into the local context and to research the effectiveness of the tiered approach
- Development of a nationally consistent model of psychosocial support for those affected by cancer appears to be an important next step in the development of supportive care in New Zealand.

Key findings from the stocktake on **information support** were that:

- Current findings overlap significantly with those presented in a report on a stocktake and review of consumer cancer information resources undertaken by CSNZ in 2006. Many of the recommendation from the CSNZ report have not been systematically progressed
- A range of consumer information principles and standards should be promoted to ensure the provision of quality consumer information regardless of the medium used. In particular the three principles of relevancy, accuracy and clarity
- The three principles noted above would be ensured through a consumer co-design approach to the development of information for consumers
- Whilst an Information Clearing House should remain a long term goal, an appropriately supported ‘information network’ would be an effective precursor.

### 6.2 IMPLICATIONS FOR A SUPPORTIVE CARE IMPLEMENTATION PLAN

The current research was targeted to three priority areas in light of funding and workforce constraints. However, the need to research and make plans for the other five domains of supportive care in the Guidance is acknowledged.
As discussed above, one of the key findings from this stocktake research is that there are a number of overlapping and overarching issues (e.g., consistency of services, communication, funding) that could be addressed to improve services in the priority areas. A review of the issues and areas for action in the Guidance indicates that these overarching themes also apply to the remaining five supportive care domains listed in the Guidance.

As it currently stands, the Guidance on supportive care provides disparate areas for action across each of the eight supportive care domains. Although the Guidance organises action areas across the eight domains into different subgroups (i.e., action areas: for service delivery; workforce development & research and monitoring) there is no overarching or coherent framework to support the development & delivery of supportive care in New Zealand more generally.

Therefore, stocktake findings point to the need to develop a framework for the delivery of supportive care. A framework and a process for integrating recommendations into it are proposed below. It is intended that any framework that is developed/adopted will be able to hold recommendations that are developed for the three priority areas as well as the other supportive care domains.

6.3 A FRAMEWORK FOR SUPPORTIVE CARE

In order to improve development and delivery of supportive cancer care services it is recommended that the Ministry:

- Develop a national framework for supportive care, that includes:
  - A model of tiered and triaged supportive care
  - Screening/assessment and referral procedures
  - Acceptable accreditation procedures
  - Decisions regarding funding responsibilities (i.e., who should fund supportive care?)
- The framework should be developed to fit with/complement current guidelines for cancer treatment (i.e., supportive care complements current treatment pathways)
- The framework for supportive care should be developed in consultation with consumer, Māori, Pacific and representatives from relevant service organisations, etc.

Such a framework would help to provide consistent direction the Regional Cancer Networks and to individuals working in cancer care in how best to assess and triage support needs and would provide a framework for integrating supportive care into cancer treatment. Additionally, it would help to address the common overarching themes identified in the stocktake including: inconsistent service provision; lack of service monitoring & evaluation; unclear and inflexible funding structures; and so on.

For the purposes of this document, the Fitch model (2000) described in Section 4 has been adapted to show how a model for tiered supportive care may be developed in New Zealand. As shown in Figure 6.1, the model suggests that support care be tiered and triaged across four levels:

- **Level 1**: a basic level of support (predominately through information) is provided to all those affected by cancer. All staff working in the cancer care sector are aware of the importance of supportive care and available services and can screen for and make appropriate referrals for supportive care needs. In addition, general health promotion/healthy lifestyle promotion including educating patients and whanau on the positive outcomes that healthy eating\(^{118}\) and exercise\(^{119,120}\) can have during a cancer journey is undertaken.
- **Level 2**: those affected by cancer who have mild to moderate supportive care needs are referred for further assessment and intervention. Interventions may be more targeted however do not necessarily warrant ongoing care coordination.

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- **Level 3**: those affected by cancer who have moderate support needs and/or who have complex needs and/or those facing inequalities in cancer service access and care are provided care coordination including specialised intervention as appropriate. At this level, patients are referred to key workers.

