

# ENGAGING

# WITH

# CONSUMERS

**A guide for district health boards**



HEALTH QUALITY & SAFETY  
COMMISSION NEW ZEALAND

*Kupu Taurangi Hauora o Aotearoa*

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»» 'Nāku tē rourou nau tē  
rourou ka ora ai tē iwi.'  
'With your basket and  
my basket the people  
will thrive.'\* »»

\* This is an oft-used whakataukī (proverb) and is not attributed to any particular iwi/individual. Joanne Henare, a member of the steering group that helped to develop this guide, reports that her cultural advisor from MidCentral District Health Board supports this whakataukī as it fits best with the concept of consumer engagement and participation.

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# Chair's foreword



Consumer engagement is a strategic priority for the Health Quality & Safety Commission. Through our Partners in Care programme, the Commission is working with the sector to build and share evidence of the value of consumer/provider partnerships.

There is growing evidence to support the relationship between consumer engagement and improved outcomes from health care. However, one of the biggest challenges we face is how to measure and evaluate consumer engagement. Importantly, how do we measure success and what does 'success' look like?

In New Zealand today, we know that consumers and providers both want to 'get it right' together. Using this guide, the Commission looks forward to working with the sector and consumers to establish a quality and safety marker for consumer engagement as a way of monitoring progress and measuring success. In turn, consumers will feel more confident in the quality of the services they are receiving.

Embedding consumer engagement in everyday practice and policy so it becomes the norm needs the drive and support of senior leadership and champions throughout the sector. The Commission is committed to supporting increasing partnerships between providers and consumers to improve quality and safety in health and disability support services. This guide is an important step along this important journey. 🍌

**Professor Alan Merry ONZM**

*Chair, Health Quality & Safety Commission*



# Chief Executive's foreword



This guide to consumer engagement for district health boards (DHBs) and other service providers came about because of our work in this area and the response from the sector. Interest in how to engage with consumers has prompted many questions about consumer engagement: why, what and how is it done? Through our work we know that some services are actively seeking to improve how they engage with consumers while others are struggling.

When we first began discussing this guide with the steering group involved, the decision was made to focus on DHBs rather than the wider health and disability sector. As work progressed and we received feedback from the sector it became clear that the guide could be used, and has relevance, across the whole sector. So, while DHBs have provided many of the stories here, the concepts and resources will be useful to all services.

One area where we need to concentrate our efforts to increase consumer engagement is at the governance and policy level. Poor performance in this area negatively affects quality improvement processes and outcomes, in terms of creating policy that is not appropriate or creates risks for consumers. By including consumer perspectives, health providers will spend more wisely and policies will be fit for purpose because consumers have been actively involved.

This guide does not have all the answers to the complex conundrum that is consumer engagement. Its primary aim is to provide information and share the successes and learnings from services that are embedding consumer engagement across their systems.

I am sure this guide will prompt discussion, raise the benchmark and challenge the ways in which we engage with consumers. I congratulate everyone involved in promoting consumer engagement and look forward to hearing more success stories. 🍌

**Dr Janice Wilson**

*Chief Executive, Health Quality & Safety Commission*



# Reflections – Director, Partners in Care



The Health Quality & Safety Commission strives to work in partnership with the health and disability sector in all its work programmes. Our consumer engagement work is delivered through the Partners in Care programme, which began in 2012–13. This work has taught us a lot about what is happening in New Zealand on the consumer front.

We have discovered that, for a small country, New Zealand has a great many silos in health care delivery, and consumer engagement is no exception. If we take into account local and regional differences, there is still limited communication and sharing of ideas and innovation about how and why services are engaging with consumers. Our key aims in producing this guide are to share information and remove barriers to engagement.

A steering group comprising consumer and provider representatives from the four regions provided advice and guidance as this guide was developed. We undertook 13 site visits and received feedback on the draft from over 300 people, both consumers and providers.

We discovered in the feedback sessions that those who attended were curious, questioning and keen. Interest levels were high and people wanted to share their stories of success and struggles at these meetings and in written feedback. It was encouraging to see the level of support for the guide and for the concept broadly known as consumer engagement.

I would like to thank the steering group for their advice and support during this project. Through teleconferences, emails, phone calls and two face to face meetings, we overcame the challenges of getting the busy and geographically diverse steering group together. Thank you for your belief and trust in the process and journey we undertook.

Thank you to those who gave feedback – your input has enriched this guide. Thanks also to the DHB quality and risk managers and service improvement staff who gave feedback and hosted the on-site visits, and to those who shared their stories. We have included many in the guide and more on the Commission's website.

I encourage you to read this guide, discuss it and use it as you strive to improve consumer engagement across the health and disability sector. 🍪

**Chris Walsh**

*Director, Partners in Care, Health Quality & Safety Commission*

# Introduction

“ This is the next frontier of patient and family engagement – using the experience, expertise and insight of patients to improve care.<sup>1</sup> ”

<sup>1</sup> Health Research and Educational Trust. 2015. *Partnering to improve quality and safety: a framework for working with patient and family advisors*. Chicago, IL: Health Research & Educational Trust. URL: [http://www.hpoe.org/Reports:HPOE/2015\\_patient\\_fam\\_engagement\\_FINAL.pdf](http://www.hpoe.org/Reports:HPOE/2015_patient_fam_engagement_FINAL.pdf) (accessed June 2015).



# Introduction

Like many organisations with a focus on health and disability, the Health Quality & Safety Commission recognises consumer engagement is pivotal to improving quality across the system.

Through our work with the sector on consumer engagement, it is apparent that the 'why, what and how' of consumer engagement are not fully understood or accepted in parts of the sector. While some services are actively seeking to improve consumer engagement, others are struggling. This guide will assist those who are struggling, and encourage those who are actively engaged to raise the benchmark.

The purpose of this guide is, firstly, to provide information about consumer engagement – both nationally and internationally; secondly, to share the successes and learnings of New Zealand providers about how they engage with consumers; and thirdly, to promote networking throughout the health and disability sector.

“Our programmes continue to provide vehicles for helping providers build stronger relationships with consumers and families/whānau – not just as consumers of services but as active partners in their own health care, who participate in designing and thinking about how health care and disability support services are delivered.

It is about building capability as we go, and we know there is much yet to do.”

This resource is a practical guide to help New Zealand district health boards (DHBs), and the health and disability services they fund, to engage better with consumers. It covers consumer engagement in the design and delivery of services, as well as the development of policy and governance procedures.

2 Health Quality & Safety Commission. 2014. *Statement of Performance Expectations 2014–15*. Wellington: Health Quality & Safety Commission. URL: <http://www.hqsc.govt.nz/assets/General-PR-files-images/Statement-of-performance-expectation-2014-2015.pdf> (accessed June 2015).



The guide explores the 'landscape' of consumer engagement in New Zealand. There are stories of success, of trials and triumphs, as well as practical examples that demonstrate how to engage with consumers.

Consumer engagement is not a new concept internationally or in New Zealand. Until recently, much of the leadership around consumer engagement has come from the mental health and addictions and disability sectors. In these sectors it is recognised that the health and disability workforce has a vital role to play in consumer engagement.

It is easy to get bogged down with the definitions, language and terms used to describe what is broadly referred to as consumer engagement. There is no one internationally accepted set of terms that meets everyone's needs or satisfies the most ardent critic.

For the purposes of this guide, the term 'consumer' refers to patients and their families/whānau/aiga who have had personal experiences in the health and disability system. The term also includes all those who might use health and disability services in the future. As members of the public they have a right to have input into services.

Other terms, such as person-centred care, patient-centred care and patient and family centred care, are also part of the broad landscape of consumer engagement.

These terms are used throughout the guide in the context of other resources.

For the purposes of this guide, the Health Quality & Safety Commission defines consumer engagement as:

**'... a process where consumers of health and disability services are encouraged and empowered to actively participate in decisions about the treatment, services and care they need and receive. It is most successful when consumers and clinicians demonstrate mutual respect, active listening and have confidence to participate in full and frank conversation. Systems that support consumer engagement actively seek input from consumers and staff at all levels of an organisation.'**<sup>3</sup>

(For more information about the Commission's definitions of consumer and consumer engagement go to: <http://www.hqsc.govt.nz/assets/Consumer-Engagement/Resources/consumer-definitions-Mar-2015.pdf>.)

