Engaging with consumers

A guide for district health boards

(edited draft)

(DO NOT COPY)
“Nāku tē rourou nau tē rourou ka ora ai tē iwi”

“With your basket and my basket the people will thrive”
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Chief Executive’s foreword
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The Commission promotes and supports consumer engagement because it improves the quality and safety of health and disability services.
About this guide

"This is the next frontier of patient and family engagement – using the experience, expertise and insight of patients to improve care.” P 5, Ref Health Research and Educational Trust (2015, March). Partnering to improve quality and safety: a framework for working with patient and family advisors. www.hpoe.org

This is a practical guide to help New Zealand district health boards (DHBs) improve their consumer engagement, particularly at policy and governance levels.

It has been written by the Health Quality & Safety Commission in response to feedback from the health and disability sector, and consulted on widely. An expert steering group made up of providers and consumer representatives from each region provided extensive input, for which the Commission is grateful.

The guide builds on the consumer experience guide and toolkit developed by the DHBs’ quality and risk managers. It showcases our learning in consumer engagement in New Zealand and gives practical examples and case studies from work currently underway in DHBs.

While this guide focuses on the hospital setting, it is adaptable to the primary care setting. We acknowledge that cultural competency and flexibility are required to adapt the guide appropriately for the culturally diverse communities here, particularly for Māori and Pacific peoples.

This guide is neither prescriptive, nor exhaustive. Where possible, useful resources and further reading are included as links. Legislation, regulation and public policy are outside of scope.

Throughout the guide the term ‘consumer engagement’ means both patients and their families/whānau. The term includes person-centred care. There are four principles of person-centred care:

- Affording people dignity, compassion and respect
- Care that is integrated: That is coordinated and
- Personalised to the person’s individual health care needs and goals
- Enables people to recognise their strengths and live a meaningful and independent life as far as is possible.

These principles are the foundations for consumer engagement.¹

¹ The health foundation; person centred care made easy
Defining consumer engagement
Definitions of the term 'consumer engagement' vary. It is often interchangeable with the concepts of patient- or person-centred care. Some definitions stress the relationship between consumers and health care providers, the behaviours or actions that organisations and consumers can take, or the settings in which consumer engagement occur. All are associated with health literacy, shared decision-making\(^2\) and patient-centred treatment planning.

The Commission defines consumer engagement as:

‘... a process where consumers of health and disability services are empowered to participate in decisions about the treatment, services and care they 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.’\(^3\)

The American Institute for Research has developed a roadmap for patient and family engagement in health care. It describes patient and family engagement as ‘bringing patient and family voices to decisions about care, to healthcare organisational design and governance, and to public policy.’\(^4\)

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\(^2\) Shared-decision making with clinicians, where appropriate and wished for by consumers, does not replace the clinical judgement of the clinician, but is used in tandem with partnership with the patient. It involves discussing treatment options, medication options and asking questions to include the consumer’s goals of treatment and the wishes of their family/whānau. When done well, shared decision-making results in consumers being more engaged, more health literate and better able to self-manage.

\(^3\) Partners in Care, HQSC 2015

\(^4\) AIR: Carman et al 2014 p3
An introduction to consumer engagement

Consumer engagement is an essential component of quality and safety in health service design and delivery. Engaging consumers and providing patient-centred care has huge benefits in treatment outcomes, prognosis, morbidity and cost savings for organisations.\(^5\)

Consumer engagement in health care is a global movement. A world health summit in 2013 focused on the critical role consumer engagement will play in shaping future health services.

\[\text{‘The solutions to the health challenges of today and tomorrow won’t come from doing business as usual; they will come from building effective partnerships and harnessing the untapped global power of ordinary people who care about improving their health. There are powerful benefits from partnering with patients, families, communities, and healthcare workers at all levels.’}\]^6

Consumers are increasingly demanding opportunities to be actively engaged, not only in their own health care through shared decision-making, but also in service design and policy formation to collaboratively develop programmes for sustainable improved health outcomes, and in governance to influence strategic direction of health care.

Consumers can be engaged as individuals, or collectively, with increasing power to influence quality and safety, from being given choices to having a real voice in partnership and giving feedback about their direct care experiences.