- **Level 4**: Those with highly complex or specialised needs receive care coordination and specialist services (e.g. psychiatric services).

Development of a systematic model of supportive care in New Zealand will require action in regards to development of service delivery (including decisions on methods for identifying needs and referral pathways), workforce development, and research and evaluation.

Ideally, the model should be used to specify activities and supports that may be provided at each level of care (i.e., Levels 1 – 4). Once the model is developed, actions to improve supportive care may be ‘stepped up’ to ensure that different levels/aspects of the tiered approach are targeted first, and within existing resources for improving supportive care (i.e., the model provides a vision of supportive care that may be realised over time).

Over time and with improved monitoring of service access, use and outcomes data, more long term goals of developing and funding a skilled workforce and developing more integrated cancer centres could be realised. Alternatively, services and or regions can work to improve delivery of services at certain ‘levels’ of supportive care as needed. Identification of need could be determined by comparing service delivery practices against national guidelines developed for a minimum standard of care or at least through the use of tools such as the Rubrics for Supportive Care.

*Figure 6.1: Proposed Model for Supportive Care in New Zealand*
A strategy for presenting & prioritising recommendations in the Action Plan

The sections on Care Coordination, Psychosocial Support and Information Support each present areas for development of supportive care service delivery based on stocktake findings (Tables 3.2, 4.2, & 5.3 respectively). As there are consistent themes across stocktake findings in these three priority areas, there are also ideas for change that are consistent or overlapping across the three areas (i.e., where they apply to more than one supportive care domain). As such, many of these actions could be condensed for the Implementation Plan. Additionally, recommendations could be targeted to different levels of the tiered approach to supportive care proposed above. For example, some recommendations such as those related to service funding apply to all levels of supportive care whereas others such as recruiting specialised staff to provide supportive care are related to the higher levels of supportive care.

Each recommendation may be headed by a triangle symbol and a Legend for linking these to the above model is presented in Table 6.1. Examples of the ways that recommendations may be presented for the Implementation Plan are presented in Table 6.2.

#### Table 6.1: Legend to Linking Keys with the Supportive Care Model

<table>
<thead>
<tr>
<th>Key</th>
<th>Match with Tiered Model</th>
<th>Key</th>
<th>Match with Tiered Model</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level 1</td>
<td>Levels 2 &amp; 3</td>
<td>Level 2</td>
<td>Levels 1 &amp; 2</td>
</tr>
<tr>
<td>Level 3</td>
<td>Levels 2,3 &amp; 4</td>
<td>Level 4</td>
<td>Levels 1, 2 &amp; 3</td>
</tr>
<tr>
<td>Levels 3 &amp; 4</td>
<td>All Levels</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

#### Table 6.2: Example Format for Recommendations in the Implementation Plan

<table>
<thead>
<tr>
<th>Level of Support</th>
<th>Example Recommendations for the Implementation Plan</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• Establish an Information Network as a precursor to the development of a national information resource clearing house</td>
</tr>
<tr>
<td></td>
<td>• Raise awareness of distress as the 6th vital sign and provide training/ CME to all staff in cancer care on the negative impacts of unmet supportive care needs on the health and wellbeing of those affected by cancer</td>
</tr>
<tr>
<td></td>
<td>• Discussion of supportive care needs should be raised in MDT meetings</td>
</tr>
<tr>
<td></td>
<td>• Regional models of care coordination should be developed to fit with any national model of care, and all providers should adapt this to inform local care coordination service delivery. The model should be developed in collaboration with patients/ whānau and providers including primary and secondary care and NGOs.</td>
</tr>
<tr>
<td></td>
<td>• Develop workforce to ensure that there are key workers and specialists available who can provide appropriate care to those affected by cancer</td>
</tr>
<tr>
<td></td>
<td>• All services have a minimum set of standards that are agreed and through which evaluation of the extent to which services are meeting the Guidance for supportive care can be realised.</td>
</tr>
</tbody>
</table>
### Example Recommendations for the Implementation Plan

