

## Partners in Care co-design case study

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# ‘Walking with you’ – Preparing for cancer treatment

## Northern Cancer Network

## Counties Manukau Health

### Context

The Northern Cancer Network has identified lung cancer for Māori and endometrial cancer for Pacific women as having disproportionately high incidence and mortality rates. Māori adults have the highest registration rates for total cancers and a mortality rate 1.5 times higher than non-Māori adults.

Endometrial cancer is the most common gynaecological cancer (Shaw et al 2016). The mortality rate from endometrial cancer increased by 11 percent between 2007 and 2016 in New Zealand; in Counties Manukau Health it increased by 49 percent. Of the 83 deaths in Counties Manukau Health from endometrial cancer between 2012 and 2016, 48 percent were Pacific women and 10 percent were Māori (Chan et al 2020). In Counties Manukau, Pacific people make up 21.1 percent of the population, Māori make up 15.7 percent, and proportionally more people are in the most deprived section of the population (Ministry of Health 2019b).

Consumers diagnosed with cancer are provided a lot of information prior to their first treatment and can be overwhelmed by this (Nguyen et al 2019). Diagnosis can be communicated in a variety of settings, such as an inpatient unit, primary care or a specialist outpatient appointment. Previous investigations demonstrated that clinical factors, systems and patient factors can impact on engagement with cancer treatment (Reynolds 2016). Patient factors include cultural beliefs, understanding of cancer, the role and influence of the family in making treatment decisions, and socio-economic factors (Reynolds 2017; Statistics New Zealand and Ministry of Pacific Island Affairs 2011).

The Cancer Action Plan 2019–2029 suggests that a well-resourced approach and improved health care system could eliminate inequities in cancer survival over time. This can be achieved by encouraging Māori leadership and partnership at all levels by encouraging consumer leadership, engagement and co-design (Ministry of Health 2019a). Patient and family engagement offer a promising pathway toward better quality health care, more efficient care and improved population health (Carman et al 2013).

Counties Manukau Health joined the Health Quality & Safety Commission’s Partners in Care co-design programme to explore consumer and health professionals’ experiences from the time of cancer diagnosis to first treatment.

### Aim

The project aimed to:

- better understand the experiences of Māori with lung cancer and Pacific women with endometrial cancer between their initial cancer diagnosis and first treatment
- apply a co-design approach with patients, family and whānau and health professionals about how to better prepare patients for their first cancer treatment.

## Start up

The start-up phase included creating a project team, gathering and reviewing current organisational data, and preparing for engagement with consumers and health professionals in order to capture and understand their experiences.

### Project team and consumer representatives

The project team included health professionals (including one who identified as Māori and one who identified as Pacific) with expertise and experience in the area of cancer (including the identified cancer streams) and consumers from the Māori and Pacific communities.

The team created a confidential shared folder which provided easy access for all members to contribute to the project activities. A Gantt chart was used to plan team activities. Weekly meetings and regular emails ensured ongoing team member involvement.

### Principles

The team followed a patient-centred approach together with strong cultural safety principles. Project meetings opened with a karakia and we adhered to Te Titiri o Waitangi principles by partnering with consumers to participate and share their knowledge and expertise. Their input was acknowledged by provision of koha.

## Engage

### Preparation

To introduce the project to patients, family and whānau, consumer representatives and health professionals, three 'elevator pitches' were prepared. These provided a short narrative to help people understand what we aimed to achieve. The elevator pitch, consent forms and interview questions were developed and tested by the team.

### Consumers

We identified 19 Māori with lung cancer and 30 Pacific women with endometrial cancer who received treatment in the period of August 2018 to August 2019. Cancer nurse coordinators (CNCs) for lung cancer, gynaecology, Pacific people and Māori led the engagement and facilitation when capturing consumer experiences.

### Health professionals

We identified 48 health professionals working directly with consumers on the lung and endometrial cancer pathway to be interviewed in person, participate in a focus group or complete a survey. An additional 22 professionals were included, including allied health representatives, general practitioners (GPs), interpreters, cultural advisors, managers and Cancer Society cancer support nurse coordinators (CSNC)) (see Table 1).

