



Demystifying Cancer Workshop - Toolkit

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Please contact for further information or support:

Ali Hamlin
Service Improvement Facilitator
Addressing Inequalities
06 350 8804
Ali.hamlin@midcentraldhb.govt.nz

Caren Rangi
Service Improvement Facilitator
Pacific Communities
021 227 2983
caren.rangi@midcentraldhb.govt.nz

Introduction

A Demystifying Cancer approach brings together communities and cancer service providers in a series of workshops delivered in a community setting, to present on and discuss cancer, the cancer journey and cancer services.

This Toolkit has been developed to support districts to plan, deliver and evaluate Demystifying Cancer workshops as one means of addressing inequalities in cancer control for those communities where there are high incidences of inequalities. In New Zealand, it is often the Maori community, Pacific communities and rural communities who experience such inequalities.

The Toolkit assists organisations who wish to run a programme of Demystifying Cancer workshops to recognise the distinct needs, issues and approaches that work best for Maori communities, and for Pacific communities. However the principles that underpin the planning, delivery and evaluation of these workshops can be applied to any group that experiences inequalities in cancer control, such as rural communities.

This Toolkit has two sections. The first section (pages 6 – 13) provides information on the cancer control environment, issues of access to services and inequalities faced by Maori and Pacific communities, and suggests appropriate approaches for developing workshops for these communities. It is hoped that this information will help those thinking of running a Demystifying Cancer workshop to clarify their objectives and desired outcomes.

The second section (pages 14 onwards) is the 'practical' part of the Toolkit and includes checklists and other resources to assist in the activities necessary to successfully plan, deliver and evaluate Demystifying Cancer workshops.

Background

A demystifying cancer approach is seen as progression towards addressing inequalities across the cancer control continuum. It seeks to enable clinicians and service providers across the continuum to engage not only with each other but also the wider community. It is tailored to a local context and to the needs of the audience. It provides a flexible and responsive forum as well as an opportunity to support and build local relationships.

In 2004, health services involved in cancer control and the Cancer Society within the MidCentral Health region came together to develop a Demystifying Cancer approach for Maori through workshops which mirrored the cancer control continuum. This included health promotion, screening, treatment, symptom management, and support during and after treatment as well as an introduction to palliative care

As outlined in the Cancer Control Strategy: Action Plan 2005 – 2010 one of the key challenges to ensuring patient-centred care is the increasing complexity of cancer management and the potential for fragmented care. Because many of the services across the cancer control continuum have developed in a piecemeal way service provision is uneven and fragmented¹. As a result people accessing diagnosis, treatment, and care have to negotiate their way through many different services.

¹ Cancer Control Taskforce. 2005. *The New Zealand Cancer Control Strategy: Action Plan 2005 – 2010*. p 56. Wellington: Ministry of Health

As cancer information can be perplexing and cause confusion, a demystifying cancer approach is a way of enabling patients and their families to work as effective partners with their health care providers to meet the many challenges that cancer presents.

“Being diagnosed with cancer, being treated for cancer and surviving cancer all bring different challenges that people respond to in different ways. It is well known that people undergoing these experiences often have strong desires and needs for information, support and a sense of reassurance that other people are travelling or have travelled the same journey...” Professor David Hill; 2002.

Across the cancer control continuum it is fundamental that there is a focus on building strong relationships to ensure equitable access to information, services and help when needed.

The cancer control continuum comprises these key areas:

- Prevention
- Early Detection and Screening
- Diagnosis and Treatment
- Supportive Care
- Palliative Care

Objectives of the Demystifying Cancer Approach

The overall objective for both Maori and Pacific communities is to demystify cancer through a series of workshops, through:

- Engaging with the communities
- Educating whanau, families
- Understanding the consumer experiences
- Identifying and addressing barriers
- Developing and strengthening cancer and health service provider relationships.

The desired outcomes of these workshops are to:

Engage with communities.

By engaging with Maori and Pacific communities improved health outcomes can be achieved. Relationships and trust are built and pathways to care can be enhanced. Active engagement with these communities recognises that they have a stake to play in cancer control. It encourages whanau and family participation, and assists providers to achieve equitable outcomes for Maori and Pacific people.

Educate Families, Whanau, Hapu, Iwi

The workshops are a forum to provide tailored information about cancer and cancer services to the community in a community setting. Improving peoples' knowledge of what services are available and how to access them should result in improved access rates for these communities.

Understand Consumer Experiences

Workshops provide a forum for the two-way sharing of information resulting in a greater understanding of issues relevant to access to cancer services for Maori and Pacific peoples. Incorporating Maori and Pacific patient, whanau and community voices is vital, and will contribute to a better understanding of the extent and nature of the cancer journey experienced.

Identify and address barriers

Workshops will provide an opportunity for service providers to hear about barriers identified by Maori and Pacific people from their knowledge or experience of cancer services. This provides a platform for these to be addressed.

Develop and Strengthen Service Provider Relationships

Maintaining good working relationships between cancer service providers is essential to the provision of best care. Workshops give service providers the opportunity to strengthen and/or develop new relationships with each other as well as with Maori and Pacific in their communities.

Organisations who wish to run workshops should recognise that not all topics will be able to be covered nor all of the community targeted within one workshop, and that a series of workshops may be necessary to present the full range of services across the cancer control continuum to as wide an audience as possible.

How can this toolkit help you?

