We began planning Patient Experience Week in early January 2015. Fortunately, we had the assistance of dedicated nursing, allied health and medical colleagues to whom we would like to express our sincere appreciation.

We are deeply grateful to the Mental Health Team, who gave so much of their time and expertise.

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We would like to express our sincere thanks to our staff, patients and whaanau (family) who gave so freely of their time. This week would not have been possible without their participation and support.

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This document can be referenced as:

All photographs and comments in this document are used with consent.
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Summary

Counties Manukau Health (CM Health) is committed to patient-centred care. The Patient and Whaanau Centred Care (PWCC) Board leads the operational implementation of this commitment. The Board commissions and supports initiatives to explore new ways of working with patients and whaanau.

In 2013, the PWCC Board commissioned the first Patient Experience Week at CM Health. The 2013 event was a great success at raising awareness of CM Health’s Patient & Whaanau Centred Care Programme. With so much happening in the fields of co-design, patient and whaanau-centred care and patient experience, the PWCC Board and Executive Leadership Team commissioned the second Patient Experience Week for March 2015.

The key objectives for Patient Experience Week 2015 were to raise people’s awareness, promote benefits and showcase the breadth and depth of activities and co-design initiatives that patients, whaanau and staff are working on together, both within CM Health and regionally.

Additionally, the Patient and Whaanau Centred Care team aimed to create an experiential empathy zone that staff, patients and whaanau could experiment with to better understand the challenges some people face due to health problems.

Patient Experience Week also provided a perfect opportunity to launch the new Consumer Council.

Finally, the Values Refresh Programme to update CM Health organisational values was promoted during Patient Experience Week, and data collected. A range of activities and events were held to achieve these objectives. While all activities added value, surveys and anecdotal feedback showed that some had a particularly great impact.

» The launch of the Consumer Council gave CM Health staff greater confidence that they can easily access support and guidance from members of our community.

» The Empathy Zone left people ‘wide eyed’ in recognition of some of the challenges people face in their daily lives.

» The presentations and posters from staff who have been using co-design methods were of great interest to those considering a similar journey, and piqued new interest in others.

» The Consumer Coffee Corner enabled over 100 students to listen and share in the health and care experiences of patients and their families/whaanau.

» The Grand Round had a patient experience theme and attracted a full house of clinicians from many specialties.

» The Youth Mental Health Regional Session enthralled attendees with illustrative dance and poignant stories of both the sadness and the joy of youth.
Introduction: Patient Experience Week at Counties Manukau

Counties Manukau Health (CM Health) supports patient-centred care as part of its ongoing strategy. The Patient and Whaanau Centred Care (PWCC) Board, chaired by the Director of Nursing, leads the operational implementation of this commitment. The Board is made up of the Clinical Director for Patient Experience, four patient representatives including the Chair of our Consumer Council, the lead for patient experience surveys, and staff from Māori and Pacific cultural units as well as other areas in the organisation. It commissions and supports initiatives to explore new ways of working with patients and whaanau.

CM Health created Patient Experience Week in 2013. The first Patient Experience Week was successful in raising awareness, understanding and knowledge of the importance of working with patients and whaanau to redesign health services. CM Health built on the previous success and added new learning to produce Patient Experience Week 2015. A new and important focus for this year was to work closely with Auckland District Health Board and Waitemata District Health Board. All three district health boards coordinated events relevant to their own community context during the same week, which helped to promote and share learning on patient experience across Auckland.

Patient experience and involvement: an important concept

There is increasing global interest in patient-centred care and the use of patient experience and expertise to co-design services. For many, it feels inherently like the right thing to do. Clinicians and managers in health care are often a small, albeit important, part of patients’ and their families’/whaanau’ lives, and patients need to retain their ability to contribute and make choices.

There is still some confusion about the meaning of patient-centred care and how it can best be achieved in everyday health and care practice. A range of attempts to define and explain the concept have been made, including seeing illness through the patient’s eyes and other practical suggestions such as involving patients in decision making processes. 1,2,3

Carman et al. share a definition which identifies patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system—direct care, organisational design and governance, and policy-making—to improve health and health care.4 They have developed a model, in conjunction with patients and family representatives, and present the forms patient engagement can take, from consultation to partnership and shared leadership.5 The PWCC Board at CM Health actively use this model to highlight opportunities where we can move from consultation to partnership at all levels.

A focus of many organisations, including CM Health, is engagement of patients, families/whaanau and staff in improving services together through shared redesign. CM Health uses the tools and methods of experience-based co-design, which draws upon people’s actual experience of both delivering services (health and care staff) and receiving those services (patients and family members).6 Teams capture experience through a range of methods including stories, surveys and shadowing. The next step is to understand what works well and what could be improved by identifying emotional ‘touch-points’ in care processes. Co-design follows; patients, carers and staff come together to share ideas for improvement and a commitment to make those improvements.

Experience-based co-design methodology ensures that attention is paid to actual experience as an indicator of patient needs. This data, combined
Introduction: Patient Experience Week at Counties Manukau

with other sources such as the Patient Experience Survey, compliments, complaints and CM Health’s recently designed Leadership Walk Around for Patient Safety, provides a composite picture of how our community experiences the services we provide.

Rationale and objectives

CM Health identified eight objectives for Patient Experience Week:

1. To raise awareness and promote the benefits of healthcare staff, patients and whaanau working together in order to design services that meet the needs of our local communities.
2. To demonstrate the breadth and depth of activity patients, whaanau and staff are working on together within CM Health.
3. To showcase current and proposed patient experience activities, including projects, research and patient experience survey results.
4. To create ‘experiential empathy’ activities that staff, patients and family members can try so that they better understand some of the challenges people face.
5. To promote the Values Refresh Programme and collect some data through the use of Graffiti feedback boards and video narrative.
6. To promote the activities of the PWCC Board and its plan of work for 2015.
7. To promote the new Consumer Council, its links to the Localities Consumer Groups and its role in advocating for our community.
8. To share learning and work in partnership across Auckland region district health boards.

Organising Patient Experience Week

Four CM Health staff members formed the core team who pulled Patient Experience Week together, with the support of many others who made invaluable contributions.

The involvement of the University of Auckland, Auckland University of Technology and Manukau Institute of Technology through nurse educators and coordinators enabled us to include medical, nursing and allied health students in our key activities, which contributed greatly to the week’s success.

We worked in collaboration with Auckland District Health Board and Waitemata District Health Board to gain maximum traction and exposure, as we have patients and whaanau that use the services of more than one district health board. We held regular regional meetings to discuss publicity and marketing for the event.

Organising Patient Experience Week took three months from concept to the actual event. Key considerations for organising the week were:

- engaging key stakeholders early
- budgeting
- logistics (particularly spaces to run events)
- organising teams to support events and displays
- showcasing work in different and interesting ways
Thinking about the purpose of the week, and the needs and interests of the target audience, was important in determining the nature and timing of events in the programme. The active involvement of patients and their whaanau in the planning phase was crucial. We obtained input from patients and whaanau through the Consumer Council.

Introduction: Patient Experience Week at Counties Manukau
The Patient Experience Week programme

The Patient Experience Week programme featured the launch of the Consumer Council, a range of activities designed to develop empathy and understanding of the patient experience, examples of the patient experience and co-design work happening at CM Health, and regional and national sessions focussed on the theme of patient experience.

The following pages describe the events in the programme. Coverage of the sessions is organised broadly as follows: sessions specific to CMH; regional sessions; national sessions.
During Patient Experience Week, CM Health announced the launch of the Patient & Whaanau Centred Care Consumer Council. This new council will support and advise CM Health inpatient and outpatient services, and will work closely with consumer groups within CM Health Localities. This means the continued development of patient and whaanau-focused care will incorporate the whole of the health and care services across our community.