## Capture

Consumers were approached and interviewed at a place of their convenience. Pacific and Māori consumer representatives provided information about respectful engagement and advised including whānau at interviews. We explained that participation was voluntary and confidential and that their feedback would not impact on their care. All data was treated with care and stored confidentially. Consumers were also given the option to receive final results of the project, should they wish to see them.

The CNCs for the Pacific population and gynaecology facilitated two in-person interviews and a focus group meeting specifically with Tongan women. The focus group meeting was conducted in the Tongan language.

Following the interviews, we developed a survey which was designed to focus on and explore further the themes identified in the interviews. The survey was sent electronically or by post to the remaining 17 consumers identified. To optimise engagement, the project team contacted consumers by phone to make sure they had received and understood the purpose of the survey.

The survey for health professionals posed similar questions to those developed for the consumer population in order to determine and highlight the similarities and differences in experience.

*Table 1: Summary of the consumers who participated by method of engagement*

<b>Group</b>	<b>Method of engagement and capture</b>	<b>Number of consumer participants/respondents</b>	
<b>Consumers (lung cancer)</b>	Interview	2	
	Whānau	3	
	Survey (electronic)	1	
	Survey (post)	1	
<b>Consumers (endometrial cancer)</b>	Interview	2	
	Focus group	3	
	Aiga	1	
	Survey (electronic)	8 (electronic and post)	
	Survey (post)		
<b>Total consumer participation</b>		Lung cancer: 7 Endometrial cancer: 14	
<b>Health professionals (lung stream)</b>	CNC	Interview	2
	Other (senior medical officers (SMOs) etc)	Survey	2
<b>Health professionals (gynaecological stream)</b>	CNC	Interview	1
	Other (Counties Manukau Health and Auckland District Health Board, SMO/Fellow, nurses, radiation oncology, medical oncology)	Survey	4
<b>Other health professionals</b>	Management	Interviews	2
	Culture (CNCs, interpreters and experts)	Interviews	7
	Allied Health and other (cancer support, physiotherapy, dietician, registered nurse respiratory clinic, GPs, Cancer Society CSNC, palliative care)	Interviews	16
<b>Total health professional participation</b>		34	

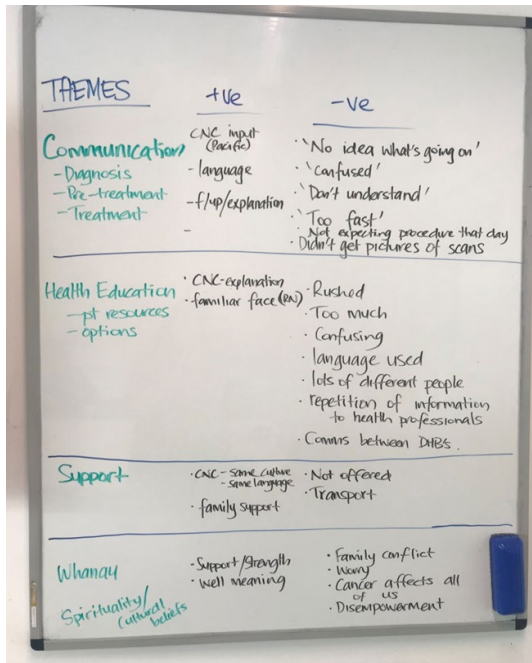
We had challenges engaging with consumers with lung cancer beyond capturing some of their experiences; those who were in our care were in the later stages of the disease and needed to focus on themselves and their whānau. However limited, the riches obtained as they shared their experiences were very valuable and are included within the case study.

Recommendations for improvement suggested by consumers from the lung cancer stream were not pursued for the purposes of this case study, but they were submitted for further attention to Counties Manukau Health cancer services.

