



Malatest
International

Health Quality & Safety Commission

Evaluation of the Partners in Care
programme

March 2016



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Executive summary

The Health Quality & Safety Commission was established in November 2010. The aim of the Commission is to work with clinicians and health managers to support and encourage quality and safety improvements, to identify areas where improvements can take place, and to drive changes that will make a real difference to consumers' experiences of health care.

The Commission's Statement of Intent 2011–14 committed to the introduction of the patient and consumer engagement and participation programme of work. The vision of the programme is to influence a fundamental shift in the engagement of health consumers from 'passive recipients' of their health care to 'active partners in care.' As active partners, health consumers will be involved in decision-making in the care they receive, and in the service design, delivery, policy and governance of the health and disability sectors in New Zealand.

The Partners in Care – consumer engagement (PIC) programme is based on growing evidence about the benefits of partnerships with consumers. In a survey of consumer representatives included in the evaluation a consumer representative wrote:

We are working for a common goal... we must all benefit in working together to make our healthcare as open and caring as possible. That we are valued and our worth is recognised. How can you help us if we don't tell you how we feel? If we are listened to with respect, that will encourage us to be open with you. And for us to tell you exactly how it is. Together we can do so much more... Consumer representative – survey

It is now year four of the PIC programme and the Commission has requested an evaluation of the programme to answer the following questions:

- How successful has the programme been in influencing change?
- To what extent have the programme's activities been guided by an evidence base?
- What are the remaining gaps in consumer engagement activities to achieve the PIC programme framework's aims and objectives?
- What are the key and emerging areas for future focus?

Information for the evaluation was drawn from:

- document and literature review
- surveys of 30 Commission staff (completed by 30), 159 organisation stakeholders, eg, district health boards (DHBs), primary health organisations (PHOs), government agencies and 127 consumer representatives
- interviews with 46 stakeholders, including Commission staff, organisation stakeholders and consumer representatives.

The Commission's role

In the PIC programme, the Commission is a catalyst for change. It provides leadership, examples of best practice, and works with its own staff, health provider organisations and consumers to build recognition of the benefits of consumer engagement and how

organisations and consumers can effectively engage. Its effectiveness is dependent on the organisations and individuals it influences to make changes.

As well as the PIC programme, all Commission staff have an important role in influencing partnerships with consumers through their programme workstreams: medication safety, infection prevention and control, adverse events, reducing harm from falls, health quality evaluation, safe surgery and mortality review.

Within the Commission, the board, senior management and staff strongly support the Commission's leadership role in consumer engagement. In response to the survey, almost all Commission staff agreed it is very important to involve consumers in decisions about their own personal health care, with one considering it to be quite important. Slightly fewer, but still most staff considered it very important to involve consumers in co-design of health services and governance of organisations that develop policies or provide health care.

While the value of consumer engagement is recognised, many Commission staff (and similarly stakeholders in other organisations), considered consumer engagement in co-design and governance was in the early stages or still developing in the Commission (69 percent and 66 percent respectively).

Commission staff felt very well supported by the PIC team and the information on the Commission intranet and website. However, many would appreciate more education and training about how to include consumers in their programme workstream.

There were different views on how the consumer voice can be effectively brought to the Commission's board. A frequent comment by Commission staff in interviews and the survey was that because the Commission did not have a consumer member on the board it did not model best practice. The absence of a consumer on the Commission's board was also noted by some of the consumer representatives and organisations who participated in this evaluation.

The evaluation suggests a number of activities within the Commission could build the organisation's consumer engagement and expand the role of staff as influencers through their work programmes and networks.

- At a strategic level:
 - Discussion between the board and Commission managers and potentially the Minister about current differences in opinion, to reach a consensus about how to include consumer views in the Commission's board.
 - Review of the Commission's annual strategic planning to more explicitly integrate consumer partnerships into each programme.
- At an operational level:
 - Programme planning to more explicitly include how consumers will be involved in each workstream and the role and expectations of consumers.
 - Greater coordination between the consumer network and consumers on individual programmes.
 - Clarity in Commission policies about consumer engagement, roles, 'job' descriptions and duration of tenure.
- Raising awareness among staff, especially those who are not managers, of the Commission's consumer engagement activities:

- Promotion of the different PIC programme activities to staff.
- Staff education and training about consumer engagement and activities such as health literacy.

How health care organisations are involving consumers in health care

There was support from the majority of organisation and consumer stakeholders about the value of engaging with consumers. All supported the value of consumer engagement in direct/personal health care. Fewer, but still the majority, supported consumer engagement in co-design and governance. Most organisations had better developed consumer engagement in direct/personal health care than in co-design or governance.

As with Commission staff, there was a general feeling among organisations and consumer stakeholders that progress has been made towards effective consumer engagement, but that it is difficult and there is still a long way to go.

Around the country consumers have been involved in a range of activities to improve direct care, including:

- developing (with the Commission) the *Let's Plan* flyer, to help people prepare for a visit to the GP
- participating in patient stories (which are shown to clinical staff and board members)
- participating in annual patient safety weeks
- being part of 'in your shoes' sessions, where consumers have the opportunity to tell health professionals and staff about their experience of health care services
- engaging in health literacy education and training.

Examples of consumer engagement in co-design include:

- co-design of information: the development of information pamphlets (what to expect when receiving treatment, how to avoid risks related to surgery, etc) as well as correspondence and feedback forms; improving signage within a health organisation; and the redesign of a website.
- co-design of services: changing visitor policies; shaping the design of wards, and new buildings/infrastructure (eg, car parks); designing service models and defining clinical care pathways.

Consumer representatives at governance/leadership levels can contribute at a more strategic level, drawing on 'learned' experience (often from other leadership roles), as well as lived experience. A greater ability to provide representative advice is needed at this level. The volume and complexity of information that needs to be absorbed to be effective in this role requires different skills. The time commitment also increases, as well as the length of engagement. Some consumers were not interested in a governance or leadership role. There was recognition that more is needed to support consumer engagement at the governance level, and of the importance of engagement at this level.

Consumer representatives/advisors interviewed or surveyed as part of this evaluation were generally positive about their engagement with health care providers. Most were positive about processes used, felt treated with respect (84 percent) and felt they were listened to (72 percent). Nearly three-quarters (73 percent) felt their contribution was valued. Overall,

two-thirds (66 percent) of consumer representative survey respondents felt that things improved as a result of feedback consumers provide.