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 the consumer’s experience and viewpoint can be lost in place of efficiency. Systems naturally focus on what is being measured. If time and efficiency and clinical outcomes are being measured, that is what clinicians will naturally focus on as targets. Engaging consumers helps ensure that person-centred care is valued.

Consumer engagement varies from person to person. Not all consumers will want to be involved at all times. For a person being told a new and frightening diagnosis, being informed about different treatment options, and actively involving the family may be enough. The person may be happy to be offered an opportunity for feedback about their care. Some people may want to get more involved in improving the experience of care for others through being a representative involved in service delivery strategy and design. Some people, with motivation and skill, may want to extend their representation of other consumers in governance.

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.\(^7\) 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,

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\(^5\) P6, World Innovation Summit for Health 2013: Patient and family engagement: partnering with patients, families, and communities for health: A global imperative.

\(^6\) P6, World Innovation Summit for Health 2013: Patient and family engagement: partnering with patients, families, and communities for health: A global imperative.

\(^7\) Coulter, A (2012) Kings Fund: Leadership for patient engagement p 16
well networked consumer councils working in parity with clinical governance and reporting to boards.

It is important to recognise that consumer engagement is not just the responsibility of the front-line clinician, it is also a core governance responsibility. The attitudes of Boards to consumer engagement and person-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 success in their organisations, and positive patient experience feedback.8

‘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.’9

In the New Zealand context, the Ministry of Health and the Commission expect DHBs to improve the consumer experience through increased consumer involvement in decision-making.10 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 managers and facilitators are starting to be resourced, and the formation of consumer councils are good examples supporting the work of consumer engagement.

[sidebar] The triple aim for New Zealand
The triple aim for quality improvement – better experience, improved population health and lower costs – cannot be realised without the meaningful engagement of consumers and their families/whānau.

There has been a recent paper calling to expand the international triple aim of health into a quadruple aim, including staff satisfaction and retention as the fourth dimension. This fourth component of compassionate caring staff who treat consumers with dignity and respect, and who listen to consumers’ needs and desires, is critical to successful consumer engagement.

ref: Bodenhiemer, T; Sinsky, C; (2014) From triple to quadruple aim: Care of the patient requires care of the provider. Annuals of Family Medicine 12(6) www.annfammed.org

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8 Bismark et al 2014
9 Bismark et al 2014, p147
10 HQSC statement of intent 2014-2018 p 34
The benefits of engaging with consumers

There is a large and growing body of international evidence to support the benefits of engaging with consumers. The benefits include better health outcomes, safer care, less waste, lower costs and better consumer and health provider satisfaction and retention. Engaged consumers have better health literacy so they are more likely to comply with treatment and medication and better able to self-manage long-term conditions. Equity of access to health care is also improved when consumers are fully engaged in their own care.¹¹

The Academy of Medical Royal Colleges UK reported in 2014 an estimate of up to 20 percent of clinical practice is wasteful; by the over-use of tests and interventions, not understanding the importance to patients of their own goals in care, 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… (A) realignment of clinical decision-making is required – where patient benefit and patient preference are balanced against patient harm and resources usage.’¹²

Consumer engagement also brings enormous benefits for staff. When staff re-engage in compassionate, person-centred care with engaged consumers, it has a powerful effect on the psychological influence of their wellbeing, as well as that of consumers. Dr Robin Youngson, creator of Hearts in Healthcare,¹³ 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 patient-centred care with engaged consumers 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.’ Dr Robin Youngson

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.