The Toolkit has two main purposes:

- 1 To assist you to consider all relevant issues in your planning to enable your workshops to be appropriate and successful for Maori and Pacific communities, as well as for cancer service providers.

See the following parts of the Toolkit:

- *Demystifying Cancer for Maori – a suggested approach*
- *Demystifying Cancer for Pacific communities – a suggested approach*

These sections provide key concepts and information to assist in developing workshops that are based on what is important for Maori communities, and for Pacific communities, from their perspectives.

- 2 To provide you with resources and suggestions to assist in your planning, delivery and evaluation of the workshops.

See the following parts of the Toolkit:

- *Suggestions for processes to successfully plan and deliver workshops*
- *Suggested resources (reference material, checklists and templates) to support the successful planning and delivery of workshops – see Appendices*

Who could coordinate these workshops?

Workshops can be coordinated by any organisation that has an interest in reducing inequalities in cancer control and improving access to cancer services. These organisations include:

- Local Cancer Networks
- Primary healthcare providers
- Iwi health providers
- Public health
- Pacific health providers
- Non-Government Organisations eg Cancer Society

Other supporting activities

Demystifying Cancer workshops are one way of strengthening community understanding of cancer and cancer services. An activity that can support the delivery of these workshops is for districts to map the cancer care coordination services across the continuum. The objectives of this mapping process are to identify:

- existing care co-ordination services and resources
- referral pathways and linkages between the services and resources
- gaps in the provision of care co-ordination
- opportunities for service improvements

This mapping process will help to identify organisations who may wish to present at a Demystifying Cancer Workshop. CCN is currently developing a toolkit to assist districts to undertake this work.

Demystifying Cancer for Maori – a suggested approach

“He huarahi tika mai i te timatanga – the cancer control journey, getting it right from the beginning”

This section contains information on:

- The Central Cancer Network (CCN) principles participation and partnership with Maori in cancer control
- Resources that provide key information on issues for Maori in cancer control
- Outcomes from a Demystifying Cancer for Maori hui held in the Taranaki region, August 2009
- Key points to consider in planning and delivering Demystifying Cancer for Maori hui

The development of this approach for Maori is underpinned by the following principles which are applied by the Central Cancer Network in its participation and partnership with Maori:

- “Kanohi ki te kanohi” – face to face engagement is vital
- Nga kaupapa tuku iho – the way in which Maori values, beliefs, obligations and responsibilities are available to guide and support activity in cancer control
- Tino Rangatiratanga – total control, complete responsibility and full authority in order to achieve best outcomes for Maori is necessary
- Whanawhanaungatanga – building of relationships through engaging
- Manaakitanga – embracing, caring and having respect for everyone’s view and skill

There are very few interventions that specifically address Maori access to cancer services². These workshops provide an opportunity for information about cancer to be tailored a Maori audience, and delivered from a positive perspective.

Resources for information on Maori and cancer control

There are a number of resources available to inform you about key issues for Maori in cancer control. CCN can assist you to access these resources.

These include:

- Local District Health Board Cancer Plan and District Annual Plans
- Cancer Control Strategy and Action Plan 2005-2010
- CCN Health Needs Assessment, January 2009
- CCN Strategic Plan 2009-2014 and Annual Work Plans
- Access to Cancer Services for Maori, (MOH, 2005)
- Community Cancer Support Service Pilot Interim Evaluation Findings (MOH, 2008)
- Matatuhi Arahi Service Plan for Maori - Cancer Society New Zealand, Wellington Division (2009)
- Tairawhiti Cancer Service Mapping Project (Tairawhiti DHB, 2008)
- Te Huarahi o nga Tangata Katoa: An analysis of the cancer journey of people from the Hutt Valley and Wairarapa District Health Boards, (July 2006)
- Hawkes Bay Engagement and Reducing Inequalities Discussion Document (CCN, 2008)

These resources can be found on the CCN website: www.centralcancernetwork.org.nz

Frameworks to assist with planning:

- Te Whare Tapa Wha – Professor Mason Durie
- Te Pae Mahutonga – Professor Mason Durie

² Access to Cancer Services for Maori: A report prepared for the Ministry of Health, Wellington School of Medicine and Health Sciences. February 2005

Reporting on Demystifying Cancer for Maori Hui, Taranaki, August 2009

The following report on the Demystifying Cancer Hui held in Taranaki August 2009 provides a useful example of how a workshop was planned and delivered for Maori.

Background

Engagement in Taranaki began in November 2008. The Local Cancer Network was yet to be established, however CCN continued the engagement process within Taranaki. CCN identified key organisations, service providers, Iwi health services, NGO's and individuals in the region with an interest in cancer control.

Ngati Ruanui Health Services (NRHS) provides community-based services as well as GP services to the Southern Taranaki region. They expressed interest in hosting a hui to provide a forum for the community to discuss cancer control as well as assist CCN in their engagement with Iwi. It was decided that a Demystifying Cancer approach would be an opportunity to achieve this.

Planning

Planning for the event was facilitated by NRHS with CCN having a supporting role. This involved assisting NRHS identify possible presenters, providing administration support and advise on the development of the programme.

NRHS hosted the hui on Monday 17th August 2009 at Wharepuni Marae. The hui was held between 10.00am – 3.00pm. The target audience was the community of the Southern Taranaki region. Including presenters there were approximately 35 - 40 participants, which was well attended by kaumatua.