<table>
<thead>
<tr>
<th>Level of Support</th>
<th>Recommendation</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Tools/standards such as the Rubrics for Supportive Care and the HON code could be used</td>
</tr>
<tr>
<td></td>
<td>• Ensure that referral trees for decisions about triaging supportive care are developed for each cancer</td>
</tr>
<tr>
<td></td>
<td>treatment centre &amp; satellite service centres</td>
</tr>
<tr>
<td></td>
<td>• Improve electronic referral &amp; patient monitoring systems to improve communication between providers</td>
</tr>
<tr>
<td></td>
<td>• All services involved in triaging and delivering supportive care collect a minimum dataset as specified</td>
</tr>
<tr>
<td></td>
<td>through the Ministry’s model, that enables monitoring and evaluation of effectiveness of service delivery</td>
</tr>
</tbody>
</table>

This proposed model of supportive care and recommended actions for the Implementation Plan are to be discussed with the IWG in a meeting on 30 June 2011. It is hoped that through collaboration, the recommendations presented in Tables 3.2, 4.2 & 5.3 of this report will be amended and/or added to as necessary and the final set of recommendations will be prioritised in the Implementation Plan. These recommendations will include both near and long-term goals for the development of supportive cancer care services.

### 6.4 Monitoring & Evaluation

As part of the development of the Supportive Cancer Care Implementation Plan (the Plan), HOI will work with CCNZ to design monitoring and evaluation processes for any recommended supportive cancer care service improvements that are agreed by the IWG.
Appendix A - Stocktake Survey

National Adult Cancer Care Coordination Stocktake Survey

The Project

The Ministry of Health has engaged Health Outcomes International (HOI) to develop a plan to implement the Guidance for Improving Supportive Care for Adults with Cancer in New Zealand. ‘The Guidance’, published in March 2010, provides clear objectives and best-practice approaches for all organisations involved in funding, planning, policy and programme development, and delivery of cancer supportive services. A Stocktake Report and the Guidance Implementation Plan will be completed by the end of July 2011.

For further information on the project please contact: andrew@hoi.com.au

‘Guidance’ definition of cancer care coordination

Care and support coordination refers to a comprehensive approach that seeks to achieve continuity of care and support, drawing on a variety of strategies that strive for the delivery of responsive, timely and seamless care across a person’s cancer service pathway.

A key worker is a healthcare provider who, with the consent of the persons affected by cancer, takes a key role in coordinating their care, promoting continuity and ensuring that they and their careers know who to go to for information and advice (NICE 2004a).

(Guidance for Improving Supportive Care for Adults with Cancer in New Zealand 2010: 48).

This survey

A component of the HOI project is to stocktake the current provision of cancer care coordination for adults. This stocktake survey aims to understand who is providing cancer care coordination, what they do and their views on the challenges faced. This is a baseline survey and it is anticipated will be built upon in the years to come.

Please continue with the survey if you provide any aspect of cancer care coordination, or are a key worker for patients with cancer. Please forward this survey to any colleagues who also undertake cancer care coordination tasks.

Note: Questions marked with an asterix (*) need to be answered before you can move onto the next page.

Contact details

1. For future correspondence purposes please provide your email address (Required)
2. If available, please provide an email address for the organisation that you work for
3. We may wish to speak with you further about your role in cancer care coordination, are you happy to be contacted? (Required)
   - Yes
   - No
Thinking about your cancer care coordination role, please answer the following questions

4. What is your job title? (Required)

5. Who do you work for? (Required)
   - DHB
   - Primary care organisation: PHO, GP etc.
   - NGO
   - Other

6. Please provide details (Required)

7. Where do you work in your cancer care coordination role? (Required)
   - Primary care
   - Secondary care
   - Regional role
   - National role
   - Maori service: Primary Care
   - Maori service: Secondary care
   - Pacific Service: Primary Care
   - Pacific Service: Secondary Care
   - Other