‘The industrialisation of healthcare with a focus on budgets, throughputs, production, and targets has dehumanised the system, causing a loss of compassion, increased patient suffering, fragmented care and burnt out healthcare workers.’ Dr Robin Youngson

More information

¹¹ P6, World Innovation Summit for Health 2013: Patient and family engagement: partnering with patients, families, and communities for health: A global imperative.
¹² Academy of Medical Royal Colleges. Protecting resources, promoting value: a doctor’s guide to cutting waste in clinical care. November 2014, p6
¹³ www.heartsinhealthcare.com
For more about the benefits of clinicians engaging with consumers, see:

- [www.heartsinhealthcare.com](http://www.heartsinhealthcare.com)
- [www.patientfamilyengagement.org](http://www.patientfamilyengagement.org)
- [http://www.ihi.org/Topics/PFCC/Pages/default.aspx](http://www.ihi.org/Topics/PFCC/Pages/default.aspx)
- [www.kingsfund.org.uk](http://www.kingsfund.org.uk)
- [http://www.wish-qatar.org/app/media/387](http://www.wish-qatar.org/app/media/387)
- [www.hpoe.org](http://www.hpoe.org)
Features of organisations engaging well with consumers

Being a health and disability provider engaged with consumers involves:

- Being person-centred, i.e., putting consumers and their families/whānau at the centre of care, so they are enabled to self-manage conditions as far as possible, and offered opportunities for shared decision-making where possible
- Listening to consumers’ values, preferences and goals for treatment
- Being respectful and genuine with consumers – being interested and humane
- Making consumer engagement safe and mutually valuable for everyone involved
- Providing consumer roles in expert advisory groups and committees
- Developing a consumer council alongside clinical governance
- Taking consumer views seriously – not just going through the motions; ‘walk the talk’, ‘what we do is who we are’
- Transparency – being open and honest, sharing information, having real consultation
- Ensuring consumers are supported and appropriately resourced – be welcoming and show patience, ‘your expertise is valued’.
- An open invitation for consumers to engage – ‘we want someone just like you’, and flexibility about how consumers can engage.

Providers who are well engaged with consumers take the following actions.

Organisational preparedness and readiness:

- Leadership facilitating consumer engagement from the Boardroom to the waiting room
- Identifying staff champions at all levels of the organisation to lead the shift in values required for consumer engagement
- Resourcing and supporting all staff to make the cultural shift to value consumer engagement, through training in values and understanding the benefits of consumer engagement and its crucial role in building staff satisfaction and retention
- Making a culture or values shift in the organisation – when the values of the organisation are person-centred, then consumer engagement is valued.

Policy and governance:

- Senior leaders in your organisation champion consumer engagement
- Developing a vision of consumer engagement for the whole organisation
- Consumer representation at senior leadership level
- Establish a consumer council alongside clinical governance
- Use patient stories in every board meeting
- Bring senior leaders to ward rounds, and make opportunities to talk to patients about their experiences.

Integrated care:

- Involving consumers and families in their own care planning
- Ensuring good mechanisms are created to support communication between hospital and community services, and avoiding duplication and repetition
• Supporting the use of shared electronic records wherever possible and permitted by the consumer
• Bedside handovers become the norm
• Consumer and family centred discharge planning, listening to their values, preferences and goals of care.

Service design and evaluation:
• Co-design of services- working in partnership with consumers
• Quality improvement initiatives all involving consumers
• Mapping patient journeys through an episode of care from GP through to hospital admission, stay and discharge
• Patient experience survey data and other consumer feedback being used in real-time feedback to health clinicians and consumers, such as through quality boards in hospitals, on DHB websites, and visible to staff and consumers
• Publicise ‘you said, we did’, showing how feedback from consumers is influencing change.

Cultural competency:
• Uphold the three key principles in health that align with the Treaty of Waitangi and Whānau Ora, and are also at the heart of consumer engagement:
  o participation at all levels
  o partnership in service delivery
  o protection and improvement of Māori health status.\(^{14}\)
• Collaborate closely with whānau, hapū and iwi, to create the best mix of services for each local community
• Education to ensure that clinicians respect the diversity of different communities, and understand and respect that their own culture may have an impact on the relationship
• Respect differences and ask questions to clarify what is important to the consumer
• Connect Māori consumer representatives together and supporting professional development.

Engaged staff:
• Support and encourage staff to review the culture and values of the organisation – this is re-invigorating and connects them with the core meaning of their work, which can otherwise get lost in the stressful demands of a busy workplace
• Provide values training involving consumers, such as ‘in your shoes, in our shoes’ – this will help to ensuring organisational values and structure reflect being patient-centred
• Promote the particular skills required to actively partner with consumers and elicit feedback – consider investing in staff training in skills such as active listening, giving room and respect for consumers’ concerns and opinions, and checking back for understanding (such as the ‘teach-back’ method).

