Progressing consumer engagement in primary care

Te whakakoke i te whai wāhi a te kiritaki ki te tiaki hauora tuatahi

Health Quality & Safety Commission New Zealand
Kupu Taurangi Hauora o Aotearoa

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Why are we here?

At some time in our lives
Most of us will need health care
Some more than others – to be fair

Whatever we need, wherever we are
You can be sure, mostly we don't want to be there
But sometimes we just need care

Look at me, see me, ask me
Not why I am here
But what matters to me, this day, this time

I will tell you if I know, if you listen openly
I will tell you what I know about why I am here
Will you, pay attention, hear what I say?
Know who you are, and who I am
And who we can both be
To help each other with my health care on this day
We are both here

Dr Chris Walsh, director, Partners in Care
Health Quality & Safety Commission

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Contents | Rārangi take

‘Mā tō rourou, mā tōku rourou, ka ora ai te iwi.’

‘With your basket and my basket the people will thrive.’

Foreword | Kupu whakataki

Consumer engagement continues to be a priority of the Health Quality & Safety Commission (the Commission). Consumer engagement is reflected in all our work programmes, and informs our five strategic priorities:

- advancing Māori health
- improving consumer and whānau experience
- achieving health equity for all
- improving patient safety and reducing mortality
- reducing unwarranted variations in patterns of care.

From our experience to date, we believe that embedding consumer engagement in everyday practice and policy requires the drive and support of senior leadership and champions throughout the health and disability sector. The Commission is committed to supporting the sector to continue making this happen.

We are fortunate to have a wide network of consumer leadership, knowledge and expertise to draw from. This helps us to identify how well the health and disability system is functioning, how people are experiencing the system and how individuals, communities and services can work together to identify solutions and improve the overall quality and safety of our system.

Since the publication of the last consumer guide,[1] consumer representation at district health board level has increased steadily. We have also seen a resurgence of the community voice in mental health and disability. This resource now looks to crucial opportunities in the primary care sector to amplify the community voice and strengthen the overall health and disability system.

Janice Wilson
Chief executive,
Health Quality &
Safety Commission

Rowena Mortimer (Ngāi Tahu, Tuahuriri, Tuahiwi)
Chair, consumer
advisory group to the
Commission's board

Introduction | Kupu arataki

The Commission recognises consumer engagement is pivotal to improving quality across the health and disability system and is an ongoing strategic priority for the Commission. Evidence consistently shows that consumer engagement, patient safety and clinical effectiveness are all linked. This resource has been developed to support primary care providers and primary health organisations (PHOs) to progress consumer engagement in primary care. It offers context, tools and examples to consider.

Our consumer engagement work is delivered through the Partners in Care programme, which began in July 2012. This work has taught us, and the sector, a lot about what is happening for consumers in New Zealand, primarily from a district health board (DHB) perspective.

In 2015 we produced *Engaging with consumers: A guide for district health boards*[2] to help increase partnerships between providers and consumers so that such partnerships become the norm, leading to improved outcomes for consumers who use health and disability services in New Zealand.

What is important now is to build on this progress and continue work that has already begun in pockets; we must broaden our focus beyond the hospital walls to the primary care sector.

The original guide includes useful and relevant material for all consumer engagement. For example, it contains definitions of consumer engagement, the evidence underpinning consumer engagement, examples of how DHBs have put consumer councils together, models of consumer engagement (such as the Carmen model) and tips on making consumer engagement happen.

Although this resource focuses on the primary care sector, other sectors such as aged care, non-governmental organisations and private providers will also find the information useful and relevant. We recommend referring to the previous guide for further information.

The Commission engages with consumers in multiple ways, and resourcing and supporting consumer engagement is embedded in our policies. In our experience, the services that have progressed and demonstrated the benefits of this engagement are those with written policies and systems in place to enable structures promoting consumer engagement.

In contrast, taking an ad hoc approach to giving consumers input into service delivery or policy is not satisfactory or sustainable. Consumers need resourcing and support to participate and provide advice. One of the ways DHBs have facilitated consumer engagement is by setting up consumer councils. Members of these councils come from different communities and ethnic groups.

Since 2015, the Commission has been progressively increasing its focus on primary care. So far, it has worked on quality improvement, supported quality improvement facilitator education and designed the national primary care patient experience survey.

A 2019 Commission report, *Towards quality improvement at scale in the New Zealand primary care setting: Findings from consumer and health service engagement,*[3] asked for information and advice from a variety of stakeholders on how to progress primary care quality improvement at scale. Stakeholders agreed that topics for quality improvement needed to be important and meaningful to consumers and health providers.

> *Pre-engage community – what do they want, what is important to them.*
> **Māori public health physician**
>
> *Start with patients – ask people what they want.*
> **Consumer chair of a DHB consumer council**
>
> *We need to ask systematically what matters most to patients and then [develop] a strong shareable plan of action for what people want.*
> **General practitioner (GP), Health Care Home**
>
> *Have consumers in the team right from the start.*
> **PHO-QIN workshop**
>
> *Participation and partnership right at the conception.*
> **Consumer workshop**

The overall tenor of the findings from this report indicates it is the right time to explore different ways consumer engagement can work with primary care. In addition, DHBs have been developing their consumer engagement strategies, which presents an opportunity to apply lessons from these initiatives to the primary care sector.

PHOs, practices and regional alliances are best placed to take a leadership role in consumer engagement in the primary care sector. Primary care is a pressured area of the health and disability system, but also one that has the most direct contact with communities. As it is the first point of contact for many people, it is crucial it takes on consumer engagement. The relationships established at the primary care level have a lasting impact across the system.

We are heartened by the significant progress that has been made since the Commission began working on consumer engagement in 2012. In recent years, we have seen the number of partnerships developed across the system expand significantly. This achievement is to be celebrated and built on as we continue to strengthen our complex health and disability system.

One view of consumer engagement is that consumers need to be sitting 'at the table, at the time'. Here, we extend this idea: they need to be sitting 'at the right table, at the right time'.

Understanding consumer engagement | He aha te whai wāhi a te kiritaki

Definitions

Consumer engagement is not a new concept internationally or in New Zealand. Our previous guide explored definitions of 'consumer' and of person- and whānau-centred care (and partnership), as well as looking at how health literacy helps consumer engagement.