The Consumer Council has 10 consumers representing a wide range of different backgrounds, ethnicities, localities, ages and exposure to different health care services provided by CM Health, either personally or as a whaanau member. In addition, we have representatives from the hospital localities helping reinforce that two-way communication linkage.

The Consumer Council will represent the interests of consumers and bring a consumer and family/whaanau perspective to the development of CM Health plans, policies, projects, publications and operational decisions. It will also raise issues that have been identified in the community.

"It’s about designing a health care system for consumers and asking staff to meet us halfway, rather than designing it for staff and asking consumers to adjust to it. There will be adjustments on both sides, but together we can design a system that meets the needs of both," said Rosalie Glynn, Chair of the Consumer Council.

CM Health is committed to giving the council the active voice it needs to achieve the vision of a healthcare system that works for staff and consumers and their family/whaanau alike. The council has a clear line of communication to the CM Health Executive Leadership Team through the PWCC Board. Consumer Council chair Rosalie Glynn holds a seat on the PWCC Board as a consumer representative, and the board reports directly to the Executive Leadership Team.
The Consumer Council: Enhancing the partnership between CM Health and our patients and family/whaanau

“It’s good to be part of a DHB that really wants to be engaged and create a health service that is for our community and engaged with our community,” said Rosalie Glynn.

Dr David Galler and Consumer Council member Barbara Broome trying out activities in the Empathy Zone.
Empathy Zone: Walk in a patient’s shoes

We can never fully experience what another does as we cannot possibly feel the same joy, fear, pain, elation or anxiety. But we can expose ourselves to part of their experience so that we can empathise.

The Empathy Zone gave staff and students a chance to walk in their patients’ shoes. It’s common for patients to have a splint or a cast on, to use walking aids, to have impaired dexterity or perception, or to find themselves on an operating table waiting for surgery or in a hoist to be lifted from bed to chair. Healthcare staff deal with people in these situations every day. Understanding how it feels to experience these things is crucial to develop empathy.

Allied Health staff ran the Empathy Zone. Representatives from the disciplines of physiotherapy, occupational therapy, psychology, social work, speech-language therapy and hand therapy each created a different experience to simulate impairment or a process of care (Table 1). In addition, the health psychology team created an empathy wall and encouraged people to attach sticky notes to it about what ‘empathy’ meant to them.

Table 1: Empathy Zone experiential activities

<table>
<thead>
<tr>
<th>Discipline</th>
<th>Activity</th>
<th>Simulated experience</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hand therapy</td>
<td>Trying different hand splints</td>
<td>Wearing a hand splint</td>
</tr>
<tr>
<td>Occupational therapy</td>
<td>Threading beads while wearing padded gloves</td>
<td>Impaired dexterity</td>
</tr>
<tr>
<td>Occupational therapy</td>
<td>Tracing a star by its reflection in a mirror</td>
<td>Perceptual impairment</td>
</tr>
<tr>
<td>Occupational therapy</td>
<td>Vision-distorting goggles</td>
<td>Visual impairment</td>
</tr>
<tr>
<td>Occupational therapy</td>
<td>Dressing in a hospital gown or pyjamas while wearing an arm splint</td>
<td>Wearing an arm splint</td>
</tr>
<tr>
<td>Physiotherapy</td>
<td>Mobilising with crutches or a wheelchair</td>
<td>Impaired ambulatory function</td>
</tr>
<tr>
<td>Psychologist</td>
<td>Empathy sessions for psychological issues</td>
<td>Depression, anxiety, other psychological disorders</td>
</tr>
<tr>
<td>Speech language therapy</td>
<td>Communicating via electronic communication aids</td>
<td>Difficulty with speech</td>
</tr>
<tr>
<td>Speech language therapy</td>
<td>Drinking thickened fluid</td>
<td>Impaired vocalisation/ Dysphagia experience</td>
</tr>
<tr>
<td>Speech language therapy</td>
<td>Talking with a mouthful of marshmallows</td>
<td>Motor speech disorders</td>
</tr>
</tbody>
</table>
Empathy Zone: Walk in a patient’s shoes

The Empathy Zone was well attended and attracted senior leaders at CM Health, as well as nursing and allied health students. Participants gained insights into the patient experience, and a better understanding and awareness of how we can support people under our care.

**Staff Reflections**

One of the challenges of running the Empathy Zone was attracting busy frontline nursing, medical and allied health staff. Running the Empathy Zone throughout Patient Experience Week, so that each profession offers a shorter, separate session, rather than holding a single concurrent two-hour Empathy Zone, may help to address this challenge next year.

“I tried on a pair of goggles, to see what it would be like for a person who has glaucoma – a condition that can cause blindness if left untreated. What I experienced were blind spots in my vision, making it very hard to see. As I banged into chairs and tables, I kept thinking how would I cope with deteriorating vision on a day-to-day basis.” Geraint Martin, CEO

“I tried out the tilt table, which is used by the physiotherapists to help spinal and stroke patients go from lying flat to an up-right position. As I was being strapped in, two things struck me. Firstly, if you are lying on your back for long periods of time, you become very familiar with the ceiling. Wouldn’t it be great to have something interesting to look at! Secondly I was putting my safety and trust in the hands of a physiotherapist I had just met. Being reassured and treated with compassion made me feel cared for and safe. Overall it was very humbling to experience what our patients go through.” Denise Kivell, Director of Nursing
Empathy Zone: Walk in a patient’s shoes

“Have you ever tried to trace a star looking through a mirror? It’s not as easy as it sounds. When you hold up an image in front of a mirror, it is reversed. However your brain still thinks it is looking at the real image, not the flipped image. That’s why you make mistakes. If you keep practicing, your brain will learn that you are looking at the flipped image and you will get better. This was a great exercise to experience what people with perceptual difficulties must go through.” Martin Chadwick, Director Allied Health

“I tried to put on a pair of pyjamas with my arm in a sling. Not only was it difficult, it was incredibly frustrating. For a brief minute I experienced what our patients must feel. I’ll be more mindful in the future.” Student Nurse
When it comes to developing empathy, CM Health believes you can never start too young. During Patient Experience Week, children at CM Health’s crèche, The Treehouse, got the chance to experience what it’s like to work in the hospital environment like their mums and dads.

A team of Counties staff who have children at the crèche, led by Dedicated Education Unit coordinator Victoria Crisp, arranged a sensory session where children could explore being hospital patients, doctors and nurses. The children had a fantastic time trying on masks, gowns, gloves and hats from the operating theatres, talking to each other on radio transmitters used by hospital orderlies and riding in wheelchairs. They also got to put on bandages and make plaster of Paris casts of their little fingers to decorate as puppets.

“It was the loudest session we had … absolutely buzzing. Even the teachers were really getting involved with it,” said Victoria Crisp. “And I think it really fits with Patient Experience Week, because the kids got to experience something that patients might – like the smell of Latex gloves, seeing surgeons dressed up in all their gear, and feeling the plaster of Paris go on and the warm sensation as it sets. It gave them an idea of what happens here at the hospital and of what their parents might do.”
Kidz First: A picture paints 1,000 words

When you ask children what it’s like to be in hospital, they often don’t reply with words. They may give a shy smile, cast their gaze cast down towards their feet, or they may not reply at all. But ask a child to draw a picture of what it’s like to be in hospital, and the response you get is often worth a thousand words.

Children in Kidz First, the paediatric wing of CM Health, told their stories through art, creative activities and graffiti boards during Patient Experience Week. We displayed their work in the Ko Awatea Centre.
Showcasing empathy and compassion via patient stories

To understand the experiences of patients, whaanau and staff we put together a combined ‘movie’ reel of patient stories and videos from different health organisations globally. These included the renowned Cleveland Clinic Empathy & Compassion Series, as well as videos and patient stories from campaigns at CM Health. 7,8

We released a special patient story that has been transformed into a incredible teaching tool. The story has been depicted by a cartoonist to showcase the patient’s journey from a different perspective.