To support the guide, we have developed a webpage with additional resources about consumer engagement. Links to this page are provided throughout. 🍌

3 Health Quality & Safety Commission. 2015. *Consumer definitions for Partners in Care programme*. Wellington: Health Quality & Safety Commission. URL: <http://www.hqsc.govt.nz/assets/Consumer-Engagement/Resources/consumer-definitions-Mar-2015.pdf> (accessed June 2015).

# The New Zealand legislation that underpins consumer engagement

“ 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.<sup>4</sup> ”

<sup>4</sup> Health and Disability Commissioner. 2009. *Code of Health and Disability Services Consumers' Rights*. Wellington: Health and Disability Commissioner. URL: <http://www.hdc.org.nz/the-act-the-code/the-code-of-rights> (accessed June 2015).



# The New Zealand legislation that underpins consumer engagement

The two important legislative documents that underpin consumer engagement in New Zealand are the *Code of Health and Disability Services Consumers' Rights* and the Treaty of Waitangi. Right 1 of the Code encapsulates the Treaty with respect to Māori.

In New Zealand, the tangata whenua (people of the land) are Māori. The Treaty of Waitangi 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 agencies and Māori, including health and disability support services. The *Code of Health and Disability Services Consumers' Rights* states that consumer rights need to be recognised in the following ways: respect, information, choice, equity, dignity, effective communication, support and full involvement.<sup>5</sup>

The New Zealand Public Health and Disability Act (2000)<sup>6</sup> upholds the Treaty of Waitangi and the need to provide mechanisms to enable Māori to contribute to decision-making and participate in the delivery of health and disability support services, which are at the heart of consumer engagement. The New Zealand Health Strategy (2000)<sup>7</sup> goes on to articulate the need to:

- uphold the three key principles in health that align with the Treaty of Waitangi, at the heart of consumer engagement:
- participation at all levels
- partnership in service delivery
- protection and improvement of Māori health status
- collaborate closely with whānau, hapū and iwi, to create the best mix of services for each local community
- connect Māori consumer representatives together and support their professional development.<sup>8</sup>

5 Health and Disability Commissioner. 2009. *Code of Health and Disability Services Consumers' Rights*. Wellington: Health and Disability Commissioner. URL: <http://www.hdc.org.nz/the-act--code-of-rights> (accessed June 2015).

6 The New Zealand Public Health and Disability Act 2000. URL: <http://www.legislation.govt.nz/act/public/2000/0091/latest/whole.html#DLM80058> (accessed June 2015).

7 At the time of going to press, the strategy was being updated.

8 Ministry of Health. 2000. *The New Zealand Health Strategy*. Wellington: Ministry of Health. URL: <http://www.health.govt.nz/system/files/documents/publications/newzealandhealthstrategy.pdf> (accessed June 2015).

“ Te Pū Manawa was established in MidCentral DHB to support Māori consumer representatives sitting on seven district clinical network groups. Members are current and past representatives and other Māori individuals with an interest in Māori health. The group make recommendations concerning Māori health initiatives. We promote a platform for Māori consumer engagement. We offer a supportive environment for representatives, and promote collaboration and collective decision-making in line with Māori tikanga. ”

Joanne Henare (Ngati Wehi Wehi, Ngati Tukorehe, Ngati Mutunga), Consumer and Family Whānau Advisor, Mental Health and Addictions Services, MidCentral DHB

For Māori resources go to: <http://www.hqsc.govt.nz/our-programmes/consumer-engagement/publications-and-resources/publication/2163/#resources-for-maori>

For disability resources go to: <http://www.hqsc.govt.nz/our-programmes/consumer-engagement/publications-and-resources/publication/2163/#resources-for-disability>. 

# The landscape of consumer engagement

“ The satisfaction of being on the consumer council is being able to make a difference and having feedback from clinicians to say that they have opened their own eyes and thought ‘Oh, I had never thought of it like that’, or ‘I could make a real change here and it would work better for me and for the patients.’ ”

**Graeme Norton, Chair, Hawke's Bay Health Consumer Council**



# The landscape of consumer engagement

Consumer engagement is an essential component of quality and safety in the design and delivery of health services.

Engaging consumers and providing person-centred care has huge benefits in treatment outcomes, prognosis, morbidity and cost savings for organisations.<sup>9</sup>

Improving consumer engagement in health care is a global movement. The World Innovation Summit for Health in 2013 focused on the critical role consumer engagement plays in shaping future health services.

**'The solutions to the health challenges of today and tomorrow won't come from doing business as usual; they will come from building effective partnerships and harnessing the untapped global power of ordinary people who care about improving their health. There are powerful benefits from partnering with patients, families, communities, and health care workers at all levels.'**<sup>10</sup>

Consumers can be engaged as individuals, or collectively, with increasing power to influence quality and safety. This ranges from being given 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.

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

The consumer engagement needs of people will vary from person to person. Not all consumers will want to be involved at all times. For a person who has been given a new and frightening diagnosis, being informed about different treatment options, checking

that they understand their choices (assessing their health literacy) and actively involving their family may be enough for them. While all people should have an opportunity to provide feedback about their care, some may not want to take up this offer immediately. Others may want to get more involved. They may want to improve the experience of care for others by being a representative involved in service delivery, strategy and design. Or, with encouragement, motivation and skill, they may even want to represent other consumers in a governance role in an organisation.

Consumer engagement is more than just a set of activities. It involves a cultural shift in organisations to welcome partnerships with consumers at all levels, from the waiting room to the board room.<sup>11</sup> 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 that consumers are represented in expert advisory groups. At the policy and governance level, it means skilled, well-networked consumer councils will be working in parity 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.

“ Consumers are level-headed, they know resources are limited, they're not asking for the sky, they know it has to be sustainable for the people who work there just as much as it is for people who might want to receive services. ”

Graeme Norton, Chair, Hawke's Bay Health Consumer Council

9 World Innovation Summit for Health. 2013. *Patient and family engagement: partnering with patients, families, and communities for health: A global imperative*. Doha: World Innovation Summit for Health. p6. URL: <http://www.wish-qatar.org/app/media/387> (accessed June 2015).

10 Ibid.

11 Coulter A. 2012. *Leadership for patient engagement*. London: The King's Fund. p16. URL: <http://www.kingsfund.org.uk/sites/files/kf/leadership-patient-engagement-angela-coulter-leadership-review2012-paper.pdf> (accessed June 2015).



## Health literacy

Health literacy is a foundation stone of consumer engagement. It is the responsibility of providers to support better health literacy for consumers. Health literate organisations make it easier for people to navigate, understand and use information and services to take care of their health.<sup>12</sup>

For more information about health literacy go to: <http://www.hqsc.govt.nz/our-programmes/consumer-engagement/publications-and-resources/publication/2163/#health-literacy>

12 Brach C, et al. 2012. *Attributes of a Health Literate Organization*. Discussion Paper. Washington, DC: Institute of Medicine Roundtable on Health Literacy. URL: [https://www.iom.edu/-/media/Files/Perspectives-Files/2012/Discussion-Papers/BPH\\_HLit\\_Attributes.pdf](https://www.iom.edu/-/media/Files/Perspectives-Files/2012/Discussion-Papers/BPH_HLit_Attributes.pdf) (accessed June 2015).

## Person-centred care

Person-centred care at the individual level is a partnership between the clinician and the person receiving care. It involves shared decision-making, discussing treatment options and medication options, and asking questions to include the person's goals of treatment and the wishes of their family/whānau. When done well, person-centred care results in people being more engaged, more health literate and better able to self-manage their own care. When this extends to an organisation, person-centred care involves integrated, coordinated care systems that seamlessly follow the consumer's journey through the system.<sup>13</sup>

For more information about person-centred care go to: <http://www.hqsc.govt.nz/our-programmes/consumer-engagement/publications-and-resources/publication/2163/#international-resources>

13 Bisognano M, Schummers D. 2014. Flipping healthcare. *BMJ* 349:g5852. URL: <http://www.bmj.com/content/349/bmj.g5852.long> (accessed June 2015).