In 2019, we invited our consumer network to describe consumer engagement. The range of words and phrases the group came up with highlights how diverse perspectives of this term can be, even among one group.

The words and ideas in Figure 1 provide a useful starting point for understanding how the term 'consumer engagement' triggers different responses depending on the lens through which someone is seeing it.

Figure 1: Views of consumer engagement among the Commission's consumer network in 2019

One-word descriptions are often not enough to capture the full meaning of people’s responses in different languages. For example, a Māori network member interprets Mana Tū in te reo Māori as meaning ‘standing within the decisions, the knowledge, the information’. Fāka’apa’apa (a Tongan term) means respect, reflecting a shared value among Pacific peoples.

Carrying out the actions required to promote aspects of consumer engagement, as described by network members, is the ultimate challenge for successful and meaningful consumer engagement.

The term ‘consumer’ can refer to an individual citizen or member of a community, patient, carer, family or whānau member, or tangata whai ora. Other terms are also possible: the Partner in Care programme recognises that different groups and communities use a range of different terms. For consistency, we generally use ‘consumer’ in this resource.

New Zealand legislation

> *Every consumer has the right to be provided with services that take into account the needs, values, and beliefs of different cultural, religious, social, and ethnic groups, including the needs, values, and beliefs of Māori.’*[4]

Two important legislative documents that underpin consumer engagement in New Zealand are Te Tiriti o Waitangi (the Treaty of Waitangi) and the Code of Health and Disability Services Consumers’ Rights (the Code). Right 1 of the Code captures the essence of Te Tiriti for Māori consumers.

In New Zealand, the tangata whenua (people of the land) are Māori. Te Tiriti, an agreement between the Crown and tangata whenua, describes the principles of mana whenua, kaitiakitanga and manaakitanga (participation, partnership and nurturing relationship), which form the basis of interactions between Māori and agencies, including health and disability support services.

The Code states that consumer rights need to be recognised in the following ways:[5]

- right to be treated with respect
- right to freedom from discrimination, coercion, harassment and exploitation
- right to dignity and independence
- right to services of an appropriate standard
- right to effective communication
- right to be fully informed
- right to make an informed choice and give informed consent
- right to support
- rights in respect of teaching or research
- right to complain.

The New Zealand Public Health and Disability Act 2000[6] includes a Treaty clause in order to recognise and respect the principles of Te Tiriti o Waitangi, with a view to improving health outcomes for Māori, and the need to provide mechanisms to enable Māori to contribute to decision-making on, and to participate in the delivery of, health and disability support services. The mechanisms in legislation support the principles of consumer engagement.

The Health Services and Outcomes Kaupapa Inquiry (Wai 2575)

Initiated in November 2016, the Waitangi Tribunal Health Services and Outcomes Kaupapa Inquiry (Wai 2575) will hear all claims concerning grievances relating to health services and outcomes of national significance. Stage one of the inquiry was a discrete and targeted inquiry into the legislative and policy framework of the primary health care system.[7] It addresses claims concerning the way the primary health care system in New Zealand has been legislated, administered, funded and monitored by the Crown since the passing of the New Zealand Public Health and Disability Act 2000 (the Act). The report makes recommendations for primary care to be at the forefront of improving services for Māori, specifically through recognising, and providing for, tino rangatiratanga and mana motuhake of hauora Māori. Reference is also made for an urgent review of primary health care funding to align to equity, reviewing and strengthening accountability and co-designing a primary health research agenda.

Strategic documents that support the legislation:

- The New Zealand Disability Strategy: www.odi.govt.nz/nz-disability-strategy/about-the-strategy/new-zealand-disability-strategy-2016-2026/read-the-new-disability-strategy/new-zealand-disability-strategy-read-online
- Whāia Te Ao Mārama 2018 to 2022: The Māori Disability Action Plan: www.health.govt.nz/publication/whaia-te-ao-marama-2018-2022-maori-disability-action-plan
- He Korowai Oranga: Māori Health Strategy: www.health.govt.nz/our-work/populations/maori-health/he-korowai-oranga
- Faiva Ora 2016–2021: National Pasifika Disability Plan: www.health.govt.nz/publication/faiva-ora-2016-2021-national-pasifika-disability-plan
- Ka Ao, Ka Awatea: Māori heath strategic framework developed with MidCentral DHB, Central PHO and Te Tihi. Its purpose is to support a significant step forward for further health gains for Māori: https://tetihi.org.nz/images/PDF/Ka_Ao_Ka_Awatea_210917.pdf

More information about the Commission's definitions of consumer and consumer engagement

- Consumer definitions for Partners in Care programme: www.hqsc.govt.nz/assets/Consumer-Engagement/Resources/consumer-definitions-Mar-2015.pdf

Why primary care should invest in consumer engagement | He aha e whakapau rauemi ai te kaitiaki hauora tuatahi ki te whai wāhi a te kiritaki

Consumer engagement is an essential component of quality and safety in the design and delivery of health services. The benefits include better health outcomes, safer care, less waste, lower costs, more satisfied consumers and health providers, and better staff retention. Engaged consumers have improved health literacy, are more likely to engage with treatment and medication, and are better able to self-manage long-term conditions. Equity of access to health care is also improved when consumers and communities are engaged in their own care.[8] Multiple approaches are required to achieve equity. One size does not fit all.

Consumers bring unique and valuable perspectives from outside the health and disability system 'looking in'. The system is there for all of us as consumers; sometimes, however, in the search for efficiency the consumer's experience and viewpoint can be lost. Systems naturally focus on what is being measured. If the system is measuring time, efficiency and clinical outcomes, that is what clinicians will focus on. Engaging consumers helps providers to understand how to deliver services based on the needs of consumers.

The primary care sector contains examples of effective consumer engagement at the levels of practices and PHOs. It also has opportunities to engage communities in improving the primary care experience and in working on solutions that are fit for those accessing services, those providing services and those who oversee service delivery.

Consumers can be engaged as individuals or whānau, or collectively, increasing their power to influence quality and safety. The extent of their engagement ranges from having greater choice and the opportunity to provide feedback about their own health care experiences to having a meaningful voice in partnership with providers to influence the design and delivery of services.

