AN IMPLEMENTATION PLAN
FOR THE

GUIDANCE FOR IMPROVING SUPPORTIVE CARE
FOR ADULTS WITH CANCER IN NEW ZEALAND

AUGUST 2011

FINAL

Health Outcomes International
The Supportive Care Guidance Implementation Plan Project has been undertaken in collaboration with Arden Corter, Kataraina Pipi and Julian King & Associates.
# Contents

## Introduction .......................... 1
1.1 Supportive care ................................................................. 1
1.2 Prioritising Action ............................................................... 2
1.2.1 Research of the priority areas ........................................ 2
1.3 The Context ......................................................................... 2
1.3.1 Policy ............................................................................. 3
1.3.2 Other Principles ............................................................. 3
1.4 Leadership for implementation ......................................... 3
1.4.1 The Ministry of Health .................................................... 3
1.4.2 Regional cancer networks .............................................. 4
1.5 Monitoring & Evaluation ................................................... 4
1.6 Financial implications .......................................................... 4

## Common Themes and Supportive Care Framework .................. 5
2.1 Overall Findings ................................................................. 5
2.2 Prioritised Actions ............................................................... 6
2.3 A Framework for Addressing Supportive Care ..................... 7
2.4 Linking the Framework to the Priority Action ...................... 9

## Care Coordination ............................................................. 11
3.1 Introduction ...................................................................... 11
3.2 Key Findings .................................................................... 12
3.2.1 Service Delivery ........................................................... 12
3.2.2 Inequality Reduction ..................................................... 12
3.2.3 Workforce Development .............................................. 13
3.2.4 Research & Evaluation .................................................. 13
3.3 Actions for Care Coordination .......................................... 14

## Psychosocial Support ......................................................... 19
4.1 Introduction .................................................................... 19
4.2 Key Findings .................................................................... 20
4.2.1 Service Delivery ........................................................... 20
4.2.2 Workforce Development .............................................. 20
INTRODUCTION

In March 2010, the Ministry of Health (Ministry) published the Guidance for Improving Supportive Care for Adults with Cancer in New Zealand, 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.

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)
- Regional Cancer Networks (RCNs)
- Non-government organisations (NGOs)
- Primary Health Organisations (PHOs)
- Māori and Pacific service providers

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- General Practitioners, allied and other health professionals.

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.

The domains of supportive care that were identified as the top three national priority areas in the Guidance and therefore form the basis of the Implementation Plan 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 research², where consumers noted greatest concern with: information provision; confusing information; consideration of patients’ circumstances in treatment planning; and emotional support.

1.2.1 Research of the Priority Areas

In order to sufficiently inform the 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. The findings of this research are contained within the Implementing Supportive Care, Priority Areas Research Report.³

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 in this plan 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. In fact, the plan notes in a number of areas the importance of developing mechanisms for sharing and widely disseminating better practice. Those who are well advanced in the various action areas could take a leadership role in furthering this better practice nationally.

Based on the research, a set of near-term and ‘realistic’ actions along with longer-term ‘aspirational’ actions have been proposed in this document.

1.3 The Context

Existing policy, strategy and priority programmes together with the findings from the workshops and research, identifies a range of contextual issues that need to be considered in delivering the recommended actions of the Implementation Plan.

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³ The research report is available on the Ministry of Health website.
1.3.1 Policy
There are a range of policies and strategies that are specifically relevant to the delivery of supportive care including:

- New Zealand Cancer Control Program (priorities – lung and bowel cancer)
- Guidance for Improving Supportive Care for Adults with Cancer in New Zealand
- Better, Sooner, More Convenient Health Care in the Community
- Whānau Ora principles/strategy/initiatives
- He Korowai Oranga: Māori Health Strategy
- Whakatātaka Tuarua: Māori Health Action Plan
- The New Zealand Cancer Control Strategy and Action Plan

1.3.2 Other Principles
In addition to the policy and strategy context noted above, there are a number of other principles and themes that are common to all domains of the Guidance. These principles need to be addressed in the implementation of any of the recommended actions and conversely many of the actions are proposed to specifically address these principles. These are listed below and discussed in more detail in section 2.1.

- Inequality reduction
- Whānau Ora approach
- Cultural responsiveness
- Co-design of services with consumers
- Equity of service access
- Funding allocated to priorities
- Timeliness of responses
- Local adaptation and flexibility
- Workforce development
- Research, Monitoring and Evaluation
- Leadership

1.4 Leadership for Implementation
The Implementation Plan includes both realistic and feasible actions that can be addressed in the short to medium term, along with longer-term aspirational actions. Leadership will be required for both.