It is important to recognise that consumer engagement is not just the responsibility of the frontline clinician. It is also a core governance responsibility. The attitudes of boards to consumer engagement and patient-centred care are an important driver of change. A recent study in Victoria, Australia, shows that positively engaged boards, with clear plans of activities to promote consumer engagement, are critical to the success of their organisations, and to ensuring positive patient feedback.<sup>14</sup>

**'High activity, positive attitude... Boards discussed a range of benefits that flowed from consumer engagement and patient-centred care including mitigating risks, improving patient outcomes, and increasing responsiveness of services to patient needs.'**<sup>15</sup>

In New Zealand, the Ministry of Health and the Health Quality & Safety Commission advise DHBs and other health and disability support services to improve consumer experience by involving consumers more in decision-making.<sup>16</sup> We know there are some effective and innovative initiatives supporting consumer engagement in our primary and secondary health services. New roles such as consumer engagement facilitators and patient experience managers are starting to be resourced. The formation of consumer councils is another good example of consumer engagement.

In New Zealand's mental health and disability sectors, the engagement of consumers in paid and unpaid roles is well established. As Te Pou o te Whakaaro Nui (the mental health, addiction and disability workforce organisation) observes:

**'Consumer advisors work mainly within... organisations to provide operational and strategic advice based on peer values... to ensure the voices of people who (use the service) influence the direction of the service.'**<sup>17</sup>

14 Bismark M, Biggar S, Crock C, et al. 2014. The role of governing boards in improving patient experience: attitudes and activities of health service boards in Victoria, Australia. *Patient Experience Journal* 1: 144–52. URL: <http://pxjournal.org/journal/vol1/iss1/19/> (accessed June 2015).

15 Ibid. p147.

16 Health Quality & Safety Commission. 2014. *Statement of Intent 2014–18*. Wellington: Health Quality & Safety Commission. p34. URL: <http://www.hqsc.govt.nz/publications-and-resources/publication/1603/> (accessed June 2015).

17 Te Pou o te Whakaaro Nui. nd. *Service user, consumer and peer workforce: a guide for planners and funders*. Auckland: Te Pou o te Whakaaro Nui. URL: <http://www.tepou.co.nz/uploads/files/resource-assets/service-user-consumer-and-peer-workforce-guide-for-planners-and-funders.pdf> (accessed June 2015).



The National Service User and Peer Support Competency Workforce Development Reference Group has recently released a set of competencies for the peer workforce and a guide for managers, employees, planners and funders.<sup>18</sup>

The Ministry of Health's 'new model for supporting disabled people' illustrates the empowerment of people living with disabilities.<sup>19</sup> Allison Franklin, a member of the Health Quality & Safety Commission's consumer network, describes the changes she has seen in the disability sector:

**'It used to be the case that "patients" had little say in the treatment and services they received. We were told what we needed and what we would get! Fortunately, over the past 30+ years, the rights of consumers of mental health and disability services have developed to the point where it is accepted and deemed mandatory that consumer involvement must be included at all levels of the health sector. The result is more appropriate and effective services that better meet people's needs.**

**'Organisations such as the Disabled Person's Assembly, People First and mental health groups have been successful in changing the ways people with disabilities and/or health conditions are perceived. We have found our collective voice and use it effectively to enhance the lives of the people represented.'** 🍌

**“** The IHI's president and CEO Maureen Bisognano says we must ask, in Barry and Edgman-Levitan's phrasing, 'What matters to you?' as well as 'What is the matter?'<sup>20</sup> **”**

18 Te Pou o te Whakaaro Nui. nd. Competencies for the mental health and addiction consumer, service user and peer workforce. Auckland: Te Pou o te Whakaaro Nui. URL: <http://www.tepou.co.nz/uploads/files/resource-assets/peer-support-competencies-2014.pdf> (accessed June 2015).

19 Ministry of Health. 2014. New model for supporting disabled people. Wellington: Ministry of Health. URL: <http://www.health.govt.nz/our-work/disability-services/new-model-supporting-disabled-people> (accessed June 2015).

20 Barry MJ, Edgman-Levitan S. 2012. Shared decision making – pinnacle of patient-centered care. *N Engl J Med* 366(9): 780–1.

# The benefits of better engagement with consumers

“ There has been a fear that consumer engagement is going to be costly. But actually it is more costly not to involve consumers. ”

Wendy Entwistle, Consumer Engagement Facilitator, Waikato DHB



# The benefits of better engagement with consumers

There is a large and growing body of international evidence to support the benefits of engaging with consumers.

“ They’ve all got a passion because of how they were treated, whether it was positively or negatively. They want to help other families in the position they were in. ”

Traci Stanbury, child health consumer representative, South Island Alliance

The benefits include better health outcomes, safer care, less waste, lower costs and better consumer and health provider satisfaction and staff retention. Engaged consumers have improved health literacy, are more likely to comply 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.<sup>21</sup>

The Academy of Medical Royal Colleges in the UK reported in 2014 that up to 20 percent of clinical practice is wasteful. This waste is caused by the over-use of tests and interventions, and a failure to understand the importance of patients’ own health care goals and what is most valuable to them. The report called for a fundamental shift towards person-centred care, so that clinical decision-making is based on patient benefit and preference.

**‘A cultural shift is required which calls upon doctors and other clinicians to ask, not if a treatment or procedure is possible, but whether it provides real value to the patient and genuinely improves the quality of their life, or their prospects of recovery... realignment of clinical decision-making is required – where patient benefit and patient preference are balanced against patient harm and resources usage.’<sup>22</sup>**

Improving consumer engagement also brings enormous benefits for staff. When staff engage in compassionate, person-centred care with consumers, it has a powerful psychological influence on their wellbeing, as well as that of consumers. Dr Robin Youngson, creator of Hearts in Healthcare,<sup>23</sup> an organisation dedicated to humanising and enriching health care, describes a health system in a ‘crisis of caring’, with huge problems caused by staff burnout and turnover. He believes that engaging with consumers, and working towards person-centred care, is the key to solving this.

**‘If health professionals can’t care, what is the impact on patient outcomes? The patient experience of care triggers a powerful biological response and the emotional memory of care lasts a lifetime. Compassionate caring is safer, more effective, satisfies patients and staff, reduces time, cost and demand. The number one priority is the health and wellbeing of the caring professionals – without this we cannot achieve patient-centred care.’**

The question is no longer whether we can afford to engage consumers, but rather, what is the growing cost of continuing to avoid consumer engagement in our health care system.

**For more about the benefits of clinicians engaging with consumers, go to: <http://www.hqsc.govt.nz/our-programmes/consumer-engagement/publications-and-resources/publication/2163/#international-resources>** 

21 World Innovation Summit for Health, *op.cit.*

22 Academy of Medical Royal Colleges. 2014. *Protecting resources, promoting value: a doctor’s guide to cutting waste in clinical care*. London: Academy of Medical Royal Colleges. p6. URL: <http://www.aomrc.org.uk/dmdocuments/Promoting%20value%20FINAL.pdf> (accessed June 2015).

23 [www.heartsinhealthcare.com](http://www.heartsinhealthcare.com)

# Principles of consumer engagement

“ We wanted more than just a token consumer representative on a group so we could tick the box and say we are doing consumer engagement. We decided to develop a framework involving consumers at every level, from governance, service delivery and at a community and individual level. We used different approaches from patient satisfaction surveys, patient experience feedback, ‘what matters to you’ surveys, co-design of services, and will be recruiting consumer representation roles on the Governance board that are remunerated. ”

**Ruth Galvin, Project Manager, Waikato Maternity Quality and Safety Programme**



# Principles of consumer engagement

There are a number of key principles underpinning consumer engagement. These have been developed by the Health Quality & Safety Commission and the steering group, with feedback from the health and disability sector.

## 1 Being open and honest

Consumer engagement is more successful when all parties involved are mutually respectful, listen actively and have the confidence to participate in full and frank conversation. It might seem easy, but in today's fast-paced health system it is very important to pause and check that communication lines are open, that people are comfortable about speaking out and that others are open to listening. Joanne Henare of MidCentral DHB recognises the importance of the need to build trust in her role as consumer and family/whānau advisor:

**'[Providers] have to feel safe too, so they will say what they're really thinking. That takes time. You've got to be diplomatic and a good negotiator to earn that kind of trust. It's a two-way thing.'**

## 2 Providing support

Support for consumer engagement means being welcoming when meeting consumers, valuing their expertise, and acknowledging and taking consumer viewpoints seriously. Support also means ensuring consumers are aware of the resources available to them to support their participation. This can include: making them aware that they can provide feedback via the organisation's website, or by phone; letting them know where clothes washing facilities are for parents of sick children; and cheap accommodation choices nearby for families.