Consumer engagement is more than just a set of activities. It involves a cultural shift in services to welcome partnerships with consumers at all levels, from the waiting room to the board room.[9] At the direct care level, this means working towards shared decision-making. At the service planning level, it means ensuring the results of patient experience surveys directly influence quality improvement initiatives and including consumers in expert advisory groups. At the policy and governance level, it means skilled, well-networked consumer councils working on an equal footing with those in clinical governance and reporting to boards. When organisations engage with consumers as partners in care at all levels, this is true partnership.

Integrated representation

Consumer councils are now well established in DHBs throughout New Zealand. We do not yet know whether a similar approach to engaging with consumers will suit the PHO environment. In Australia, primary health care reform has revealed that much work is still needed to make a visible and successful model of consumer engagement business as usual. New Zealand is likely to face the same concerns. However, given that consumer councils are now established at DHB level, it is reasonable to assume that primary health could tap into this framework. Consumers also have opportunities to become members of PHO boards and the broader links to DHB councils open up the possibility of increasing understanding and leverage in integrated care between primary and secondary services. This may well be the aspirational vision.

The Australian PHO study revealed that it is also possible to encourage and support information flow between the community and clinical councils by having a member of each council attend the meetings of the other and having standing updates on both agendas.[10]

An example of a DHB consumer council that is integrated with a PHO comes from John Hannifin, independent chair of the MidCentral DHB and Central PHO Consumer Council, which was set up in 2017 to help the organisations 'achieve a person and whānau-centred partnership in models of care where patients are partners in their own health care and consumer engagement and participation occurs throughout the district'. The council's terms of reference allowed it to work with community-based health issues and to partner with the Central PHO. This PHO covers the same geographical area as the DHB, making partnership easier. One reason for the council's success is that it can work both within and outside the hospital setting.

In 2018, information-gathering showed a significant gap in the provision of high-quality care for people in the district who experience persistent pain – a group representing approximately 21 percent of the district's population. Along with its companion organisation, the Independent Clinical Council (which has the same role as the Consumer Council but its members are clinicians), the Consumer Council developed a case to help this group.

Some consumers were a significant component of the steering group for this initiative and others were involved in focus groups, providing their experience of dealing with ongoing pain. Through a co-design process, the consumers were able to change the title of the initiative from a 'chronic pain service' to a 'living well with pain' model of care. The important principle in the new model of care for 'living well with pain' is that it is based on the person, whānau, community and primary care while each of these has a relationship to secondary (or specialist) care services. A consumer involved with the process commented that, 'this authentic consumer engagement is a really positive and valuable experience. I am so pleased that I have been given this opportunity' and, 'I am sure that if something like this pathway had been in place a few years ago then things would have been different for me'.[11]

Chiquita Hansen, chief executive officer of the Central PHO, comments that a lot has happened across the MidCentral district to improve access to primary health care since it has established a team-based model of care:

> *Gone are the days [when] the GP needs to see everyone for everything. However, we [the PHO] have not systematically kept consumers fully informed of this change and we are really enjoying working with the Consumer Council to socialise this team-based way of working. Having a high-functioning Consumer Council is extremely valuable and makes access to 'consumer voice' very accessible to primary health care.*

Investing in diverse representation builds shared ownership of services and, ultimately, improves the quality and experience of care.

If PHOs are unable to link into existing DHB consumer councils (and do not have the resources to support their own form of a consumer council) the following example is worth considering.

The Community Health Council is a great opportunity for our community to have input into a system we partake in. I think there is a great future ahead where community voices like ours will become part of the systems that will be created.

Kelly Takurua, Community Health Council member

The Community Health Council (CHC) is an advisory council for WellSouth Primary Health Network (hospital and community health services including GPs) and the Southern DHB. The CHC aims to make sure that communities, whānau and patients have a strong voice in planning, designing and delivering services across the Southern health system. The CHC was established in February 2017 with eight community members and chair, Professor Sarah Derrett.

Since then, it has developed a *Community, Whānau and Patient Engagement Roadmap*. The roadmap has full support from DHB commissioners, iwi governance, Clinical Council, and executive leadership teams at both the DHB and WellSouth.

The CHC has been involved in a number of activities for the DHB, including:

- recruiting DHB staff
- developing the DHB website
- writing a joint discussion paper with the clinical leadership group around accommodation requirements for family and whānau in the new hospital that is under development
- providing input into the primary and community care strategy and action plan
- developing the DHB feedback brochure
- recording patient stories.

CHC's involvement in the wider community includes:

- being a member of the Health Consumer Council National Collective
- participating in a Ministry of Health workshop seeking consumer input for a digital health record
- attending a forum on implementing the *Choosing Wisely* initiative (see page 26)
- being a member of the sexual health services governance group.

I feel that patients have such a wealth of knowledge when it comes to how health care can be planned, as we are the ultimate users of the system and the ones affected by the policies created.

Ilka Fedor, CHC member

For more information about the work of CHC, see: www.southernhealth.nz/sites/default/files/2019-08/CHC%20our%20first%20year_0.pdf.

Responding to primary care experience data

An emerging trend in patient feedback is that users of health services increasingly give voice to their own experience in narrative form.[12] (usually as qualitative comments in surveys). With this form of feedback, primary care can further analyse open-ended comments in survey data to understand, explore and consider how to address variances. Using co-design as a method would further enhance the partnership between consumers and primary care in terms of quality improvement.

The Commission continues to roll out the primary care patient experience survey. For the first time in 2018/19, we made results from the survey publicly available on our website.[13] The February 2019 report attracted widespread interest, recording over 4,000 views. Our emphasis has been on maintaining a high participation rate in practices and increasing response rates from Māori and Pacific populations. We continue to encourage PHOs and practices to review and understand their survey results and use the results for improvement.

By February 2019, over 800 practices nationally had participated in the survey; this equates to over 80 percent of all practices in New Zealand. The response rate over the year has remained consistent at around 20 percent. This data set gives PHOs and practices an opportunity to understand the experiences of patients and work with communities to respond to those experiences.