1.4.1 The Ministry of Health
The more strategic and broader activity has been designated as the responsibility of the Ministry. A number of the actions and in particular the development of frameworks and models of supportive care, will require substantial input and as such will need to be specifically included in the cancer control work programme of the Ministry. This is in alignment with the priority of the national cancer programme: Standardising a range of models of care and treatment pathways. The potential to tie strategic developments to pilots involving lung and bowel cancer also reinforces the national priorities.
1.4.2 Regional Cancer Networks

Given the role of Regional Cancer Networks (RCNs) in facilitating and coordinating services across health providers at all levels and bringing various providers and consumer organisations together to ensure co-operation and integration of services where appropriate, they would appear to be the obvious body to have carriage of coordinating supportive care developments at the regional level. In fact, this would simply be a continuation of existing practice, albeit a specific plan would be in place to provide guidance.

This is not to suggest that other partners including; regional cancer centres, DHBs, NGOs and consumers would not have a significant role (including leading some actions), rather the RCNs would assume the overarching coordination role for the Implementation Plan.

1.5 Monitoring & Evaluation

Monitoring and evaluating the extent to which supportive care for adults with cancer in New Zealand is accessible, of high quality and improves the quality of life for people affected will occur at a number of levels.

At the broadest level, Cancer Control New Zealand (CCNZ), will as part of its ongoing supportive care work programme, develop a supportive care outcomes framework. This framework will be used to monitor how supportive care activities undertaken in the sector contribute to supportive care outcomes more broadly. This will be published on the CCNZ website.

As part of the development of the Supportive Cancer Care Implementation Plan (the Plan), a range of key performance indicators have been developed to measure the extent of implementation of the plan over time. Additionally, a series of Rubrics have been developed as part of this project that can be used to facilitate the extent to which an organisation meets the expected outcomes of the Guidance domains.

Given the leadership roles of the Ministry and the Regional Cancer Networks, it is envisaged that they will undertake the overall monitoring and reporting role with respect to the extent to which the Implementation Plan has been implemented and the outcomes arising.

1.6 Financial Implications

The implementation plan does not include detailed financial implication for each of the recommended actions. As noted in the Guidance, the Ministry of Health will consider the costs of developing new services and enhancing existing support services where required. These will be prioritised and form the basis for future budget planning.

Additionally, at the regional, local and organisational level, it is expected that funding decisions and funding bids will be made with respect to the relevant priority of a recommended action for the local context.
COMMON THEMES AND SUPPORTIVE CARE FRAMEWORK

This section presents the overall findings of the targeted stocktake of supportive care with a focus on those issues that were common to the priority areas of care coordination, psychosocial support and information support. Also presented is a framework for assisting service planners, managers, funders and decision makers with addressing the range of prioritised supportive care developments across four tiered levels of need.

2.1 OVERALL FINDINGS

Findings from the targeted stocktake showed that there were common issues affecting care coordination, psychosocial support and information support and areas for improvement that transcended any particular supportive care domain. These common issues are as follows.

- **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 types of supports/services. This includes for example a minimum standard of; staff competencies, assessment and referral process; and access to high quality information support.

- **A need to review funding issues:** Clearer and more flexible funding structures will support improvements and greater equity 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 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. Electronic systems (i.e. information network or clearing house and patient information management systems) will be key to improving and monitoring communication processes, albeit continually improving face-to-face communication within the priority areas will also be critical.

- **A need for integrated assessment:** The importance of assessing supportive care needs for patients and their whānau was highlighted in all areas. Developing a consistent approach to assessment for all patients and promoting the benefits of assessment to all staff in the sector are key to improving outcomes and experiences for patients and their whānau. This should be supported by all cancer services staff having the skills in assessment of supportive care need.

- **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 and subsequent patient access to supportive care. Additionally, there is a need to improve the availability and dissemination of relevant, clear and accurate information about cancer and its management and the available supportive care services for both patients and whānau.
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- **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. All organisations would benefit from undertaking cultural audits.

- **A need for taking a Co-design approach to supportive care**: Co-design is an experience based design approach where patients, whānau and healthcare providers work together in equal partnership to identify issues and improvement opportunities. There is a need to use co-design approaches in developing supportive care strategies and resources in order to improve the patient and whānau experience of supportive care and as a consequence their outcomes.