\(^{14}\) The New Zealand Health Strategy, 2000
A New Zealand Framework

There are a number of different frameworks that can be used to describe consumer engagement from a ladder to a matrix of engagement. (ref Carman et al, Coulter, A, and Gary Hickey). Consumers can be engaged as individuals and collectively with increasing power to influence quality and safety, from being given choices to having a real voice in partnership. Consumers can give feedback about their direct care experiences, and consumers can have representatives in health service design, policy and governance to influence strategic direction of health care.

Consumer engagement also varies from person to person. Not all consumers will want to be involved at all times. For a person being told a new and frightening diagnosis, being informed about different treatment options, and actively involving the family may be enough. The person may be happy to be offered an opportunity for feedback about their care. Some people and may want to get more involved in improving the experience of care for others through being a representative involved in service delivery strategy and design. Fewer people, with motivation and skill may want to extend their representation of other consumers in governance.

The invitation of this guide is to place the consumer at the centre of care. We have developed the framework below to encapsulate what it means to be fully engaged with consumers in your organisation:

More information
For more about frameworks for consumer engagement see: A Multidimensional Framework for Patient and Family Engagement in Health and Health Care.  


Ways to engage consumers

Assess your organisational readiness

The American Institute for Research roadmap for patient and family engagement in health care\textsuperscript{16} suggests eight change strategies relating to direct care, organisational design, and governance and public policy. These change strategies are a useful way to organise the approach to getting your organisation ready to engage consumers.

The roadmap stresses that all steps must be made in partnership with patients and family:

- patient and family preparation
- clinician and leadership preparation
- care and system redesign
- organisational partnership
- measurement and research
- transparency and accountability
- legislation and regulation
- partnership in public policy.

Dr Gary Hickey and colleagues\textsuperscript{17} conceptualise consumer engagement as a continuum from ‘choice to voice’ and from the individual consumer to collective representation. They suggest organisations use this ladder of engagement framework to gauge where they are on the continuum and where they would like to be. In some areas of your organisation, consumers may be at the information stage; other areas may have consumer representatives sharing decision-making in parity with clinical governance.

\textit{Link to diagram below:}

<table>
<thead>
<tr>
<th>Consumer ladder of participation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full control</td>
<td>Consumers control decision-making at the highest level</td>
</tr>
<tr>
<td>Sharing power</td>
<td>Consumers share decisions and responsibility, influencing and determining outcomes</td>
</tr>
<tr>
<td>Participation</td>
<td>Consumers can make suggestions and influence outcomes</td>
</tr>
<tr>
<td>Consultation</td>
<td>Consumers are asked what they think but have limited influence</td>
</tr>
<tr>
<td>Information</td>
<td>Consumers are told what is happening but have no influence</td>
</tr>
<tr>
<td>No control</td>
<td>Consumers are passive recipients</td>
</tr>
</tbody>
</table>

Your organisation is likely to be doing many activities to engage consumers already, particularly at the level of direct care. For example, patient experience surveys, comment


\textsuperscript{17} At the Faculty of Health and Social Care Sciences, Kingston University and St Georges University of London
boxes on wards, complaints and compliments, and feedback on your website. You may also have completed experienced-based co-design research projects involving consumers, or have consumer representation on expert advisory committees or disease groups.

This checklist will help you assess what your organisation is already doing, and where to start to engage consumers at higher levels. Insert “partnering with consumers: a self-assessment tool” checklist here

More information

For more about assessing your organisation’s readiness to partner with consumers see:
- ACSQ partnering with consumers self-assessment tool
- IHI hospital self assessment checklist

For more about checklists, see:
- www.ahrq.gov/professionals/systems/hospital/engagingfamilies/index.html AHRC (agency for healthcare research and quality) training guide
  - supporting patient and family engagement: best practices for hospital leaders
  - Ways to learn more – information to help get hospitals started
  - How patient and family engagement benefits your hospital
  - Readiness to partner with patient and family
  - Am I ready to become an Advisor?
- IHI Patient and family centred care organisational self-assessment tool http://www.ihi.org/resources/Pages/Tools/PatientFamilyCenteredCareOrganizationalSelfAssessmentTool.aspx