Using the results of the adult inpatient experience survey to improve the experience of consumers

The adult inpatient experience survey has been running since May 2014. The way DHB services have been responding to the survey data offers examples that primary care could consider in deciding how it will respond.

The results of the adult inpatient experience survey consistently show that a high proportion of patients do not receive enough information to understand the side effects of their medication or how to manage their condition after they are discharged from hospital. Some DHBs tested interventions in 2018 to help improve patient experience:

- **Patient-focused discharge summaries (Northland DHB):** Northland DHB co-designed a new discharge summary to make content clearer and easier for patients to understand.
- **Home safe checklist (Waikato DHB):** Waikato DHB developed a 'home-safe' checklist to identify any gaps in patients' knowledge about their condition, medication or ongoing care plan.
- **Follow-up medication phone calls (Nelson Marlborough DHB):** Patients in a specific ward received a follow-up phone call from hospital staff in the days following discharge, so staff could share information about medication side effects and condition management, and answer any questions patients had.
- **'Always knowing who to contact' (Canterbury DHB):** Canterbury DHB wanted to understand and address one of the lower-scoring questions in the national adult inpatient experience survey – 'Did the hospital staff include your family and whānau or someone close to you in discussions about your care?' It investigated the issue by reviewing the DHB's patient feedback report, interviewing former patients or family and whānau members, and holding focus groups with ward staff and a quick response session with medical staff. From this work, the concept 'We always know who to contact' was developed. In practice, it means that patients nominate a family or whānau member as a point of contact for hospital staff, and staff make sure patients and their families and whānau have a record of who their clinical team is and when is a good time to call.

Using co-design

Co-design is a useful method to involve consumers in decisions about how services should be designed to meet the needs of everyone with a stake in them. The Commission has promoted its use since 2012, and a range of services both inside and outside of the health and disability system has been progressively taking up this approach. While co-design has many other terms to describe it (such as co-production and co-creation), a Commission consumer network member, Bernadette Pereira, puts it simply as, ‘You and me, let’s do it together’.

> *Co-design is about understanding experiences, designing solutions with patients, whānau and staff at every step of the way, right from the initial concept to implementation and not considering it as another model, but as the best and only way of working that ensures we deliver the right care and solutions for all.*
>
> **Renee Greaves, patient and whānau care advisor, Counties Manukau Health**

In the primary care setting, co-design has produced useful lessons. Koral Fitzgerald, of the Canterbury Clinical Network, reflects on Pegasus Health PHO’s involvement with co-design in 2019:

> *Being engaged in a collective alliance of health care leaders, professionals and providers from across the Canterbury health system, many of the health professionals in the co-design groups understood the importance of collective impact: without the buy-in and co-leadership of consumers, true and sustainable progress in health design cannot be achieved.*
>
> *Co-design projects require relationships being built and/or enhanced between the health professionals, funders and the consumers. There is a ‘dance’ that plays out: whilst recognising that consumers’ relationship with design may be less informed than those working in the health system, all participants*

> *complete the process more informed by the tools and facilitation provided and, perhaps even more so, through understanding the viewpoint from each other's shoes.*
>
> *I observed successful participation in health co-design must have a mix of leaders: those in the strategic/managerial roles; those 'on the ground' who are aware of the realities of delivering care, and the current (or future) recipients of health care.*

The following observations from Martine Abel-Williamson[14] offer potential for co-design, where primary care and community services have not met the needs of people with disabilities.

> *Many disabled persons still struggle to access GP and community clinics due to lack of physical access. Others may still struggle with matters such as medication management, not because they are not health literate, but because there is not the option of accessible labels on drug packaging such as in large print and in braille, as is the case in Europe.*
>
> *Many home-testing kits, such as for bowel cancer, cannot be used by some disabled persons independently and*

Co-design is an important process that engages consumers, whānau, staff and other stakeholders. It helps us gain insights into the experiences of delivering and receiving care, through learning about the emotional side of people's journey. Co-design is listening to people and designing the solutions with them rather than consulting on something that has already been designed without their input.

Dr Lynne Maher, improvement and innovation clinical director for Ko Awatea, Counties Manukau Health

community nurses are then required to do more home visits as would have been the case if those self-testing kits would have been designed with full access in mind.

When supporting disabled persons, professionals often take charge instead of assist, which is one of the biggest barriers to dignified health care.

A day in the life of the Toiora exercise class

Te Kete Hauora co-designed the Toiora exercise class for people with diabetes, as part of the Whakakotahi primary care improvement challenge in action. The core element was the community of people who came together to co-design the class and take part in its first 12 weeks.

Te Kete Hauora is the patient advisory group that the Hutt Union & Community Health Services (HUCHS) developed. It is led by Colleen Dunne, a Hutt Valley DHB physiotherapist, along with Te Kete Hauora members Patria Tamaka, Hine Chase and Mere Te Paki.

The purpose of the class was to encourage the group to push themselves without going beyond their own limits or causing injury, as they did a combination of aerobic, resistance, balance and flexibility exercises.

All participants had to get medical clearance before beginning the class. When they began, they also received an information sheet on physical activity benefits and precautions, a home exercise programme, a physical activity recording sheet and a Toiora t-shirt.

The co-design approach allowed feedback from the group to be gathered week by week, class by class, so that the class could change as it progressed. Before classes began, a pre-assessment and interviews openly addressed personal goals and any concerns.

> *This has been a perfect marriage between evidence-based practice and community facilitation of self-management through a support group. The main ingredients are education, recognition and reassurance on concerns and goals, demonstration and empowerment in [group members'] ability to adapt management to their individual needs.*
> Colleen Dunne

> *The combined approach from the multidisciplinary team/nurses/community/management has been an amazing help in managing my chronic disease. I think this has to be the approach despite the resource heaviness or demand. I don't think it [would] be successful with a solo clinician.*
> A class participant

Mere Te Paki, HUCHS community health worker, is clear on the kaupapa of any further Toiora work.

> *It needs to be owned by the community. It's about strengthening relationships.*

Read the full story: www.hqsc.govt.nz/our-programmes/primary-care/news-and-events/news/3198

The following are more examples of co-design projects that have happened in both primary and secondary care.