How has the PIC programme influenced change?

Several interviewed stakeholders talked about changes across the health sector that were led at least to some extent by consumer engagement in mental health. It is not possible to directly attribute changes in attitudes to consumer partnerships in health care to the Commission's activities. However, the Commission is recognised as an organisation that is leading sector-wide change. The general view is that the Commission is effective in promoting partnerships between providers and consumers.

Making changes is a staged process that requires awareness of the benefits of change, of the need to change, knowledge of how to make changes, and the ability to make changes and reinforce them. Most organisation stakeholders and consumer representatives included in the evaluation were aware of the Commission's activities to influence change (just under three-quarters of each group surveyed).

Awareness of the benefits of change: Many examples were provided of the benefits of effective engagement with consumers. Benefits include better health outcomes for consumers and more efficient and effective health service delivery. The cost savings of more efficient services and the reduction in waste were described as representing value for money.

Awareness of the need to change: In all regions consumers and organisations felt there were people in leadership who were behind/actively supported the approach (even if this was not yet as widespread within an organisation as hoped) – and the journey had at least started.

Knowledge of how to make changes: Knowledge of how to make changes to involve consumers was highlighted as an area of uncertainty for many.

- In direct/personal health care, the Commission's work on health literacy has contributed to more effective communication between consumers and clinicians. The evidence-based health literacy resources for health professionals and *Let's Plan for better care* are examples of tools that have enhanced individuals and organisations ability to make changes.
- While there were some examples of consumer engagement in service design and delivery, for many DHBs consumer engagement in co-design still meant development of pamphlets and other information for consumers. In 2012, the Commission ran a co-design course supporting providers and consumers to learn about co-design (which was very well received), and has shared examples of co-design initiatives.
- Consumer engagement in governance was more effective where the consumer and the board chair were experienced in governance roles. Although aimed at chairs of meetings in general, the Commission's guidance to chairs about how to involve consumers contributes to effective engagement.

The ability to make changes: Examples of what was working well and where there are challenges was provided through interviews and surveys.

Generally, engagement worked better for consumers and organisations when:

- there was a clear reason for engagement, for example, engagement about single issues or specific programmes, and consumers and organisations had shared expectations about the partnership
- when consumers felt respected and an equal member of the team and that what they said made a difference.

There were also some frequently mentioned barriers to consumer engagement:

- Lack of consumer awareness of consumer representative/advisor roles and feelings they did not have anything to contribute
- Finding consumers who were the right fit for the task required
- The need for education and training for consumers and organisations:
 - For consumers, support for them in the role as representatives was frequently raised, most often induction, providing 'representative' views and how to operate effectively at the governance level
 - For organisations, education for them about how to work with consumers.

Monitoring – sustaining and reinforcing change: For many consumers and organisations, once they had experienced effective engagement they recognised the benefits. These benefits were mainly around improved processes and care for consumers. Other benefits noted were more cost-effective services and improved staff job satisfaction and morale. The development of targets and/or quality improvement markers for consumer engagement was suggested as a way to focus health provider organisations on consumer engagement.

To what extent has the programme been guided by an evidence base?

Initial planning and development of the PIC consumer engagement programme was based on a review of evidence confirming the value of consumer engagement.

Developing effective partnerships in health care is an emerging area. The Commission has:

- used existing evidence where it is available for activities it develops or commissions to support consumer engagement
- contributed to building the body of knowledge by evaluating new activities and publishing information and evaluation findings.

Remaining gaps in consumer engagement activities to achieve the PIC programme framework's aims and objectives

The Commission and PIC programme have filled the previous gap for a lead agency in consumer engagement. However, changing attitudes and increasing consumer engagement require a major culture shift especially in organisations that are just starting to recognise the need for change.

The Commission is a relatively small agency and cannot do this alone. It has led the way but support is required from other key central government agencies to make consumer engagement a strategic priority, align their activities with those of the Commission and model 'best practice'. In this way a clear message is sent to organisations in the health and disability sector that consumer engagement is a strategic priority.

To date most of the Commission's work has been focused on DHBs. Stakeholders commented on the gap and the Commission's future work programme includes an increased focus on primary care through PHOs.

At an operational level there are gaps in understanding the consumer representative role and knowing how to effectively engage. The Commission has developed a suite of resources to guide consumer engagement. However, active promotion of consumer engagement and how to do it is necessary.

Active promotion needs to be multi-pronged to be effective, targeting chief executives through to frontline staff. The PIC team has started this process through various channels including consumer engagement grand rounds. Follow up with practical advice, education and training, and support for change is required. The Commission's mandate does not include operationalising programmes and providing education and training. However, there is no clear alternative.

What are the key and emerging areas for future focus?

The first years of the PIC programme have raised awareness of the need for change and to promote the benefits of change by highlighting the advantages of consumer engagement. The PIC programme's evidence-based resources and tools, and best practice examples of how change can be achieved, have helped some organisations make changes.

Organisations are at different stages on a pathway to effective consumer partnerships. A continued focus on awareness-building is necessary for some in the early stages of development whereas others would benefit from more guidance about how to engage consumers. Some have well developed consumer engagement in direct/personal care and may benefit most from more advice about how to include consumers in governance.

There was recognition among many of the stakeholders that while good progress has been made, there is still a long way to go. The need for the Commission to persist and stay the course was noted, and captured well in the quote from a consumer representative below.

It's a long, arduous journey into foreign territory as most of us have not felt as though we are in charge of our health. This takes time, new awareness and a few messy attempts to get started. It's important for the Commission to persist, even if it seems progress is slow.

Consumer representative – survey

The PIC programme's limited resources were noted by internal and external stakeholders. Some commented that the programme budget is unlikely to change substantially. Therefore, a Commission-wide focus on how best to use the resources available is the next step. The importance of involving consumers in decisions about the next steps was highlighted.

A detailed overview of potential next steps is provided in the body of this report.

1. The Partners in Care – consumer engagement programme

What is consumer engagement?

Consumer engagement is 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.

Engaging with consumers: a guide for district health boards (2015), Health Quality & Safety Commission

The health system has developed in a way that has encouraged passivity in consumers, where they present with problems for clinicians to fix.

