

## Partners in Care – case study

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### **A review of the patient experience when accessing head and neck cancer services at Nelson Marlborough District Health Board and tertiary services at Canterbury District Health Board**

#### **Context**

Nelson Marlborough District Health Board (NMDHB) is committed to improving the consumer experience for head and neck cancer consumers throughout the complex treatment pathway, which involves contacts with multiple services across two DHBs. The consumer needs a smooth pathway to transition across the care continuum.

Some of the consumers that accessed our service commented on the challenges they faced with a multiple DHB approach; this included communication and travel issues. A small team of healthcare professionals and consumers was appointed to look at how the service could improve the treatment and care pathway for these consumers.

#### **Aim**

As a team we wished to investigate and corroborate the anecdotal conversations we have had over the past years from consumers of the head and neck cancer teams, both locally within Nelson Marlborough District Health Board and within our tertiary provider located in Christchurch.

In gathering feedback from recent and current consumers of this service, we wished to identify any areas in which we can improve and enhance the experience for both the consumers and their support persons.

#### **Capture**

Information was captured using an adapted patient experience survey supplied by the Health Quality & Safety Commission. The adapted questionnaire was reviewed by two consumers to identify any key areas not covered in the survey. The revised survey can be found in Appendix Two.

Details for consumers of head and neck cancer services were retrieved from oncology services' manual ledgers. The adapted questionnaire, covering letter and self-addressed envelope were then posted out for completion and return. The response rate was 35.7 percent. Given the nature of the disease, which affects predominately middle aged Pakeha men, we have been limited in our consumer group, and during the timescale of our project we have received no feedback from female or Māori/Pasifika clients.

#### **Understand**

As the questionnaires filtered back, the team reviewed these and mapped them by way of post-it notes onto a pre-formatted large piece of paper, sectioned into key moments of the

consumers' journey across the services. Common words and emotional words were identified and mapped. This gave great visual impact to certain touch points which had given the consumers the greatest concern. One-to-one interviews were also conducted by a member of the Clinical Governance team, to give neutrality and impartiality to the feedback received.



**The map**

During this time we met again with our consumers to ensure the mapping reflected we had interpreted their feedback correctly. This also gave us time with the consumers to discuss the finer aspects of the identified touch points. These were identified as:

- Travel to Christchurch – patients mentioned that at times confirmation of travel arrangements were made very late, requests for earlier flights had been turned down and this caused some anxiety.
- Attendance at the multidisciplinary team meeting – there are often a number of specialists in the room for this meeting. Their aim is to discuss options from all of their perspectives and agree the best treatment plan. While overall patients seemed to be satisfied with the meeting, it was also described from a patient perspective as *'very daunting sitting in a room with those entire specialists talking about me'*. Another patient described the meeting as *'Okay, but I seemed on display'*.
- The follow up care in Nelson – the results of the emotion questionnaire indicated that patients were generally positive about the follow up care provided, however there did seem to be a need for a resource that provided contact details of key support workers, links to more information from cancer organisations, and access to other patient stories.

## **Improve**

There are a number of discussions happening about how the consumer travel journey and the multidisciplinary team meeting could be improved.

Work on co-designing improvements to follow up care in Nelson has progressed further. Through the project we demonstrated a clear need for some clear and concisely written

information for our consumers to have as reference material. In acknowledging the consumers' concerns, two draft documents have been devised and reviewed by consumers involved in the project. See Appendix Three for the current examples.

These documents will also be reviewed by the nursing team for any further critique. Once this has occurred, a process of distributing the documents to the consumers and their support persons will be adopted as a regular part of a clinic visit.

## **Working as a co-design team**

The majority of the team had not previously utilised the co-design method of working with consumers on a project. Working with consumers created a sense of getting the real feeling and facts, as opposed to those issues we held as medical practitioners. Due to the clinical commitments of the team, it was difficult for all members to attend the co-design sessions with the consumers, however by using emails we were able to coordinate everyone's input into the project. The depth and honesty in the feedback from the consumers enabled us to get a sense of the actual concerns as opposed to our perceived concerns. In a sense it also revalidated the need for the project.