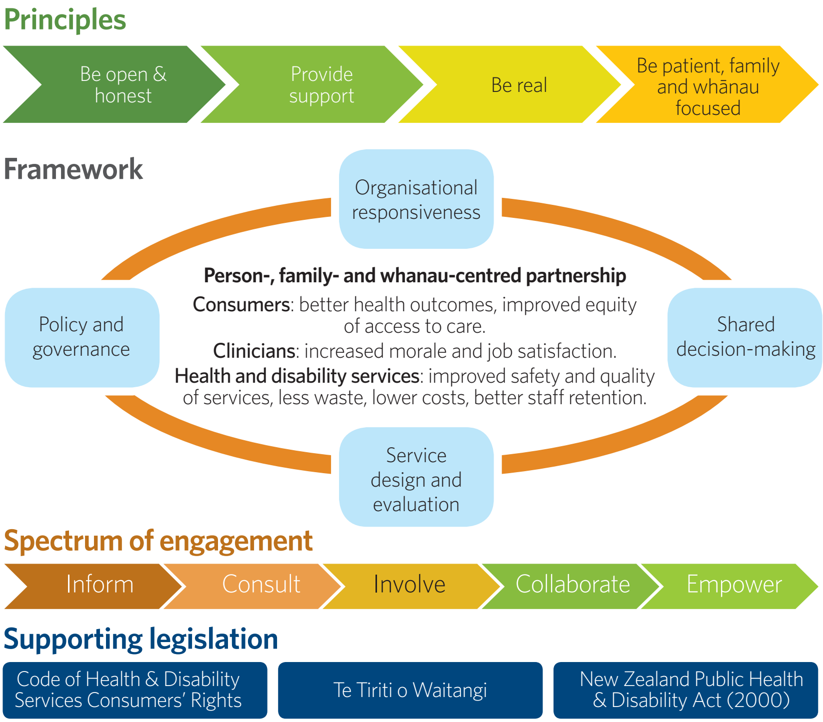
- 2018/19 examples of DHB and primary care co-design projects: www.hqsc.govt.nz/our-programmes/partners-in-care/work-programmes/co-design/#[2018-19]

- Hutt Valley DHB gathered input from consumers and staff to help people get to their therapies outpatient appointments at the right time and in the right place. For more information, go to: www.hqsc.govt.nz/assets/Consumer-Engagement/Partners-in-Care-Resource-page/Case_Study_-_Hutt_Hospital_Therapies_Outpatients_-_HVDHB_June_2017.pdf
- Taranaki DHB worked with community mental health workers, administration workers and community pharmacists to improve the process for getting repeat prescriptions. For more information, go to: www.hqsc.govt.nz/assets/Consumer-Engagement/Publications/Case_Study_-_Improving_repeat_script_process_-_Taranaki_DHB_June_2017.pdf
- Waitemata DHB ran co-design workshops to gain a better understanding of the experience and cancer journey of patients and their family and whānau, which it could use in designing and delivering cancer services in the future. For more information, go to: www.qualityaccounts.health.nz/quality-initiatives/quality-initiatives/cancer-care-co-design
- Nelson Marlborough Health cardiology services carried out a project to help patients achieve 100 percent medication adherence at 3 and 12 months post-stent procedure across three general practices. For more information, go to: www.hqsc.govt.nz/our-programmes/primary-care/news-and-events/news/3040
- For more information about the HUCHS case study (described above), go to: www.hqsc.govt.nz/our-programmes/primary-care/news-and-events/news/3038

A framework for consumer engagement | He anga mō te whai wāhi a te kiritaki

Many guides and frameworks on consumer engagement are available. Figure 2 provides an overview of the various aspects involved in engaging with health and disability consumers.[15] It both adapts and draws together the ideas in other models. It is relevant to both the primary care sector and the broader health and disability environment in New Zealand. This is not a definitive framework, but we propose it as a starting point.

Figure 2: A framework for consumer engagement



Principles

- Be open & honest
- Provide support
- Be real
- Be patient, family and whānau focused

Framework

- Organisational responsiveness
- Shared decision-making
- Service design and evaluation
- Policy and governance

Person-, family- and whanau-centred partnership

Consumers: better health outcomes, improved equity of access to care.

Clinicians: increased morale and job satisfaction.

Health and disability services: improved safety and quality of services, less waste, lower costs, better staff retention.

Spectrum of engagement

Inform → Consult → Involve → Collaborate → Empower

Supporting legislation

- Code of Health & Disability Services Consumers' Rights
- Te Tiriti o Waitangi
- New Zealand Public Health & Disability Act (2000)

A partnership centred on the person, family and whānau

- When meeting a consumer, the clinician takes the time to listen and understand what is important to the person and their family and whānau.[16] Targets are important but can miss the point.
- Provide a welcoming environment. Ensure front-desk staff know the importance of getting the first interaction right. It often sets the pattern for the consumer's experience of the rest of the visit.
- Work with communities to tailor educational resources for those who use the service.
- Acknowledge and work with the expertise that consumers and their families and whānau have about their own health and wellbeing.
- Focus on supporting consumers, families and whānau to increase their health literacy.
- Be respectful and genuine with consumers – be interested and humane.

> *The most important part of my experience with our health care system was the people who stood beside me throughout it. And that wasn't just my family – it was a team of truly incredible medical professionals, who I will forever be connected to.*
>
> *The staff that made the biggest impact for my family and I were those that saw us as part of the health care team. They understood the psychological impact that isolation can have and made allowances to minimise this.*
>
> *They approached their job in a holistic way and gave support on a real and personal level. They made an effort to get to know us as real people – they were humble, hugged me when I cried, talked to me when I was lonely, laughed with me and ultimately saved my life.*
>
> **Jake Bailey, young cancer survivor**

- Take consumer views seriously. Instead of just going through the motions, ‘walk the talk’ and live up to the promise – ‘what we do is who we are’.