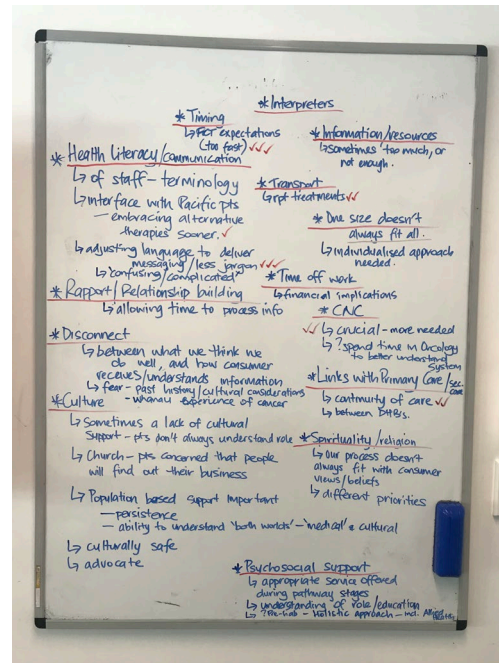
## Understand

A thematic analysis was undertaken on the data gathered from both consumers and health professionals (Figure 1). This analysis resulted in seven themes and over 30 ideas for improvement.

Figure 1: Whiteboard exercise for thematic analysis of consumer and health professionals' experiences.



Themes from consumers



Themes from health professionals

## The seven themes and ideas for improvement

### 1) Communication

Communication was a major theme in all the data gathered. The need to have a support person and/or whānau present for the initial diagnosis consultation was highlighted, and the suggestion was made that a phone call could be made to encourage attendance to the appointment. While clarity about the diagnosis is important, so is the way it is introduced. One interpreter described an appointment where the health professional said 'You've got cancer'. This felt harsh and could be improved by eliciting the consumer and whānau's understanding of the illness first and building on this. Once the word cancer has been spoken, the rest of the conversation is often a blur for consumers and whānau. Added to this is the complexity of language and jargon that is unfamiliar to people; many said that they left the appointment overwhelmed and without a clear understanding of their diagnosis and what it meant for them. Ongoing discussion to recheck consumers' understanding and re-iterate details is critical.

Understanding of, and preparation for, the impact of different treatments was an area that most consumers said they needed more support in. This includes the need for health professionals to make a clear distinction on treatment intent. One health professional said, 'Pacific people believe that if treatment is discussed, it relates to being curative, even if it may be palliative.' From the survey, 60 percent of health professionals thought consumers were not sufficiently prepared for their first cancer treatment. An interesting finding from the survey was that 7 out of 8 consumers indicated that they were well informed, which does not resonate with the information obtained from the focus group and interviews. This may indicate a limitation of the survey which could be explored further.

Comments from health professionals:

'I personally think, everything happens so fast and lots of information is given, it's hard to process for anyone. I think it's important to break down the information and deliver it bit by bit. Maybe GPs and community support teams should be involved more to deliver information at their pace.'

'I think there is a lot of work in ensuring the patient understands their diagnosis, but the pathway to navigate oncology treatment can be less clear for the patient.'

When explaining different types of gynaecological cancers and describing where the cancer is anatomically, clinicians use a range of different terms. In the focus group, Tongan women described that they often only used a single term for the whole of their reproductive system rather than understanding the different components. One woman said, 'Some of my body parts I don't know the name of.'

There often appears to be a 'mismatch' between what the health professional is attempting to explain and what the consumer understands. Below are some of the quotes collected during interviews.

Comments from consumers:

'I needed someone to talk to me more about the illness, the next step, explain to me so that I can make the choice, someone who won't leave you alone.'

'At the first appointment, have a whānau advocate, like a case officer, because there are a lot of things you don't understand at all.'

Comments from health professionals:

'They are scared ... they ask me questions that I don't have an answer to...'  
(interpreter comment)

'When the patient is with the doctors and nurses, they disclose only what they think the medical health professionals can support with (diagnosis and treatment); when the patient is with the psychology/social team, they disclose more aspects of their life stresses.'

Making use of an interpreter where needed and clearly understandable visual aids or images would contribute to better understanding of the diagnosis. In order to see better health outcomes for Māori and Pacific patients, we need to deliver our message in a way that patients and whānau can understand and relate to.