Our aim was to highlight that there are many angles and elements to patient experience.
Putting co-design into practice: Case studies

We need to understand the experience of patients and work with them to design care that better meets their needs. One of the key attitudes we need to change is to move away from the concept of doing things to and for patients, towards a concept of doing things with them. Co-design methodology has become popular in improvement circles. Under the co-design approach, staff, patients and patients’ families/whaanau work in partnership to design healthcare.

At CM Health, co-design using experience-based design methodology has been used to improve care across a number of services. Experience-based design is based on four key elements:

» Capture the experiences of patients and staff as they move through the care journey.

» Understand the experiences captured to identify key touch-points in the care journey.

» Improve care services based on a clear understanding of these touch-points.

» Measure the success of the improvement made.

Patient Experience Week showcased two examples of our co-design projects.

Critical Care Complex – Including whaanau in long-term patient meetings

The Critical Care Complex (CCC) uses co-design methodology to improve the experience patients and their families have in the Complex. The project began three years ago, when CM Health was exploring visiting arrangements. There was some resistance among staff towards open visiting, so the initial focus of the co-design was to help understand the reasons for that.

The project group is led by Charge Nurse Steve Kirby, and involves staff from the floor and educators in the Critical Care Complex (CCC), as well as past patients and family representatives. They started small, with six people, but as the project moved through different phases the group’s size fluctuated between six and thirty. Because they were looking at the interactions of patients and their families with the CCC, it seemed logical to take a co-design approach that included them in both the discussion and new design.

The group began by capturing the experiences of patients and their families in post-discharge interviews. Communication, separation, fear and frustration emerged as key themes. They captured a lot of information to present to staff to help them to understand the patient and family perspective. Staff decided to run a test of extended visiting.

During the test, the concerns of some staff that open visiting would lead to unmanageable numbers of relatives being present 24 hours a day were shown to be largely unfounded. Staff were better able to understand that what people wanted was clear information, to be included, to have choices and to be aware of those choices.

As a result of the co-design work, the group has facilitated the allocation of more space for family meetings in the CCC, and a focus on including Maori health representatives. Visiting has become more flexible. Importantly, the
Patent Experience Week March 2015

Putting co-design into practice: Case studies

The team has been able to develop different ways of thinking, which in turn has enabled successful implementation of a new way of partnering with patients and their families.

Changing the culture of a clinical area and the way it functions requires planning and determination. Success depends on including the whole team from the beginning: staff, patients, family/whaanau. “Don’t have this feeling that you’ve got to keep it within the staff first until they are used to it, and then introduce it to patients, and then introduce it to families. It needs to be done all at the same time. Even if that group starts small,” advised Kirby.

Centre for Youth Health – Working with transgender youth

The Centre for Youth Health (CYH) is a specialist youth service that promotes the wellbeing and healthy development of young people in the context of their family and wider environment. One of its specialities is providing services to transgender young people. Services may include medical transition, blockers and hormones, and psychological support to help young people transition successfully from their biological gender to the gender they identify with. The CYH supports around 50 transgender adolescents per year, with an average age of 16 years.

Transgender young people are a vulnerable group with high rates of self-harm and suicidal thoughts. Many are fearful of telling their parents they’re exploring gender reassignment for fear of rejection. Only about one third of transgender young people have disclosed that they are transgender to someone close to them. However, family acceptance and support is crucial for their mental health and wellbeing, as well as necessary for young people to be able to access healthcare.

CYH facilitated a co-design project to explore how to support parents to access healthcare for transgender young people. The project began in January 2014. CYH used experience-based design methodology to bring clinicians, transgender young people and their families together to jointly understand their experience with the CYH transgender service.

They began by capturing the experiences of two transgender young people and their mothers by using a questionnaire that focussed on the emotional experience of contact with the service throughout the care journey, and then followed this up with a meeting to explore the responses in more depth.

Young people felt awkward and shy at clinic, but they were also excited, determined and impatient to begin their transition.

Janice Crone, Registered Nurse, Centre for Youth Health and whaanau member Helena Stevens co-designing solutions.
Putting co-design into practice: Case studies

Emotionally, mothers were at a much earlier stage in the journey towards transition. They described being ‘hit’ with a lot of new information and not having enough time to process what being transgender would mean for their young person and the family. They were confused, worried and anxious, and felt unsupported. They also felt that they were being blamed by fathers, family and friends.

Both the young people and mothers expressed particular anxiety about the father’s reaction. Mothers felt they were caught in the middle, trying to support their child through anxiety about the paternal reaction while they were still struggling to deal with their own confusion and concerns for their child.

A need for excellent information about what to expect from the first clinic appointment and links to other services was articulated very strongly by both youth and family members. The existing information pamphlet was targeted mainly at health professionals, and was not easily accessible to patients and their families.

CYH worked with the young people and their mothers to co-design information that had content they needed and could understand, was visually appealing with plenty of colourful photos, including pictures of the CYH clinicians, and which also provided useful links to information from a variety of sources.

CYH also established pre-clinic whaanau/family visits to introduce families to clinicians and help allay anxiety. This is offered on a case-by-case basis, depending on the safety of the young person and their consent to the visit.

The nurses have found these visits have worked well. The main outcome is that they have helped young people to facilitate discussion with their families and helped parents to understand what their transgender young person is going through. Feedback from the parents is that they feel better prepared for the first clinic visit, as they have had time to come to grips with the transition the young person wants to make.

However the issue is approached, finding out that their child is transgender is often a shock to parents when the young person hasn't been able to talk to them about it. They may suspect there’s something ‘different’ about their son or daughter, but beginning actual gender transition is another step altogether. CYH’s project with transgender young people has positively supported young people and their families to work through gender transition together.
In 2013, a group of registered nurses were tasked with formulating an education proposal for CM Health. Due to a worldwide shift from a historically medical focus to a model that concentrates more on meeting the needs of the individual patient, placing the patient at the centre of care has become a priority.

Using data collated from existing patient feedback, the group constructed a patient survey designed to prospectively survey patients on their experiences. The survey was adapted from the NHS experience-based design framework.

Over half of the existing feedback the group reviewed was positive. Of the negative feedback, the main themes that emerged were around communication, care/treatment, attitude/courtesy and accessibility. As the majority of complaints came from surgical services, the group ran a pilot of the patient surveys there, with an initial focus on communication. They surveyed 60 randomly selected patients who had been in hospital for longer than three days. Staff were also interviewed about their perceptions of the patient experience, and the data was integrated with the patient responses to provide an overall view.

The patient responses were surprising. In the survey, patients said that while they did experience negative aspects or moments of their care, overall they felt their care was good. However, verbatim comments that patients made while being interviewed for the survey that told the group that sometimes they really felt like just a number; that they were not regarded in the context of their individual lives and that while in hospital they felt their outside world was forgotten about. Patient comments identified three main themes:

- communication, waiting times, and not wanting to feel like ‘just a number’.

Feedback from staff (60 randomly selected nurses) told us that they thought patient complaints arose from miscommunication, lack of understanding and waiting times. Staff felt that improved communication skills were the key to addressing negative patient feedback.

The next steps for the group are to implement regular patient experience surveys using the tools they have designed into wards. Ward staff will collect information for their own area to get a real-time sense of areas for improvement in their local ward environment. To implement this, the group has:

- developed a patient-centred awareness campaign, including posters and notices in the CM Health staff newsletter to engage staff around patient experience
- planned the introduction of monthly half-hour in-service sessions to capture patient experiences within each individual unit/ward – with the idea of five patient stories shared using the patient survey template
- devised a session guide and an adapted reflection model to help the facilitator of the session stimulate critical reflection
- supported the development of a ‘champion’ role to drive the initiative.
Not Just a Number: Listening to the experiences of patients and their families

To improve the patient experience, we must support service providers with the resources and tools to promote a culture of patient-centeredness by drawing from the patient experience itself. By providing real-time responses, this survey data can be used to drive change. In the words of Last:

“Sharing the understanding you have gained from listening to your patients’ narrative in this new way of consulting can serve to enthuse and inspire your clinical colleagues to consider the idea of a change in practice.”