Programme

The programme consisted of organisations that provided services throughout the Southern Taranaki Region. Information was presented through verbal, static and video mediums

Oral presentations were provided by:

Toi Ora Healthy Lifestyles	Health Promotion
BreastScreen Aotearoa	Screening Services
Taranaki Cancer Society	Health Promotion / Supportive Care Services
Tui Ora Nurse Led Services	Clinical Navigator Pilot
Te Rangimarie Hospice	Palliative Care
CCN Governance Representative	Local Cancer Network establishment in Taranaki / Local activity
CCN Management Team	Regional Update / Engagement with Maori

Static displays were provided by:

Breast Screen Aotearoa

Video presentation was provided by:

Regional Cancer Treatment Services, MidCentral Health - "What to expect when attending the Radiation Oncology Department".

Information resources were provided by:

Taranaki Cancer Society
BreastScreen Aotearoa
Te Rangimarie Hospice

Toi Ora Healthy Lifestyles
CCN

(These were provided in the form of powerpoint presentation handouts, pamphlets, and booklets)

Feedback from participants

The feedback from participants was part of korero whakamarama (reflection of the day) held at the end of the hui.

- Many participants were unaware of what services were available in Southern Taranaki
- Raised awareness about the Cancer Society and the support they offer whanau
- Great opportunity to network with other services and know what each other provides
- Great to have hui on the Marae
- Sharing of information about cancer should happen on a regular basis
- Great to have services come to talk to us
- It was a good opportunity to let the services know what happened to whanau in the past
- Good to be able to ask questions and have answers before leaving
- “Kanohi ki te kanohi” enables you to get a greater understanding
- More time needed for discussion

Outcome of Hui

It was evident from feedback received that the objectives of the programme were met. It provided an appropriate forum for the most up to date information on services to be provided, and resources provided were practical and informative. The marae setting provided a safe environment which supported participants to be able to “korero”.

Dialogue between service providers occurred, relationships were strengthened and new opportunities for engagement identified.

Providers acknowledged that:

- Cancer Services need to prioritise Maori if they are to address inequalities
- Maori-led interventions need to be better resourced
- There is a need to ensure that Maori expertise is integrated into decision-making within all mainstream services

Key points to consider in planning and delivering Demystifying Cancer Hui for Maori:

- 1 **Involve** Maori whanau and Maori providers in the planning, development, design and implementation process
- 2 **Embrace** Maori concepts and give information to Maori / whanau in their own environments so that Maori will effectively engage
- 3 **Provide** appropriate information to Maori / whanau
- 4 **Marae** setting - Feedback from those who have implemented this approach previously recognise the value of these hui being delivered on a marae. A marae setting can offer the following benefits:
 - The messages are being taken to the people instead of expecting the people to come to the messages, and are delivered in a supportive setting
 - A marae is where people formally come together on a specific occasion for a specific function. This gives mana to the event
 - An opportunity to strengthen cultural awareness within service providers who may not have had the opportunity before to engage with Maori in their own setting
 - Maximises opportunities for korero

When a Marae setting is selected it is important to ensure that the appropriate Marae protocol is understood and incorporated into the planning eg Powhiri process, appropriate dress, koha. It is important to ensure that attendees (both presenters and audience) are aware of any requirements of them.

Guidance is available on tikanga and marae protocol; however protocols can differ between marae and it is important to confirm the arrangements each time. It is important to seek Maori expertise on this.

Alternatively the hui can be delivered from any venue that has appropriate facilities for hosting an event of this type, including:

- A space large enough to cater for the expected numbers of attendees
- Seating that can be rearranged
- Areas where static displays can be set up and manned
- An area where morning tea and lunch can be taken
- Kitchen facilities to assist with the catering
- Toilet facilities
- Sufficient free parking
- Smokefree and healthy environment eg Low fat / healthy foods

Whatever type of venue is chosen, it should be recognised that there are aspects of protocol that should always be applied (e.g powhiri, whakatau, karakia).

5 Timing of the Hui - When determining the date for the hui consider if there are any other major events happening in the cancer control sector or that may involve Iwi so as not to limit the ability for people to participate. The time of day of the hui will be dependent on the availability of your target audience. Consideration should be given as to whether the hui is best held during the day or in the evening and whether a weekday or weekend is appropriate

Demystifying Cancer for Pacific communities – a suggested approach

This section contains information on:

- The Central Cancer Network (CCN) principles for addressing inequalities for Pacific communities in cancer control
- Resources that provide key information on issues for Pacific people in cancer control
- Key points to consider in planning and delivering Demystifying Cancer for Pacific communities workshops

The following principles underpin the work that CCN undertakes to address and reduce inequalities for Pacific communities, including the advice developed in this toolkit .

- Understand the real diversities of Pacific communities - *ethnicities, age, “resident” status, location, extent of community development, extent of interaction with wider community, languages*
- Recognise the need for a multi-faceted, coordinated approach
- Identify Pacific community strengths and established networks *and utilise in addressing inequalities (within their capacity)*
- Facilitate linkages and opportunities to build relationships between Pacific communities and cancer services
- The voices of Pacific communities and those of cancer services are equally important
- Clearly identify the extent to which inequalities are impacted on by cultural issues vs “other” issues
- Develop key strategies with Pacific groups

Resources for information on Pacific peoples and cancer control

There are a number of resources available to inform you about key issues for Pacific peoples in cancer control. CCN can assist you to access these resources.