- **A need for Workforce development**: A need to develop the workforce's understanding of the importance of supportive care (all components) and the means by which it can contribute to better outcomes.

- **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 that are discussed in the relevant section.

### 2.2 Prioritised Actions

The sections to follow on Care Coordination, Psychosocial Support and Information Support each present recommended actions for development of supportive care service delivery based on stocktake findings. Due to the overlapping nature of the supportive care domains, there are a number of recommendations that are similar across the three priority areas. Addressing these overlapping action areas as a first step for implementation may provide a means to achieving greater impact with more focused effort and enable progression of supportive cancer care service development at a time when resource constraints preclude immediate action of all recommendations outlined within this plan.

The following actions are considered immediate priorities:

- **Develop a national framework for addressing supportive care** as discussed in the section below. In developing this framework, it is anticipated that prioritised activity will also become evident.

- **Develop service models for care coordination and psychosocial support** in accordance with the recommendations contained within those specific sections.

- **Implement workforce development** activities to identify and enact strategies for raising awareness of the importance of recognising and attending to supportive care needs. This should also include documenting minimum competencies required of cancer care staff working at different levels of supportive care.

- **Establish an information network** to ensure the information needs of patient and whānau are adequately addressed.

In addition to these near term actions, it is intended that over time, the more ‘aspirational’ recommendations for service development outlined in this Implementation Plan will be addressed. Additionally, the actions in this plan will be applied, where possible, to the development of other supportive cancer care domains outlined in the Guidance.

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Although it is noted that work in ameliorating the issues that transcend any particular supportive care domain will also have the effect of progressing service development and delivery in these areas. It is also recognised that the priorities for action will differ from region to region in accordance with the prevailing situation in a region and/or local priorities.

2.3 **A Framework for Addressing Supportive Care**

As it currently stands, the Guidance on supportive care provides comprehensive, but disparate areas for action across each of the eight supportive care domains. There is no overarching or coherent framework to support an integrated approach to addressing the different components of the guidance particularly across the common issues. A supportive care framework can facilitate discussion of the integrated requirements (of each guidance component) at each level and the developments/actions that will be required to improve supportive cancer care. This would also enable greater reach than the priority areas identified in this report.

For example, the need for patient/whānau assessment of supportive care is a theme that runs through all eight supportive care domains. As such, assessment provides a useful example of the need for a framework to bring together assessment needs in each component, as illustrated below.

- All patients are deemed to require a general assessment of supportive care need that encompasses aspects of all eight supportive care components, rather than eight different assessments. This will require a collaborative approach from people with particular expertise from each of the eight components to develop a general assessment tool. Should the general assessment indicate the need for higher-level support for a particular component (e.g. psychological support), then a more specific and detailed assessment relevant to that component would be undertaken.

This example can be applied across other common issues of supportive care such as minimum service standards, workforce development needs, data collection, provision of information, funding etc.

It is strongly recommended that the Ministry develop a national framework of supportive cancer care that:

- details the ‘tiers’ of supportive cancer care and the roles of all staff in the cancer sector at each tier of the model so that patient/whānau needs may be assessed and as required triaged/referred to the appropriate level of support
- specifies supportive care screening/need assessment
  - procedures (including the tool(s) that could be used)
  - critical occurrences (when assessments must be undertaken, for example, at first specialist appointment, at care transition points such as moving from active treatment to survivorship etc.)
  - referral processes (e.g. mandates for supportive care referral decision trees for each cancer treatment centre)
- outlines acceptable service specifications for in-service development and delivery of supportive care, including a minimum dataset and associated accreditation procedures
- specifies funding responsibilities (i.e. who should fund supportive care?)
- complements current guidelines for cancer treatment (i.e. cancer treatment pathways)

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5 In addition to the need for regular and recurrent assessment on the cancer care continuum.
This Implementation Plan presents a draft framework, however, it is intended that any framework that is ultimately developed/adopted by the Ministry will be able to hold any future recommendations for service developments in the other four domains of supportive care described in the Guidance.

Figure 2.1 presents a framework for supportive care that may be adapted by the Ministry of Health. Based on work by Fitch 2000, the framework presents supportive cancer care tiered and triaged across four levels. The framework reinforces that supportive care is not a distinct specialty, but is the responsibility of all health and social care professionals delivering care. It requires a spectrum of skills, extending from foundation skills to highly specific expertise and experience. Open and sensitive communication is important, as is good coordination between and within organisations and teams to ensure the smooth progression of patients from one service to another.