“Nurses were loud, Everybody can hear. I was embarrassed.”
Patient

“My experience was awful. They were not caring at all and I felt like just a number.”
Patient

“I’ve been kept informed and I know what needs to happen.”
Patient

“Nurses listened to me, took their time and helped me when I was sick.”
Patient

References:

Project Group:
Vanessa Wheeler
Riana du Preez
Karen Coubray
Elizabeth Bryce
Anne Hutley
Danielle Naylor
Beth Beaver
Premila Kumar
On Wednesday of Patient Experience Week, around 100 nursing and allied health students crowded into the Ko Awatea Lecture Theatre for Students and Consumers Coffee Corner.

Coffee Corner offered students a chance to meet with patients and their whaanau in a café-style listening session. Groups of 8-10 students gathered around tables with healthcare consumers and engaged in conversation and story-sharing to explore the patient’s experience of care.

Conversations ranged widely. Some of the topics discussed were:

- the value of a holistic approach to patient care
- how patients feel about student involvement in their care
- the importance of coordination between services
- the importance of keeping patients informed about their care in an appropriate and timely fashion
- the need to understand the cultural values of patients and their families
- how empathy with busy staff, politeness and vulnerability act as social pressures on patients
- good ways of drawing out honest feedback from patients.

Talking to patients and their families in-depth about their experiences helped students to gain an understanding of healthcare from a patient’s perspective. Afterwards, students reflected on the experience:

“Our gentleman likes seeing staff members working together. He believes that when everyone is on the same page, the patient receives the best care.” Student

“This has given me a lot of good ideas. I’ll talk to my patients at my placement as well to see what more I can do for them.” Student nurse

“For me, it is basically about listening to them. Take down as much information as you can, then do the discharge planning and referrals from there. And make sure you give them enough information to help them achieve better results.” Student nurse

“It’s about building a therapeutic relationship with our patients.” Student nurse

“One of the main things she [the patient] felt was really important was holistic care. She highlighted that although the main focus is to get the patient better, another thing that was very important to her as a healthcare consumer was just doing simple things like making eye contact during a conversation and asking her how her day was. She felt strongly that healthcare professionals should practice holistic care more often.” Student nurse
Students and Consumers: Sharing stories and using reflection to improve the patient journey

“She [the patient] highlighted a negative point that a nurse came in when there were visitors and just stripped off her gown, revealing her to strangers. She would have appreciated more discretion; more consideration of her dignity. It’s important that we treat consumers with dignity and respect.” Student nurse

“One important thing he [the patient] said was that there isn’t much coordination of care. For example, if they come to hospital, that’s it. They get looked at and then sent out. Most of them don’t know if there are other programmes out there that can help them.” Student nurse
Engaging staff

An important part of Patient Experience Week is engaging frontline staff in our wards and services. We held the majority of our events in the Ko Awatea Centre at CM Health’s main campus, Middlemore Hospital, but we also encouraged staff to undertake displays and activities in their own units. In this way, Patient Experience Week got exposure at some of CM Health’s satellite sites, as well as at the Middlemore campus. Two examples of staff celebrating Patient Experience Week in their own units are described below.

Radiology

Radiology provides a key opportunity for engagement with patients. Most inpatients come through Radiology at some point during their hospital stay, and the service also reaches a large number of outpatients. So the experience patients and their whaanau have in Radiology is very important.

The Radiology service conducts regular patient experience surveys. Comments from the surveys are grouped by modality and fed back to staff so areas for improvement can be identified and acted on. They also provide the Radiology service with a rich understanding of patient experiences. These will be used to co-design services for the future.

For Patient Experience Week, Radiology staff created a display of patient quotes from the surveys. The quotes highlight positive aspects of the service, as well as some that provoke reflection about areas for improvement. The display was placed in a high-traffic area and was frequently browsed by both staff and patients.

Ward 35 North

In Ward 35 North, Charge Nurse Clivena Ngatai and Nurse Educator Karen Coubray were inspired by the opening session of Patient Experience Week. They wanted to showcase the regular positive feedback the ward gets from patients and their whaanau. The two nurses created a Patient Experience Week display in the ward’s reception area, decorated with artwork, balloons and quotes from patients. It’s been a valuable tool for raising awareness, with people stopping to comment on the display and ask what Patient Experience Week is all about. Ward 35 North staff intend to continue developing this concept into the future.
Grand Round: Patient and Whaanau Experience

Patient Experience Week featured a themed clinical grand round. The grand round was well attended by clinicians at CM Health, as well as being shown in Samoa via a live video link. Presenters spoke on patient-centred care, co-design and empathy.

The patient at the centre: a reflection of an Acute Care registrar

Acute Care registrar Yeri Ahn shared two encounters with patients to reflect on patient-centred care (Boxes 1 and 2).

Box 1: Patient 1 – Mrs S

Patient characteristics

» 47-year-old Fijian Indian female admitted with her sixth episode of diabetic ketoacidosis during the last 18 months

» Documented history of depression and anxiety, but not currently on treatment

» Prescribed subcutaneous insulin for her diabetes

» High HbA1c

» History of DNA (did not attend) to outpatient clinics and investigations – last seen over 20 months ago

» Biochemically and clinically ready for discharge

Conversation between clinician and patient

Doctor: So your sugars were dangerously high again on this admission. Do you sometimes miss your insulin?

Patient: Yeah sometimes I miss it.

Doctor: So in a week how often would you miss your daily dose?

Patient: Don’t know, maybe twice, three times, I’m not sure.

Doctor: What do you think is making you miss these doses?

Patient: I don’t really know, but I don’t really want to talk about it anymore to you.
Grand Round: Patient and Whaanau Experience

Box 2: Patient 2 – Mr P

Patient characteristics

» 58-year-old Tongan male admitted with chest pain with negative serial investigations

» History of coronary artery bypass grafting over 20 years ago, complicated by post-op infections requiring multiple subsequent admissions

» Current admission is his 13th in two years

» Negative exercise tolerance test, stable DSE (dobutamine stress echocardiogram) and angiogram in the last 26 months

Conversation between clinician and patient

Doctor: So Mr P, all of your tests were negative and it’s unlikely that your chest pain was due to the heart.

Patient: But I know what heart pain feels like.

Doctor: Yes, but this time it likely wasn’t. You have had such recent investigations and after consultation with the heart doctors we agree you can go home now.

Patient: But why does the pain happen and if the pain comes on again what should I do?

Doctor: Seek medical attention.

Patient: And then what?

What is patient-centred care?

The term ‘patient-centred care’ was coined by Enid Balint, a British psychoanalyst, in 1969. It was first offered as a form of mini-psychotherapy for patients whose illnesses were thought to be partially or wholly psychosomatic. Then, in 1977, an American psychiatrist called Engel incorporated the biopsychology model, taking into account the patient’s social context. In New Zealand, we have the Whare Tapa Wha healthcare model, which aims to address the four pillars of health: physical, spiritual, family/whaanau and mental components. All of these concepts point to a holistic model of health and seek to focus attention on the individual patient’s needs, rather than on the clinician.

Now, in the 21st century, interest in patient-centred care reflects the recognition that the way healthcare is delivered is as important as advances in biomedicine if we are to bring about optimal health outcomes for patients. The Picker Institute, a non-profit organisation dedicated to advancing the principles of patient-centred care through research, education and organisational protocols, identifies seven principles of patient-centred care:

» Respect for patients’ values, preferences and expressed needs.

» Coordination and integration of care.

» Information, communication and education.