## 2) Health literacy and cultural competency

Health literacy came through as a strong theme for consumers and health professionals. Consumers described not being able to understand complicated terminology used by health professionals, being given too much information at once, and not having enough time to process

information. Health literacy has often been considered an issue focused on consumers; however, it also needs to be considered by health professionals. Health professionals need to reflect on their understanding of the consumer's culture and their own culture and behaviours and how they might impact on the choices consumers make. Being open to a discussion on the traditional medicines of Māori and Pacific people and their use alongside mainstream medicine may be important to the consumer, and this could impact on the default rate of consumers who perceive that they need to choose between one or other therapy in their cancer journey.

Comments from a health professional:

'Educate yourself, not only about the Treaty, but the generational impact of being disadvantaged, of white privilege. It is not a colour thing, but being raised differently impacts your world view. You need to understand a person's journey to better equip yourself to look through a non-judgemental lens to provide more equitable care, leaving your own bias behind.'

### 3) General support

Both consumers and health professionals appreciated the value of additional supports. This can include cultural support (provided by interpreters, nurses or navigators), the ability to see patients at home, and the input from cancer support: psychology and social work, physiotherapy, and dieticians). The longstanding relationship with the GP was mentioned positively by both GPs and consumers. Consumers and health professionals acknowledged the value of receiving support from the same person through the pathway, as this contributes to a more trusting relationship. Health professionals highly commended the role and input of the CNCs in this regard. Early engagement with population-based CNCs (Māori and Pacific) has been proven to enhance patient experience and better engagement with treatment. From the interviews, the experience of CNCs (Māori and Pacific) indicated that, if this support is not present, it can lead to reduced engagement with the health system, treatment is reduced and it is likely to result in worse health outcomes. To achieve equitable health outcomes, we need to focus on those who are more vulnerable.

Considering transport challenges for consumers to attend regular appointments was highlighted by health professionals, but it was only mentioned by a small number of consumers. Many of the consumers who engaged with the project had good family support and accessing treatment had not been a problem for them. Health professionals indicated that they thought attending treatment can cause financial distress in the form of lost earnings, both for consumers and those assisting/accompanying them.

Comment from a health professional:

'When you have social deprivation, you are already disadvantaged and you are dealing with a serious illness (possibly a life-threatening/life-ending illness) and when you don't have enough resource, you are disadvantaged even before you got there to start the race. So for me – that's unethical ... Absolutely give more support to those who are inequitably disadvantaged.'

Consumers need to feel supported as part of preparing for treatment. The role of the CNCs – with specific reference to the Māori CNC and Pacific CNC – and the relationship of the GP are amplified. Practical support must also be included for vulnerable consumers.

#### 4) Family/Whānau/Aiga

Support from family, whānau and aiga for consumers diagnosed with cancer is seen to be a positive aspect of the patient's cancer journey. Each family has a unique set of circumstances, and the quality of information is as important for the extended family as it is for the patient.

We found that some of the consumers we spoke to did not want to worry their family and felt that sharing their diagnosis with them would be too much of a burden for their family. Some were worried about their privacy, especially around the site of the cancer.

Comment from a consumer:

'I have lots of families, but I don't want them to know what I'm going through ... also of where the cancer is, privacy, there are words I cannot express to them.'

Others said that the treatment decision may not be solely the consumer's decision. It might be made collectively, and therefore it is essential that the family understands the diagnosis and options to make an informed treatment decision together.

Comment from a consumer:

'I ended up stopping them, for I wanted to see my family first ... they had to make me another date and I would bring them back with me.'

Comment from whānau:

'...when you hear the word cancer, it affected all of us...'

Effective communication and support should be available and offered to the whānau as required alongside the person who has cancer.

#### 5) Cultural beliefs and spirituality

Health professionals felt that during the consultation, traditional healing was being discussed and accommodated as part of the treatment plan and is working well. However, Māori consumer feedback reflects that not all consumers have a positive experience of this.

Comment from a consumer:

'The doctor said that they will try our medicine (kawakawa) for two months before making a decision, then go for a scan to see if anything changes, but none of that ever happened.'

Comment from a consumer:

'She [Counties Manukau Health doctor] didn't like it. But Auckland doctors, they gave us the opportunity to trial it. The chemo doctor was okay with it, but not the radiation one.'

Traditional treatment is highly regarded by many people and can include a combination of herbal medicines and fofo (massage). Some Pacific consumers value the community narrative more than the medical system's expertise.