Years gone by it used to be that patients were grateful to receive what they received and no one questioned it. People in white coats were god-like. Organisation DHB – interview

Increasingly there has been a recognition of the need to shift from traditional interactions to ‘collaborative’ interactions, where patients believe they have an active role to play in their health, are supported in defining their own goals and in shared decision-making with their clinician.¹

Proactive consumer engagement helps to improve systems and services by making them more aligned to consumer needs, and through this increasing the likelihood of earlier treatment, better quality and safer care.

If services are more consumer friendly, people will engage earlier. That means they will have less advanced health needs, which is better for them and for the health system. Consumer representative – interview

Without proactive consumer engagement, the impetus for change is usually either motivated internally through system failures (eg, adverse events) or from external advocacy to improve the quality and safety of care. Waiting until there is a problem creates avoidable costs for consumers (physical, psychological and economic) and organisations (review processes, staff morale and more expensive treatments).

There is growing evidence about improved outcomes from consumer engagement, although it is difficult to separate out improvements that are directly attributable to consumer participation. It is also important to note a lack of evidence is not the same as a lack of effect.²

How do you demonstrate the benefits and value such as freeing up resources and using consumers to save money? Commission manager – interview

¹ Co-creating health framework, Dr Phillips, Director of Allied Health, Hawkes Bay.

² Crawford, M.J., Rutter, D., Manley, C., Weaver, T., Bhui, K., Fulop, N., Tyrer, P. (2002), Systematic review of involving patients in the planning and development of healthcare. British Medical Journal, 325:1263-7.

Consumer engagement can improve outcomes for consumers and health care providers through:

- direct care – where shared decision-making and communication increase understanding and adherence to care plans
- co-design of service delivery models – consumer engagement helps to ensure providers know how to deliver services based on the needs of consumers. Services that reflect consumer needs and where consumers feel part of decision-making are better quality and safer services. As well as improving the experience for consumers, there can be huge benefits in treatment outcomes, prognosis, morbidity and cost savings for organisations³
- governance – where consumers contribute to critical decisions about organisations' strategic priorities.

Effective consumer engagement and building partnerships with consumers requires a fundamental shift in mentality and culture, for both consumers and clinicians. Making changes is a staged process that requires awareness of the benefits of change, of the need to change, knowledge of how to make changes, the ability to make changes and monitoring progress to reinforce changes.

The Health Quality & Safety Commission's Statement of Intent 2011–14 committed to the introduction of the patient and consumer engagement and participation programme of work. The vision of the programme is to influence a fundamental shift in the engagement of health consumers from 'passive recipients' of their health care to 'active partners in care'. As active partners, health consumers will be involved in decision-making in the care they receive, and in the service design, delivery, policy and governance of the health and disability sector in New Zealand.

The overall Partners in Care (PIC) framework and programme of work was developed in 2012. The key themes for the first four years focused on building awareness, communicating information about the need for change and developing tools and resources to support change. Each of the first four years had a key theme:

- leadership and awareness-raising
- collaboration
- innovation
- evaluation.

Each year had goals relating to health literacy, consumer participation and capability.

An appended logic model summarises the Commission's approach to the PIC programme (Appendix 1). The Commission's activities to promote consumer engagement include:

- modelling best practice – developing Commission policies and practices about consumer engagement, integrating consumer engagement into its programmes and developing a Commission consumer network.
- raising awareness of the benefits of consumer engagement

³ 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>. Cited in HQSC (2015)

- developing and evaluating resources, tools and processes that can be taken up by other organisations
- sharing with the sector examples of what is working well.

2. The evaluation approach

Evaluation questions:

It is now year four of the PIC programme and the Commission has requested an evaluation of the programme to answer the following questions:

- How successful has the programme been in influencing change?
- To what extent have the programme's activities been guided by an evidence base?
- What are the remaining gaps in consumer engagement activities to achieve the PIC programme framework's aims and objectives?
- What are the key and emerging areas for future focus?

The evaluation used a mixed method approach, guided by a logic model (see Appendix 1) and an evaluation framework (see Appendix 2) developed in consultation with the Commission. Information for the evaluation was drawn from:

- document and literature review including a review of information on the Commission's website
- online surveys of:
 - Commission staff (completed by 30 of 49 staff (61 percent))
 - organisation stakeholders, eg, DHBs, PHOs, agencies (completed by 159)
 - consumer representatives (completed by 127 consumer representatives including 12 of 16 members of the Commission's consumer network (75 percent)).⁴

The majority of consumer representatives/advisors surveyed were associated with a DHB. The majority were female, aged over 50 (and most aged over 60), of New Zealand European ethnicity and educated to university degree level or higher

- interviews with 46 stakeholders including Commission staff, organisation stakeholders and consumer representatives.

Organisation and consumer views have been received from across all 20 DHBs (some had higher levels of participation in the evaluation than others). Appendix 3 provides a summary of evaluation participants by type and area.

⁴ Online surveys were distributed to organisation staff and consumers by the quality and risk managers in each DHB. This method of distribution was required to reach the relevant stakeholders as email lists were not available to the evaluators. Distribution by quality and risk managers was complemented by distribution by the evaluators to email addresses that were available. For example, to the Commission's consumer network. The approach to distribution of the survey link means that a denominator is not available to calculate the response rate.

Interview guides and questionnaires were developed to align with the evaluation framework and were provided to consumers on the Commission's consumer network and DHB quality and risk managers for comment before being finalised.

Qualitative data were analysed to identify the main themes using the evaluation questions as an analysis framework. Survey data were analysed using SPSS ('Statistical Package for the Social Sciences').

2.1. Strengths and limitations of the evaluation approach

The strengths of the approach included the following:

- The development of a logic model and evaluation framework provided a theoretical foundation for the evaluation.
- Consultation during a planning phase, including stakeholder input into questions for the interviews and surveys.
- A mixed methods approach to data collection that included feedback from a range of stakeholders. Information from different sources enabled triangulation of findings.

The limitations of the approach included the following:

- Survey distribution to consumer representatives was largely dependent on key personnel within DHBs, PHOs and other organisations. Initial consumer and organisation contacts passed on the survey link and/or recommended people to interview. This approach meant no denominator was available to calculate a response rate. No information was available to examine any differences between responding and non-responding stakeholders. However, there was a sense from stakeholders that the demographic profile of those responding to the survey reflected the pool of consumer representatives, but without a central register of consumers, further assessment of respondent characteristics against the average cannot be made.
- For organisations, the majority of surveys and interviews were undertaken with staff in DHBs. However, this does align with the initial focus of the Commission's PIC programme on DHBs.