Level 1:
A basic level of support (predominantly through information) is provided to all those affected by cancer. All staff working in the cancer care sector is aware of the importance of supportive care and available services and can screen for and make appropriate referrals for supportive care needs if this indicated. In addition, general health promotion/healthy lifestyle promotion including educating patients and whānau on the positive outcomes that healthy eating and exercise 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.

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 identified key workers, for example, social worker, clinical nurse specialist, cancer care coordinators, tumour stream team member, navigators etc as is appropriate.

Level 4:
Those with highly complex or specialised needs receive care coordination from an identified key worker and specialist services (e.g. specialist psychological services).

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7 Guidance on Cancer Services: Improving supportive and palliative care for adults with cancer. NICE, 2004 p.20.
Ideally, the supportive cancer care framework should be used to specify activities and supports provided at each level of care/support. Once the framework is developed, priority actions to improve supportive care within each level are addressed within available resources. Over time and with improved monitoring of service access, use and patient outcomes data, more long term goals may be realised for improving supportive care at each level.

Alternatively, services and or regions can work to improve delivery of services at specific ‘levels’ of supportive care as indicated by local need. Identification of need may be determined by comparing service delivery practices against national guidelines developed for a minimum standard of supportive care.

2.4 LINKING THE FRAMEWORK TO THE PRIORITY ACTION

This Implementation Plan links actions for improving supportive care in the three priority areas back to this framework for supportive cancer care by indicating the level of service delivery where action is to be focussed or that will be affected by each recommendation.

This is denoted by a four level triangle with the respective levels of action coloured. Table 2.1 presents a key for activity at various levels.
### Table 2.1: Legend for Keys in Action Tables

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<th>Key</th>
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<td><img src="image" alt="All Levels" /></td>
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</tr>
</tbody>
</table>

Responsibility for carrying out each recommended action 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).
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 care 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 Thinker workshops identified systems and individual level 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
  - 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**

The following provides the key findings with respect to the area of Care Coordination.

3.2.1 **Service Delivery**

- 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
  - 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.

- 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.

- 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.

- 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).

- 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.

3.2.2 **Inequality Reduction**

- 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\(^1\) 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.

3.2.3 Workforce Development

- It appears communication training for all working in the oncology sphere will be beneficial in 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).
- Key to patient and whānau accessing support is receipt of information about services and the 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. It appears there are significant gaps in this area.
- It appears there is support for the development of competencies for cancer support workers such as navigators. This could assist patients and whānau to receive the highest standard of care and assist navigators by providing them with the resources, competencies and the skills to undertake their role as effectively and efficiently as possible. It also appears the requirement for basic competencies could improve the credibility of care coordination services and increase inward referrals.

3.2.4 Research & Evaluation

- Universally, all stakeholders 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 *Voice of Experience* Research.\(^\text{12}\)
- Currently, measurements of care coordination, when undertaken are generally linked to service level reports or aligned to contract or Ministerial reporting requirements such as referral times. It appears services are generally reporting on out dated 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.
- 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.

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).

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### 3.3 Actions for Care Coordination

**Table 3.1 Actions for developing Care Coordination**

<table>
<thead>
<tr>
<th>Action Area from Guidance</th>
<th>Areas for Implementation Planning</th>
<th>Action Levels</th>
<th>Recommended Actions</th>
<th>Key Performance Indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Service Delivery</strong></td>
<td>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.</td>
<td></td>
<td>• 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)</td>
<td>• An agreed national definition of cancer care coordination is documented</td>
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<tr>
<td></td>
<td>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</td>
<td>• Nationally, develop a model for care coordination, specifying the minimum standards for: service delivery, cultural service provision, assessment, documentation and minimum training requirements. (O)</td>
<td>• A national model of cancer care coordination is documented</td>
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<td>• 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.</td>
<td>• A minimum dataset relative to cancer care coordination is developed and implemented</td>
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<td></td>
<td>• At service, regional and national levels, develop minimum data set to inform service contracting &amp; funding decisions. (ST)</td>
<td>• Local models of cancer care coordination are developed, implemented and evaluated</td>
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<td></td>
<td>Develop communication processes/systems for providing coordination of care for those affected by cancer along the continuum of care</td>
<td>• Develop a national information sheet template (for adaption 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</td>
<td>• A national information sheet template of available service is developed</td>
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<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>
<td>• Local information sheets are developed</td>
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<td>• Local systems and protocols for care coordination are developed in accordance with the local model</td>
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<td>Action Area from Guidance</td>
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<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>▲</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>
<td>▪ Evidence of workforce development in care coordination tasks</td>
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<td></td>
<td>Ensure that all service providers are delivering culturally competent care for Māori and others</td>
<td>▲</td>
<td>▪ Based on the national minimum service standards, identify regional level service gaps. (ST) and then BAU</td>
<td>▪ Service gaps are identified and prioritised for action</td>
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<td></td>
<td>Ensure sustainable funding for culturally appropriate services (including Māori and Pacific services) as required to support local populations</td>
<td>▲</td>
<td>▪ Address identified and prioritised service gaps at the national and regional levels. (O)</td>
<td>▪ Evidence of service gaps being addressed</td>
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</tbody>
</table>