Comment from a health professional:

'Cancer is associated with dying, that treatment doesn't work, and they would rather pursue herbal medicines which are advertised on radio by a high-standing Pacific woman in the community.'

Spirituality is viewed as a wide concept, which could encompass a person's being – including those who have gone before. Health professionals need to acknowledge that some consumers may want to accommodate their faith as part of their treatment. Consumers mentioned that offering a loto (prayer) to bless the consumer and the medical team before a consultation or surgery would be valued. To a younger generation, spirituality may mean something different, but most of the Pacific community are affiliated with some religion.

An understanding of the cultural needs and beliefs of consumers and whānau is needed, especially to be able to support them through the early stages of their cancer pathway when they would make decisions about their treatments.

Comment from a health professional:

'Saying "You can potentially die from this" to obtain engagement is not relevant. In the Pacific culture death is not feared, it is accepted and embraced as in the hands of God. The fear is about engaging with the medical system, experiencing side effects. This impacts on the time that they rather could have spent more quality with family.'

## 6) Values

Several values were highlighted by both consumers and health professionals during this project, such as the importance of connection, building relationships, and the need to acknowledge uniqueness and develop an individualised approach (kotahitanga and whakawhanaungatanga). Furthermore, we need to be mindful about how patients and whānau are approached and treated (manaakitanga and rangatiratanga).

Comment from a health professional:

'A little bit of kindness, manaakitanga goes a long way.'

Consumers and health professionals identified the significance of time and trust. The initial wait between the referral, initial appointment and diagnosis felt like a long time for some consumers,



while others needed more time to process the information before making a decision to engage with treatment or not.

Comment from a consumer:

‘Everything went too fast.’

## 7) Preparation for treatment

Within the Survey Monkey questionnaire, we asked consumers and health professionals the following question:

What can we do better to support people during the time between finding out about cancer, and starting treatment?

The responses from the two groups were remarkably similar (see Figure 2 and Figure 3).

*Figure 2: Consumers’ responses to the question ‘What can we do better to support people during the time between finding out about cancer, and starting treatment?’*