Organisational responsiveness

- Provide multiple avenues for past, present and future consumers and communities to engage in delivering and designing health care services.
- Resource and support all staff to make the cultural shift to value consumer engagement. You can achieve this through training and workshops. Creating opportunities and time for staff to gain more knowledge and experience is necessary to promote open and honest dialogue.
- Identify and promote staff champions of consumer engagement at all levels of the organisation.
- Involve consumers when inducting new staff, to help demonstrate the importance of care centred on the person, family and whānau.
- Promote the skills required to actively partner with consumers and draw out their feedback, such as active listening, giving room and respect for consumers’ concerns and opinions, and checking back for understanding, to help improve consumers’ health literacy.[17]
- Ensure your organisation is analysing and understanding the data from the primary care patient experience surveys and responding to the findings.

Martin Carrell, the quality programme manager at Pegasus Health PHO, notes:

> *We are starting to see little changes that are enough to demonstrate that there is value in the [primary care] survey.*
>
> *For example, a couple of practices have picked up that waiting times are an issue for patients. As a result, they have adjusted their appointment book to enable catch-up time during the day or to have more acute slots to meet the urgent need. They are more conscious of patients waiting so make more of an effort to contact patients to alert them if there are significant delays.*[18]

The Commission has had several requests to consider translating the patient experience surveys into Māori and Pacific languages as a way of increasing the number of people who complete them. Discussions have been ongoing with both the primary care patient experience survey governance group and the Māori and Pacific teams in the Ministry of Health about translation, and other ways of making the survey more accessible to Māori and Pacific patients. There are plans to translate the surveys, however we are aware translation may not address the following:

- It may not overcome cultural barriers such as lack of trust in the system, data sovereignty issues, lack of engagement in health care and being worried about providing feedback as it may affect future care.
- It would not be possible to include patient comments in the translated versions. The comments fields are a rich source of information that provide important context to the scores.
- The cost of translating is relatively high.
- Translation could also take the focus away from addressing the cultural barriers.

Shared decision-making

- Involve consumers, families and whānau in their own care planning and listen to their values, preferences and goals of care, when considering treatment options.
- Support the use of shared electronic records wherever possible if the consumer allows this.
- *Choosing Wisely* is an international initiative that aims to bring clinicians and the public together to discuss options for treatment (eg, polypharmacy). *Choosing Wisely* New Zealand presented a case study demonstrating how gathering consumer perspectives was effective in the overall delivery of a symposium. Attendees found the most important lessons from the symposium related to patient engagement.[19]

Service design and evaluation

- Use co-design with consumers in all quality improvement and service design initiatives.
- Ensure good mechanisms are created to support communication between health services, pharmacy services and community services, avoiding duplication and repetition.
- Map patient journeys through an episode of care from the community through to health care services and, where relevant, hospital admission, inpatient stay and discharge.
- Provide multiple avenues for giving real-time feedback to consumers, communities and staff about how consumer input has influenced service design and delivery.
- See every problem identified in a service as an opportunity to use co-design for improvement.
- Recognise that co-design is a way of delivering the right solutions.

Policy and governance

- Create a person-centred vision statement for the organisation. When the values of the organisation are person-centred, then the organisation values consumer engagement.
- Have leadership facilitate consumer engagement from the board room to the waiting room.
- Use senior leaders in your organisation to be champions for consumer engagement.
- Develop a vision of consumer engagement for the whole organisation.

> *This video[20] shows effective consumer representation at the governance level and how this works with clinical leadership. It explores the governance model of the Board of Directors of the World Federation of Hemophilia, a board with equal representation of clinicians and patients, family and whānau.*
>
> **Deon York, member of the board, World Federation of Hemophilia**

- Resource facilitator or manager roles focused on consumer and community engagement in your organisation.
- Include consumer representatives at senior leadership level.
- Resource paid consumer roles in expert advisory groups and committees.
- Use patient stories in team, management and board meetings.
- Link with established consumer councils to give them input to projects and to ensure system integration.
- Have at least two consumers sitting on PHO boards or regional alliances.

For more about international guidelines and frameworks for consumer engagement, go to: https://www.hqsc.govt.nz/our-programmes/partners-in-care/publications-and-resources/publication/2163/#international-guidelines

For more about New Zealand guides, frameworks, training guides and competencies, go to: https://www.hqsc.govt.nz/our-programmes/partners-in-care/publications-and-resources/publication/2163/#NZ-examples

Strengthening consumer engagement in primary care: Further considerations |

Te whakapakari i te whai wāhi a te kiritaki ki te kaitiaki hauora tuatahi: Ētahi whai whakaarotanga anō

This section highlights some other ways of strengthening consumer engagement in primary care.

Online connection

Increasingly, consumers wish to interact online with their health service providers. The use of online patient portals, such as ManageMyHealth™, is on the rise in primary care.[21] At the same time, primary care is increasingly sharing electronic records with secondary services and hospitals. Patients can order repeat prescriptions, make appointments, read test results, learn about their medicines, join community forums, ask questions and give feedback – all online.

> *Most disabled people live integrated and independently within our society, so historical institutionalised ideas and practices should be dead and buried, but there are still huge issues around disabled patients and consumers being empowered and enabled to make our own decisions, or to be able to rely on supported decision-making.*
>
> *It's often not our impairments that hold us back, but the low expectations others have of us.*
>
> Martine Abel-Williamson

Patient information is increasingly accessed via the web, and is a powerful tool for improving consumers' health literacy. Consumers often conduct online searches for side effects of medication and management of diseases. Websites such as Health Navigator[22] and Medsafe[23] provide high-quality sources of such advice, and many DHBs also offer online information for patients. We would, however, caution consumers to be aware that various chat forums and other such websites can give false information and they should only trust official sites to give them the correct information.

Social media is another easy way for patients and the public more generally to give feedback and receive information. Many organisations have or are in the process of setting up Facebook pages or Twitter accounts. The Commission encourages organisations to review their web presence and build in patient portals with a consumer tab providing information about their services, how to get involved and who to contact.

Practice manager and registered nurse Heidi Bubendorfer notes the positive impact of digital portals:

> *[D]igital tools are empowering patients to be more involved with their health care. Easy access to electronic medical information, diagnostic tools and symptom-checkers means GPs are no longer seen as the exclusive source of medical knowledge, therefore, a more equivocal, collaborative approach is developing between patients and doctors.*[24]

Working with diverse communities

Primary care is familiar with engaging with diverse communities. The principles of engaging and communicating are widely documented. Familiar themes continue to surface, suggesting practices vary in how much they have taken up these principles. When thinking about representation of diversity, and engaging consumers from specific communities, the following approaches may be useful.