» Physical comfort.

» Emotional support and alleviation of fear and anxiety.

» Involvement of family and friends.
Grand Round: Patient and Whaanau Experience

» Transition and continuity.11

With such principles, patient-centred care shifts the focus away from a paternalistic model of the provider taking responsibility for the care of the patient and his or her problem, and towards the patient maintaining responsibility and decision-making over his or her own health with help from the care provider.

However, for many, what it actually means to be patient-centred remains unclear, and translating the concept into the day-to-day business of caring for patients is a struggle.

Patient-centred care in practice

For the reality of practice, the patient perspective is essential in defining and measuring outcomes for patient-centred care. This may be unique at each health centre. Patient-centred care teams, such as the one here at Counties DHB, are key to achieving a culture of practice that focuses on, and fosters, patient and family involvement in treatment decisions. At CM Health, patient questionnaires and surveys reporting the patient’s perception, experience and satisfaction with encounters are used to measure outcomes for patient-centred care.

The four main themes identified in these surveys at CM Health since October 2014 are:

» communication

» shared decision-making

» multidisciplinary team input

» support for self-management

But why should we do it? Is there evidence behind patient-centred care? Evidence linking the practices of patient-centred care to actual improved patient health outcomes is variable. This is likely due to lack of clarity about what is being measured, optimal methods of measurement, and the definitions of outcomes. A 2012 Cochrane review on the effectiveness of interventions to promote patient-centred care showed that such interventions can be effectively transferred to providers, but it yielded mixed results on patient satisfaction and health behaviours. A later review published in 2015 concluded that “…personalised care planning is a promising approach that offers the potential to provide effective help to patients, leading to better health outcomes”13

Thus, there is a debate about the benefits and challenges of implementing patient-centred care. Some of the benefits are: patients are responsible for their own health; patients become more knowledgeable; dispersion of power more equally between patient and clinician; and proven transfer of patient-centred skills to clinicians. On the negative side, there are concerns about: outcomes being difficult to define; variable impact; difficulty created for patients who lack a knowledge or economic basis to learn health skills; unpredictable adverse effects of failures in self-care; and the ethics of offloading decision-making onto patients.

To examine patient-centred care in practice, let us return to the encounters with Mrs S and Mr P. These two encounters illustrate some of the myths about patient-centred care identified by the Picker Institute.14
Grand Round: Patient and Whaanau Experience

Mrs S

Upon further consultation with Mrs S, it became clearer that her self-care had deteriorated significantly since a very public murder of her daughter and granddaughter 18 months ago, and she was suffering from serious psychiatric issues. She was seen by the psychiatrist, social worker, psychologist and diabetes nurse and discharged with outpatient follow-up. This scenario matches Picker Institute Myth #12: ‘Our patients aren’t complaining, so we must be meeting all their needs’.15

Mr P

Mr P had a family meeting organised with an interpreter and cultural support worker to unpack his past medical history and his misunderstandings and concerns about his recurrent chest pains. He was discharged with GP follow-up and has not re-presented so far in five months. Reflections on this scenario match Picker Institute Myth #9: ‘Being patient-centred is too time-consuming’.16

In conclusion, patient-centred care is complex, and this model of healthcare is still in development. However, it is necessary to adopt this culture on an individual, team and organisational level if we are to empower patients towards positive health behaviours.

‘The power of our words’: exploring empathy and compassion in a hospital setting, and ways to maintain our own compassion

Miriam Wood, health psychologist with the Cardiology and Rheumatology services at CM Health, explored the central role of compassion in caring in the health services.

A personal story – Miriam Wood

On Waitangi Day two years ago, my mother received a deep puncture wound in her arm while pruning a rose bush. Ten days later she went to speak and her words wouldn’t come out. She went to eat and she couldn’t swallow. An ED admission, hospital stay and investigations came back clear. But this medical mystery became an emergency when my brother, linking the puncture wound with the symptoms, and with the help of Dr Google, convinced the house officer that Mum had contracted tetanus. The house officer spoke to the consultant, who called an expert in America. Suddenly, Mum was transferred as a Priority One from Rotorua Hospital to Waikato. We watched over three days as Mum became weaker and tetanus spasms took over her body. These scenes were truly horrific and far more reminiscent of medieval drawings like this than anything I had associated with modern day medicine. As mum deteriorated, the decision was made to put her in an induced coma. I remembered feeling immense relief. Mum wouldn’t have to be conscious for what could truly be a living hell, but I also had an incredible fear about what lay ahead. Gathered around mum’s hospital bed prior to her intubation, we were told by an ICU registrar to say our farewells. “Don’t ask about timeframes, don’t ask about outcomes,” he said. “In ICU we can’t tell you these things.”

As a daughter, I could guarantee these were the words the registrar said to us. As a psychologist, I’m not quite so sure. Psychology theory tells us that at times of extreme stress our senses are heightened. Time can feel distorted and our memories can be processed in a different way. Recollections can be unreliable. But, regardless of the exact words, I’m sure of the emotions that I
felt at that time. Eight weeks pregnant, grappling with nausea, and already feeling extremely anxious, this encounter left me feeling utterly powerless and I flipped into a state of hysteria.

I have no resentment or bitterness towards the doctor concerned, but it’s a good opportunity for us to learn. Empathy is two-way street. Perhaps he was having a bad day, rushed off his feet and pushed beyond his capacity. Maybe he was tired of dealing with anxious families and patients who don’t do what they should. Why hadn’t mum just got a vaccination? Maybe he needed some more education, perhaps a health psychology talk on compassion and empathy, or maybe he was anxious about intubating someone whose jaw was locked – surely a daunting task even for the most experienced physician.

There were probably no right words to make us feel better at this time, but what my family and I desperately needed to know was that the team would do their best. A more compassionate statement might have been: “Often we can’t predict outcomes in intensive care, but we’ll do our best to look after Kathy and support her body to fight the tetanus. We will keep you updated with any changes in Kathy’s condition and you’re welcome to contact us for updates as well.” These kind words would have been far more empowering, recognising that we needed to know that Mum was being cared for, that we’d be informed, but also that we could get information if we needed it.

Thankfully, after six weeks in a coma and nearly three months in hospital, Mum made an almost full recovery. She has resumed all her usual activities, and is an active Granny K to our now 18-month-old Sam. We have many memories of the wonderful compassionate care Mum and our family received. And because we had a positive outcome, it’s easy to forget the exceptions of the not-so-compassionate care. However, it’s worth exploring how compassion can be enhanced in the hospital setting.
Grand Round: Patient and Whaanau Experience

Empathy vs. compassion

Empathy and compassion go hand-in-hand, but carry slightly different meanings. Empathy is the feeling we get when we put ourselves in someone else’s shoes, whereas compassion is the action that we take as a result of that feeling. Training only in empathy can actually have a negative effect, because empathy in itself without action can be a negative emotion. However, add in compassion, and it can have a positive effect for all.

Compassionate care is associated with greater patient satisfaction, better doctor/patient relationships and improved psychological states among patients. It’s also in most disciplines’ code of ethics, including the New Zealand Medical Council.18

Compassion also has direct benefits for healthcare professionals. According to Seppala, “…research suggests that compassionate approaches are pleasurable, increase social connections, decrease the focus on oneself and may buffer against stress.”19

From Left: David Horgan, Miriam Wood, Mike Wood, Kathy Horgan and Gerard Horgan.
The Transactional Model of Physician Compassion illustrates the interplay of factors that affect the compassionate response, and shows areas we can intervene to improve compassion (Figure 2). What’s happening in the organisation, the clinical problem presented, the patient and their family all affect the compassionate response: it’s not just about the clinician. Interventions to increase compassion may be considered for each factor.