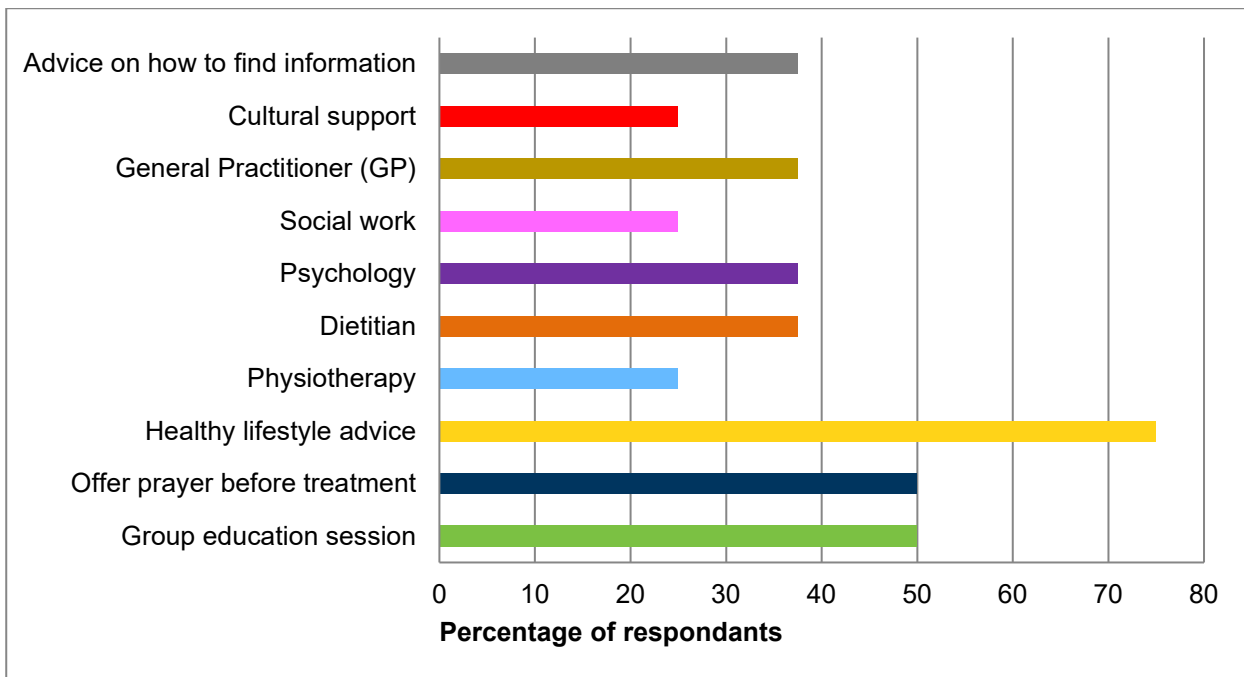
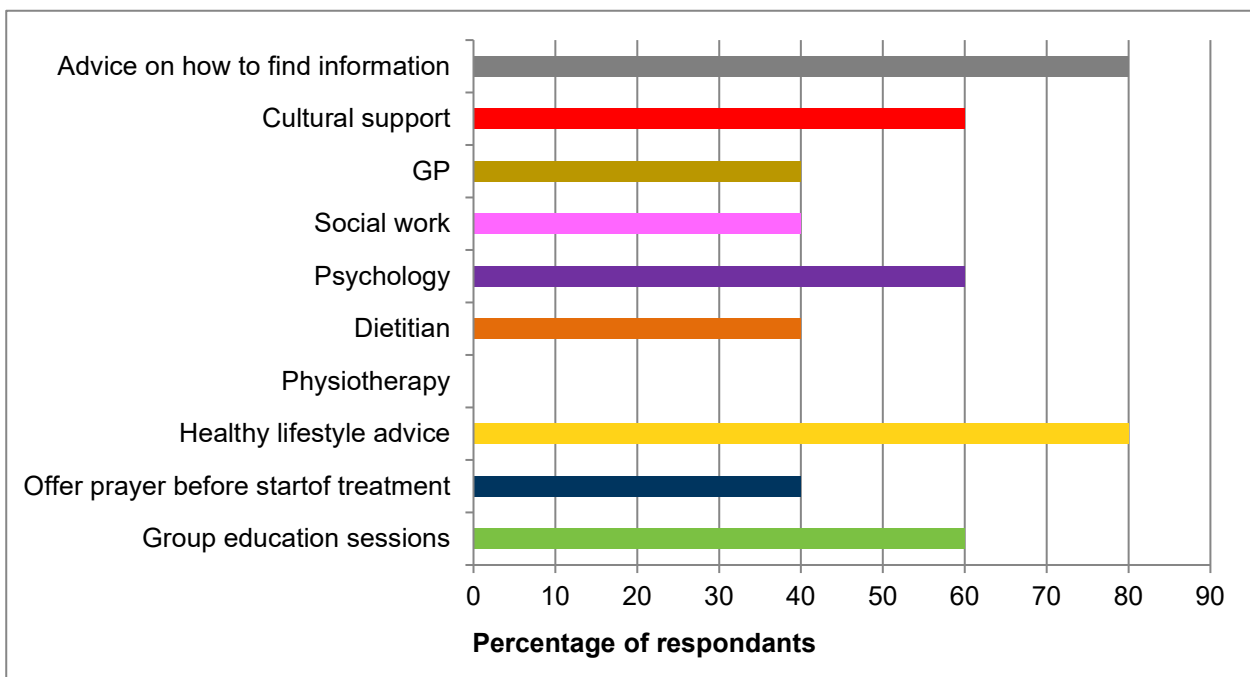


Figure 3: Health professionals' responses to the question 'What can we do better to support people during the time between finding out about cancer, and starting treatment?'



Both consumers and health professionals indicated that healthy lifestyle is of most importance in preparing endometrial cancer patients for treatment, while cultural support is more significant for consumers with lung cancer. Health professionals working in this area especially value the input of social work so that patients can be informed of the variety of support available prior, during and after treatment.

Comments from health professionals:

'Education is crucial; endometrial cancer especially affects less health educated people. Wholesome health advice with green prescription, dietician, and bariatric referrals should be a routine package for these women. Psychology and cultural support are a limited resource so far and could help with complex cases where patients are not understanding or not coping well with a standard management plan.'

