Supporting people and whaanau/families living with long term conditions

THE COUNTIES MANUKAU HEALTH CO-DESIGN DISCOVERY PHASE REPORT
Introduction

In mid-2018, the Counties Manukau Health Board requested a proposal which described the design and implementation plan for enhanced models of care that support people and their whaanau living with long term conditions. In consideration of the Counties Manukau Health (CM Health) community this work needed to reflect its population and commitment to equity.

In order to design new models of care we are using a co-design approach. To date we have gathered key perspectives from the community and sector partners about their current experiences of delivering and receiving care and ideas they have to inform future models.

In this context the definition of co-design is as follows: co-design is an important part of a collaborative process to identify challenges or opportunities, engage people; consumers, whaanau and staff, capture their experiences and ideas, organise the learning that it brings to create new understanding and insight from the perspective of the care journey and emotional journey, continue together in partnership to review learning and ideas, plan and implement improvements then finally; review what difference that has made.

This Discovery Phase report summarises the engage and capture phases of the co-design process, see Appendix One for all the phases in a co-design approach. The report illustrates the early stages of organising the learning through the development of key themes drawn from interviews and hui.
Methodology

Co-design brings service users, their whaanau and health professionals together to understand and improve healthcare experiences, systems and processes. It acknowledges that lived experience is a valuable form of expert knowledge that forms an essential part of the design or redesign of health and care processes and services.

Co-design utilises a Delphi technique¹ as a method of achieving a level of consensus of opinion around a specific topic by engaging people with expertise, which in the case of this programme of work is those with lived experience of delivering or receiving models of care for long term conditions.

The co-design process has been underpinned by the following principles, see ‘Principles of Co-design’ figure opposite, and been guided by the expertise of Dr Lynne Maher² and supported by her Ko Awatea colleagues. These expert colleagues have expressed confidence in our process especially regarding the depth and reach of the engagement that has been achieved in this stage of the co-design.

Also see Appendix Two for a full description of co-design principles.

Everyone who has participated has been provided with information about the purpose of the project, how their experiences will help inform the work and how their feedback will be used. Any comments that any people provided were completely non identifiable.

Consumers have also signed consent forms relating to their participation and permitting photographs to be taken.

Consumer participants and their whaanau have also been provided with contact details that they can use if they have and questions following their participation and have all been provided with a koha as per the CM Health Policy.³

The CM Health Executive Leadership Team has provided governance and oversight of the process and the CM Health Board has been updated regularly as to the progress of the project.

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¹ https://www.students4bestevidence.net/the-delphi-technique/
² Innovation and Improvement Clinical Director and international expert in co-design methodology
³ CM Health Policy: Recognising Community Participation v 4.0
Acknowledgements

A co-design process such as this one that the Primary Care team embarked on can only include information that is as rich as the people that come along to local feedback events and share their experiences. The people who have participated in this journey have left the team with a gift of their stories, expertise and knowledge, and we wish to acknowledge everyone that has taken time to attend the co-design hui since we began this journey in August 2018.

An integral part of this co-design process has been to understand as many of the experiences from the perspectives of the culturally diverse community that CM Health serves.

In order to achieve this in a meaningful way, the CM Health Primary Care team has partnered with Mana Whenua i Tamaki Makaurau and been supported by the CM Health Maaori Health Gain Team. The CM Health Asian Health Gain Advisor and the CM Health Pacific Health team including Fanau Ola management have also consulted and guided the team during this co-design journey.

In addition, the Primary Care team have benefited from the insight and connections provided by the Counties Manukau Health Consumer Council lead by Rosalie Glynn and special thanks to members of Asian communities – Debbie Siau and Zhengxiu Xie who connected us with their networks; as well as Tevita Havea who supported the Church based Tongan community engagement.

The Primary Care team wish to acknowledge all this support, guidance and leadership and are confident that CM Health’s journey to understand the needs of whaanau will continue as part of ongoing service design and delivery.