## **Measure**

Prior to commencing on the co-design, we had no local resources to provide to consumers and their support persons to explain the processes for the services that they will encounter and what they entail. As we navigated our way through the co-design process we also were made aware for the need for a contact sheet with details of the ancillary services.

At this moment in time, we have to submit it for final approval and circulate it amongst other members of the wider team to ensure that these sheets are given to the consumers in a consistent manner. We will share our findings at the Christchurch multidisciplinary team meeting and with the travel department here in Nelson, after some consultation with senior managers.

## Names, email addresses, organisation and DHB of team members

Name	Role	E-mail address	Organisation or DHB
Dr Nicola Hill	Senior Medical Officer	<a href="mailto:Nicola.hill@nmdhb.govt.nz">Nicola.hill@nmdhb.govt.nz</a>	NMDHB
Ms Anya Chisholm	Personal assistant	<a href="mailto:Anya.chisholm@nmdhb.govt.nz">Anya.chisholm@nmdhb.govt.nz</a>	NMDHB
Ms Kristine Marriott	Clinical Governance	<a href="mailto:Kristine.marriott@nmdhb.govt.nz">Kristine.marriott@nmdhb.govt.nz</a>	NMDHB
Mr Martin Hucklesby	Clinical Governance	<a href="mailto:Martin.Hucklesby@nmdhb.govt.nz">Martin.Hucklesby@nmdhb.govt.nz</a>	NMDHB
Ms Cath Christmas	Registered Nurse - Oncology	<a href="mailto:Cath.christmas@nmdhb.govt.nz">Cath.christmas@nmdhb.govt.nz</a>	NMDHB
Ms Maura Foley	Registered Nurse - ENT	<a href="mailto:Maura.foley@nmdhb.govt.nz">Maura.foley@nmdhb.govt.nz</a>	
Mr and Mrs One	Consumer		
Mr Two	Consumer		
Mr Three	Consumer		
Mr Four	Consumer		

## Appendix One – Patient Survey Front Sheet

**Thank you for agreeing to help with this Head and Neck experience survey.**

This experience questionnaire will help you think about how you feel at different stages in your journey. Some columns may not be relevant to your experience.

### How did you feel?

Circle the words that best describe your feelings at each stage, or write your own words below

### Why?

We'd like to know why you felt like this. Was it friendly staff, a nice conversation, or a long wait.

## Appendix Two – Patient Survey Form

<p><b>After seeing your GP and being Referred</b></p> <p>Happy</p> <p>Supported</p> <p>Safe</p> <p>Comfortable</p> <p>Lonely</p> <p>Sad</p> <p>Write your own words here</p> <div style="border: 1px solid black; height: 40px; width: 100%;"></div> <p>What would have helped you at this time?</p> <div style="border: 1px solid black; height: 80px; width: 100%;"></div>	<p><b>Why did you feel like this?</b></p> <div style="border: 1px solid black; height: 300px; width: 100%;"></div>	<p><b>During first Appointment</b></p> <p>Happy</p> <p>Supported</p> <p>Safe</p> <p>Comfortable</p> <p>Lonely</p> <p>Sad</p> <p>Write your own words here</p> <div style="border: 1px solid black; height: 40px; width: 100%;"></div> <p>What would have helped you at this time?</p> <div style="border: 1px solid black; height: 80px; width: 100%;"></div>	<p><b>Why did you feel like this?</b></p> <div style="border: 1px solid black; height: 300px; width: 100%;"></div>
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<p><b>Waiting for Tests/results</b></p> <p>Happy</p> <p>Supported</p> <p>Safe</p> <p>Comfortable</p> <p>Lonely</p> <p>Sad</p> <p>Write your own words here</p> <div style="border: 1px solid black; height: 40px; width: 100%;"></div> <p>What would have helped you at this time?</p> <div style="border: 1px solid black; height: 80px; width: 100%;"></div>	<p><b>Why did you feel like this?</b></p> <div style="border: 1px solid black; height: 300px; width: 100%;"></div>	<p><b>Going to Theatre in Nelson (if applicable)</b></p> <p>Happy</p> <p>Supported</p> <p>Safe</p> <p>Comfortable</p> <p>Lonely</p> <p>Sad</p> <p>Write your own words here</p> <div style="border: 1px solid black; height: 40px; width: 100%;"></div> <p>What would have helped you at this time?</p> <div style="border: 1px solid black; height: 80px; width: 100%;"></div>	<p><b>Why did you feel like this?</b></p> <div style="border: 1px solid black; height: 300px; width: 100%;"></div>
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**Going to Christchurch**