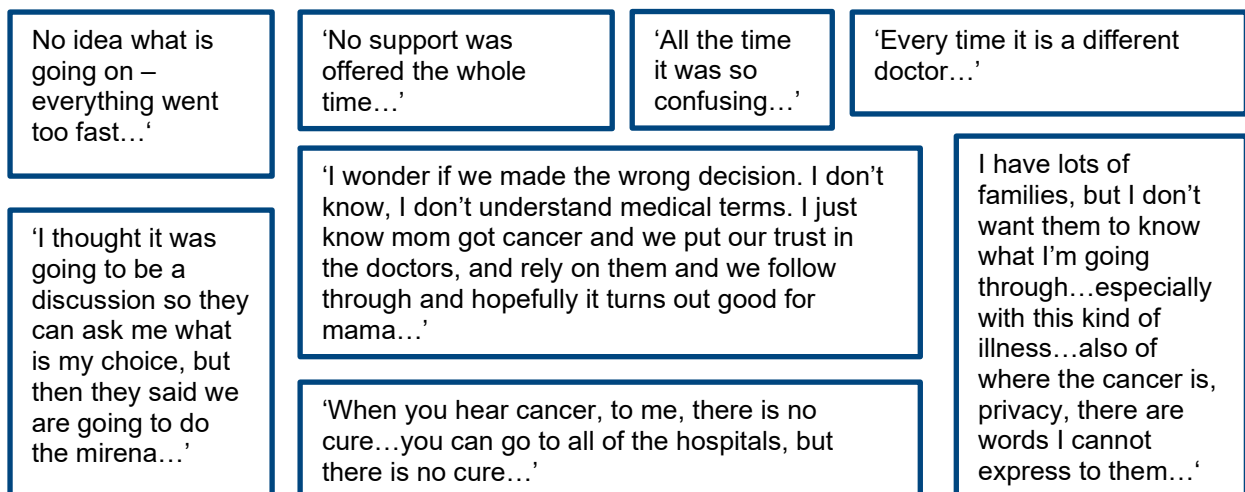
'The better prepared a patient is for surgery, even for a short time, the quicker the recovery will be – stopping smoking, walking and general fitness, managing diet especially if diabetic.'

Comment from a consumer:

'I have decided I need to do some exercise, go on a diet and start to eat the right food. At the same time, I have to exercise my mind. I grew up in an environment where we can eat what we want to eat ... It makes me feel better and makes me more active. When I told my children, they were supporting me, encouraging me ... we decided to have a roster to bring the mail from the mailbox ... even when we go to restaurants, they make sure I don't get something from THAT side.'

We were thankful for the many quotes that consumers and whānau felt able to share with us. These are represented throughout the case study and within Figure 4.

Figure 4: Selection of quotes from patients



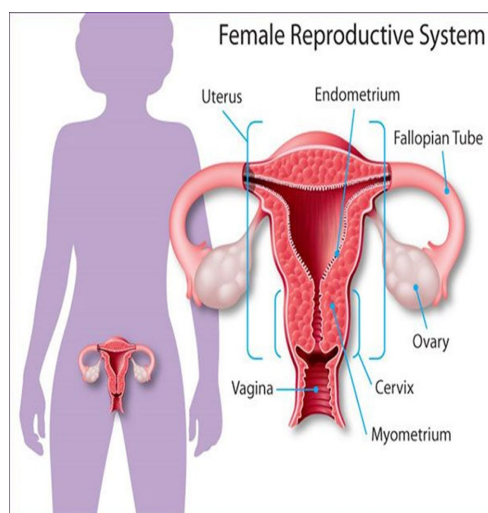
## Improve

We identified over 30 ideas and recommendations for improvement. While our focus for this work was from diagnosis to first treatment, the conversations ranged from the initial interactions with primary care, through the outpatient and secondary care settings, and back to primary and community care. While we aspire and have planned to work through all of the ideas and

recommendations, we decided that the first focus was to improve the information provided for people who have endometrial cancer and specifically focus on the hysterectomy procedure.