The information that is included in this report has been compiled from the following activities:

<table>
<thead>
<tr>
<th>Activity</th>
<th>Number of hui</th>
<th>Approx. numbers participating</th>
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<tbody>
<tr>
<td>Maaori whaanau feedback hui</td>
<td>5</td>
<td>85</td>
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<tr>
<td>Pacific peoples talanoa</td>
<td>5</td>
<td>150</td>
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<tr>
<td>Asian communities listening workshops</td>
<td>4</td>
<td>45</td>
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<tr>
<td>Including: Mandarin, Cantonese and Indian speaking consumers</td>
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<td>Counties Manukau Health Consumer Council</td>
<td>3</td>
<td>30</td>
</tr>
<tr>
<td>Primary care provider feedback forums</td>
<td>18</td>
<td>150</td>
</tr>
<tr>
<td>Secondary care specialty services and cultural support teams</td>
<td>12</td>
<td>50</td>
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What we learnt
Key insights from both consumers and providers during our engage and capture phase process

From both our consumer and provider feedback sessions we heard about the importance of a “People centred care” model encompassing whaanau/family in care delivery.

Emerging from the collective data set, we have been able to group the feedback from both consumers and providers into the following 4 domains:

- **Setting**
  Easy access to the care and support we need

- **Team**
  Working together and with us, equipped with the right tools

- **Partnership**
  Acknowledge our language, our story and our journey

- **Need**
  Finding and supporting those of us with most need
Key insights from consumers

In November 2018, the Counties Manukau Health Board agreed that the priority populations for receiving extra support with the funding available should be Māori, Pacific and People living in Quintile 5 living with two or more long term conditions – of which indicative numbers are approximately 13,000 people.

With these key populations in mind this co-design phase has deliberately sought to engage with people/whānau representative of these cultures.

The next section highlights the key findings from the different consumer groups but common to all ethnicities are the following three themes:

• The importance of a trusting relationship, which begins with valuing me/us through a process of genuine and compassionate engagement and understanding of what I/we need as a person/whānau.

### MĀORI WHĀNAU THEMES

The following themes were synthesized from 14 ideas generated from Māori whānau that attended hui at Te Awamarahi Marae in Port Waikato and Te Wānanga o Aotearoa in Mangere. Values that work for whānau were also identified and have been used as headings but with a “what works for whānau focus”.

These values are:

- Whanaungatanga
- Manaakitanga
- Tikanga
- Kaitiakitanga
- Rangatiratanga

### WHANAUNGATANGA

- **Trust – relationship/engagement**

  Māori whānau stressed the importance of taking time to get to know whānau and appreciate their unique needs, abilities and challenges. Only by establishing this relationship will a trusting partnership develop. *“Here’s this doctor that doesn’t know me and who I am and how I am feeling – can’t do that in 13 minutes. Will only dish out meds.”*

  **NOTE:** Whanaungatanga also includes engagement and communication.

- **Help us to understand**

  Many identified the need for more time with their health care providers which would allow education delivered in a way that they can understand. This would enable whānau to know more about their conditions and realise the importance of the prescribed treatments. *“But how does he know that I have diabetes? He didn’t explain it to me and I am not going to take the tablets he gave me” and “He doesn’t know what he is taking it for – he just trusts the doctors”.*
• **Access**
This theme encompasses many different aspects of access including location of services, setting and affordability. “Many Māori can’t go to the doctor, don’t feel welcome, expensive” and “We need to prioritise food over medicine”. We heard many whaanau request that health care for their Kaumatua should be cheaper “I was thinking that any Kaumatua shouldn’t have to pay the same price”. In addition whaanau stated that they would like to have more access to health care in a setting of their choice. “Would be better if we had more local doctors.”

**MANAAKITANGA**

• **Being done with rather than done to**
whaanau stressed the importance of being meaningfully involved in care planning and care decisions “I was told, not consulted or included.”

This theme demonstrates the value of *whakamana* = to empower vs *whakama* = embarrass or made to feel dumb. A partnership approach would ensure that whaanau feel valued, cared for, and nurtured through understanding what works for whaanau and is meaningful for them.

**TIKANGA**

• **Understand us – importance of TIKANGA – A-WHAANAU**
Doing what works for whaanau, listening to whaanau voice and responding to whaanau needs.

An understanding and respect for cultures, world views and traditional ways enables trust. Māori whaanau told us that “If you want our trust then you need to listen to our people’s story” and “The doctor just shut it down – they didn’t understand what it was”.

**KAITIAKITANGA**

Protection for whaanau that includes whaanau choice of services and shared decisions regarding their pathway plan.

- Keeping whaanau safe and supporting them to make informed decision on the wellness.
- Whaanau expressed their choice and preference in also choosing traditional Māori knowledge, rongoa, mirimiri and kaupapa Māori services. “We get too far away from our natural meds, why can’t our people use it, should be included.”