Make the culture and values shift

For organisations to engage consumers and put patients and their families at the centre of care, a shift in organisational values and culture has to occur. A values or cultural shift within an organisation will not just happen. It will need support, resourcing and champions. There is a lot written about the importance of leadership to affect the kind of cultural shift that is required to fully engage consumers. Leaders can be found throughout an organisation. It is crucial that senior leaders set clear expectations and role-model respect for consumers’ views. (ref Angela Coulter leadership article, Kingsfund, )

Organisations will need to reflect this cultural shift through clearly articulated values and mission statements, and operational policies in consumer engagement. For example, remuneration for consumer representative’s time and costs, and clear terms of reference and role descriptions for representatives on committees and groups.

It is also important to:
- Publicly celebrate successful initiatives that have involved consumers.
- Provide dedicated staff such as consumer engagement facilitators or managers, whose role is to support the development of consumer leaders, facilitate the
development of a consumer network and provide training for new consumer representatives

- Promote the cultural shift towards person-centred care and involving consumers at all levels amongst staff. Review the organisations' culture and values with staff. This can not only support staff, but is re-invigorating and connects staff with the core meaning of their work.
- Invest in staff training in communication skills such as active listening skills, giving room and respect for the consumer's concerns and opinions, and checking back for understanding, such as the “teach-back” method.
- Appoint consumer representatives to roles in policy development and governance levels, such as expert advisory groups. This is a key driver of cultural change in organisations. Such representatives widen thinking and support innovative solutions that might not be developed otherwise. (Further information about appointing consumer representatives is on page X.)

Insert “For more information Text box” here

with references to Kingsfund, Angela Coulter, AIR roadmap, AHRC
http://www.kingsfund.org.uk/leadership/leading-collaboratively-patients-and-communities?dm_i=28QT,6TYY,3NQXG7,F0O5,1

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 engagement 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, via the DHB website, in writing by post, or in feedback boxes, or through phone calls to the DHB.

Another way to capture consumer experience is by mapping the patient journey and using this in experience-based co-design quality improvement initiatives. Mapping the patient journey shows gaps in service provision, and areas where simple improvements, such as signage and information, can make an enormous difference to the consumer experience.

The telling of powerful stories is increasingly being used as a method of learning. 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 videoed 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.
Involve consumers in service planning, policy and quality improvement

Many consumers are involved in organisations collectively by representation on expert advisory groups, disease-focused standing committees and special projects such as service redesign. 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 a committee or group. Some DHBs\(^\text{18}\) have formed consumer councils made wholly of consumer representatives, and others are in development. These councils have a strong relationship with clinical governance and report to the board.

"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." P6


www.hpoe.org

Additional resources Link: Case study example: the formation of the Northland consumer council story here?

Get connected

Increasingly, consumers wish to interact online with their health service providers. Patient portal use is on the rise in primary health, for example, Managemyhealth,\(^\text{19}\) alongside the increased use of shared electronic records with secondary services and hospitals. Patients can order 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. Google searches for side effects of medication and management of diseases are very common. Websites such as HealthNavigator\(^\text{20}\) and Medsafe\(^\text{21}\) 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 Commission encourages DHBs to review their web presence, and build in patient portals.

\(^{18}\) At the time of publication, Hawke’s Bay, Canterbury, West Coast, Counties Manakau and Northland DHBs had consumer councils.

\(^{19}\) www.managemyhealth.co.nz

\(^{20}\) www.healthnavigator.org.nz

\(^{21}\) www.medsafe.govt.nz
Simple things you can do now
There are some simple things that you can do straight away to support better consumer engagement: 22

- **Patients and families** can give their feedback to health services providers, find out more information about their health conditions, get ready for their next health care visit, keep track of their medicines and medical information, and volunteer to become more involved. The 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.

- **Health care clinicians** 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.

- **Organisations** can establish family presence 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 publically throughout the organisation and through multiple sources, and ensure the feedback loop is closed through ‘you said, we did’ initiatives.