For consumer representatives, it might involve ensuring they are paid for being on consumer councils or an expert advisory or steering group. New consumer representatives might need support with practical things such as having parking spaces set aside for consumers attending meetings, or providing food

and refreshments for a focus group. They may need to be shown a chart to see where their group fits in the organisational structure, and a glossary explaining any unfamiliar terms and acronyms. It is also very useful to have a staff member participating in the group who can help consumers to develop in their role.

**“** Some members of the consumer council face transport, childcare and computer access issues. Solutions have been tailored to individual needs. For example, one member who lives rurally will video-link into the consumer council meetings via the local Community Trust primary care provider. Another council member does not have computer access, and this was negotiated through a local primary school. **”**

**Liane Penney, Portfolio Manager, Northland Health Services Plan**

Staff too may need support to engage with consumers, for example, values training or professional coaching for frontline clinicians, and other staff may be required to build their confidence to work directly with consumers on quality improvement projects.



### 3 Being real

Consumers know when services are simply 'going through the motions' of consulting with them, and so do the providers of those services. It is not enough to simply add a consumer representative and 'tick the box'. Consumer engagement needs to be genuine. All parties should feel there is a purpose to the engagement taking place and real possibilities for change and improvement.

### 4 A patient and family/whānau focus

Consumer engagement is about being sensitive and empathic in communicating with consumers and keeping the focus on patient-/family-/whānau-centred care. People delivering health and disability services sometimes get so caught up in the cost of services and major health issues that engaging with patients and family/whānau gets sidelined. It is important that providers and staff are supported to maintain their focus on patient/family/whānau as a core aspect of care.

**For international guidelines and frameworks about consumer engagement go to: <http://www.hqsc.govt.nz/our-programmes/consumer-engagement/publications-and-resources/publication/2163/#international-guidelines>** 

### *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*

**Chris Walsh, 2015**

# A New Zealand framework for consumer engagement

“ Having a set of values and some behavioural standards that define what it means when we're living up to the values has been one of the single biggest promoters of cultural change here. It gives us an incredibly solid platform to say to staff that consumer engagement is not about corporate messaging, it's what the community is telling us matters. ”

Jay O'Brien, Patient Experience Manager, Waitemata DHB



# A New Zealand framework for consumer engagement

The framework below encapsulates what it means to be fully engaged with consumers in a holistic, system-wide way. You can use this framework to assess how well your organisation is tracking in consumer engagement.



Some actions that can be taken to implement consumer engagement follow.

## Person and family/whānau-centred care

- Clinicians checking 'what matters to you' in each clinical encounter.
- Offering opportunities for shared decision-making with consumers wherever possible.
- Focusing on supporting consumers and families/whānau to increase their health literacy, and encouraging self-management of long-term conditions.
- Actively listening to consumers' values, preferences and goals for treatment.
- Being respectful and genuine with consumers – being interested and humane.
- Taking consumer views seriously – not just going through the motions; 'walking the talk', living up to the promise 'what we do is who we are'.
- Providers ensuring their environment is welcoming and staff are kind in every interaction.
- An open invitation for consumers to engage at all levels – 'we want someone just like you, your opinion is valued'.



“ To move beyond tokenism requires courage, drive and a commitment to partnership in its true sense. The sub regional disability advisory group achieves a balance of people based on locality, ethnicity and community linkages and includes people experiencing disability and service providers. A combined five-year plan for improving access for people with disabilities using health services has been developed. This is an example of a robust consumer group that promotes genuine engagement and feedback. ”

**Dr Pauline Boyles, Senior Disability Advisor, Service Development & Integration Unit, Wairarapa, Hutt Valley and Capital & Coast DHBs**

## Organisational responsiveness

- Providing multiple avenues for past, present and future consumers and communities to engage in health care service delivery and design.
- Resourcing and supporting all staff to make the cultural shift to value consumer engagement. This can be achieved through training in values such as ‘in your shoes, in our shoes’ workshops.
- Identifying and promoting staff champions of consumer engagement at all levels of the organisation.
- Using consumers in the induction of new staff about person-/family-/whānau-centred care.
- Promoting the particular skills required to actively partner with consumers and elicit feedback. Invest in staff training in skills such as active listening, giving room and respect for consumers’ concerns and opinions, and checking back for understanding, to support the improvement of consumers’ health literacy.

“ A lot of my work is around consumer feedback via a number of mechanisms the DHB has in place, including:

- cards and an online form that ask three things – which service or department the consumer is talking about; what the DHB did well; and what the DHB could have done better
- surveys and focus groups
- including consumers in audits of nursing and midwifery care
- leadership walks around the DHB incorporating conversations with consumers. ”

**Wendy Entwistle, Consumer Engagement Facilitator, Waikato DHB**

## Policy and governance

- Creating a person-centred vision statement for the organisation – when the values of the organisation are person-centred, then consumer engagement is valued.
- Leadership facilitating consumer engagement from the boardroom to the waiting room.
- Using senior leaders in your organisation to be champions for consumer engagement.
- Developing a vision of consumer engagement for the whole organisation.
- Resourcing consumer and community engagement facilitator/manager roles in your organisation.
- Consumer representation at senior leadership level.
- Resourcing paid consumer roles in expert advisory groups and committees.
- Considering developing a consumer council alongside clinical governance.
- Using patient stories in board meetings.
- Bringing senior leaders to ward rounds, and making opportunities to talk to patients about their experiences.



“ It is not enough for boards to review performance measures. When they hear stories of the patients and families whose lives have been affected by quality and safety events, boards will drive for improvement with a much greater sense of urgency and commitment.<sup>24</sup> ”

### Shared decision-making

- Involving consumers and families/whānau in their own care planning and listening to their values, preferences and goals of care, when considering treatment options.
- Supporting the use of shared electronic records wherever possible and permitted by the consumer.
- Bedside handovers involving family/whānau become the norm.
- Involving consumers in their discharge planning and checking with them about family/whānau participation.

“ We wanted to involve consumers in a fuller way. We felt it was important to do the groundwork, building up strong connections with consumers across our maternity sector – at the hospital, the birthing units, PHOs and with midwives in the community. ”

Ruth Galvin, Project Manager, Waikato Maternity Quality and Safety Programme

### Service design and evaluation

- Using co-design with consumers in all quality improvement and service design initiatives.
- Ensuring good mechanisms are created to support communication between hospital and community services, avoiding duplication and repetition.
- Mapping patient journeys through an episode of care from the community through to hospital admission, inpatient stay and discharge.
- Using patient experience survey data as real-time feedback to health clinicians, consumers and communities, such as through quality boards in hospitals and on DHB websites, and visible to staff and consumers.
- Providing multiple avenues for real-time feedback to consumers, communities and staff about the influence of consumer input into service design and delivery.

“ Co-design is about designing solutions with our patients/whānau 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 solutions. ”

Renee Greaves, Patient and Whānau Care Advisor, Counties Manukau Health

**For more about international guidelines and frameworks for consumer engagement go to:** <http://www.hqsc.govt.nz/our-programmes/consumer-engagement/publications-and-resources/publication/2163/#international-guidelines>

**For more about New Zealand guides, frameworks, training guides and competencies go to:** <http://www.hqsc.govt.nz/our-programmes/consumer-engagement/publications-and-resources/publication/2163/#NZ-guides>

24 Reinertsen JL, Bisognano M, Pugh MD. 2008. *Seven Leadership Leverage Points for Organization-Level Improvement in Health Care (Second Edition)*. IHI Innovation Series white paper. Cambridge, MA: Institute for Healthcare Improvement. URL: <http://www.ihl.org/resources/Pages/IHIWhitePapers/SevenLeadershipLeveragePointsWhitePaper.aspx> (accessed June 2015).

# The spectrum of consumer engagement

“ We developed the Taranaki DHB patient-centred care framework at clinical board level with a consumer representative co-leading the work with me from the start. It took energy, effort and persistence to progress the work, however in all co-design work I think it is vital to ‘walk the talk.’ That effort has paid off with the success of our framework. We’ve now run a competition to name the consumer engagement work with the result being, ‘Health Together: Hauora Huihui.’ ”

Mary Bird, Service Improvement Advisor, Taranaki DHB



# The spectrum of consumer engagement

A well-known diagram (shown below) that represents the range of consumer engagement was developed by Carman and associates at The King's Fund in the UK.<sup>25</sup> This shows how consumers can be engaged in their own care and as representatives of their communities and issue groups throughout an organisation.