**RANGATIRATANGA**

Enabling whaanau to lead their wellness including whaanau self-assessment, what works for whaanau to lead their plan and then to be able to measure whaanau progress and success.

- **Whaanau based**
Recognition of the significance of whaanau in people’s lives, health and wellbeing. “My whaanau is my care team” and “We need to speak up if we are going to change it for future generations”.

WHAANAU FROM TE AWAMARAHI MARAE HUI
The themes captured below originated from two sessions with the Pacific People’s Health Advisory Group and were added to after engagement with Pacific families in separate Samoan, Tongan and mixed Pacific community feedback sessions. The separate Pacific events were organised through the Church communities of our CM Health Fanau Ola colleagues.

- **Care for the family, not the individual**
  It is important to Pacific people that health professionals ensure that all the family are considered in the support and care of the Pacific person with long term health conditions. “No privacy in the Pasifika, it is the whole family’s business.”

- **One stop shop**
  Pacific people were keen to have all their supporting health services in one easy to access location. They felt that this would be a good option to try and reach some of their community that are not currently supported. “Coordinated, supportive with lots of parking.”

- **Help to get in and around health and social services**
  It was highlighted that our health system is very difficult to navigate, especially for people who have English as a second language, “please talk to me in language that I understand and use everyday language”. The Pacific people’s feedback saw value in establishing more supporting roles to help their people get the support they need. “Need connectors to reach families that aren’t connected.”

- **Teach people to own their health**
  Pacific people that we spoke to are aware that there is a need to support their people to take control of their own health and accept some responsibility in the choices they make. They see an important role for the younger members of their communities to assist in supporting this change in mind-set. “Self-responsibility, teach the family, cultural shift” and “start the messages young, think about prevention in schools”.

- **Access to health services**
  Recognition of the importance for Pacific people to have access to culturally supportive health services that are “acceptable, affordable and in my language” and “In Tonga it is normal to go to the hospital for care; our people are doing the same in New Zealand and we need to change this mind-set”, “I get frustrated when I have to wait; I get fed up and just leave”

- **Relationship**
  Pacific families’ value being listened to and feeling cared for by health professionals that they trust. “Choice is important - some prefer a non-Pacific doctor, some prefer a Pacific doctor”. Other comments included; “My doctor tells me straight – he tells me like my uncle or father – not like a doctor” and “my doctor has the same nurse, really nice to be called by name. Everyone does, even the locum doctor does and this makes me feel connected and so I can be open and be honest about why I am there”

 PARTICIPANTS IN THE PACIFIC PEOPLES HEALTH ADVISORY GROUP SESSION
ASIAN PEOPLE’S THEMES

The themes identified below came from the feedback sessions during which we captured the experiences of our diverse Asian communities.

There were sessions organised for Mandarin and Cantonese speaking Asian groups as well as two more focus groups for South Asian community groups. All of these sessions had appropriate interpreters to support information sharing. The themes were also validated by feedback provided in a special community meeting during which CM Health’s Community and Public Health Advisory Committee members met with Asian community members at the Saanjh Community Trust.

• Language and understanding
  Language is perceived by Asian communities as a barrier. Asian people will go out of their way to find a suitable doctor. For example they may choose to wait for long hours or travel great distances to see a General Practitioner (GP) who speaks their language and can help them understand “At times, I paid double to allow myself to have enough time to address all my health issues and ask my own GP questions regarding the multiple health concerns that I have.”

• Managing ourselves
  It is important to the Asian communities that they stay as well as they can in order to support and look after the rest of their extended family. “My children and grandchildren are helping, but they are also busy and working long hours. Sometimes I get worried about them more than myself.”

• Value of good health
  Asian people prioritise their health and wellbeing and seek support to remain well. “My health is my own responsibility. I always write down on a piece of paper what I want to ask my GP before seeing him. I measure my own blood pressure and record down the readings, and I let my GP know if I take notice of anything with my body. I try to work with my GP.”

• Health and wellbeing through social connectedness
  Community based health opportunities “tell our groups, our communities what is going on and where, support our group and organisation as they will tell us and make arrangements for us”.