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.

|                       | Service providers undertake audits, surveys and service improvement initiatives to establish service delivery appropriateness for Māori and others. (O) and then BAU | ▲            | ▪ Evidence of services being culturally appropriate or working towards this goal |
|                       | Use a consumer co-design approach when developing and implementing services. (ST) and then BAU | ▲            | ▪ Māori and consumers from other cultures are involved in co-design processes |
|                       | Nationally/regionally document, evaluate and disseminate successful Whānau Ora approaches to care coordination through the information network (ST) and then. (BAU) | ▲            | ▪ Evidence of better practice being widely disseminated and replicated |
|                       | Ensure an adequate range of support is provided for whānau who are providing the care coordination within the whānau (training, assessment) | ▲            | ▪ Evidence of whānau being supported in providing care coordination |

|                       | Based on the national minimum standards, identify regional level gaps in culturally appropriate services. (ST) and then BAU | ▲            | ▪ Service gaps are identified and prioritised for action |
|                       | Address service gaps at national and regional levels in accordance with agreed models of supportive care. (O) | ▲            | ▪ Evidence of service gaps being addressed |
### Action Area from Guidance

<table>
<thead>
<tr>
<th>Areas for Implementation Planning</th>
<th>Action Levels</th>
<th>Recommended Actions</th>
<th>Key Performance Indicators</th>
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</table>
| Ensure needs assessments are culturally appropriate for the target population and are conducted across multiple points along the continuum by appropriately trained staff | ![Progress Icon] | • Develop culturally appropriate needs assessment tools utilising a co-design approach (O)  
• Where assessment tools exist (and where relevant), these should be shared for use by other appropriate service providers (O) and then BAU  
• Ensure the involvement of whānau (O) and then BAU | • Culturally appropriate assessment tools are co-designed, implemented, evaluated and shared with other service providers |
| 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) | ![Progress Icon] | • Ensure the range of cultural specific services is included in National and Regional service directories and patient information sheets (BAU)  
• 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)  
• Locally, where they exist, Māori specific service providers should promote their services and collaborate/liaise with general service providers (BAU) | • Cultural specific services are promoted in service directories and through other locally appropriate mechanisms |

### Workforce Development

38. Provide appropriate system-focused training for staff to ensure a seamless interface between hospital and community-based support services for people with cancer and their carers.

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<th>Workforce development</th>
<th>Action Levels</th>
<th>Recommended Actions</th>
<th>Key Performance Indicators</th>
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</table>
| Increase sector awareness of the benefit of care coordination and of supportive care services available in each area or region | ![Progress Icon] | • 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  
• 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 | • Evidence that mechanisms exist for ensuring all staff are made aware of the importance and benefits of cancer care coordination |
| | | • Nationally and regionally, increase awareness of the regional supportive care service directories (BAU) | • Evidence of increased promotion and access of service directories |
## Action Area from Guidance

**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**

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<th>Action Levels</th>
<th>Recommended Actions</th>
<th>Key Performance Indicators</th>
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<tbody>
<tr>
<td></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>
<td>• Baseline competencies for all staff documented</td>
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<tr>
<td></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>
<td>• Baseline competencies for care coordinator staff documented</td>
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**Provide support for and resourcing of Māori workforce development initiatives**

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<tr>
<th>Action Levels</th>
<th>Recommended Actions</th>
<th>Key Performance Indicators</th>
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<tr>
<td></td>
<td>• Nationally, ensure that cultural knowledge is included as part of the baseline competencies required of all staff. (S)</td>
<td>• Cultural knowledge is a baseline competency</td>
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<td></td>
<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>
<td>• Evidence of up-skillling of Māori workforce</td>
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<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>
<td>• Evidence of bi-cultural training and education provided</td>
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**Research and Evaluation**