These include:

- Local District Health Board Cancer Plan and District Annual Plan
- Cancer Control Strategy and Action Plan 2005-2010
- CCN Health Needs Assessment January 2009
- CCN Strategic Plan 2009-2014 and Annual Work Plan
- Access to Cancer Services for Maori, February 2005 (MOH)
- Community Cancer Support Service Pilot Interim Evaluation Findings (MOH, 2008)
- Tairawhiti Cancer Service Mapping Project (Tairawhiti DHB, 2008)
- Te Huarahi o nga Tangata Katoa: An analysis of the cancer journey of people from the Hutt Valley and Wairarapa District Health Boards (July 2006)
- CCN Pacific Communities Stocktake December 2009
- Tairawhiti Pacific Health Needs Report 2009

These resources can be found on the CCN website: www.centralcancernetwork.org.nz

Key points to consider in planning and delivering Demystifying Cancer Workshops for Pacific communities:

- 1 Work alongside recognised leaders in the various Pacific communities to recruit participants to workshops. In particular, Pacific womens groups such as PACIFICA often play a role in promoting health issues in their communities
- 2 Seek the support of Pacific health professionals to promote and support workshops
- 3 The choice of an appropriate venue is dependent on the particular Pacific communities or groups being targeted; however the following aspects should be considered:
 - Venues should be familiar and easily accessible e.g. Pacific church and community halls
 - Seek the advice of Pacific community leaders as to suitable venues
- 4 When seeking participants from across a range of different Pacific ethnic communities, consider that there might be different requirements for language support. Also consider that some Pacific communities may prefer to have a workshop (or time within a workshop) that is just for people from their community (e.g. Tongan people only) as this will allow them to more comfortably discuss issues in their own language if required

Demystifying Cancer for Communities – a Toolkit

This section contains information on:

Pre-workshop processes:

- Initiating a workshop
- Scoping the workshop
- Logistical arrangements

During the workshop:

- Facilitation
- Evaluation

Post workshop:

- Evaluation report
- Debrief on the Toolkit

The following processes are suggested for planning, delivering and evaluating a workshop. Additional notes are provided on each of the steps in the process (following the diagram below), along with references to suggested resources that could be used to support the processes (contained in Appendix One).

PRE-WORKSHOP	Purpose of step in process
1 Initiating the Workshop	Address criteria to determine if the series of workshops should proceed
2 Scoping the Workshop	Set specific objectives for the workshops and form the scope of the workshops including; targeted participants, workshop programme, (topics and presenters), possible site visits and evaluation
3 Logistical Arrangements	Plan and confirm appropriate logistical arrangements for presenters, participants, venue, resources and communication
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DURING THE WORKSHOP	
4 Facilitation	Confirm the facilitation role and arrangements for the day of the workshop
5 Evaluation	Confirm the evaluation process for the day of the workshop
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POST- WORKSHOP	
6 Evaluation report	Identify evaluation information to be reported on in line with the Evaluation Process (Step 5), including recommendations post-workshop
7 Debrief on the toolkit	Identify what has been learnt from the application of the toolkit and areas of improvement

Pre-workshop

1 Initiating the Workshop

We recommend that any organisation that is considering coordinating a programme of Demystifying Cancer workshops should address the following questions, as a basis for deciding whether to go ahead or not.

We also recommend that you refer back to the earlier sections on the suggested approaches for Demystifying Cancer for Maori hui, and the Demystifying Cancer for Pacific communities workshops.

An Initiation Phase Checklist has been provided to assist in this process, and further explanatory information is provided in this section. This checklist can be used to inform stakeholders of the outcome of deliberations, and provide key information on which to base the planning phase.

What specific issues relating to access to cancer services are you seeking to address through this workshop?

Demystifying Cancer workshops are aimed at addressing access to cancer service issues. If specific issues for Maori and Pacific people are known then this helps to plan a relevant and useful series of workshops. Workshops can also provide a means of identifying other issues regarding access, as well as other inequalities in cancer services.

Key points to consider are:

- What is the nature of the barriers to access being experienced in your area?
- Who are experiencing these barriers (e.g. all Maori consumers, consumers of specific services, consumers in a particular geographical location)?
- What information do you have to demonstrate the issues around access?
- Based on the nature and range of barriers, how might you structure a series of workshops?

Who will benefit from this workshop?

The target groups for these workshops will be those people/groups identified above as those who experience issues regarding access to cancer services. However consideration should also be given to involving those groups or organisations who have a strong association with them.

In Maori communities these may include:

- Whanau, Hapu and Iwi groups
- Maori health and social service providers
- Maori Womens Welfare League
- Kohanga Reo and Kura Kaupapa Maori

In Pacific communities this may include:

- Churches
- Ethnic-specific associations
- Women's groups such as P.A.C.I.F.I.C.A
- Cultural and sporting groups

The CCN Pacific Communities Stocktake Report (December 2009) identifies a number of Pacific groups in each district in the region who may benefit from a Demystifying Cancer Workshop.

Key points to consider are:

- Who are the different groups and individuals that you think will benefit from a series of workshops?
- What are the specific benefits that each different group/individual could gain?

What support do you have from other stakeholders for this workshop?

Gaining support in principle for the workshops from a wide stakeholder base from within the district is an important enabler for successful workshops. It is important to engage with the key groups who are involved in cancer control, and Maori and Pacific communities to inform them of your intention to have workshops and discuss how they could both support and obtain benefit from a workshop.