• Understand our differences
  Each Asian sub group we heard from spoke of the importance of understanding the differences of their culture and customs. “We want to try ancient remedies before going to Western alternatives, so by the time we get to the GP it may be quite late. Can doctors be more accommodating of Asian people wanting to try alternative therapies so that we can be honest and upfront, and perhaps get Western and ancient treatment at the same time?” and “I don’t like to hear your way only, I want you to understand us and where we are coming from. Can you please talk to me in a way that respects me and my culture? I want to hear and understand in our Indian way”
CONSUMER COUNCIL THEMES

The CM Health Consumer Council has been providing support and guidance to the team throughout this phase of the co-design process and the following section was their feedback from a deep dive workshop in November 2018.

- **Patient and whaanau expectation**
  The Council members provided their insight as to the way in which patient and whaanau understanding and expectation could be managed better. “Design a stepped approach and explain to patients that there is support available if people choose to work in partnership with their care team.”

- **Understanding**
  The Council described many examples where patient and whaanau education and understanding of long term condition could be improved. “Many people living with long term conditions normalise their symptoms and we need to challenge this” and “It doesn’t have to be this way, you don’t need to live in pain (e.g. Gout)” They also reflected that normalisation is affected by different cultural perspectives. “Tongan people will be polite and say yes they are fine, when maybe they are not.”

- **Variation in delivery of care**
  There was strong feedback from Council members that the application of the current model of care supporting people with long term conditions was extremely variable and this variability was not just provider to provider, but also between practitioner to practitioner within providers. The advocated for consistency in model of care delivery. “Some people are put in the too hard basket and don’t even get offered support.”

- **Community focus**
  All of the Council members present agreed that this work needs a whole of community approach with health messaging delivered through many different forums and taken to areas of greatest need. “Use people with mana to deliver messages in local churches and community settings.”

- **Supporting youth**
  An area identified by the Council members that needs particular attention is the transition of support from child/youth speciality services to adult services. They provided experience and insight that this is an opportunity for primary care providers to support people/whaanau with and act as key navigators. “Use the funding to support the coordination and follow up required.”

![Whiteboard Notes from the Consumer Council Workshop](image-url)
Key insights from providers’ perspectives

From August 2018 to March 2019, the team have engaged with a broad range of provider stakeholders through a variety of channels. These have included providers, clinicians, governance groups, subject matter experts, Primary Health Organisations, and District Health Board Speciality teams; as well as Locality hosted forums and individual innovative provider ‘deep dives’ regarding their models of care.

The objective of this initial engagement was to gain insights and understand possibilities, share stories, and collect information on:

I. What’s working;
II. What’s not working, and
III. Opportunities for the future.

The following is a summary of the key perspectives from providers.

- **Flexibility and addressing wellness and the social determinants**
  There was consistent feedback from providers regarding the need to tailor the intervention package to what people/whaanau need, and that this may not be the traditional doctor consultation. Examples given include use of funding to provide medicines and transport.
  “We need to have the ability to direct funding towards people with the greatest need and/or where it would have the greatest impact” and “we currently have an environment that is lacking in capacity, rigid, fragmented, frequently changing and not well aligned to patient/family needs”, whilst a secondary care team acknowledged the “Complexity of socio determinants means that patients find health service navigation impossible”.

- **Engagement and relationship building**
  There was conflicting feedback from providers regarding patient and whaanau engagement in the current model. Engagement approaches that were stated as working included making a dedicated workforce available, offering patients more time and a single point of contact and continuity of care.
  “Reach people wherever they are, only when we have engaged successfully can we co-plan” and “Anecdotal feedback is very positive, patients all appreciated having continuity of care providers – one single point of contact to enable trust and action”.

Conversely, other providers described patient engagement as problematic, citing complexity of the system, lack of time, restrictive inclusion/exclusion criteria as intervening issues.

“Lack of time with the patients as we have to spend too much time on claiming versus actual patient care.”

And secondary care teams’ reflections include “there was a lot of good out of Planned Proactive Care (PPC) – but it wasn’t reaching the right people”.

- **Assessment and planning**
  There was strong agreement from providers that using a person centred approach is something that is working in the current model especially to understand a person’s aspirations and their whaanau needs.
  “A person centred strengths based approach is working in long term conditions management” and “whaanau based assessment is a priority”.
  However, there was also a significant amount of feedback that the current assessment and care planning tools were not working well.
  “The Partners in Health tool and the shared care plan are what we have to use, and they take so much time and they are mostly not suitable for the people/whaanau that we are supporting.”