- Physician factors – understanding the importance of compassionate care; practicing self-care; understanding the circumstances that produce an over- or under-compassionate response for them as an individual.
- Clinical factors – learning to tolerate uncertainty; accepting a wide variety of disease outcomes; avoiding a defensive reaction if we can’t ‘cure’ someone’s problem.
- Patient factors – educating patients; managing patient expectations.
- Environmental and institutional factors – adequate, uninterrupted time for consultations.

Figure 2: Transactional Model of Physician Compassion
The Youth Mental Health Regional Session opened with a thunderous and moving performance of music and dramatic arts by the Phoenix Performing Arts Group. Phoenix was set up in 2007 as a grassroots organisation which engages young people in performing arts as a mechanism for self-awareness and a way to find their creative voice. Their members range in age from childhood to late twenties. Phoenix’s performance featured a fusion of dance, vocals, spoken words and instrumental acoustics based on youth consumer perspectives.

Youth consumer advisors

Michelle Atkinson of Auckland District Health Board, Shreya Rao of Waitemata District Health Board, and Joyce McDonald of CM Health are youth consumer advisors. Their role is to act as a voice for young people at the senior leadership level in each district health board (DHB) to make healthcare services appropriate for our youth.

Each youth consumer advisor (YCA) has personally experienced mental health issues. A core part of the philosophy behind using YCAs is the recognition that people with lived experience have expertise which is as valid and relevant as a formal qualification.

They work at the systemic level, with involvement in governance meetings, recruitment, projects, service development, training and resource development, consumer consultation and service performance evaluation.

Service development projects are a big part of their role. One example is the redesign of the waiting room at Whirinaki, a community-based service for children and young people with emotional, behavioural or mental illnesses. The waiting room was dark, cluttered and depressing. Using feedback from patients, families and staff, McDonald transformed it into a bright and welcoming space. She brought in beanbags and pink chairs, display bookshelves and a wide range of up to date magazines. She’s also working on an inspirational quote wall and vinyl wall decorations to finish off the new décor. Young people who come in are more relaxed in cheerful new environment, reading through magazines while they wait to go into their session. Training is another key role that the YCAs play. They work to inform clinicians what young people want from services and the things that are important to them. At CM Health, McDonald works across child and adult services to provide stigma and discrimination training in the patient units. She also provides a consumer perspective for Risk Assessment Safety Planning training, and does conference presentations to raise awareness of what young people with mental health issues need from healthcare providers.

The YCAs measure their level of participation in their DHBs using Hart’s Ladder (Figure 3). Hart’s Ladder is a scale that measures the extent and authenticity of youth involvement.
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Figure 3: Hart’s Ladder

- **Level 8**: Youth-initiated, shared decision making with adults
- **Level 7**: Young people initiate and lead action
- **Level 6**: Adult-initiated, shared decisions with young people
- **Level 5**: Young people are informed and consulted
- **Level 4**: Young people are informed
- **Level 3**: Tokenism
- **Level 2**: Decoration
- **Level 1**: Manipulation

Having a working relationship with respect both ways between consumer advisors and decision makers is important in influencing the level of participation DHBs achieve with young people through the YCAs. McDonald characterises her role at CM Health as between Levels 6 and 8, a high level of participation that is supported by the good working relationship she has with her service manager.

In the future, the YCAs are keen to develop youth peer support initiatives and have greater involvement in primary care for early intervention opportunities to help young people with mental health issues before problems become severe.

“When consumer participation is a normal thing rather than a special thing, when it’s the status quo and it’s integrated into lots of services, not just DHBs, that’s when you actually create services that are more fit for the population and have an appropriate power balance between the people delivering services and people using services.” Michelle Atkinson-ADHB

Using technology to connect with youth

Kieran Moorhead is a consumer advisor at Changing Minds, a mental health organisation dedicated to information, education and systemic advocacy. He spoke at Patient Experience Week about using technology to improve outcomes for young people.

Ninety-nine per cent of young people are connected to the internet. Sixty-four per cent of New Zealanders between the ages of 15 and 65 use smartphones, and this is expected to increase to 90% by 2018. For the young people of today, the internet is where they connect – an interactive global use which encourages self-expression and the building of communities through online social networking.

The World Health Organization recommends that mental health services need to engage young people in environments where they interact – the
internet and social media. It emphasises the use of tools and networks with which young people engage, such as mobile phones, social networking, games and virtual rewards.23

The challenge is navigating through all the different digital channels, tools, networks and ideas to find those that are potentially useful to health services and supporting the wellbeing of youth. There are hundreds of thousands of different apps on iTunes, but only a limited number of them are relevant to mental health. In addition, there is debate about the efficacy of these apps, and engagement is quite low: 74% of people ‘drop off’ before using the app ten times.24

Nonetheless, online tools and games are intrinsically rewarding, and offer potential for teaching young people coping strategies and ways of dealing with stress. Our task is to think creatively about how we develop digital tools for young people to ensure their effectiveness in improving welfare and to capitalise on the advantages that the digital medium offers.

A recent study done in Australia looked at how we can use technology to support young people’s wellbeing. It found that:

» young people were overwhelmingly positive about engaging with healthcare providers through technology

» both young people and clinicians are already using a variety of technologies to supplement treatment, such as apps, games and text messaging

» both young people and clinicians agree that technology should not replace face-to-face interaction, but should supplement existing services

» it is crucial that any adoption of technology be done using a co-design approach.25

As technology, particularly smartphones, play a greater role in our lives, we have an obligation to ensure that health services are at the forefront of engagement through these media. To do this successfully, we must work with young people to make sure we engage with them in ways that are relevant and helpful to them. Co-design and participatory approaches will bring benefits for both service users and providers.

The West Auckland Youth Health Hub

The Youth Health Hub provides mental health services to youth in Rodney, North Shore and Waitakere for Waitemata DHB. It offers a number of programmes and services to support youth health and development:

» Your Choice is a primary mental health service for young people aged 10-24 who experience mild to moderate mental health and drug- or alcohol-related issues. It uses talk therapy, performing arts and individual, family or group programmes to help young people build self-esteem and deal with their problems.

» Young Dads is a programme to build self-esteem, communication skills and responsibility among young fathers aged 14-24.
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» School Based Health Services provides primary health care to young people attending five alternative education centres in West Auckland.

» Youth Health Clinics where young people can access specialist services for mental and sexual health issues, transgender support, alcohol and drug abuse, and other related problems.

The Youth Health Hub is committed to designing services in partnership with young people. Youth Development Lead Cherrill Rave leads the collection of feedback from service users. Young people are asked whether they would recommend the service to their friends and family, and their responses are unpacked to ensure a clear understanding of what’s good about the Hub, and what needs improving.

Rave also leads the Hub’s Rangatahi Engagement Group. The Group comprises ten young people, who are all consumers of Youth Health Hub services. The youths provide staff and strategic team leaders with consultancy and feedback to ensure that Youth Health Hub services are youth-friendly and youth-focused. At the same time, membership of the group helps youth affected by mental health challenges to grow into leaders.

Two members of the Rangatahi Engagement Group shared their experiences.

Amy Brosnihan – Rangitahi Engagement Group

“I remember I always used to hang out with the girls. [One day] I went into the girls’ toilet and a teacher pulled me out and said, ‘You’re not allowed to go in that toilet,’ but I didn’t want to go into the boys’ one. And that day I saw my sister in the bathroom and I saw that I didn’t have the same genitalia she did.

In Year 10 at high school I first got introduced to the health clinic in school and I got along with my nurse really well. I would actually pretend to have headaches so I could talk to her about my transition – yes, I came out in Year 10. In Year 11 I would always get pulled out of class for wearing makeup or tying my hair up and it got to the point where I had to leave school, and that’s when I was 15.