- Happy
- Supported
- Safe
- Comfortable
- Lonely
- Sad

Write your own words here

What would have helped you at this time?

**Why did you feel like this?**

**Treatment in Christchurch (surgery, Chemo and radiation)**

- Happy
- Supported
- Safe
- Comfortable
- Lonely
- Sad

Write your own words here

What would have helped you at this time?

**Why did you feel like this?**

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**Follow up in Nelson**

- Happy
- Supported
- Safe
- Comfortable
- Lonely
- Sad

Write your own words here

What would have helped you at this time?

**Why did you feel like this?**

**Follow up in Christchurch**

- Happy
- Supported
- Safe
- Comfortable
- Lonely
- Sad

Write your own words here

What would have helped you at this time?

**Why did you feel like this?**

**Community Follow up**

- Happy
- Supported
- Safe
- Comfortable
- Lonely
- Sad

Write your own words here

What would have helped you at this time?

**Why did you feel like this?**

**Other Support Services  
Dietician, Speech Language  
Therapist**

- Happy
- Supported
- Safe
- Comfortable
- Lonely
- Sad

Write your own words here

What would have helped you at this time?

**Why did you feel like this?**

## Appendix Three – Patient information



Nelson Marlborough  
District Health Board

**NMDHB  
Head And Neck  
Cancer Pathway**

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**Patient Information: After Treatment**

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On your return from treatment in Christchurch you may want advice from the following people:

**Oncology Nurses** - support and nursing advice for recovery and side effects of treatment. Phone 03- 5393665

**Speech Language Therapists** - support with speech and swallowing problems after treatment. Phone 03-5461797

**Dietitians** - advice with supplementary feeding, PEG feeds, oral supplements and dietary advice. Phone 03-5461837

The links below will take you to useful information and patient stories:

<http://headandnecknetwork.blogspot.co.nz/>  
<http://www.cancerconnections.com.au/groups>  
[www.stilltalking.org](http://www.stilltalking.org)  
[www.cancersoc.org.nz](http://www.cancersoc.org.nz)  
[www.cancer.org.au](http://www.cancer.org.au)

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Nelson Marlborough  
District Health Board

**NMDHB  
Head And Neck  
Cancer Pathway**

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**Patient Information**

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You have been referred to the Christchurch Multi-Disciplinary Meeting to discuss your treatment plan. We recommend that you take a support person with you to this appointment. Travel is funded by NMDHB.

**Getting To Your Christchurch Appointment**

- Please put aside a day for travel, as your flight times may require you to spend a full day in Christchurch.
- If you have not received flight details 3 days before your appointment please contact the NMDHB Travel Desk – phone 03-5461727.

**At Christchurch Hospital** you will be:

- met by a specialist Ear Nose and Throat nurse
- taken into the meeting where there will be between 12 and 20 healthcare specialists who are involved with looking after people with head and neck cancers.

Your case will be discussed in front of you and you may be asked some questions and have the opportunity to ask questions.

You will be given a patient diary to take away with you with a summary of your appointment.

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