3. The Commission's leadership in consumer engagement

Key messages:

The Commission's role as a leader in building consumer partnerships in health care is supported through strategic planning and by the Commission's board, senior managers and staff.

The sector (organisation stakeholders and consumer representatives/advisors) are aware of the Commission's role and the general view is that the Commission is effective in promoting partnerships between providers and consumers.

Commission staff are aware of and support consumer engagement and the Commission's leadership role. However, as with other organisations there is work still to do among staff to develop their skills in consumer engagement.

Looking ahead, the Commission should continue to prioritise the PIC programme with both an external focus to build sector awareness and capability and an internal focus to build internal capability as champions of consumer engagement and to model 'best practice'.

Information for this section of the report was drawn from interviews with Commission board members, chief executive, general manager and the leads of each programme workstream including the PIC programme, as well as from a survey of staff.

3.1. The Commission is seen as the appropriate agency to lead consumer engagement in the sector

The Commission is seen by organisation stakeholders and consumer representatives as an appropriate organisation to provide sector leadership about consumer engagement. As a Crown Agent,⁵ the Commission has more independence from government decision-making than central government agencies, giving it a level of independence and the ability to identify and highlight where improvements are needed in the health sector.

The Commission is the right organisation for PIC to be sited in – it goes straight to patient care and quality. Commission manager – interview

In delivering the PIC programme and its other programmes, the Commission is a catalyst for change and its effectiveness is dependent on providing leadership, setting an example, and encouraging and working with health and disability sector providers to implement changes.

⁵ Crown Entities are made up of groups of Crown Agents, Autonomous Crown Entities, Independent Crown Entities and Crown Entity Companies. Each group represents relative degrees of distance and independence from government decision-making. They constitute a group of government agencies, both by design and by function. <https://www.hqsc.govt.nz/assets/Consumer-Engagement/Publications/Training-guide/015-Crown-entities-explanatory-note.pdf>

3.2. The PIC programme is a strategic priority within the Commission

Consumer engagement is a key part of the Commission's work to improve health quality and safety.

Consumer engagement is fundamental to creating partnerships between providers and consumers and their families/whānau. Enabling participation is key to providing a people-centred environment for consumers. Outcomes may not always change but the journey will be shared and people will be listened to. Systems will be safer, more transparent, and more accountable. Commission staff – survey

The PIC programme was endorsed by the Commission's board as a strategic direction. The Commission's leadership role in consumer engagement is strongly supported by the chief executive, general manager and senior staff. One described partnerships with consumers as:

An absolute foundational platform that the Commission has based itself on. Commission manager – interview

The PIC programme sits across the Commission's other programmes (medication safety, infection prevention and control, adverse events, mortality review, falls prevention and safe surgery). The consumer voice is starting to be considered in prioritising other work programmes within the Commission.

When we prioritise new work coming into the Commission the consumer voice is quite strong in that consideration. Commission manager – interview

Although building understanding of consumer engagement within the Commission team was described as taking time, managers noted that recognition of the value of consumer engagement had increased through the board and the organisation since the start of the PIC programme.

We went from three consumers to 25 involved in some way in the Commission's work programmes (14 on the network). We are getting more and more understanding which is a result of leadership from the CE and GM. Commission manager – interview

We are seeing a shift at board level to include a consumer on the mortality review committee. Commission manager – interview

The survey of Commission staff indicated that senior management support for consumer engagement had flowed through to staff. The Commission's staff are important influencers in building consumer engagement in the sector. Programme workstream leaders are seen as champions of the PIC programme and as influencing change through the activities of their workstreams. Some commented about the need for more integration of the PIC programme through the annual business plans for other programmes.

We need to think about how to build the Commission staff influencer role. All of us talk about it in our programmes. Commission manager – interview

Nearly all Commission staff responding to the survey considered it very important to involve consumers in decisions about their own personal health care. The majority also considered it very important to involve consumers in co-design of health services and governance of organisations that develop policies or provide health care (eg, as board members) (Figure 1).

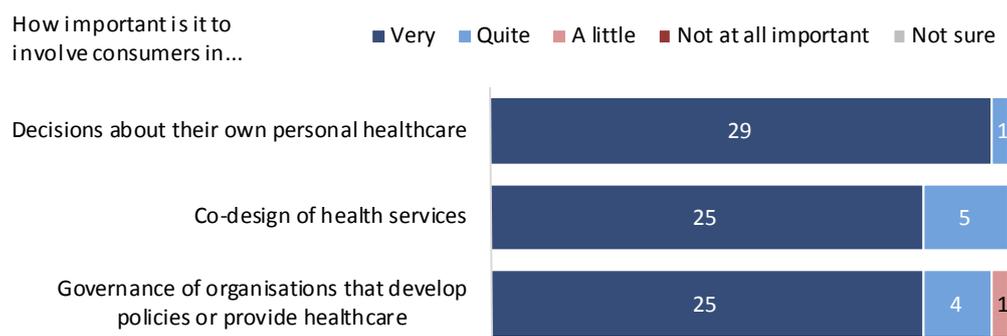


Figure 1: Commission staff views on importance of involving consumers (Source: Commission staff survey)

3.3. Modelling best practice within the Commission

In interviews, Commission stakeholders talked about the effectiveness of the PIC programme lead and the excellent support the PIC team provided to their programme workstreams. It was evident from interviews that there was considerable dependence on the PIC director to assist with consumer engagement by other staff members. Although time consuming, in this way staff were receiving informal education and training as the PIC team assisted them to develop consumer engagement in their programme workstreams.

However, many also noted the PIC team was under-resourced.

It is a strategic priority but I don't see it resourced or operationalised as such. Commission manager – interview

We need more resources within the Commission. Our strategic areas are really under-resourced. Commission manager – interview

The Commission engages with consumers through a PIC consumer network and through consumer representatives on each programme workstream's expert advisory groups or involved in some other way in each programme. The Commission also seeks advice from existing consumer organisations, eg, Grey Power.

The Commission's consumer network meets four times a year and network members have been involved in co-designing the PIC programme. Most network members considered their network has been effective in increasing the engagement of consumers as partners in health care.