Some examples of stakeholders are listed below (please note there may be others specific to your district):

- Local Cancer Network
- Whanau, hapu, iwi organisations
- Cancer Society
- Primary Health Organisations
- District Health Board
- Iwi Providers
- Pacific community organisations
- Pacific health providers
- BreastScreening Services
- Central Cancer Network

Is the workshop logistically feasible?

The feasibility of running workshops depends on the extent to which it can be demonstrated that the benefits outweigh the investment.

The potential benefits are:

- Reduction in inequalities for Maori and Pacific communities in respect of access to cancer services
- Established or improved engagement with Maori and Pacific communities
- Improvements to access to cancer services
- Improvements to systems within cancer services
- Increased community knowledge and skills regarding cancer services
- Improved linkages with other stakeholders in cancer control

The potential investment required is:

- Financial – a small budget to meet the costs of the venue, catering, etc
- Time to plan and deliver successful workshops

Key points to consider when determining costs:

- Numbers of participants targeted
- Number and range of speakers required to deliver sessions at the workshops
- Availability and cost of suitable venue

- Extent and nature of support from other stakeholders
- Available budget for workshop
- Intended timing and frequency of workshops

COMPLETE THE INITIATION PHASE CHECKLIST (See Appendix 1).

If your recommendation is to proceed with workshops then the next suggested step is to establish a Steering Group of stakeholders to plan, deliver and evaluate the workshops.

2 Scoping the Workshop

Steering Group

It is suggested that at this stage a small group of interested individuals form a Steering Group to coordinate the planning, delivery and evaluation of the workshops. It would be beneficial to include someone from the community that the workshops are being targeted to.

Information gathered during the Initiation Phase provides a good starting point for the Steering Group to clearly determine the scope of the workshops. The information noted below needs to be clearly specified. A **Scoping Checklist** is provided in Appendix 2.

Objectives of the workshops

The workshops are designed to meet the objectives below:

- Engage with communities
- Educate whanau and families
- Understand consumer experiences
- Identify and address barriers
- Develop and strengthen service provider relationships

It is acknowledged that within these wider objectives, there will probably be some specific objectives that you wish to address through the workshops. These specific objectives should be detailed as clearly as possible, as this will determine the appropriate scope for the workshop programmes, and the basis for the evaluation of the success of the workshop. The objectives should also be succinct enough to be included in any communications about the workshops.

Organisations are also encouraged to run these workshops as health-promoting events, and consider aspects such as:

- Low fat and healthy food
- Incorporating some physical activity
- Sunsmart practices over summer
- Encompassing tikanga Maori or Pacific practices in the delivery of workshops

Targeted participants

It is important to clearly specify WHO the workshops are targeting, as this will also help determine an appropriate scope for the workshop programmes as well as appropriate methods for presenting information at the workshops. The information gathered during the Initiation Phase (Question 2, Who will benefit from these workshops and how?) should help here. Characteristics to consider when determining who is being targeted are:

- Ethnicity
- Age group
- Geographical location
- Groupings – community/organisation/whanau/consumers

Again, it is important to clearly describe who the workshops are for, and to include this information in any communications about the workshops.

Potential for site visits

Depending on where the workshops are being held there may be opportunities for visits to cancer service providers to be included in the programme or for the services to have an 'open day' in support of the workshops. Services may include primary health organisations, Iwi Providers, screening services eg Breast screening, secondary services eg chemotherapy day units and NGOs eg Cancer Society.

Workshop Programme – Topics and Presenters

The following should be considered when setting the programme for the workshops:

- Topics (as per the Cancer Control Continuum – see page 4)
- Specific focus areas in each topic (as identified in the Initiation Phase)
- Method of presentation of topic and focus area:
 - Presentation to participants, including facilitated discussions, and/or
 - Static display of information, and/or
 - Supply of resources on the topic (written, visual)
- Suitable organisations and/or presenters to be involved in the presentation of information.
- How to involve consumers in the delivery of messages during the workshops

The workshops are designed to ensure all parts of the Cancer Control Continuum are addressed. The list below shows each component of the continuum and suggests organisations and/or individuals who may be potential presenters or somehow involved in workshops.

Components of the Cancer Control Continuum	Potential content	Potential Presenters
Prevention	Tobacco control Nutrition and Physical Activity SunSmart Smokefree	Health Promotion Public Health Iwi Providers PHO's Cancer Society

Components of the Cancer Control Continuum	Potential content	Potential Presenters
Early detection and screening	Cervical screening and HPV Breast screening	Local GP NCSP Regional Screening Programmes PHO's Smear takers BreastScreen Aotearoa Independent Service Providers
Diagnosis / Treatment	Chemotherapy and radiation therapy treatment	Cancer Centre e.g. oncologists Nursing Specialists DHB Cancer Services
Supportive Care	Patient Information, including use of Patient Diary Psychological support Social support Care co-ordination Living long-term with cancer Complementary and alternative medicine Spiritual support	Cancer Society Iwi Support Services District Health Nurses Specialist Nurses PHO Services Social workers Psycho-oncology services Adolescent/Young Adult Co-ordinators Central government social services e.g. Work and Income
Palliative Care	Respite care End of life care Palliative care settings	Hospice
Other services/organisations involved in cancer control	Consumers – patient journeys Other NGOs – services Local Cancer Network – Cancer Plan initiatives Other regional and national networks/groups – cancer control activity Central Cancer Network – roles and responsibilities	

Key points to consider when setting the programme:

- Ideally, all parts of the continuum should be presented at a workshop or over a series of workshops. Particular emphasis should be given to those where there are known barriers to access
- There may be other services that are specific to your particular district
- At a minimum, each presentation should cover:
 - The scope of the services they provide
 - How people can enter and leave their services
 - How their service links to other services along the continuum, including their primary relationships

It is suggested that identifying an individual to facilitate the workshop on the day is useful to coordinate discussion and provide continuity through the programme. Points to consider when selecting a facilitator:

- Match the facilitator to the audience eg Maori facilitator for a Maori audience

- Someone skilled in promoting discussion
- Knowledge of cancer control would be beneficial

Evaluation Process

The Evaluation Process is crucial for measuring the success of the workshop and the extent to which objectives have been met, both for the organisers and the participants. Conducting the evaluation will be a key task of the Steering Group. The key starting point for the Evaluation Process is clearly articulating the objectives and scope of the workshop (see notes above). An **Evaluation Form Template** has been provided for participants to use, so that as organisers you can measure whether the workshop has met the participants' objectives. It is important to establish participants' objectives as early as possible in the planning of the workshop and reiterate these on the day of the workshop.

This template sets out key questions to ask the participants. Organisers should give some thought to the best means of gathering answers to these questions:

- Verbal feedback – people will come in and out over the day and having someone asking for feedback as people are leaving would provide a good range of information
- Written forms – these could be available for attendees to complete
- Facilitating a feedback session at the end of the day can allow for group discussion to occur

The next step is to prompt participants to determine if objectives have been met at the conclusion of the workshop. The Evaluation Process suggested here also considers that some of the impact of the workshop will not be felt until sometime after the workshop, so it is recommended that there is a follow-up with some participants three months after the workshop. This will also help inform decisions around subsequent workshops.

An **Evaluation Report template** and **Evaluation Forms** are provided in the Appendices.

COMPLETE SCOPING CHECKLIST (See Appendix 2)
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3 Logistical Arrangements

Most organisations are well-experienced at organising logistics for meetings and workshops. A **Logistical Arrangements Checklist** has been developed as a reminder of key points to cover off (see Appendix 3).

The checklist covers these areas:

- Budget
- Recruiting participants
- Presenters/organisers for:
 - Workshop presentations
 - Static displays
 - Resources
- Venue arrangements:
 - Room and resources including audio-visual requirements

- Catering and refreshments
- Site visit / open day organisation
- parking
- Health promoting event check:
 - Food
 - Smoke Free
 - Activities
 - Tikanga Maori and Pacific practices
- Communications Plan – this should include the objectives, scope and a summary of the workshop programme already developed. A ***Communications Plan Checklist*** has been provided, as well as a ***Workshop Flyer Template***.

**COMPLETE LOGISTICAL ARRANGEMENTS CHECKLIST (See Appendix 3) AND
COMMUNICATION PLAN (See Appendix 4)**

During the workshop

The focus for the day of the workshop should be that everyone is clear on their respective roles and responsibilities and that the workshop runs in accordance with the set programme.

Considerations on the day include:

- Steering Group members take on coordination roles to ensure the workshop runs smoothly.
- Enable presenters to have access to the venue prior to the start time of the workshop to ensure static displays are set-up
- Testing any audio-visual setup to ensure it is working properly

The following supporting resources have been developed:

- An ***Evaluation Form Template*** for the participants, so that as organisers you can measure whether the workshop has met the participants' objectives. It is important to establish participants' objectives as early as possible in the planning of the workshop and reiterate these on the day of the workshop.

COMPLETE EVALUATION FORM TEMPLATE (See Appendix 7)

Post- workshop

The main post-workshop activity is for the Steering Group to complete an Evaluation Report to measure whether the organiser's objectives in running the workshop have been met. An ***Evaluation Report template*** has been provided to assist workshop organisers in measuring:

- How the actual workshop went in relation to what was originally planned
- Participants' satisfaction (from their individual evaluation forms)
- Next steps

Central Cancer Network is also interested in whether or not this Toolkit has been useful to you for planning and delivering your workshop. A ***Demystifying Cancer Workshop Debrief Form*** has been included to record your comments on the usefulness of the Toolkit, to assist in further development and refinement of the Toolkit.

**EVALUATION REPORT TEMPLATE (See Appendix 6) AND DEMYSTIFYING
CANCER WORKSHOP DEBRIEF FORM (See Appendix 8)**

Appendices - Demystifying Cancer for Communities - Workshop Resources

1. Initiation Phase Checklist
2. Scoping Checklist
3. Logistical Arrangements Checklist
4. Communications Plan Checklist
5. Workshop Flyer Template
6. Evaluation report Template
7. Evaluation form (participants) Template
8. Demystifying Cancer Workshop Debrief Form

Appendix 1

Demystifying Cancer Workshop - Initiation Phase Checklist

The following questions should be addressed to determine the justification for, and feasibility of, running a Demystifying Cancer Workshop for Maori or Pacific communities. Completion of the checklist should provide a sound basis on which to make a recommendation about running a workshop.