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22 Adapted from AIR Roadmap for patient and family engagement in health care page 51.
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 and overcome by recruiting 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.

Think about the process of choosing a consumer representative like finding a candidate for a job vacancy. 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. In the interests of transparency, you should follow a process and include relevant information as if you are publically advertising for the role.

Some of the other key things to consider when finding a consumer representative follow.

Role

Think about the role the consumer representative will hold. For example, is 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 the stories of others in their community. Being well networked is an important part of consumer representative roles in governance.

Skills

Think about the transferable and personal skill set of the consumer that you will need. 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 themselves. 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 this with a short period of education and support.

These questions are also good to consider:
• Do they need experience in working at executive levels, in senior management, or on boards?
• Do they need good computer or financial literacy?
• Must they be able to interpret data or graphs, or is it more important they can understand data from a non-technical point of view?
• Have they demonstrated experience working with cross-community groups?
• Do you need a particular cultural perspective?
• Are they good at working collaboratively?
• Are they outcome focused?
• Are they well networked in their own communities so they can canvas views and represent the interest area?

Support
Consumer representatives need encouragement, support and some initial training to understand the context of their role in a hospital and the health system. The following are useful:

• an organisational structural chart, particularly one that shows where other groups with consumer representatives are
• a glossary of technical terms to help them understand technical language
• encouragement to participate, particularly at first – staff in organisations can support consumer representatives by giving them space to speak and by respecting their views
• dedicated administrative support – consumer representatives need to know who to contact about minutes, papers, invoicing and parking.

Consumer representatives also need support from one another. Two representatives in some groups may be more beneficial than one. It is important that consumer representatives can link up via email or phone or through regular meetings. 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. Where these roles have been established, the cultural shift towards partnerships with consumers has happened more swiftly and easily.

Remuneration
Being a consumer representative takes skill and time. Representatives should be remunerated in some way for their time. Practical help, such as a parking space and petrol vouchers, can be very useful. The Commission’s policy is that consumers are paid in accordance with State Services Commission guidelines.

Advertising
Consumer representation starts with an invitation. Organisations should 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 in several ways:
- on your organisation’s website
- on relevant public noticeboards
- on the Commission’s Partners in Care web pages
- disseminated through 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.

*Insert text box here of Northland DHB consumer council formation story here?*

**Recruitment tools, checklists and examples**

*(need to add links to examples here)*

- Role description
- Remuneration for time policy
- Dedicated staff position of “consumer representative facilitator”
- Support and training – link to HQSC consumer rep training guide
- Terms of reference the advisory group the consumer is joining
- Glossary of terms for the advisory group the consumer is joining
- Organisational structural chart
- Methods and means to link to other consumer representatives
- Terms of reference for a consumer council
- Nomination forms for consumer representatives
- Letter of introduction/ EOI to consumer organisation
- Selection criteria for consumer representatives
- Advertisements/brochures inviting consumer representatives
- Checklist AHRC “am I ready to become an advisor?”
- Checklist AHRC “Am I ready to engage with patient and family advisors?”
Measuring consumer engagement

As we become more person-centred in our care delivery systems, the consumer’s journey throughout the episode of care should be valued and measured. Reports of pain, understanding of explanations, treatment proposals in line with their own life goals, ease of navigation through the hospital and having the presence of family in times of great vulnerability are all important.

‘Measures don’t just tell us about the performance of a system – they can drive the performance of the system… If we want to put patients first, we need to put person-centred measures first, (and) put the right measures in the right place by thinking about context and coherence.’

One of the challenges of measuring consumer engagement is that it is often conceived as a value or principle. The inherent problem is, how do we measure the extent to which the system takes account of what matters to the patient? How do we alter our measurements from the accuracy of answering ‘What is the matter with you?’ to answering ‘What matters to you?’ While we cannot measure a principle or value easily, we can measure discrete activities (eg, counting the number of groups with consumer representatives) to assess the structure of the organisation in its policies, and the processes that have been developed with consumer input.