The Let's Plan resource came from consumer network comments that people don't know what to say when they go to the GP. Commission manager – interview

Interviewed workstream managers were mainly positive about the contribution or potential contribution of new consumer members and many provided examples of how consumer engagement had contributed to their workstreams.

This piece of work would not have ended up being the quality it was without this consumer's input. Commission manager – interview

We try and make sure we have the consumer voice represented in the governance of everything we do. They do tend to challenge [things] quite well. The Atlas has a consumer summary because it was pushed by the consumer on the group. With the equity Atlas the consumer brought a new perspective... with a push to consider equity between rural and

*urban. Consumers have contributed to helping people to think outside of their paradigm.
Commission manager – interview*

The survey of Commission staff included questions about what the Commission did to promote consumer engagement in the organisation. Nearly all respondents agreed the Commission promotes the importance of consumer engagement to staff (Figure 2). Potential extension of the Commission’s engagement with consumers and development of staff as champions of consumer engagement included more staff education and training about health literacy, and inclusion of consumers in induction programmes for new staff. A substantial proportion of staff were not sure about some of the ways the Commission could promote consumer engagement.

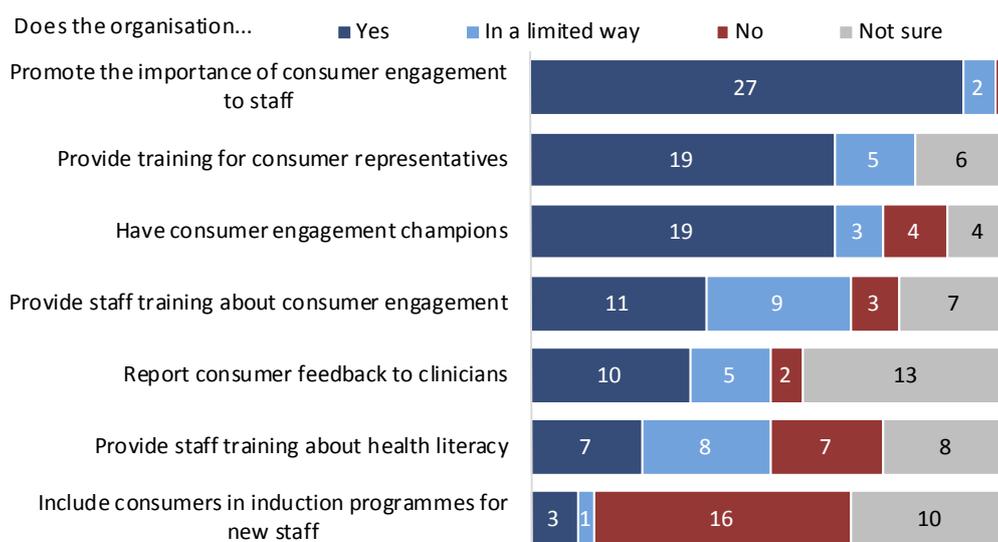


Figure 2: Commission staff perceptions of the organisation’s activities in promoting consumer engagement (Source: Commission staff survey)

There was considerable discussion in interviews and in response to the survey about consumer representation on the Commission’s board. Membership of the Commission’s board is by ministerial appointment and therefore changes need to be approved by the Minister of Health.

There were different opinions about the need for consumer representation on the Commission’s board. Some considered that diversity of thinking was most important in the make-up of a board.

We want people who can ask the questions the inner circle (of health professionals) would not ask. Commission stakeholder – interview

Reflecting the need for diversity, the background of board members has changed from a group that all had medical backgrounds to include lay members who bring different perspectives.

The consumer voice is brought to board meetings through:

- board members’ own experiences, especially lay members of the board
- feedback from consumers who are part of the Commission’s programme workstreams

- the PIC director who is invited to comment on consumer perspectives and brings a consumer story to each board meeting.

However, most Commission managers and programme workstream leaders considered that there should be at least one board member who had the mandate to represent consumer views. Some staff commented in the survey about the need for consumer representation on the Commission's board.

I feel we should have consumers on our board so we 'practise what we preach'. Commission staff survey

There is no consumer that sits on the Board. There is an expectation of the sector but we don't have one on our Board... do as we say but not as we do. But there is a consumer story upfront at the Board meetings, there is a view that everyone is a consumer so you don't need a consumer representative. Commission manager – interview

Discussion about the difficulties of including consumer representation on the Commission's board reflect the challenges expressed by other health and disability providers:

- It is difficult to find consumers who have the skills required to contribute at governance level across the breadth of topics that are covered and who want to be representatives at board level.
- Gaining broad and equitable representation from consumers is challenging.
- Consumers on a board have responsibility to the organisation they are representing and also potential liabilities.
- Board membership and responsibility to the organisation have the potential to limit consumers providing free and frank opinions.

3.4. Commission staff awareness of consumer engagement activities is mixed

Nearly all staff responding to the survey were aware of the Commission's consumer network and the PIC programme's activities to improve health literacy and increase consumer participation (as shown by the numbers in brackets on Figure 3 below). Slightly fewer were aware of its activities in supporting leadership capability for providers and consumers.

Amongst those who had heard of these different activities, there was some uncertainty as to the effectiveness of the different activities, suggesting the need for more internal promotion of the PIC programme (Figure 3).

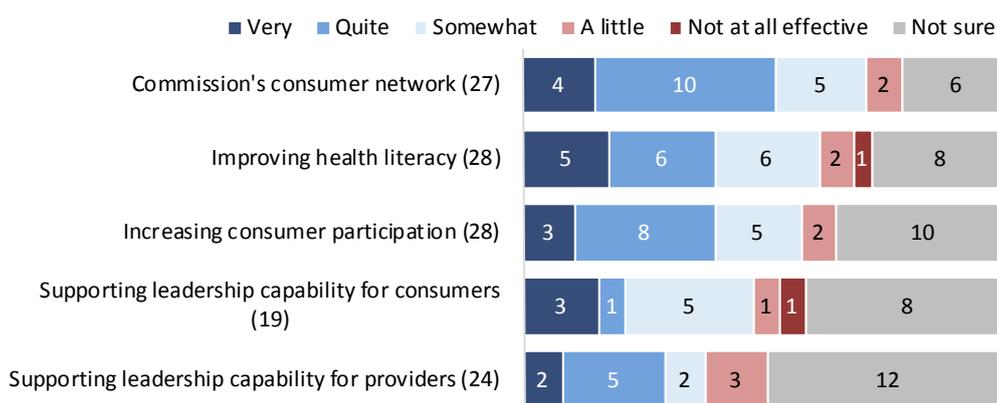


Figure 3: Commission staff views on the effectiveness of different PIC programme activities (Source: Commission staff survey)

3.5. Strengthening consumer engagement in the Commission

Although there is strong support for consumer engagement, Commission staff considered there was still work to be done to fully establish consumer engagement in the Commission (Figure 4) with slightly more considering consumer engagement in governance and leadership was still in the early stages than involving consumers in co-design of programmes.