Ref	Question	Information gathered	Outcome
1	<i>What specific issues relating to access to cancer services are you seeking to address through this workshop?</i>	<p>What is the nature of the barriers to access being experienced in your area?</p> <p>Who are experiencing issues regarding access (e.g. all Maori consumers, consumers of specific services, consumers in a particular geographical location)</p> <p>What information do you have to demonstrate the issues around access?</p>	
2	<i>Who will benefit from this workshop and how?</i>	<p>Groups/people experiencing issues regarding access (as identified above), potential benefit:</p> <p>Members of health workforce (specify), potential benefit:</p> <p>Organisations/community groups, potential benefit:</p>	
3	<i>What support do you have from other stakeholders for this workshop?</i>	<p>Stakeholders consulted, nature of support obtained</p>	
4	<i>Is the workshop logistically feasible?</i>	<p>Potential benefits:</p> <p>Potential costs:</p> <ul style="list-style-type: none"> • Numbers of participants targeted • Number and range of speakers required to deliver sessions at workshop • Availability and cost of suitable venue 	

Ref	Question	Information gathered	Outcome
		<ul style="list-style-type: none"> • Extent and nature of support from other stakeholders • Available budget for workshop • Intended timing and frequency of workshops 	
	Recommendation:	Proceed with a workshop / Do not proceed with a workshop	

Appendix 2

Demystifying Cancer Workshop – Scoping Checklist

Ref	Step	Tasks	Outcome
1	Set objectives for the workshop	Set objectives, in terms of overall objectives of Demystifying Cancer workshops (see pages 4 – 5 of Toolkit) and information gathered on Initiation Phase Checklist Questions 1 and 2	The objectives of this workshop are: <ul style="list-style-type: none"> • To demystify cancer through providing information on cancer services (all/specific) and how to access those services • To engage with (a specified) community • To engage with and better understand consumer experiences • To help educate (a specified) community • To support and strengthen relationships between cancer service providers
2	Identify targeted participants	Identify targeted participants – as identified in the Initiation Phase Checklist Question 2	The targeted participants are:
3a	Set topics and focus areas	Set topics based on the Cancer Continuum (see page 4) and particular focus areas. It is expected that a Demystifying Cancer workshop will cover all aspects of the Cancer Continuum, but that emphasis should be given to services provided where there are particular access issues (as identified in the Initiation Phase Checklist)	Topics and focus areas: <ul style="list-style-type: none"> •
3b	Identify presenters/ providers of information	Identify how information on each topic will be presented at the workshop and suitable presenters for each of the topic areas. This will mean identifying the relevant service providers, and suitable people from those providers to make a presentation or provide information for the workshop – it could be in the form of a static display or resources provided	For each topic and focus area identify: <ul style="list-style-type: none"> • Presenter and scope of presentation • Static display • Resources

Ref	Step	Tasks	Outcome
4	Determine evaluation process	Decide on an appropriate evaluation process that will enable you to determine: <ul style="list-style-type: none"> • The extent to which your objectives for the workshop have been met • The extent to which participants' objectives have been clearly identified then addressed by the workshop 	Refer to separate Evaluation Forms in the Appendices

Demystifying Cancer Workshop – Logistical Arrangements Checklist

The main purpose of the logistical arrangement checklist is to avoid confusion over workshop arrangements. A logistical arrangements checklist can be useful to remind all of the tasks involved in assuring a successful workshop.

<i>Tick Box</i>	<i>Arrangement</i>	<i>Person Responsible</i>
	Pre-Meeting Tasks	
<input type="checkbox"/>	Discuss the amount of meeting space needed	
<input type="checkbox"/>	Discuss the budget requirements	
<input type="checkbox"/>	Recruit presenters	
<input type="checkbox"/>	Choose the meeting space that meets the needs of the group (wheelchair access, size, parking, privacy)	
<input type="checkbox"/>	Ensure the venue is smoke free	
<input type="checkbox"/>	Discuss feasibility of site visits in conjunction with the workshop	
	If possible – discuss travel requirements to site(s)	
<input type="checkbox"/>	Book the venue	
<input type="checkbox"/>	Confirm arrangements for a key for the venue, security alarm arrangements and locking up at the conclusion of the day	
<input type="checkbox"/>	Arrange for needed equipment (projectors, chairs, laptop, datashow, white screen, whiteboard, phone)	
<input type="checkbox"/>	Check the location and number of electrical outlets	
<input type="checkbox"/>	Check the kitchen facilities and organise tea/coffee/water jugs etc as needed	
<input type="checkbox"/>	Check the bathroom facilities and organise toilet paper and hand towels if necessary	
	Planning the agenda	

Tick Box

	Arrangement	Person Responsible
<input type="checkbox"/>	Discuss and arrange for tikanga Maori and Pacific practise requirements	
<input type="checkbox"/>	Decide on the meeting format	
<input type="checkbox"/>	Discuss the workshop schedule (total time needed and time needed for specific presentations)	
<input type="checkbox"/>	Assign responsibilities for organising members	
<input type="checkbox"/>	Plan for breaks, physical activity and refreshments	
	Notify participants	
<input type="checkbox"/>	Use flyers, newsletters, telephone calls, word-of-mouth	
<input type="checkbox"/>	Use public sources, bulletin boards, church notices	
	Gather resources	
<input type="checkbox"/>	Contact members who have roles in the workshop. Confirm their participation and provide any information they will need	
<input type="checkbox"/>	Secure as needed, written materials and prepare any copies to be distributed	
<input type="checkbox"/>	Gather registrations materials (pens, name tags, pins, sign-in sheet etc)	
<input type="checkbox"/>	Confirm requirements for those using static displays (whiteboards, pens, paper, pins, bluetack etc)	
<input type="checkbox"/>	Arrange for audiovisual material and equipment if needed and check to be sure everything works before the day	
<input type="checkbox"/>	Collect other basic supplies that may be needed (masking tape, markers, chalk, tacks, poster boards, scissors, extension cord, contact numbers)	
	Tasks to be done before the meeting	
<input type="checkbox"/>	Arrange for catering including low fat/healthy options	
<input type="checkbox"/>	Make sure the speakers have water	