> *When we listen to consumers and whānau, they really help us to understand what's important to them. This is when we realise how important it is to be treated as [a] person, not a condition or bed number. They want to understand what's actually happening, what options are available and how they can contribute to their own health and wellbeing.*
>
> **Dr Lynne Maher, improvement and innovation clinical director for Ko Awatea, Counties Manukau Health**

In general, when seeking new consumer representatives from a specific cultural background, think about what you are looking to gain – is it the ability to represent the experiences of their community, or is it expertise in local customs and protocol? Be clear, in promoting the role, that the representative must be able to provide that specific perspective or expertise through either their own experience or having access to it through their networks. Think about what method of engagement will work best to make consumers feel more comfortable about having their say.

Consider a range of ways of collecting feedback rather than relying on only web- or paper-based methods.

What is relevant to consider also varies with the particular community you are engaging with. While the following discussion does not cover all communities, it does summarise some consideration for communities in New Zealand.

Three tips for working with diverse communities

- Be open and honest. Own what you do and don't know.
- Get to know your communities and seek their expertise and advice.
- Be patient. True partnership takes time and energy – it will be worth it.

In any engagement with communities, you should always factor in te Tiriti relationship between Māori and the Crown. Māori are generally under-represented in surveys and other tools that measure patient experience. The opportunity to give feedback 'kanohi ki te kanohi' (face to face) to other Māori in a safe environment is cathartic and a way to share stories of good and not-so-good care.

Some communities (such as Māori or Pacific peoples) may not support a method of seeking feedback by speaking to young people individually, separate from the wider community.[25] Younger people may feel unwilling to speak up and potentially challenge their elders. Think about these dynamics in advance.

For Pacific peoples, you could use a Pacific-style fono. Use creative methods of participation that include food, humour and opportunities to move around the room. Key to working with any community is meeting them at 'their place'. What is comfortable for them?

When working in partnership with diverse communities, be ready to respond to the needs of people who 'are not all the same'. Counties Manukau Health sought advice and input from an identified priority population, including Māori, Pacific and Asian peoples living in the areas of greatest hardship with two or more long-term conditions.[26]

Values Māori identified during the consultation were (pp 6-7):

- **whanaungatanga** – building trust and taking time to get to know whānau, delivering education in a way whānau understand and can access more easily
- **manaakitanga** – being done with rather than done to, taking a partnership approach
- **tikanga** – understanding us, listening to us: '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** – keeping whānau safe and supporting them to make informed decisions. This includes the choices and preferences for some to choose traditional Māori knowledge – 'we get too far away from our natural meds, why can't our people use it, should be included'
- **rangatiratanga** – allowing whānau to lead their plan – 'my whānau is my care team'.

Counties Manukau Health also asked for feedback from Pacific and Asian communities. For Pacific peoples, family rather than the individual was central to care. Navigating health services would be improved by a 'one stop shop' and more supporting roles to help them navigate the health system. Trust and choice were also identified as important.

For Asian communities, similar themes arose. In addition, a major barrier to health care is language. Some people will wait longer for an appointment and travel further to get a doctor that speaks their language. Each Asian sub-group repeated the theme of, 'we are not all the same'. Another concern was a desire for different therapies: 'Can doctors be more accommodating of Asian people wanting to try alternative therapies so we can be honest and upfront, and perhaps get Western and ancient treatment at the same time?'

Some ways that providers can develop relationships to help increase health literacy are to greet consumers in their most commonly spoken language and check how to pronounce each individual's name.

The consultation also involved asking for providers' perspectives. Primary care providers emphasised the need to work collaboratively across primary, secondary and community services. Having team-based care with expanded workforce roles was beneficial.

People with disabilities offer different opportunities for primary care to engage with them at service-delivery level. For instance, Bay of Plenty DHB has noted the importance of communicating with patients and their families and whānau in a way that is patient-centred and timely. Common themes were that it is important to:[27]

- get the initial greeting right – make eye contact and use the person's name
- treat the person with respect and courtesy
- talk with the individual rather than the others around them
- listen and give the person time to express themselves
- treat the person as an individual, not a disability
- realise that routine does matter
- establish trust
- be careful about what is said and how it is said.

The LGBTQI+[28] community experiences health disparities and is a group often overlooked in engagement. This is particularly evident for the transgender community.

Transgender health care is a rapidly evolving area of medicine. People from gender-diverse communities seek advice and support from their health services. Primary health care and GP services are often the first point of contact for people seeking this advice. Once again, the need to feel safe and be treated with respect and dignity in these

> *Engaging with disabled people is mostly the same as for anyone else; don't make assumptions about what I can or can't do or understand. Listen to what I have to say, trust that I know myself and when something isn't right.*
>
> *But it can also be about other things like, don't ask my support person, taxi driver or NZSL [New Zealand Sign Language] interpreter questions about me, unless that's what I want. I might like to schedule multiple appointments together to save time, travel or support costs. Feeling unwell may have nothing to do with my main disability or impairments.*
>
> *Most of all, explain things so I can understand and provide information in accessible formats, and let me take the details away to think about or discuss with others in my own time.*
>
> **Ezekiel Robson, member of the Commission's consumer network**

services has been identified as critical to the health and wellbeing of this community.[29]

The 2008, New Zealand Human Rights Commission (HRC) report, *To Be Who I Am*, identified major gaps in 'the availability, accessibility, acceptability, and quality' of this medically necessary care, in 'both obtaining general health services that many other people take for granted, and in being treated with dignity and respect throughout that process.' Since 2008, work to improve gender-affirming health care services has been undertaken by small groups of dedicated health professionals around New Zealand, but there is evidence that much of what was highlighted by the HRC may still remain true.

Transgender community leadership in transgender health care is key to developing culturally safe services. The following example of co-design (page 37) emphasises the benefit of partnership between providers and the transgender community in progressing a pathway for transgender surgery in Canterbury.