A multi-dimensional framework for patient and family engagement in health and health care

| CONTINUUM OF ENGAGEMENT                     |  |  |   |
|---|--|--|---|
| LEVELS OF ENGAGEMENT                        | CONSULTATION   | INVOLVEMENT  | PARTNERSHIP AND SHARED LEADERSHIP   |
| <b>Direct care</b>                          | Patients receive information about a diagnosis.  | Patients are asked about their preferences in a treatment plan.  | Treatment decisions are made based on patients' preferences, medical evidence and clinical judgement.                             |
| <b>Organisational design and governance</b> | Organisation surveys patients about their care experiences.                                  | Hospital involves patients as advisors or advisory council members.                                      | Patients co-lead hospital safety and quality improvement committees.  |
| <b>Policy-making</b>                        | Public agency conducts focus groups with patients to ask opinions about a health care issue. | Patients' recommendations about research priorities are used by public agency to make funding decisions. | Patients have equal representation on agency committee that makes decisions about how to allocate resources to health programmes. |

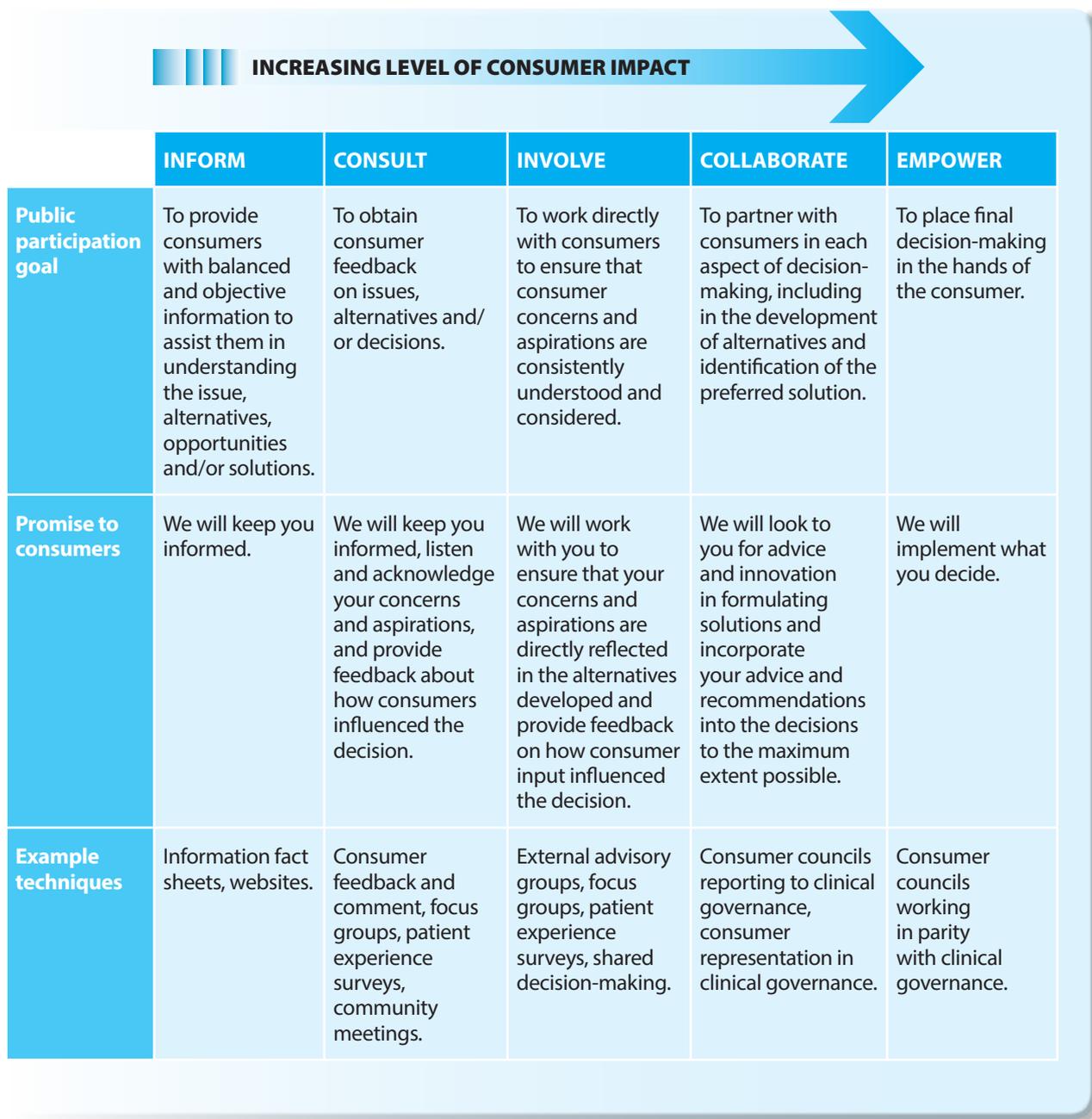
#### Factors influencing engagement:

- Patient (beliefs about patient role, health literacy, education)
- Organisation (policies and practices, culture)
- Society (social norms, regulations, policy)

Your organisation is likely to be doing many activities to engage consumers. As the continuum of engagement describes, your service may already be at the involvement level, conducting focus groups, asking opinions or holding meetings involving consumers. The aspirational goal would be to strive for partnership and shared leadership by ensuring consumers have representation on committees at governance level.

The International Association of Public Participation Australasia (IAP2) also describes a spectrum of public participation. This spectrum sets out the promise being made to the public (and consumers of health) at each participation level. It shows how different levels of participation are legitimate depending on the goals, timeframes, resources and levels of concern about the decision being made. It provides practical examples of engagement at each level of the organisation. This model has been adopted widely in Australia and in some New Zealand DHBs.

23 Carman K, et al. 2013. Patient and family engagement: A framework for understanding the elements and developing interventions and policies. *Health Affairs* 32(2): 223–31. URL: <http://www.rwjf.org/en/library/research/2014/02/a-multidimensional-framework-for-patient-and-family-engagement-i.html> (accessed June 2015).



The diagram above is adapted from the IAP2 spectrum of public participation and relates to health consumers engaging in decisions about their care and health services.<sup>26</sup>

**The international self-assessment tools at the following link will help you assess what your organisation is already doing, and where to start to engage consumers at higher levels – <http://www.hqsc.govt.nz/ourprogrammes/consumer-engagement/publications-and-resources/publication/2163/#international-selfassessment>** 

<sup>26</sup> International Association for Public Participation. 2007. IAP2 spectrum of public participation. Louisville, CO: International Association for Public Participation. URL: [http://static.qwad.com.au/iap2/files/IAP2%20Spectrum\\_vertical.pdf](http://static.qwad.com.au/iap2/files/IAP2%20Spectrum_vertical.pdf) (accessed June 2015).

# Facilitating consumer engagement in your organisation

“ The Consumer Council was set up initially on a voluntary basis. Within six months we decided to remunerate council members on the same basis as other governance groups under the Cabinet fees framework. We were able to do this because, although they are technically a management group (reporting through the DHB CEO), they also report directly to the board, therefore making them an advisory committee. In restructuring the operation of our three statutory committees (Hospital Advisory Committee, Community and Public Health Advisory Committee and Disability Support Advisory Committee) we essentially replaced regular meetings of these committees with the Consumer Council and the Clinical Council, which freed up some money. The annual cost of the Consumer Council is now approximately \$43,000, which includes a payment of \$250 per meeting for 16 members and 11 meetings a year. ”

**Ken Foote, Company Secretary, Hawke's Bay DHB**



# Facilitating consumer engagement in your organisation

Consumer engagement requires support, resourcing and champions. See below for some suggestions for senior leaders to consider implementing in their organisation.

- Showcase successful initiatives that have involved consumers.
- Provide dedicated staff, such as consumer and community engagement facilitators or managers. Their role is to support the development of consumer leaders, facilitate the development of a consumer network and provide education and training for new consumer representatives.
- Invest in staff training in communication skills, such as active listening, providing room and respect for the consumer's concerns and opinions, and checking that consumers understand through approaches such as the 'teach-back' method.
- Appoint consumer representatives to roles in policy development and governance levels, such as expert advisory groups.
- State the remuneration for consumer representatives' time and costs.
- Provide clarity in terms of reference and role descriptions for representatives on committees and groups.

**For more information about the Health Quality & Safety Commission's policy on paying consumers go to:**

<http://www.hqsc.govt.nz/assets/Consumer-Engagement/Resources/policy-paying-consumers-Mar-2015.pdf>

## Capture the patient experience

Feedback from consumers about their experience of care is the fundamental building block of consumer engagement, and drives the cultural shift towards more person-centred care. It is vital to allow for different ways to give feedback.