My dad wouldn’t let me stay at home, so I had to live in a tent for three months. That’s when I started to do sex work. I did that for three years, and then I asked my mum to help me into an alternative, to do something with my life. That’s when I met Liz [of the Youth Health Hub] and I asked her about hormone pills. She was very good to me; she helped me big time. It was a life saver for me, being on hormones and counselling.”
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Caleb Swann – Rangatahi Engagement Group

“I felt like a lab rat. I was always pretty much in hospital, because of my chronic liver disease. As a newborn child it was a struggle just to keep me alive, and for me it was just hospital, hospital, doctors – they became my family. I guess for everyone else they get a chance to decide things for themselves, but I always felt like decisions were made for me. All I knew was needles, changing dressings … it was just normal.

My first doctor when I was a child was the best, she was awesome and made me feel like a kid, because I didn’t know what a real childhood was. Then when I was about ten I got a doctor who didn’t know how to relate to people – he just treated them like a patient, saying, ‘You’ve got this. This is what you need to fix yourself. I’ll wave my magic wand and you can go.’ I felt talked down to, as if I was dumb.

Then I got Dr Rachel Harry, and she made me feel like a young adult. She introduced me to the Youth Health Hub. At first, I thought, ‘Just another service!’ but eventually I met with them, and these guys actually cared about how I was feeling and what was important to me. It was good to talk because I was used to just sheltering myself, feeling like nobody else needs to know I exist and I’m just a name, another pin cushion to be stabbed into or the next surgery or whatever. But the Youth Health Hub always make me feel welcome – smiles, cups of tea, always being cheerful.”

“Personal stories are where real understanding of people’s experience is found. Listening directly to people about their health experiences, and the impact of what we do on their lives, is the best way to really understand what works and what doesn’t.” Jarrad O’Brien, Patient Experience Manager, Waitemata District Health Board

Handle the Jandal: Enabling youth leadership to improve health

Alexandra Nicholas: My story

My name is Alexandra Nicholas. I was born and raised in South Auckland as the second of four siblings. I am Cook Island and Maori. My parents were strongly faith-based and they instilled in me values such as selflessness, service and love for other people.

When I was 18, my family moved to Australia. I stayed in New Zealand because I had gained a scholarship to study and because I thought I was in love! Four years later, with a degree but no boyfriend, I had put on a bit of weight. I was never a skinny girl, but this time I had put on much more than I should have. I thought I needed to do something for my health, so I did a seven day detox diet which kicked off a keen interest in health and weight loss.

Fast forward eighteen months: I had lost 30kg and was working out obsessively. I was weighing myself every day, I was afraid of food, I started to remove myself from friends, and I ended up back here where I was born in Middlemore Hospital. But this time I was in Emergency Care with what the doctors thought was a minor heart attack, and I was diagnosed anorexic.
Youth Mental Health Regional Session: Understanding the healthcare experience of young people

I thought: what the heck is that? Food is not a problem for me and my culture; in fact, it’s one of the things we love, and so it was a real shock [to be diagnosed anorexic]. I was referred to a mental health service. The first day I arrived, my European eating disorders nurse said to me, “It’s unusual for Maori-Pacific girls to come through this service.” I interpreted that to mean, ‘We don’t know what to do for you. You are an anomaly and we don’t know how to help you.’ I already felt that way, but that just reinforced the message. The second thing I felt was outrage. I knew my community, I knew how many Maori and Pacific people live in Counties Manukau, and I thought: How can we have a service that doesn’t know how to help me as a Pacific person?

Ironically, at the same time I was working at Counties Manukau District Health Board in a different role. I was one of nine staff selected to do a 14 week online course learning the leadership practices of community organising. And so much of this resonated with my culture and with what really mattered to me that I started to think about how to take this sort of approach and apply it to Pacific mental health from my own experience. And this was my opportunity to then take what I’d learnt and the outrage I felt as a patient who was labelled in the system, and apply it in a positive way to help other youth.

In September 2012, Alex Nicholas became the lead organiser for a community organising campaign to improve mental health outcomes for Pacific youth in the Counties Manukau community. By January 2013, she had recruited a core leadership team of five young Pacific youth, self-named the ‘FOB (Fresh Off the Boat) 5’.

The FOB 5’s first goal was to find out what Pacific youth felt was the core problem they experienced related to their own mental health and wellbeing. They knew what the statistics said: high rates of suicide, unemployment, youth pregnancy and depression. But after listening to over 100 youth, they found that youth in the Pacific community interpreted and defined the problem in a different way. Pacific youth felt that they were living in two different worlds: one world steeped in faith, family and traditional Pacific culture, and the other based on the individualistic culture and expectations of school, university and work in Western society. The result was feeling pressure that they didn’t know how to cope with. Dealing with pressure became the focus of the campaign.

The campaign was called Handle the Jandal – a reference to the use of jandals often used as a disciplinary tool in Pacific culture, which they hoped to reframe as youth building resilience to handle the pressures of living in ‘two worlds’. Nicholas and the five youth leaders recruited 25 other youth to a two-day training workshop in community organising led by experts from the USA. As they recruited more young people, they created a ‘snowflake’ structure for the campaign, with each of the FOB 5 interdependently leading their own team (Figure 4).
Youth Mental Health Regional Session: Understanding the healthcare experience of young people

Figure 4: The snowflake campaign structure of Handle the Jandal

At the training, the 25 youth voted that their first goal would be to organise a workshop event in partnership with other youth-focussed organisations to teach young people practical ways of dealing with stress in education, health, relationships and through creative and performing arts. The workshop, Connect to Download, was held in October 2013. It attracted 150 youth, parents and community leaders, and was organised, driven and run entirely by the youth leaders of Handle the Jandal.

In April 2014, they ran a second workshop, Rise to Conquer. It was a great success, attracting nearly 500 youth and community members plus 100 partners from youth-focussed health and social organisations. Again, the event was run ‘by youth, for youth’. One of the goals of this second workshop was to define the specific issues contributing to the pressure young Pacific people experience. Three core issues emerged, which formed the basis of three new sub-campaigns:

- Brown Touch Down – addressing failure rates in education among young Pacific youth studying health degrees at university.
- Reach Out – improving relationships and communication between Pacific youth and their parents.
- The Big D – tackling depression among Pacific youth.

Handle the Jandal keeps growing, recruiting more youth leaders and involving more young people. By 2015, the core leadership team had expanded to 12 teams across the three sub campaigns according to the snowflake structure. They constantly work to develop and expand leadership among young people involved in the campaign and recently delivered the first community organising training run entirely by the youth leaders of Handle the Jandal to nearly 70 youth.

Leadership development is central to the community organising approach that underpins the campaign. Organising creates agency within a constituency most affected by an issue by developing leadership skills within these disempowered populations and capitalising on the internal resources of that community to effect the change they desire. This approach has been evident throughout Handle the Jandal. The campaign is led, driven, and owned by Pacific youths with the support of Ko Awatea. It is about Pacific
Youth Mental Health Regional Session: Understanding the healthcare experience of young people

Youth taking action to solve their own problems and keep them solved. Reflections on the success of Handle the Jandal reinforce lessons that have emerged from many of the sessions held during Patient Experience Week, particularly from the Youth Mental Health Regional Session:

» Do things with people, not to them.
» Enable leadership – give people the power to make decisions for themselves; give them meaningful responsibility; embrace failures as learning opportunities.
» Let youth define problems themselves, from their own perspective.
» Connect to people’s values to secure commitment and engagement.
» Prioritise relationships, not requirements.
Future Taking Flight: Learning from the Air NZ experience of redesigning the consumer journey

“We changed from selling seats to selling experience.” Victoria Bamford, Aircraft Interiors Supply Manager, Air New Zealand

Healthcare providers can learn much about the importance of understanding the patient experience, mapping the patient journey through care, and working collaboratively to reshape services by looking at consumer experience work done by organisations in other sectors. Commercial companies have a similar need to accurately understand their customers’ experience of products and services. The aviation industry in particular, with its comparable concern for high safety standards, has a long association with the health sector.