39. Ensure all coordinating cancer care and support models are accompanied by independent evaluations.

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<th>Action Levels</th>
<th>Recommended Actions</th>
<th>Key Performance Indicators</th>
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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>
<td>• Reporting on the effectiveness of care coordination for patient outcomes</td>
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<td></td>
<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>
<td>• Reports of the extent and quality of care coordination against the standards documented in the rubrics</td>
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<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>
<td>• Data collection is included in service agreements</td>
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<tr>
<td>Action Area from Guidance</td>
<td>Areas for Implementation Planning</td>
<td>Action Levels</td>
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| Support the dissemination of best practice service improvement approaches, research and evaluation activity |                                   |              | ● 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)  
● 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) | ● Evidence of better practice being widely disseminated and replicated |
4.1 **Introduction**

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:

- the mental health and wellbeing of people with cancer and their carers is considered at all stages of the cancer pathway
- 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
- the work-related mental health needs of staff caring for such people are acknowledged and managed
- 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
- timely and acceptable practical and financial support are available to those affected by cancer
- 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 relation to these objectives, stakeholders in the Strategic Thinker 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.
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. Psychosocial distress is now 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. Additionally, research shows that appropriate psychosocial support can lead to medical cost offset through reduced ‘did not attend’ (DNAs) appointment, improved treatment adherence, reductions in unnecessary medical appointments and procedures and reduced hospital visits. In light of the benefits of psychosocial support for patients and health systems, programmes are being implemented overseas to develop triaged models of supportive cancer care in order to incorporate psychosocial support into the treatment pathway.

The following sections present key findings in regards to psychosocial support service delivery, workforce development and research and evaluation in New Zealand, and present recommended actions for the development of psychosocial support services to align with recommendations in the Guidance.

4.2.1 **SERVICE DELIVERY**

Action areas in the Guidance on psychosocial support service delivery relate to: integrated services; tiered psychosocial support; screening and assessment; referral and service coordination; and service access and responsiveness. The following are key findings in regards to the current state of psychosocial support service delivery in New Zealand.

- Psychosocial services are under-resourced, and this is contributing to service gaps and contrary to recommendations in the Guidance, there are few cancer services that have integrated psychosocial support services.
- Where psychosocial support is available, service referrals and coordination processes are mostly informal and rely on relationships between staff across service boundaries rather than on formal assessment and referral processes (e.g. referral decision trees). Lack of common IT platforms exacerbates this problem.
- 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. However, across and within cancer treatment centres, this work is inconsistent.
- Cancer sector staff in New Zealand reported that they do a good job at recognising significant distress, although it is likely this is over-estimated. Additionally, milder forms of distress may go unrecognised and untreated in a significant proportion of patients as is noted in the research.
- There are differences both within and across centres in the practice of formal distress screening (i.e. use of screening tools). As such, it is likely that there are variations in the assessments and subsequent supports that patients are provided.

4.2.2 **WORKFORCE DEVELOPMENT**

Action areas in the Guidance on psychosocial workforce development largely focused on the capacity and capability of the workforce. Key findings in this are as follows.

- Staff report concerns about screening for psychosocial distress such as: insufficient departmental and staffing levels to manage the number of distressed patients identified; over-diagnosis/false positives; and lack of confidence in conducting assessment and triaging supportive care.
Health Outcomes International

- It is not clear that all staff working in cancer care appreciate the importance of attending to psychosocial wellbeing in order to affect positive patient outcomes, including improved health.
- Although there are pathways for cancer sector staff to obtain psychosocial support, very few staff are reported to take up their own supportive care because of a lack of time, lack of perceived need and/or a desire to obtain support offsite.
- There is a lack of appropriate services for different cultural groups and in particular, there is a need to build capacity and ensure that Maori psychologists, key workers and whanau are supported to provide culturally specific services.

4.2.3 Research & Evaluation

The Guidance on research and evaluation of psychosocial support services largely focused on the importance of determining the efficacy and effectiveness of psychosocial support services for people affected by cancer. Currently it appears that:

- few services are consistently collecting data on psychosocial support service referrals, patient uptake of referrals or data on the effect of psychosocial support service delivery on patient outcomes
- currently, most services are not accountable for the psychosocial support they provide, unless specifically contracted to provide psychosocial support
- without data on the effectiveness of psychosocial services in affecting positive patient and health system outcomes, funding is not likely to be made available for development and continued support of psychosocial services.