The patient experience survey was developed by the Commission's Health Quality Evaluation team as part of a summary set of quality indicators, covering an internationally recognised range of aspects: safety, patient experience, effectiveness, access/timeliness, efficiency and equity. The patient experience survey is now an established part of quarterly reporting for all DHBs.

In addition to the survey, consumers should be able to give unsolicited feedback at any time, either via the DHB website, in writing by post, in feedback boxes on-site or through phonecalls to the DHB.

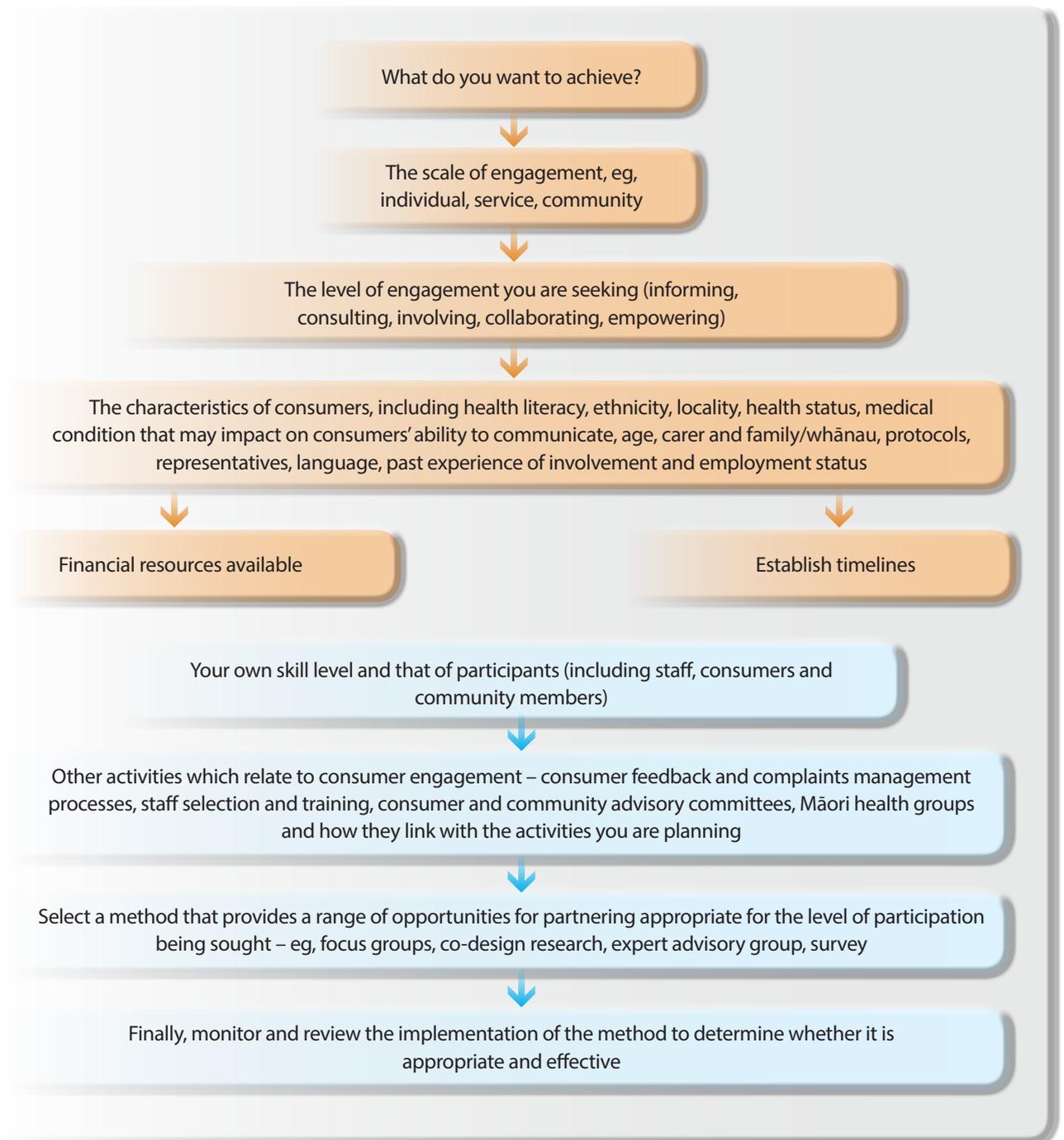
Another way to capture consumer experience is by using experienced-based co-design to map the patient journey and use their experience of the system as the basis for making quality improvements. Mapping the patient journey often shows gaps in service provision and areas where simple improvements such as signage and information can make an enormous difference to the consumer experience.

Story-telling is another tool that is increasingly being used. Some boards have patient stories or face-to-face patient feedback at their meetings. Some DHBs have senior leadership grand rounds, including listening to patients' views in the wards. Patient stories can be filmed and uploaded onto DHB websites, and used as invaluable conversation starters. They can be used by boards, in quality improvement initiatives and to induct new staff to an organisation.



## Prepare for consumer engagement

The decision chart below has been adapted for New Zealand and may help you plan for consumer engagement co-design projects in your organisation.<sup>27</sup>



For more information about planning for consumer engagement projects and selecting practical methods, go to the SA Health website at: [http://www.sahealth.sa.gov.au/wps/wcm/connect/f8d1d0004e454788aa0caf8ba24f3db9/Guideline\\_Engaging+Consumers+and+Community\\_Dec2014.pdf?MOD=AJPERES&CACHEID=f8d1d0004e454788aa0caf8ba24f3db9](http://www.sahealth.sa.gov.au/wps/wcm/connect/f8d1d0004e454788aa0caf8ba24f3db9/Guideline_Engaging+Consumers+and+Community_Dec2014.pdf?MOD=AJPERES&CACHEID=f8d1d0004e454788aa0caf8ba24f3db9)

27 SA Health. 2013. Guide for engaging with consumers and the community. Adelaide: SA Health. URL: [http://www.sahealth.sa.gov.au/wps/wcm/connect/f8d1d0004e454788aa0caf8ba24f3db9/Guideline\\_Engaging+Consumers+and+Community\\_Dec2014.pdf?MOD=AJPERES&CACHEID=f8d1d0004e454788aa0caf8ba24f3db9](http://www.sahealth.sa.gov.au/wps/wcm/connect/f8d1d0004e454788aa0caf8ba24f3db9/Guideline_Engaging+Consumers+and+Community_Dec2014.pdf?MOD=AJPERES&CACHEID=f8d1d0004e454788aa0caf8ba24f3db9) (accessed June 2015).



## Involve consumers in service planning, policy and quality improvement

Consumer representatives bring business and personal skills, life experience and community networks to the committee table, and help ensure person-centred quality improvement.

At the higher level of an organisation it can be useful to have two consumer representatives on each committee or group. Some DHBs<sup>28</sup> have formed consumer councils made up entirely of consumer representatives, and others are in development. These councils have a strong relationship with clinical governance and report to the board.

“ It hasn’t always been easy getting the consumer voice heard and valued but we do seem to be moving to an environment that allows more in-depth discussions at the committee table and this provides more opportunities for members to canvass those issues that matter to patients and their families. The added impetus from HQSC’s quality and consumer initiatives should help strengthen that approach but ultimately it’s over to boards, management and clinicians to optimise consumer input to positively influence change. ”

**Barbara Robson, MidCentral DHB Board member and consumer representative**

## Get connected

Increasingly, consumers wish to interact online with their health service providers. The use of online patient portals is on the rise in primary health, for example, ManageMyHealth™.<sup>29</sup> This is happening alongside the increased use of shared electronic records with secondary services and hospitals. Patients can order

28 At the time of publication, Hawke’s Bay, Canterbury, West Coast, Counties Manukau and Northland DHBs had consumer councils.  
29 [www.managemyhealth.co.nz](http://www.managemyhealth.co.nz)

“ Co-designing as a consumer is powerful. I see it as helping to shape a culture shift in an industry. For me the most important aspect is seeing the change from an organisation that does things to and for patients, to one that does things with their patients/whānau. ”

**Renee Greaves, Patient and Whānau Care Advisor, Counties Manukau Health**

repeat prescriptions, make appointments, learn about their medicines, join community forums, ask questions and give feedback – all online. Patient information is increasingly accessed via the web, and is a powerful tool for health literacy improvement. Online searches for side effects of medication and management of diseases are very common. Websites such as Health Navigator<sup>30</sup> and Medsafe<sup>31</sup> provide a quality source of such advice, and many DHBs also provide their own sources of patient information.