More information on working with diverse communities

The Ministry for Pacific Peoples launched the Pacific Aotearoa Vision at its summit on 13 November 2018. To see this work, which includes the *Lalanga Fou* report, go to: www.pacificaotearoa.org.nz

For the Yavu document, go to the Ministry for Pacific Peoples website: www.mpp.govt.nz/language-culture-and-identity/yavu

For advice on rainbow youth, established organisations in New Zealand can provide direction for health and disability services: www.ry.org.nz

For more information on guidelines for gender-affirming health care: https://researchcommons.waikato.ac.nz/bitstream/handle/10289/12160/Guidelines%20for%20Gender%20Affirming%20Health%20low%20res.pdf

For more information on working with young people of minority genders and sexualities: http://insideout.org.nz/

For more information on ensuring ethnic communities are strong and connected: www.ethniccommunities.govt.nz/

For more information on developing stronger Asian communities: www.asiannetwork.org.nz/

A paper examining the challenges of Asian health and Asian health promotion in New Zealand: http://hauora.co.nz/assets/files/Occasional%20Papers/15128%20%20FINAL%20%20Health%20promotion%20forum%20Asian%20promotion%20article.pdf

The Ministry of Health also has useful information on Asian and migrant health: www.health.govt.nz/our-work/populations/asian-and-migrant-health

For more information on New Zealand's Positive Ageing Strategy: www.superseniors.msd.govt.nz/documents/msd-17470-2014-ageing-strategy-report-final.pdf

A co-design case study resourced by the Commission: Gender-affirming care in Canterbury

This group sought to improve both the quality of, and access to, gender-affirming health care in Canterbury. It comprised three members of the transgender community, a member of Manawhenua Ki Waitaha,[30] a GP with an interest in transgender health and a Pegasus Health manager.

Gender-affirming services involve interactions between clients and a multitude of health professionals and services including, but not limited to, GPs, mental health professionals, endocrinologists and surgeons. This varied mix of individual services and organisations often leads to a poor consumer experience.

The group's work has contributed to the following positive outcomes:

- The number of health professionals in practices supporting their transgender clients and forming a network of champions has grown from fewer than five to around 15 GPs.
- HealthInfo has been updated from a simple and outdated single page on gender dysphoria, to over 10 pages of information on gender identity, gender diversity, support networks and gender-affirming care.
- The HealthInfo information will now also feed into the Leading Lights pathway for primary health teachers supporting gender questioning and gender-diverse students.
- The gender-affirming care pathways on the Canterbury Health Pathways are in final draft stages. The current single pathway on gender dysphoria will be replaced by five health pathways specific to different ages and services, including a surgical pathway that previously did not exist.

- Communication between the community and health professionals, particularly in primary health care, has increased.
- The co-design group has worked as a pilot for a shared community and clinical advisory board to advise on gender-affirming care services design. This advisory board would be valuable as an ongoing resource to the Canterbury health system to contribute to quality improvement, service updates, community engagement, education and so on.
- This co-design team attended the first Aotearoa transgender health symposium in Hamilton in May 2019, thanks to sponsorship by the Commission and support from Pegasus Health.

Working as a co-design team

These elements were critical to the success of the group's work:

- All members have a very good understanding of health inequities and of the current gaps in gender-affirming services in Canterbury and nationally.
- Transgender community members on the group have been gracious about previous breakdowns in communication and relationships with the Canterbury health system and have been willing to give this process a go to improve outcomes for their community. Group discussions have always felt safe and positive.
- All members are passionate about health equity and improving access and health outcomes for transgender people in Canterbury. They all were proactive in raising awareness and looking for opportunities for the group to contribute to this kōrero.

- The strength of the group is having members with different points of view who are able to relate and connect to different groups of people, both in the transgender community and in the health system, and both locally and nationally.
- It has been invaluable to have three people in the group with personal lived experience of gender-affirming care and close relationships with many others with lived experience.
- Having a member who is the parent of a transgender child brought the whānau perspective to the group.
- It has also been invaluable to have a clinician in the group with experience in supporting clients to access gender-affirming care, with excellent relationships within primary and secondary health care. Her experience of developing other health pathways helped in developing a successful strategy.

Progressing consumer engagement in primary care: Bringing it all together | Te whakakoke i te whai wāhi a te kiritaki ki te tiaki hauora tuatahi: Te whakatōpū mai

This resource does not claim to have all the answers on how to progress consumer engagement in primary care but should be viewed as a starting point for some services. For others, it may add to the work already underway.

Bringing it all together requires the courage to be open, have a clarity of vision, be willing to engage, work with and value building relationships and, finally, calmness in the face of mounting pressure to 'keep things the same'. We are not all the same, but we want the same thing for our health: timely access, appropriate care, and compassion and empathy from health professionals.

The following is certain:

- ✓ The health sector has responsibilities under legislation to engage with consumers and uphold their rights when decisions are being made and consumers are accessing health services.
- ✓ Consumer engagement is an investment. Consumers are the greatest untapped resource in health services and turning this tap fully will enhance this investment.
- ✓ Partnership with consumers and providers should be underpinned by the principles and tools used in co-design.

- ✓ Consumer representation and advice fails if it is ad hoc. Planned and well-supported infrastructure is needed to facilitate this.
- ✓ Responding to what patient experience data tells services is crucial to quality improvement.
- ✓ Using a framework suited to your service and designed with communities helps providers understand and progress consumer engagement.
- ✓ There is enough evidence that involving consumers in the design of services will improve services: doing nothing means nothing will improve.
- ✓ 'Sitting at the table, at the time' remains as an important principle. Crucially, consumer engagement is also about 'sitting at the right table, at the right time'.

In our complex health and disability system, there are many areas we seek to improve together. No matter what part of the system we focus on, the unifying perspective comes from the people who need to access services. The patient experience cannot be found from any other source. By working with communities and really understanding what these perspectives mean, improvements become relevant to the people our system is here to serve.

Deon York, programme manager, Partners in Care

Endnotes | Tuhipoka

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30 The Manawhenua Ki Waitaha board was established to ensure manawhenua have oversight and influence on the decision-making of the Canterbury DHB; the Ngāi Tahu representative body in Canterbury for health issues.

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