We drew on the learning gathered during the capture phase and used that in the development of a revised information pamphlet. We aimed to make the language easier to understand, we removed information that was not deemed to be relevant or helpful, and we asked consumers to select images from a range of options. The images they selected were quite different to those that health professionals had previously used. For example, consumers chose an image of a uterus which was also seen encompassed within the body (Figure 5) rather than an image of the uterus as a solitary organ as had been used in previous information.

Figure 5: Working with consumers to design a new brochure



## Measure

We identified 10 consumers who had a hysterectomy/Mirena procedure following their cancer diagnosis to evaluate the pamphlet. After we posted and emailed the pamphlet and evaluation form to the consumers, we contacted them by phone to check they had received it and to ask if they had any questions about the evaluation form. Four responses were received and indicated that, overall, the women felt the pamphlet was helpful. Importantly, women commented very positively on both the language and images used. They also felt that the amount of information was 'enough'.

### Comments from consumers:

'For English as my second language it was very easy to understand. It's pretty much straight forward thank you.'

'I found the pamphlet easy to understand with the basic language used ie, 'tummy'. Information and visual was good and very easy to understand. Well done!'

While we will seek further responses from women as they use the information pamphlet, we are very happy that those who have provided feedback so far feel that this new version does provide useful information in a way they find easy to understand.

This was one of the range of ideas that have been turned into recommendations for action as a direct result of our co-design work with consumers, whānau and staff. These recommendations have been presented to the CMH Cancer Steering Group and are being discussed as part of the work plan for 2020/21. This project has also gained the attention of the Northern Cancer Network, who have requested our findings to support the development of regional initiatives. These opportunities are likely to make significant improvements for consumers' experience of endometrial cancer diagnosis and treatment throughout the Northern Region.

## The value of working as a co-design team

Being able to work in a team provided the ability to discuss and fine-tune drafts such as the elevator pitch, interview questions and the case study. We obtained valuable guidelines for approaching the consumer community. We needed to be mindful of keeping consumer input on the foreground and not to decide on a solution prior the outcome of the results. In some ways, these are easier said than done, as it requires not only a change in mind-set to consider the consumer voice, but also a change in the way we do things.

Some members of the project team commented on the value of working with consumers on the project.

'Hearing the voice of the patients as part of our project team, and those who participated in interviews and surveys was an incredible experience. I actually felt while working on this project that a patient is present the whole time – every step of the way. Thank you for sharing your stories, your openness and honesty have impacted the way I think and work forever.'

Karin Jansen  
(Social Worker, Cancer Support)

'It has been incredibly humbling to hear your stories. As health care professionals we might know a lot about health but what we need is to know more about the people we serve. Without this, we won't be able to make the positive difference we hope to make.'

Kate Dupper  
(Clinical Nurse Specialist, Palliative Care)

'Thank you for sharing your experience with us. You have given us invaluable knowledge which will help to guide and inform improvements for all people.'

Larissa Ferguson  
(Clinical Nurse Manager, Cancer Services and Palliative Care)

'I have truly valued the time I have spent talking with patients about their cancer journey. It has enriched my understanding of what this journey means for patients and their whānau. I feel privileged to be involved in improving this experience.'

Tricia Wenzlick  
(Cancer Nurse Coordinator)

'It was great to be part of a team committed to listening to patients' stories and working for change. I was proud of the GP colleagues we interviewed who shared their desire to walk with their patients on the cancer journey.'

Sue Tutty  
(General practitioner)

## The project team

Name	Role
Larissa Ferguson	Project sponsor, Counties Manukau Health
Karin Jansen	Project manager, Counties Manukau Health
Kate Dupper	Team member, Counties Manukau Health
Keleni Tupou	Team member, Counties Manukau Health

Sue Tutty	Team member, Counties Manukau Health
Kato Peauafi	Consumer team member, Counties Manukau Health
Kathy Magolan	Team member, Counties Manukau Health
Leani Curtis	Team member, Counties Manukau Health
Patricia Wenzlick	Team member, Counties Manukau Health
Tanya Weeks	Team member, Counties Manukau Health
Pauline Whaitiri	Consumer team member, Counties Manukau Health

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