Social media is another easy way for patients and the public to give feedback and receive information. Many DHBs have, or are in the process of setting up Facebook pages or Twitter accounts. The Health Quality & Safety Commission encourages DHBs 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. 🍌

“ Establishing a patient and family advisory council is an effective way to create a formal structure to seek and incorporate patient feedback on an ongoing basis.<sup>32</sup> ”

30 [www.healthnavigator.org.nz](http://www.healthnavigator.org.nz).

31 [www.medsafe.govt.nz](http://www.medsafe.govt.nz).

32 Health Research and Educational Trust. 2015. *Partnering to improve quality and safety: a framework for working with patient and family advisors*. p6. Chicago, IL: Health Research & Educational Trust. URL: <http://www.hpoe.org/resources/hpoehretaha-guides/1828> (accessed June 2015).

# Simple things you can do now

“ We have just started using quality boards on every ward, pin-up noticeboards displaying quality measures which have been co-designed with consumers. The boards have four blocks, representing our four values. On the boards we display the results of our patient experience surveys and our in-house staff surveys. We have a section called ‘you said, we did’ where we show the changes that have been made as a result of patient feedback at the ward level, not just the whole organisation, so it is very valuable real-time feedback. The staff experience section is similar. We know that everything we do for patient experience we do for staff, because how staff experience and engage is a driver of positive patient experience. ”

**Jay O'Brien, Patient Engagement Manager, Waitemata DHB**



# Simple things you can do now

There are some simple things that health care staff, clinicians and organisations can do straight away to support better consumer engagement.<sup>33</sup>

## Encourage patients and families/whānau

Encourage patients and families/whānau to give feedback, find out more information about their health conditions, get ready for their next health care visit and keep track of their medicines and personal health information. Make patients and families/whānau aware of how they can become more involved as consumers. The Health Quality & Safety Commission's work is supporting these actions with resources for consumers and health care providers to assist health literacy, and through training for consumer representatives.

**For more information go to:** <http://www.open.hqsc.govt.nz/patient-safety-week/publications-and-resources/publication/1826/>

## Health care professionals

Health care professionals can welcome feedback from consumers, ask them what is important to them and check with them about their understanding, using 'teach-back' and other communication tools. They can work to maximise the use of web-based feedback and patient portals in their organisation, and they can encourage their own professional bodies to have consumer representation when developing new guidelines and recommendations.

**For more information go to:** <http://www.hqsc.govt.nz/our-programmes/consumer-engagement/publications-and-resources/publication/2046/>

## Organisations

Organisations can revisit family and consumer engagement policies, organise grand rounds and staff training about consumer engagement, find champions of consumer engagement among staff and promote activities, encourage patient feedback publicly throughout the organisation and through multiple sources, and ensure the feedback loop is closed through 'you said, we did' initiatives.

**For more information go to:** <http://www.hqsc.govt.nz/our-programmes/consumer-engagement/publications-and-resources/publication/2163/#international-guidelines> 🍌

33 Adapted from Carman K, et al. 2014. A roadmap for patient and family engagement in healthcare practice and research. Washington, DC: American Institutes for Research. p51. URL: <http://patientfamilyengagement.org> (accessed June 2015).

# Choosing consumer representatives

“ To be a consumer representative you need a passion, and a longevity within the health system. Consumers know they are in it for the long haul. They have a passion because of how they have been treated, either positively or negatively, can see how it can be better, and want to help other families in the future. ”

**Traci Stanbury, child health consumer representative,  
South Island Alliance**



# Choosing consumer representatives

It can be hard to find suitable consumer representatives. Some organisations perceive barriers relating to notions of the 'same old suspects', or 'professional consumers'. These barriers can be addressed by recruiting more widely, using a transparent process, and by challenging thinking.

If a clinician can represent collective views from their professional community and demonstrate the wisdom of their experience, a consumer can do the same. Remember today's patient who is managing the process of a new diagnosis and treatment journey might be tomorrow's representative.

There can be different amounts of energy and time involved in choosing consumer representatives depending on the type of input needed. A policy or governance group wanting consumer input requires different skills to a small focus group. It helps to think about the process of choosing a consumer representative in the same way as finding a candidate for a job vacancy, for example, letting people know that there is an opportunity to submit an expression of interest. Follow a transparent process and include relevant information as if you are publically advertising for the role. You may have a consumer already in mind. Perhaps one of your group members has received some powerful feedback from someone who has identified themselves, and that has resonated with you. Or maybe there is a patient who was treated some time ago who might be perfect for the skills you need. In this scenario, you could formally approach them in writing with an expression of interest.

Other key things to consider when finding a consumer representative follow.

## Clarify the role

Think about the role the consumer representative will hold. For example, is it to provide a consumer perspective on:

- patient information
- the design of a new outpatient waiting room
- family-friendly policies under review
- managing a chronic condition?

Do you need the consumer's own personal views or for them to represent a range of views from the community? For a disease group, you might need someone with personal life experience of that disease, who is able to not only utilise their own story, but also the stories of others in their community. Being well networked is an important part of consumer representative roles in governance.

## Identify the skills

Think about the transferable and personal skills you are looking for in your consumer representative. A core requirement for a consumer representative is the ability to use life experience in useful and meaningful ways, and to be able to see beyond their own situation and represent their community of interest. You may want someone with lived experience of a particular disease, but this is not always necessary. Other desirable requirements include:

- reasonable health literacy
- a working knowledge of the structure of the health system in New Zealand
- some knowledge of the population health issues and inequities that New Zealanders face, or the ability to understand these with a short period of education and support.

Consider the following questions:

- Does the role require experience in working at executive levels, in senior management or on boards?
- Do you need good computer or financial literacy?
- Will the role involve interpreting data or graphs, or is it more important to understand data from a non-technical point of view?
- Is demonstrated experience working with cross-community groups a requirement?



- Do you need a particular cultural perspective for the role?
- Does the group need to work collaboratively?
- Is the group strongly focused on outcomes?
- Does the role require strong links to communities so multiple views can be canvassed and represent the interest area?

## Provide support

Consumer representatives need encouragement, support and some initial training to understand their role in a hospital and the health system. Some organisations have resourced a dedicated patient engagement manager or facilitator whose role is to promote consumer engagement and support consumer representatives. This appears to be a pivotal role with potentially great influence. Experience shows that where these roles have been established, the cultural shift towards partnerships with consumers has happened more swiftly and easily.

Consider providing:

- a chart of the organisation's structure, particularly one that shows that there are other groups in the system with consumer representatives
- a glossary of technical terms to help people understand technical language or acronyms
- a staff member of the group, whose role includes mentoring consumer representatives, giving them space to speak, respecting their views and encouraging consumer representatives to participate in discussions
- dedicated administrative support. Consumer representatives need to know who to contact about minutes, papers, invoicing and parking
- linkages to other consumer representatives to discuss ideas, seek support and build confidence. Two consumer representatives in some groups may be more beneficial than one. Consumer representatives can link up via email, phone, social media or through regular meetings
- practical help, such as providing parking spaces or petrol vouchers, to make attendance easier.

## Remuneration

Being a consumer representative takes skill and time. Valuing the expertise of consumers as highly as the experience of staff is an important part of breaking down barriers to consumer engagement. Having a policy about the support and remuneration of consumers helps to ensure everybody within an organisation is on the same page. For example, the

Health Quality & Safety Commission has a policy that consumers who undertake more substantive input (such as in work programmes or attending day meetings) are paid in accordance with State Services Commission guidelines.

Discussions about remuneration need to be open and transparent to ensure consumers don't feel they are being taken advantage of or feel embarrassed to raise it as a legitimate concern.

When considering financial remuneration it is useful to ask these questions:

- Is the consumer taking time off work, meaning they will lose money?
- What are the expectations of the consumer when it comes to financial support?
- Where will the money be sourced from and how will it be paid?

## Advertising

Consumer representation starts with an open invitation to all consumers, encouraging them to get more involved. Organisations can actively recruit consumers interested in a higher level of engagement, and keep that invitation open through advertising.