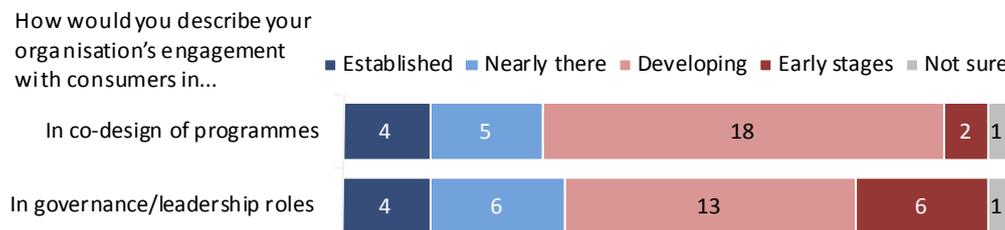


Figure 4: Commission staff perception of the organisation's engagement with consumers (Source: Commission staff survey)

Many Commission staff also commented that building effective consumer engagement was difficult.

We have reached a point now where we get it, right across the Commission, but there is less understanding of how to make the consumer aspect real. Commission manager – interview

There have been challenges in including consumers in the Commission's work that included the following:

- Examples of mismatches between consumer skills and the particular role for that consumer and/or a lack of understanding of the role.
- Lack of connection between consumers on different programme workstreams and the Commission's consumer network who could potentially support other consumers.
- Difficulty in seeing how the consumer voice could add to very technical aspects of the Commission's work.

Specific barriers to consumer engagement were explored through the Commission staff survey. The main barriers identified by staff were: lack of consumer understanding (about their own health and health systems); and finding consumer representatives for committees or groups (Figure 5).

The biggest problem is finding a consumer who provides 'real consumer' input. Most consumers we interact with are highly health literate, and not at all like the majority of large consumers of healthcare. Commission staff – survey

Approximately three-quarters of staff thought that not knowing how to include consumers was somewhat or a major barrier to consumer engagement.

While there has been a clear message that consumers need to be involved in Commission work, there has not been much clarity on how consumers are expected to provide input and what they are expected to influence. Much of the Commission's work has been focused on healthcare providers and not targeted directly to consumers. This gap between us, the providers and their consumers has led to some confusion internally. Commission staff – survey

While many staff were aware of consumer engagement resources on the Commission's intranet and website, and of education and training opportunities, few said they had actively used these.

The challenge for us is how we link into what [PIC programme lead] is doing and understand it... I would love to go to some of the training myself (but I have not signalled that to her yet). Commission manager – interview

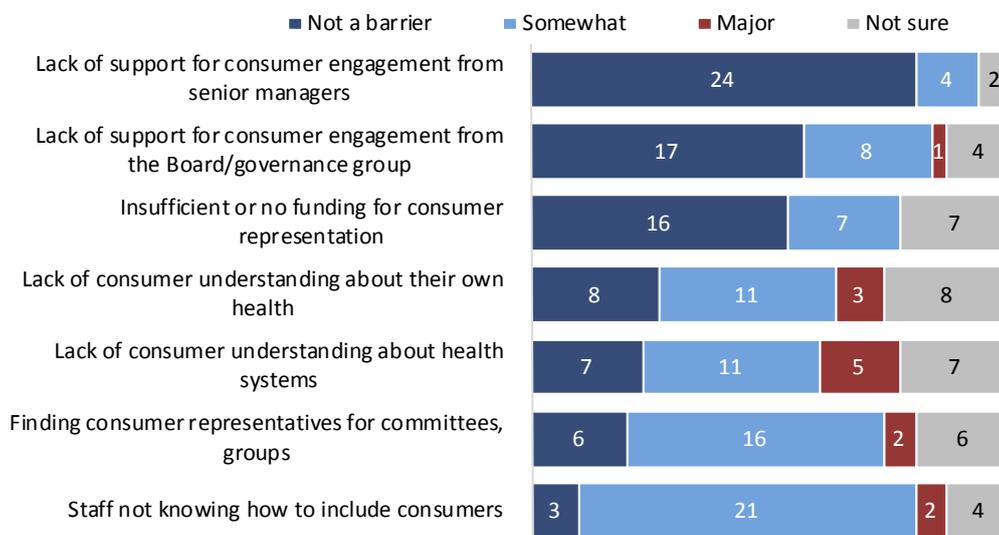


Figure 5: Commission staff perceptions of barriers to including input from consumers in the organisation (Source: Commission staff survey)

3.6. Future focus within the Commission

The evaluation suggests a number of activities within the Commission that could be considered to build the Commission's consumer engagement and expand the role of Commission staff as influencers through their work programmes and networks.

- At a strategic level:
 - Discussion between the board and Commission managers and potentially the Minister about current differences in opinion to reach a consensus about how to include consumer views in the Commission's board.
 - Review of the Commission's annual strategic planning to more explicitly integrate consumer partnerships into each programme workstream.
- At an operational level:
 - Programme planning to more explicitly include how consumers will be involved in each workstream and the role and expectations of consumers.
 - Greater coordination between the consumer network and consumers on individual programmes.
 - Clarity in Commission policies about consumer engagement, roles, 'job' descriptions and duration of tenure .
- Raising awareness among staff, especially those who are not managers, of the Commission's consumer engagement activities:
 - Promotion of the different PIC programme activities to staff.
 - Staff education and training about consumer engagement and activities such as health literacy.

4. How health care organisations are involving consumers in health care

Key messages:

Health and disability sector organisations and consumers are at different stages in the evolution of partnerships between consumers and providers.