We can also measure patient experience or patient reported outcomes. A patient reported outcome is anything the patient feeds back to clinicians, without interpretation or interference, about their health care experience or understanding of their health condition or health status. It could be feedback about:

- the structure of the health system and processes
- their patient journey through the health system
- satisfaction with their understanding of their condition, treatment and outcomes
- the extent to which they felt included in treatment decisions.

In mental health, measuring patient reported outcomes is increasingly common but in general health this work is much newer. Although there are numerous measures for quality of outputs and activities from an efficiency perspective, there are few measures for patient reported outcomes.

The National Quality Forum in America recently published a paper about the benefits and use of patient reported outcomes, demonstrating a clear pathway from measuring structural, process and outcomes for patients in the health system.

‘Historically, with the exception of collecting feedback on satisfaction or experience with care, patients remain an untapped resource in assessing the quality of healthcare and of long-term support services. Patients are a valuable and, arguably, the authoritative source of information on outcomes beyond experience with care.

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23 P16 Alf Collins: measuring what really matters
These include health-related quality of life, functional status, symptom and symptom burden, and health behaviours.  

The Institute for Healthcare Improvement offer web-based training for organisations interested in patient reported measures. They believe being able to measure patient reported outcomes such as symptoms, lifestyle and daily activities, will be crucial in showing improvement in person-centred care over time. The IHI state 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” (p74) (ref: Savitz, L; Luther, K; (2015) patient-reported measures: collecting this data is critical to the value equation (2015) healthcare executive 2015 Jan: 30 (1): pp74-77

In NZ, the patient experience survey is an excellent start in capturing 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. The checklist for organisations on page X is a useful tool for tracking how your DHB is progressing with consumer engagement, and these could be reported in your quality accounts. In addition, the collating and aggregating of feedback over time is a measure of increasing engagement.

To measure how well consumer engagement is being imbedded in your organisation, you can build changing values into your staff performance reviews, count the number of consumer representatives you have working alongside your organisation, and publically report quality initiatives that have involved consumers.

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24 (P3, patient reported outcomes in performance management http://www.qualityforum.org/Publications/2012/12/Patient-Reported_Outcomes_in_Performance_Measurement.aspx)
Further reading and useful links

- Institute for Health Improvement: Patient and family centred care website [http://www.ihi.org/Topics/PFCC/Pages/default.aspx]
- IHI Patient and family centred care organisational self-assessment tool [http://www.ihi.org/resources/Pages/Tools/PatientFamilyCenteredCareOrganizationalSelfAssessmentTool.aspx]
- Kingsfund UK; patient-centred care quality improvement innovation and research [www.kingsfund.org.uk](http://www.kingsfund.org.uk)
- [www.managemyhealth.co.nz](http://www.managemyhealth.co.nz) Patient portals in NZ
- [www.healthnavigator.co.nz](http://www.healthnavigator.co.nz) Patient information website
- [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) measuring patient reported outcomes
  - supporting patient and family engagement: best practices for hospital leaders
  - Ways to learn more – information to help get hospitals started
  - How patient and family engagement benefits your hospital
  - Readiness to partner with patient and family
  - Am I ready to become an Advisor?
- Carman et al: Patient and family Engagement: A framework for understanding the elements and developing interventions and policies (full ref required)
- Angela Coulter: Leadership for patient engagement (full ref required)
- Academy of Medical Royal Colleges. Protecting resources, promoting value: a doctor’s guide to cutting waste in clinical care. November 2014
- Bismark, M; Biggar, S; Crock,C; Morris, J; Studdert, D (2014) The role of governing boards in improving patient experience: attitudes and activities of health service boards in Victoria, Australia. Patient Experience Journal Vol 1, pp 144- 152
• Bodenhiemer, T; Sinsky, C; (2014) From triple to quadruple aim: Care of the patient requires care of the provider. Annals of Family Medicine 12(6) www.annfammed.org

• Richards, T; Montori,V; Godlee, F; Lapsley, P; Paul, D; (2013) Let the patient revolution begin. Patients can improve healthcare: it’s time to take partnership seriously. BMJ 2013; p346


• Savitz, L; Luther, K; (2015) patient-reported measures: collecting this data is critical to the value equation (2015) healthcare executive 2015 Jan: 30 (1): pp74-77