Tick Box

Arrangement	Person Responsible
Arrange the venue (chairs and tables and audiovisual equipment)	
Complete physical arrangements (turn on lights. Adjust curtains, make sure comfortable room temperature)	
Ensure that arrangements for site visits are clearly identified together with transportation arrangements and maps for those travelling individually	
Distribute handouts	
After the meeting	
Distribute and collect the evaluation forms from the attendees	
Send an evaluation form to the appropriate people (speakers and hosts)	
Send a thank you to the appropriate people (speakers and host)	
Follow up discussion/decisions with any necessary letters and telephone calls	
Begin planning for the next workshop	

Appendix 4

Demystifying Cancer Workshop – Communication Checklist

Deliverable/Description	Target Audience(s)	Delivery Method	When	Who Responsible
Information on scope of proposed workshop, and presentations required	Potential presenters	<ul style="list-style-type: none"> Email/letter, follow-up phone calls 	At least 8 weeks prior to workshop	Workshop organiser
Confirmed workshop programme and arrangements	Potential attendees to workshop Workshop Facilitator	<ul style="list-style-type: none"> Email/letter/in Workshop Flyer 	At least 6 weeks prior to workshop	Steering Group Workshop organiser
Reconfirmation of workshop arrangements	Presenters and attendees Venue hosts Workshop Facilitator	<ul style="list-style-type: none"> Email/letter, follow-up phone calls 	At least 3 weeks prior to workshop	Workshop organiser
Reminder of workshop	Presenters and attendees Venue hosts Workshop Facilitator Other potential attendees	<ul style="list-style-type: none"> Email/letter 	One week prior to workshop	Workshop organiser

Demystifying Cancer Workshop Flyer

**“Understanding the Cancer Journey – A Demystifying
Cancer Workshop”**

A Demystifying Cancer approach brings together communities and cancer service providers into a community setting in a series of workshops, to present on and discuss cancer, the cancer journey and cancer services.

This workshop has been put together for (target community) by (host) and involves (list the cancer services who are involved) and includes:

(list the workshop sessions)

Date:

Where:

When:

Please RSVP to:

Appendix 6

Demystifying Cancer Workshop – Evaluation Report Template

The main post-workshop activity is for the Steering Group to complete an Evaluation Report to measure whether the organiser's objectives in running the workshop have been met. This ***Evaluation Report template*** has been provided to assist workshop organisers in measuring:

- How the actual workshop went in relation to what was originally planned
- Participants' satisfaction (from their individual evaluation forms/other evaluative activities)
- Next steps

Ref	Section	Description
1	Introduction	General description of workshop held – when, where and for who.
2	Objectives of workshop and targeted participants	From Sections 1 and 2 of Scoping Checklist
3	Planned workshop programme	General description of planned workshop programme (topics and focus areas, planned presentations and activities)
4	Actual workshop programme	Detailed description of: <ul style="list-style-type: none"> • Extent to which the actual workshop programme aligned with planned workshop programme, the differences if any, and reasons • Extent to which overall workshop objectives met and reasons • Extent to which participants' objectives met and reasons (from evaluation activities undertaken during/at conclusion of workshop)
5	Conclusion	Conclusion of the extent to which the workshop achieved the planned objectives, and the outcomes achieved
6	Intended next steps	Plan for follow-up activity from workshop (activities and timeline) including: <ul style="list-style-type: none"> • Additional workshops • Intended further engagement with target group • Intended follow up with services who participated in workshop on future activities to improve access to services

Demystifying Cancer Workshop Evaluation Form

The purpose of this form is to help the workshop organisers evaluate whether or not this workshop has fulfilled your objectives.

Questions for community members:

- 1 What did you hope to get out of this workshop?**

- 2 What learnings will you take away from this workshop?**

- 3 What did you enjoy about the workshop?**

- 4 What do you think could be improved about the workshop and why?**

- 5 After attending this workshop do you feel more informed about cancer and cancer services?**

- 6 If required would you feel comfortable about accessing cancer services?**

- 7 Do you have any feedback to the service providers about the services they provide?**

- 8 Any other comments?**

Thank you for your time. Please note your name and contact details below if you are happy to be contacted by the organisers.

Questions for service providers:

- 1 What did you hope to get out of this workshop?**

- 2 What learnings will you take away from this workshop?**

- 3 What did you enjoy about the workshop?**

- 4 What do you think could be improved with the workshop and why?**

- 5 After attending this workshop what changes do you think you will make to cancer service delivery?**

- 6 Any other comments?**

Thank you for your time. Please note your name and contact details below if you are happy to be contacted by the organisers.

Demystifying Cancer Workshop – Debrief Form

This report can be used to feedback to local stakeholders and CCN on the outcome of the workshop.

Workshop held:	<i>Date, Venue, Town/City</i>
Workshop hosts:	<i>Name of group/organisation who hosted workshop</i>
Targeted participants:	<i>Description of targeted participants (community /age/area)</i>
Debrief form completed by: <i>Name and role of person completing form</i>	

Summary of Demystifying Cancer Workshop:

- **How many participants attended?**
- **What organisations presented information?**
- **What organisations provided static displays?**
- **Summary of feedback from participants – community and providers**
- **Opportunities for service improvement identified during the workshop**