8. Please provide details (Required)

9. Please tick all of the following tasks that you do to coordinate cancer care for patients (Required)

<table>
<thead>
<tr>
<th>Tasks</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Triage referrals</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Explaining investigations</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Supporting through investigations</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Organising investigations</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Explaining treatment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Organising treatment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Triage of symptoms/ side effects</td>
<td></td>
<td></td>
</tr>
<tr>
<td>General psychosocial care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Organising/ supporting childcare issues</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Organising/ supporting other dependent relative/ whanau issues</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Providing budgeting advice or referral for advice</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Providing housing advice or referral for advice</td>
<td></td>
<td></td>
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<tr>
<td>Organising accommodation during treatment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Referral to other service/ s for supportive care e.g. NGO</td>
<td></td>
<td></td>
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<tr>
<td>Provision of cultural support</td>
<td></td>
<td></td>
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<tr>
<td>Referral to others for provision of cultural support</td>
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<td></td>
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<tr>
<td>Provision of spiritual support</td>
<td></td>
<td></td>
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<tr>
<td>Referral to other for provision of spiritual support</td>
<td></td>
<td></td>
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<tr>
<td>Provision of information or resources about the service provided by you/ your work place</td>
<td></td>
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<tr>
<td>Provision of information 'packs' e.g. Breast Cancer, Lung Cancer, Bowel Cancer and so on</td>
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</tr>
<tr>
<td>Provision of ‘general’ cancer service information/ resources</td>
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<tr>
<td>Organising appointments</td>
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<tr>
<td>Organising transport</td>
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<td></td>
</tr>
<tr>
<td>Referral to others to organise transport</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Providing letters to patients employer/ workplace</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attending multi-disciplinary team meetings where treatment decisions are made</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communicating with Nursing staff</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communicating with medical staff (in a hospital setting)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tasks</td>
<td>Yes</td>
<td>No</td>
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<tr>
<td>----------------------------------------------------------------------</td>
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<tr>
<td>Communicating with Allied Health staff (physiotherapist, speech language therapist, occupational therapist or dietician)</td>
<td></td>
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<tr>
<td>Communicating with Social Work staff</td>
<td></td>
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<tr>
<td>Communicating with Community Health Worker staff</td>
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<tr>
<td>Communicating with District Nurse's</td>
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<tr>
<td>Communicating with Cultural Support workers</td>
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<tr>
<td>Communicating with GP</td>
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<td></td>
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<tr>
<td>Communicating with NASC staff</td>
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<tr>
<td>Communicating with Travel Coordinators regarding funding</td>
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</tbody>
</table>

10. Please provide detail of any other tasks not noted above

11. Are there any particular groups (ethnic, cultural, age, disease) that in your experience requires additional cancer care coordination? (Required)
   - Yes
   - No

12. Who requires additional cancer care coordination? (Required)

13. What additional cancer care coordination is required? (Required)

14. Do you provide cancer care coordination for (Required)
   - Patient
   - Patient and whanau/family

15. What are the tasks you perform for the whanau/family? (Required)

16. From your perspective, what are three main issues you experience in coordinating cancer care? (Required)
   - Issue 1
   - Issue 2
   - Issue 3

17. Any other comments
APPENDIX B - STOCKTAKE SURVEY RESPONDENTS

Profession of survey respondents

The majority of responders were Nursing Staff (52%), with medical staff (11%), social workers (9%) and Managers (7%) being other significant respondents.

![Figure B.1: Respondents Professions](image)

Employers of survey respondents

The majority of responders are employed by DHBs (56%) and 18% are employed in primary care organisations: PHO, GP, etc. Sixteen percent work for NGOs and a further 10% for ‘other’ employers.

![Figure B.2: Respondents Professions](image)
Areas of work

As noted below, there is an almost even split between respondents who work in secondary care and primary care. There were 112 respondents from these two areas, comprising almost 75% of total submissions. In addition to this, 1 response was from a Pacific provider (1%) and a total of 4 respondents were classified as Māori providers (3%).

Figure B.3: Areas of Work