To advertise publically, start by putting out an expression of interest. Include a role description describing the skill set you seek, terms of reference for the group involved and a remuneration statement. The expression of interest can be published:

- on your organisation's website
- on relevant public noticeboards
- on the Health Quality & Safety Commission's Partners in Care webpages
- via other consumer representatives in your organisation to their networks
- in writing to special interest community groups or non-governmental organisations (NGOs) in the area you wish to recruit.

Give people enough time to respond. Some NGOs and community groups hold monthly meetings, so you may need to allow at least 6–8 weeks before closure date.

Once you have received expressions of interest, select candidates to interview based on your criteria. Devise a shortlist, then organise either a face-to-face or phone interview or a group interview. A group interview can be a useful way to see how candidates interact with each other. At the interview you could have a mock 'issue' to discuss, which can be sent out with the invitation for interview.



Northland Health set up its Consumer Council in late 2014. You can read about this online at: <http://www.hqsc.govt.nz/assets/Consumer-Engagement/Publications/DHB-guide/DG007-Northland-health-consumer-council.pdf>

Various recruitment tools, checklists and examples are available here: <http://www.hqsc.govt.nz/our-programmes/consumer-engagement/publications-and-resources/publication/2163/#NZ-examples>.

They include:

- role description
- remuneration for time policy
- dedicated staff position of 'consumer representative facilitator'
- support and training – link to the Health Quality & Safety Commission's consumer representative training guide
- terms of reference for the advisory group the consumer is joining
- glossary of terms for the advisory group the consumer is joining
- organisational structure chart
- methods and means of linking with other consumer representatives
- terms of reference for a consumer council
- nomination forms for consumer representatives
- letter of introduction/expression of interest to consumer organisation
- selection criteria for consumer representatives
- advertisements/brochures inviting consumer representatives
- checklist 'Am I ready to become an advisor?'
- checklist 'Am I ready to engage with patient and family advisors?' 

“ After taking account of the patient safety and quality review and the aims of the Northland Health Services plan, the patient- and family-centred care project was established. A key piece of work was to establish a consumer council. The project, led by the chief medical officer, director of nursing and a clinical director, is strongly supported by the chief executive, executive leadership team and primary care alliances. ”

Liane Penney, Portfolio Manager, Northland Health Services Plan

# Measuring consumer engagement



# Measuring consumer engagement

What does successful consumer engagement look like? How will services and consumers know that consumer engagement is happening on all levels?

The National Quality Forum in America published a paper about the benefits and use of patient-reported outcomes, distinguishing structure, process and outcomes for patients in the health system. The National Quality Forum defines a patient-reported outcome as 'any report of the status of a patient's health condition, health behaviour, or experience with healthcare that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else.'<sup>34</sup>

**'Historically, with the exception of collecting feedback on satisfaction or experience with care, patients remain an untapped resource in assessing the quality of health care and of long-term support services. Patients are a valuable and, arguably, the authoritative source of information on outcomes beyond experience with care. These include health-related quality of life, functional status, symptom and symptom burden, and health behaviours.'**<sup>35</sup>

The Institute for Healthcare Improvement (IHI) offers web-based training for organisations interested in patient-reported measures. It believes that being able to measure patient-reported outcomes, such as symptoms, lifestyle and daily activities, is crucial for showing improvements in person-centred care over time. The IHI states that patient-reported outcomes offer 'a mechanism through which patients can have a voice in their treatment planning and decision-making based on their own self-assessments.'<sup>36</sup>

In New Zealand, the patient experience survey captures aggregate patient-reported data about satisfaction with care. Like any quality improvement initiative, improvements in consumer engagement should be specific, measurable, achievable, realistic and time-bound. Our webpage lists useful tools to help DHBs track how well they are progressing with

consumer engagement (see page 40). These measures could be reported in your quality accounts. The collation and aggregation of all forms of consumer feedback over time is in itself a measure of increasing engagement.

At the system level, measuring the success of consumer engagement means looking at all areas in which consumers have been involved – service design and delivery, policy development and governance.

To measure how well consumer engagement is being embedded in your organisation, you can do things such as build it into staff performance reviews, review the diversity of consumer representatives you have working alongside your organisation, and publicly report quality initiatives that have involved consumers.

At the individual patient level, it could be feedback about:

- the structure of the health system and processes
- the patient's journey through the health system
- the patient's understanding of their condition, treatment options and outcomes
- the extent to which the patient has been included in treatment decisions.

At the consumer representative and community level, measurement of consumer engagement could include:

- satisfaction surveys or qualitative interviews by consumers and the community about the level of influence in the organisation's decisions
- the diversity of consumers engaged in the organisation
- ongoing evaluation of the work of consumer councils, both from members and from the organisation.

The future for the measurement and evaluation of consumer engagement may lie in the development of a quality and safety marker. A marker would set expected levels of improvement and public reporting against negotiated thresholds. This could be part of the common accountability mechanisms, such as quality accounts, the annual report on quality improvement

34 National Quality Forum. 2013. *Patient Reported Outcomes (PROs) in Performance Measurement*. p3. Washington, DC: National Quality Forum. URL: [http://www.qualityforum.org/Publications/2012/12/Patient-Reported\\_Outcomes\\_in\\_Performance\\_Measurement.aspx](http://www.qualityforum.org/Publications/2012/12/Patient-Reported_Outcomes_in_Performance_Measurement.aspx) (accessed June 2015).

35 Ibid.

36 Savitz L, Luther K. 2015. Patient-reported measures. *Healthcare Executive* 30(1): 74–7.



activities. Any marker would need to be developed in partnership with services to ensure it meets agreed objectives and is an improvement tool for services to set goals and celebrate achievements.

**For more information about the Health Quality & Safety Commission's quality and safety markers go to: <http://www.hqsc.govt.nz/our-programmes/health-quality-evaluation/projects/health-quality-and-safety-indicators/>**

**For more information about patient-reported outcomes go to: <http://www.hqsc.govt.nz/our-programmes/consumer-engagement/publications-and-resources/publication/2163/#patient-experience>** 🍌

Further reading  
and useful links  
on the Health  
Quality & Safety  
Commission  
website

FURTHER READING AND USEFUL LINKS ON THE  
HEALTH QUALITY & SAFETY COMMISSION WEBSITE



## Further reading and useful links on the Health Quality & Safety Commission website

- New Zealand practice examples and interviews – <http://www.hqsc.govt.nz/our-programmes/consumer-engagement/publications-and-resources/publication/2163/#NZ-practice>
- New Zealand examples of consumer engagement documentation, policies, terms of reference and position descriptions – <http://www.hqsc.govt.nz/our-programmes/consumer-engagement/publications-and-resources/publication/2163/#NZ-examples>
- International resources about person-centred care and patient and family/whānau engagement – <http://www.hqsc.govt.nz/our-programmes/consumer-engagement/publications-and-resources/publication/2163/#international-resources>
- International guidelines and frameworks for consumer engagement – <http://www.hqsc.govt.nz/our-programmes/consumer-engagement/publications-and-resources/publication/2163/#international-guidelines>
- International organisational self-assessment tools – <http://www.hqsc.govt.nz/our-programmes/consumer-engagement/publications-and-resources/publication/2163/#international-self-assessment>
- New Zealand examples of web-based patient information and patient portals – <http://www.hqsc.govt.nz/our-programmes/consumer-engagement/publications-and-resources/publication/2163/#NZ-web-examples>
- Patient-reported experience and outcome measures articles – <http://www.hqsc.govt.nz/our-programmes/consumer-engagement/publications-and-resources/publication/2163/#patient-experience>
- International evidence research and articles about consumer engagement – <http://www.hqsc.govt.nz/our-programmes/consumer-engagement/publications-and-resources/publication/2163/articles-and-research>
- Co-design resources – <http://www.hqsc.govt.nz/our-programmes/consumer-engagement/publications-and-resources/publication/2163/#co-design>
- New Zealand consumer engagement guides, frameworks and competencies – <http://www.hqsc.govt.nz/our-programmes/consumer-engagement/publications-and-resources/publication/2163/#NZ-guides>
- Health literacy resources – <http://www.hqsc.govt.nz/our-programmes/consumer-engagement/publications-and-resources/publication/2163/#health-literacy>
- Māori resources – <http://www.hqsc.govt.nz/our-programmes/consumer-engagement/publications-and-resources/publication/2163/#resources-for-maori>
- Disability resources – <http://www.hqsc.govt.nz/our-programmes/consumer-engagement/publications-and-resources/publication/2163/#resources-for-disability>. 



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