There was support from the majority of organisation and consumer stakeholders about the value of engaging with consumers. All supported the value of consumer engagement in direct/personal health care. Fewer, but still the majority, supported consumer engagement in co-design and governance.

Similarly, stakeholders considered engaging consumers in decisions about their own direct/personal health care was better developed than engaging consumers in co-design or governance and leadership.

Health and disability organisations have a responsibility to make it easier for people to use information and services, and to navigate through different services to take care of their own health.⁶

Over two-thirds (69 percent) of organisation stakeholder survey respondents had worked with consumer representatives in the past 12 months and just under half (48 percent) had worked with consumer advisory groups. Similar numbers said that working with consumer representatives/advisors or consumer networks was a major or quite big part of their role.⁷ (See Table A2 in Appendix 3 for details of organisation types represented in the stakeholder and consumer representative survey responses.)

Whilst just under two-thirds (63 percent) of organisations surveyed promoted the importance of consumer engagement to staff, fewer than one-quarter provided more than limited education and training for staff about consumer engagement (24 percent) and health literacy (21 percent) (Figure 3).

As with Commission staff, there was a general feeling amongst organisations and consumer stakeholders that consumer engagement was developing.

I feel great strides have already been taken for services to be consumer inclusive. More services are becoming aware of the need to seek consumer participation, to ensure consumers are welcomed and that content is understood and relatively jargon free. Consumer representative – survey

⁶ Brach C, Keller, D., Hernandez, L.M., Baur, C., Parker, R., Dreyer, B., Schyve, P., Lemerise, A.J., and Schillinger, D. I. 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. Cited in HQSC (2015).

⁷ Only four respondents did not consider working with consumer representatives/advisors or consumer networks a part of their role at all. All were employed by a DHB, two in managerial roles, one in a health provider clinical role and one in a non-clinical role.

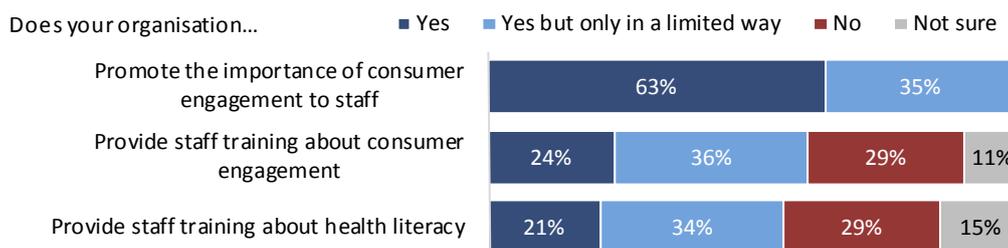


Figure 6: Organisations’ activities to promote and support consumer engagement (Source: Organisation stakeholder survey)

Consumers described changes to the way health care was provided as a result of their input. A key factor in achieving change was support from people in leadership roles, as illustrated in the quote from a consumer representative below.

I have been thrilled at the impact my role has had on the department I am in. I believe this is because the chair promotes my role and always listens when I bring up issues and does her best to see matters are dealt with promptly... I get full support for my role and I believe this comes from 'the top'. Consumer representative – interview

4.1. Consumer engagement in direct/personal health care

Patient engagement, shared decision-making with patients and patient-centred care can lead to better outcomes and improved quality.⁸ Consumer engagement in direct care was also seen as beneficial for organisations, as their input could help identify pragmatic solutions.

Consumers give a balanced, reasonable approach to responding to complaints... [which is] very helpful. Sometimes they are refreshingly pragmatic... They say 'You don't have to go that far.' It helps us to move onward, it gives us permission... Organisation DHB – interview

Nearly all consumers and organisations surveyed thought it was very important to involve consumers in decisions about their direct/personal care (Figure 7).

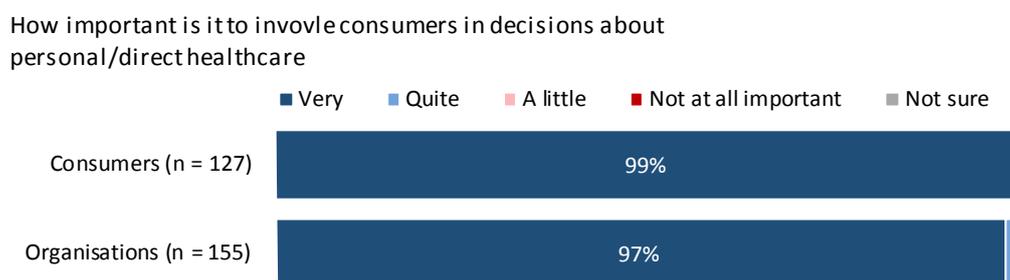
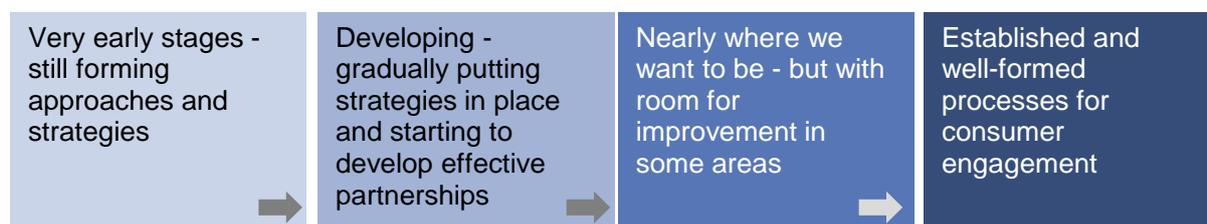


Figure 7: The importance of engaging consumers in decisions about direct care (Source: Organisation and consumer representative surveys)

⁸ Coulter, A. 2012. Leadership for Patient Engagement. London: The King’s Fund. URL: www.kingsfund.org.uk/leadershipreview.

In the surveys, respondents were asked about the different levels of consumer engagement in the organisation they worked for or represented. Respondents were asked to consider consumer engagement along a continuum from 'early stages' to 'established'.



Consumer and provider partnerships are most developed in direct/personal health care. The majority of consumers and organisations thought consumer engagement in direct/personal care was at least developing – gradually putting strategies in place and starting to develop effective partnerships'. Over a quarter in both groups considered engagement in direct care was 'nearly there' to 'established'.