With these key findings 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 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).
### 4.3 Actions for Psychosocial Support

<table>
<thead>
<tr>
<th>Action Area from Guidance</th>
<th>Areas for Implementation Planning</th>
<th>Action Levels</th>
<th>Recommended Actions</th>
<th>Monitoring and Evaluation</th>
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<tr>
<td>10. Ensure that psychological support and services are available as part of an integrated cancer service</td>
<td>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</td>
<td>▲</td>
<td>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)</td>
<td>• An agreed national definition of psychosocial care is documented</td>
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<td>▲</td>
<td>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)</td>
<td>• A national model for psychosocial support is documented</td>
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<td></td>
<td>▲</td>
<td>At the service level and regionally, local adaptation and implementation of the psychosocial support model should undertaken. (O) and then BAU.</td>
<td>• A minimum dataset relative to psychosocial support is developed and implemented</td>
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<td></td>
<td></td>
<td>▲</td>
<td>At the service, regional and national levels, develop minimum data set to inform service contracting &amp; funding decisions. (ST)</td>
<td>• Local models of psychosocial support are developed, implemented and evaluated</td>
</tr>
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<td></td>
<td>Electronically track &amp; use psychosocial service data to inform funding for incorporating psychosocial services within cancer services</td>
<td></td>
<td>• At service, regional and national levels, develop minimum data set to inform service contracting &amp; funding decisions in relation to psychosocial services. (ST)</td>
<td>• Psychosocial data is collected, analysed and reported for resource allocation decisions</td>
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<td></td>
<td>Promote patient and practitioner awareness of psychosocial services and available support services across the continuum of care</td>
<td></td>
<td>• 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 &amp; training to conduct basic distress screening &amp; make appropriate referrals. (O)</td>
<td>• Baseline psychosocial competencies are documented and implemented for all staff in cancer care</td>
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<td>Action Area from Guidance</td>
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<td>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</td>
<td>Ensure clearly articulated responsibilities for funding psychosocial support services</td>
<td>• 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)</td>
<td>• Funding requirements for psychosocial support are clearly documented and understood</td>
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<td></td>
<td>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</td>
<td>• Nationally, ensure referral processes for providing psychosocial support are included as part of service specifications. (O)</td>
<td>• Referral processes are documented</td>
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<td></td>
<td>Link referral processes to work in information management so that referral processes are systematised and so that referral and uptake data may be tracked</td>
<td>• 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 &amp; referred as appropriate. (S)</td>
<td>• Evidence of screening for psychosocial support needs across the continuum</td>
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<td>Utilise service data to identify staffing levels required to provide psychosocial support</td>
<td>• 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)</td>
<td>• A staffing model for psychosocial support is developed for each cancer network</td>
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<tr>
<td>12. Ensure that staff providing mental health services are qualified to do so, and work within the scope and competencies</td>
<td>Raise awareness of distress as the 6th vital sign and educate health professionals about the negative impacts of untreated distress.</td>
<td>• Include training in conducting basic distress screening &amp; making appropriate referrals a component of National baseline training/ CME for all staff in cancer care. (O)</td>
<td>• Evidence of basic distress screening training</td>
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Ministry of Health
Implementing Supportive Care Guidance Project
Guidance Implementation Plan - August 2011
<table>
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<tr>
<th>Action Area from Guidance</th>
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<th>Monitoring and Evaluation</th>
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<td>Develop workforce to ensure that</td>
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<td>Ensure that staff are appropriately</td>
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<td>regionally, identify</td>
<td>development plan for</td>
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<td>psychosocial support across the</td>
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<td>continuum of cancer care</td>
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<td>13 &amp; 21. Determine the</td>
<td>Develop systems for monitoring,</td>
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<td>• Nationally, prioritize</td>
<td>• Evidence of research</td>
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### 14. Accompany the development of the psychological services with systematic evaluation

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<tr>
<th>Action Area from Guidance</th>
<th>Areas for Implementation Planning</th>
<th>Action Levels</th>
<th>Recommended Actions</th>
<th>Monitoring and Evaluation</th>
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<td></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></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>
<td>• Evidence of pilot projects and evaluation</td>
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<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></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>
<td>• Service monitoring is routinely included in service agreements</td>
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### 15. Continue to improve equitable access to social support services