Air New Zealand is recognised internationally as a pioneer in understanding the customer experience. In 2006, anticipating the introduction of a new aeroplane for long-haul flights, the company launched an ambitious programme to design the best possible experience for their customers. The aim of the programme was to give the airline a competitive edge, design a new customer experience and position Air New Zealand as a leader in its field.

The programme consisted of two phases: research and insights, and product design and testing.

Research and insights phase

Air New Zealand began the process of redesigning their long-haul flights by developing a thorough understanding of how customers experience their service. Traditionally, customer experience work in the aviation industry focusses on the in-flight experience, but Air New Zealand realised that they needed to take a broader perspective. To the customer, the flight experience doesn’t begin when they step on the plane: it also includes the journey through the airport, the commute, and even factors such as getting up earlier than usual to meet the check-in deadline.

Working with an external research partner, IDEO, Air New Zealand spoke to New Zealand, UK and US-based long-haul passengers and observed their behaviour during flights. IDEO also needed to understand the constraints of the operating environment from the company’s perspective, so they acted as cabin crew. In addition, they needed to understand New Zealand culture, and Air New Zealand’s brand. The company took IDEO through places and experiences that showed them the essence of New Zealand and Air New Zealand service.

Through IDEO, Air New Zealand identified the value drivers for their customers. The research and insights phase revealed the importance of the overall flight experience in meeting customers’ needs. Control over aspects of the flight experience, such as entertainment, food, boarding and seating was a key driver. In economy class, customers are forced to compete for resources like space and meals, and face unwritten rules about reclining seats or having window shades up or down that can make seats feel like a physical and emotional trap. Customers wanted to be freed from these things.

Air New Zealand realised that their customers fit two broad profiles: those who wanted to be left alone and disconnect from the world during a flight,
Future Taking Flight: Learning from the Air NZ experience of redesigning the consumer journey

Design and testing phase

Based on the information garnered from the research and insights phase, Air New Zealand convened a design group to focus on economy and premium economy class seating. The group was tasked with designing a seat that would enable Air New Zealand’s in-flight hardware to satisfy the value drivers of its customers.

The group built and tested prototypes of seat models. Prototypes were tested by a full range of customers, including children and frequent fliers, as well as actors assigned specific customer profiles. Setting clear and consistent criteria for measurement and evaluation was important to keep the design and testing process on track. The airline took the value drivers of customers and commercial factors into account to set these criteria.

The Sky Couch eventually emerged as the successful model. This seat model enabled Air New Zealand to move from selling seats to selling experiences. It created a buzz of interest and breadth of reach that the airline wouldn’t otherwise have been able to achieve.

Lessons for healthcare

Value drivers are context-specific, but the principle of needing to understand the consumer journey in its entirety applies equally to aviation and healthcare. Healthcare providers must undertake their own research and insights phase to achieve an understanding of the patient experience before they can begin to design services that meet patients’ needs. Working with an external partner such as IDEO, which can provide expertise in this area, was valuable for Air New Zealand, and the cost was not excessive in the context of the whole project.

It’s important to create an environment where it’s ‘safe’ to be creative. Mistakes are inevitable during creative work. Being good at acknowledging, dealing with and moving on from mistakes was valuable in Air New Zealand’s design and testing process.
Evaluating Patient Experience Week

The evaluation

Two of the sessions held during Patient Experience Week were evaluated. The Students and Consumers Coffee Corner was evaluated using a feedback survey. Twenty-nine students completed it. The survey asked four questions:

» What was it like to ask patients about their hospital experiences?
» What was the most important thing you learned?
» What surprised you most about your patient’s responses?
» What do you think you can do to ensure patients have a more positive experience in the future?

The Empathy Zone was evaluated using a survey adapted from the Empathy-building Simulation Exercise and Discussion Preparation tool designed by The Advisory Board Company.26 Forty-three attendees completed it. The survey asked five questions:

» How did the simulation make you feel?
» Before you completed this simulation, how had you assumed your patients felt about this experience?
» After completing this simulation, how do you think patients feel about this experience?
» Will what you learned during the simulation change how you care for patients who experience something similar? How?

» Please record any other thoughts or feelings about your simulation.

Feedback from the surveys was analysed to identify themes.

The findings

Students and Consumers Coffee Corner

When asked what it was like talking to patients about their experiences in hospital, students described how enlightening and informative it was. Learning to see the patient as a whole person was important.

It was very insightful in terms of what the patient experienced and how he felt during his stay in hospital.

It was very informative, and it was good to hear about the hospital setting from a patient’s perspective.

It was really an eye-opener for me. While medical professionals learn rules, procedures and routines, I feel that most of the time we forget that it should not only be about treating the illness but about caring for the sick person as a whole, with dignity and respect.

It taught me to look at the perspective of the health consumer and be considerate of their holistic care.

Students enjoyed the informal style of the Coffee Corner.

The informal café-style session facilitated open, in-depth discussion.
Evaluating Patient Experience Week

It was calm and open, and easy to ask questions.

The most important things students learned were the importance of holistic care, treating patients with dignity and respect, listening to patients and good communication.

Nurses should focus not only on the presenting problem, but on the patient’s holistic care.

Have more patience and think that the patient is a living person with feelings.

Active listening and respect. Treating patients more holistically – seeing the whole picture of the patient.

Communication is very important.

Students were surprised by how open patients were to sharing their experiences, and recognised how important this sharing is to understand how care can be improved. Some were saddened or embarrassed by stories of poor care.

Hearing the negative comments about things nurses have done wrong from the patient’s point of view, like stripping off her hospital gown without asking permission in front of visitors who were not family.

Students identified showing compassion, listening, introducing themselves properly and building a rapport as ways they could change their practice to ensure patients had a better experience in the future.

LISTEN!!!

Ask the patient what’s important to them.

Remember the basics – introduce myself, greet appropriately, treat the patient as a whole person.

Empathy Zone

The Empathy Zone simulation gave participants an insight into the loss of control, fear, vulnerability and frustration patients may experience, and helped them to develop awareness and empathy with how these feelings impact on patients.

Some of the simulations made me feel like I had no control, or limited control, over what was happening and what I was doing.

It’s more frightening than I thought it would be. You lose a lot more of your independence than I realised.

Simulations made me feel very vulnerable. I did not know where I was going, I could not see anything, and I did not feel confident to do anything.

It made me realise how difficult it must be for people with these conditions to carry out day-to-day tasks.
Participants commented that the improved sense of empathy and understanding with what patients experience would affect their practice. They emphasised the need to work with patients rather than just doing things to them, as well as listen carefully to understand how patients feel.

It will change the level I start treatments at, as I now have more of an idea how patients feel.

It will make me more aware of what patients are thinking and have more of a focus on this as well as the physical side of care.

I will help my patients by explaining everything with them before, during and after I care for them. This will help them to trust me. I don’t have to make them feel small; I can work with them to make them feel good and help them.

I’ll be more sympathetic to them as they adapt to their acquired disability.
Conclusion

Improving the experience of our patients and whaanau enhances the health system for all of us. To create a better experience for our patients, we need to understand health care from their perspective and actively involve them as partners in their care and in service co-design.

Patient Experience Week featured a range of events, activities and sessions that showcased the patient experience. The programme was designed to help staff develop understanding and empathy, raise awareness of the work being done at CM Health and across the Auckland region on patient experience and co-design, and to promote the important role of the PWCC Board and the new Consumer Council.

The Week met its objectives. Participants found it inspiring, and many identified changes they would make to their healthcare practice as a result of their greater insight and empathy with how healthcare can feel from a patient’s perspective.

Counties Manukau Health believes that continuing to foster collaboration between patients, whaanau and healthcare providers will cultivate better outcomes for all within our organisation. We will continue to provide opportunities for all to understand the value in listening to our patients and their families.
References

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