- **Team based care**
  There was a significant amount of feedback from providers regarding the benefits of team based care and the need to work collaboratively across primary, secondary care and community services with expanded workforce roles.
  “Integrated and comprehensive team based support with more navigator type roles such as health coaching, peer support and kaiawhina.”
  Secondary Care teams provided feedback supporting working as one team.
  “The biggest opportunity is for us to work together with respiratory patients – five minute intervention by practice nurse plus referral on to respiratory nurse clinic to continue the journey.”
  “Our Fanau Ola nurses have the time and we can relate and home visiting with the GP or nurse would be ideal.”
  “Multidisciplinary team meetings in the localities have meant that all of the various teams included in the care of our patients have got to meet each other and to discuss how best to go forward in some of the challenges that people face.”
CULTURALLY SAFE MODELS OF CARE
Providers state that there is availability of a culturally and linguistically diverse workforce to work with Māori and Pacific people.
“There is a need to consider the culture of practitioners to deliver culturally safe services that are non-judgemental and will do whatever it will takes.”

COORDINATION AND CONTINUITY
Care coordination by nurses was stated as something that is working well, benefits that were mentioned include better access for patients to their nurses who were able to proactively follow up.
“This is an area where we are seeing that nurses are best placed to be actively monitoring and central point of contact for patients.”
There were some concerns noted by providers about the challenges of coordinating care including a lack of information about community services for care coordinators to be able to access readily. There was recurrent feedback from secondary care teams regarding the current electronic shared care platform that was not seen to be working in terms of providing visibility of who was involved in patient care and being able to communicate in an asynchronous manner.
“Best idea for the future would be to be able to communicate better amongst the care team – both ways.”

ACCOUNTABILITY
Feedback from providers is that CM Health needs to decide what outcome they desire from the investment and then ensure that there is a robust outcome and evaluation framework built into the new models.
“The DHB needs to be clear on priorities and not chop and change.”
Accountability is also something that providers acknowledged could be improved across all parties in terms of the patient perspective.
“Sometimes I wonder where “we” as the health system/service has been in some of our families’ lives.”

WORKFORCE CAPACITY AND CAPABILITY
More time is required when working with people/whānau living with complex needs from providers’ point of view. Many providers felt that they had limited capacity due to staffing insufficiencies, administrative burden and funding which came at the cost of patient care and workforce training/capability building.
“More time spent in claiming/IT compared to face to face patient time.”
Secondary care team insights included;
“Practice nurses don’t need or want study days, they want to know who we are and how they can contact us and how we can work together on cases.”
“Secondary supporting resources need to focus on support for primary care. Do not take over case management for three months and then drop patients back for general practices to try and manage.”
“There is a need to get real and resource diabetes management appropriately.”
“It’s all about the Fundamentals of Care: good quality Primary Care with consistent use of evidence based care packages for LTC management”
Where to next in the long term conditions co-design process?

This report has summarised a significant amount of information that has been generated out of the ‘engage and capture’ phase of the co-design process.

In order to continue in the principled manner in which this process has been conducted and to ‘be true’ to the whole journey, the next steps are to share and validate the findings in this report with the people who contributed their experiences and time to the feedback sessions.

We are comparing what we have learnt from our engagement process with recommended best practice and validated local models of care.

It is then our intention to apply ongoing co-design methodology to develop local models of care/interventions proposals that will ultimately lead to improvement in the way people living with long terms conditions are supported to live well and stay well within their own communities.
Appendix One

PHASES OF A CO-DESIGN PROCESS—SOURCE: LYNNE MAHER, KO AWATEA

1. **Start up** – Scope, plan, aim
2. **Engage** – Consumers, whaanau and staff
3. **Capture** – Consumer, family and staff experiences using a range of methods
4. **Understand** – Emotions and “touch points” along the journey of care
5. **Improve** – Work together to identify and prioritise what to improve
6. **Measure** – Check to see if experience is improving
Appendix Two

CO-DESIGN PRINCIPLES – SOURCE: LYNNE MAHER, KO AWATEA

1. **True partnership** – enable the active involvement and participation of people who are impacted by the design of health and care processes and systems. This includes consumers, carers, families and whaanau and health workers.

2. **Respect** – the expertise of all involved, ensure that all have an equal voice and practise shared ownership.

3. **Teamwork** – work together on a shared goal, trust the process and learn together.

4. **Safety** – is paramount for all involved. Maintain an environment which feels safe and brings confidence for everyone.

5. **Value** – the lived experience of delivering and receiving care.

6. **Be true** – to the process, the means is as important as the end.