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<tr>
<th>Action Area from Guidance</th>
<th>Areas for Implementation Planning</th>
<th>Action Levels</th>
<th>Recommended Actions</th>
<th>Monitoring and Evaluation</th>
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<tbody>
<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></td>
<td>Refer to recommendations in action area 10.</td>
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<td></td>
<td>Reduce stigma associated with use of psychosocial support services</td>
<td></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>
<td>• Evidence of strategies to reduce stigma associated with accessing psychosocial services</td>
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<td></td>
<td>Reduce practical barriers to psychosocial support</td>
<td></td>
<td>• Assess patients’ practical barriers to accessing psychosocial supports and ensure appropriate referrals to care coordinators and/or social workers. (S)</td>
<td>• Evidence of routine assessment of practical barriers</td>
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<tr>
<td>Action Area from Guidance</td>
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<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></td>
<td>• Regionally, regularly update the regional support service directories. (BAU)</td>
<td>• Service directories are current</td>
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<td></td>
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<td></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>
<td>• Evidence of increased promotion and access of service directories</td>
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<td></td>
<td>Ensure that all patients are aware of the supportive care service directories</td>
<td></td>
<td>• Nationally, include regional service directories on the information sheet of core supportive care services provided to patients on service entry. (O)</td>
<td>• Service directories included on sheet of core services</td>
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<td>17. Develop and use social support needs assessment tools</td>
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<td>Refer to recommendations in action area #10</td>
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<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></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>
<td>• Evidence that psychosocial support is tied into development with care coordination and information support</td>
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<td></td>
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<td>• Ensure psychosocial support is linked to developments in care coordination. (S)</td>
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<td>Refer to recommendations in action areas #11, 13, 21</td>
<td></td>
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<tr>
<td>19. Ensure people affected by cancer are able to access financial and social support</td>
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<td>Refer to recommendations in action areas #10, 15</td>
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<tr>
<td>20. Establish systems to assess the training needs of hospital and community based social support provider</td>
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<td>Refer to recommendations in action areas #10, 12</td>
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</table>
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:
  o patients and whānau are generally overloaded with information at the beginning of the cancer pathway
  o 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**

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:

5.2.1 **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 three simple consumer information principles of Relevance, Accuracy and Clarity.

△ 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 could be ‘accredited’ utilising a symbol similar to that illustrated below.

5.2.2 **RESOURCE DESIGN & DEVELOPMENT**

Whilst generally, the consumer information principles are being addressed (albeit rarely through a formal process) in the design and development of consumer information resources, two specific areas would benefit from further action: (1) consumer involvement; and (2) guidance to consumers with respect to using the web.

The issue of involving consumers in the design, development and dissemination of resources 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
- seek the international HONcode classification (or similar) for their websites
- produce and disseminate consumer guides on accessing the web for health information.

5.2.3 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.

5.2.4 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.

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: (1) A co-design approach with an appropriate range of consumers is undertaken; and (2) 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).
## 5.3 Actions for Information Support

### Table 5.1 Actions for developing Information Support

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<thead>
<tr>
<th>Action Area from Guidance</th>
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<th>Key Performance Indicators</th>
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</thead>
</table>
| 1. Ensure people affected by cancer have ready access to a wide range of high-quality resources | Ensure that 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 HealthInsite). (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 consumer guidelines for accessing TM/CAM services. (O) | • A national system is in place for ensuring:  
• consumer information is relevant, accurate and clear  
• developing minimum standards for web-based information  
• a national web-based information directory is available  
• Consumer guides to accessing internet information are developed and distributed  
• Consumer guidelines for accessing TM/CAM are document |
| 2. Ensure consumer cancer information is culturally appropriate | Develop a range of appropriate resources 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 | • Evidence of cultural consumers involved in co-design of information |
<table>
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<tr>
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<tbody>
<tr>
<td>3. Ensure consumer representatives are involved throughout the design, development and evaluation phases of information resource production</td>
<td>Use a consumer co-design approach to design, develop and disseminate cancer information.</td>
<td></td>
<td>• 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</td>
<td>• Evidence of consumers involved in co-design of information</td>
</tr>
<tr>
<td>4. Ensure staff are familiar with the available consumer cancer information</td>
<td>Ensure the workforce can easily facilitate consumer access to appropriate information</td>
<td></td>
<td>• 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</td>
<td>• Evidence of cancer information directories</td>
</tr>
<tr>
<td>5. Establish a national information resource clearing house</td>
<td>Develop the foundations for a future information resource clearing house.</td>
<td></td>
<td>• 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</td>
<td>• Information network established</td>
</tr>
</tbody>
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