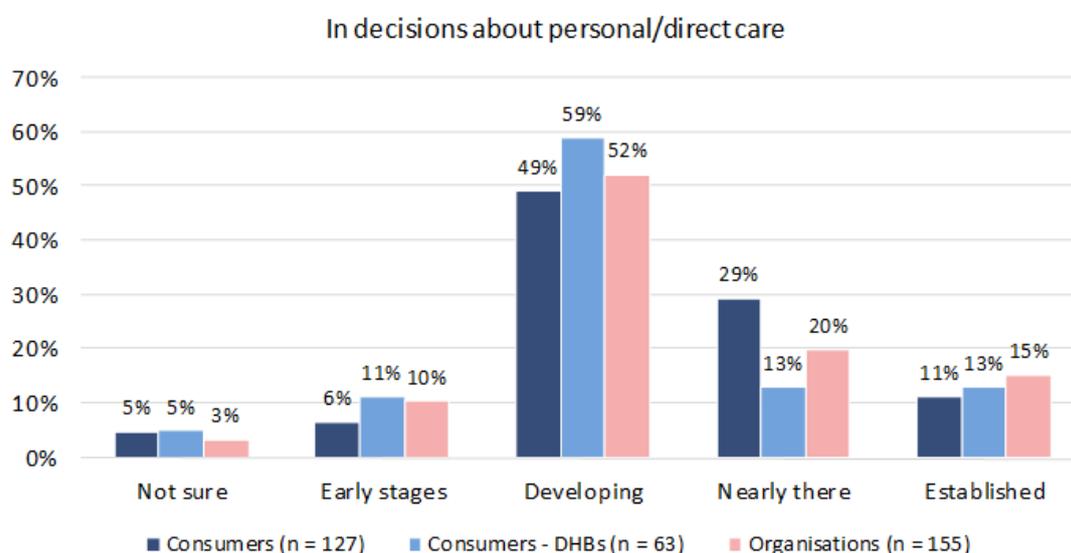


Figure 8: Views about consumer engagement in direct/personal care in their organisation (Source: Organisation and consumer representative surveys)⁹

In the context of the organisations represented by organisation stakeholder survey respondents (86 percent DHBs – see Appendix 3, Table A2), over two-thirds (67 percent) said their organisation communicated consumer feedback to clinicians and 59 percent gave patients access to their records. Some reported IT challenges and some resistance from clinicians to sharing health records.

Around the country consumers have been involved in a range of activities to improve direct care, including:

- participating in patient stories (which are shown to clinical staff and board members)

⁹ Results from the consumer representative survey are shown for: all survey respondents (n=127) and a subset of consumers who were answering this question about a DHB (n=63).

- participating in annual patient safety weeks
- being part of 'in your shoes' sessions, where consumers have the opportunity to tell health professionals and staff about their experience of health care services
- engaging in health literacy education and training.

Example: Listening sessions – Hawke's Bay

Staff are trained about how to hold 'listening sessions' with consumers (where staff aim to listen for 90 percent of the time and talk for 10 percent). The process is structured, but not the questions. This allows people to talk and to 'tell their story' in their own way and with their own words.

The approach worked successfully in hearing what it was like to be 'in the shoes' of older Māori. Kuia and kaumātua were invited to a listening session. Changes were made to the seating arrangements; to begin with the seats were arranged in sections, to help increase privacy. However, the layout was not appropriate as it meant people had their backs to one another. The layout was changed into more of a circle.

Staff understood the importance of proper introductions, so everyone knew who was in the room and where they had come from (recognising the importance of whakapapa). Taking time to build relationships, following protocols and taking care in the pronunciation of Māori names and words meant staff were able to create an environment that allowed a deeper engagement. An insight gained from this engagement was that for older Māori, entering into a hospital is a foreign environment, more so than for most people, as it also involves entering a Western, bio-medical world view, and efforts by staff to build a relationship of trust could help reduce the impact of the alien environment.

4.2. Consumer engagement in co-design

Co-design is a process where consumers work with health care organisations to develop information or services in a way that takes account of consumers' needs and helps them participate in their health care.

Consumers can support the co-design process by drawing on 'lived experience', as well as lifting from their individual experience to provide a more representative perspective.

Consumer engagement in co-design can include shorter involvement (for example, improving signage or developing a pamphlet), through to more ongoing support for service re-design or new build designs.

Mental health and maternity services were considered by stakeholders to have more established co-design practices. In interviews there was a sense that the more holistic approach to treatment and care in these services also helped provide inroads for consumer engagement. Some attributed the current strength of consumer engagement in these areas as due to serious failures in the past.

In maternity we have an amazing group of extremely passionate, knowledgeable, effective consumer reps who are doing their best to improve quality, working in partnership with people in DHBs as much as possible. I think the maternity sector is really doing an awesome job actually. Consumer representative – maternity, interview

In mental health the representation is integrated into planning and management. It and maternity services were early adopters – the rest of the organisation is at the early stages of consumer engagement. Organisation DHB – interview

4.2.1. Co-design of information for consumers

The vast majority of consumers and organisations surveyed thought it was very important to involve consumers in designing information for consumers (Figure 9).

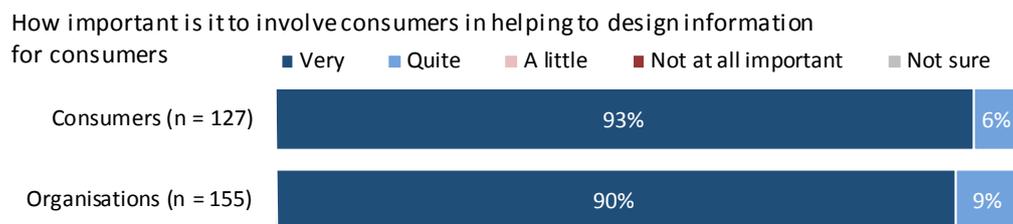


Figure 9: Importance of consumer engagement in designing information for consumers (Source: Organisation and consumer representative surveys)

The majority of consumers and organisations thought consumer engagement in designing consumer information was at least developing, and over one-third of consumers considered their organisation was ‘nearly there’ or ‘established’ (Figure 10).

Organisation stakeholders considered organisations (predominantly representing DHBs) to be less advanced in engaging consumers in helping to design and develop information for consumers, compared with consumer representatives (Figure 10).

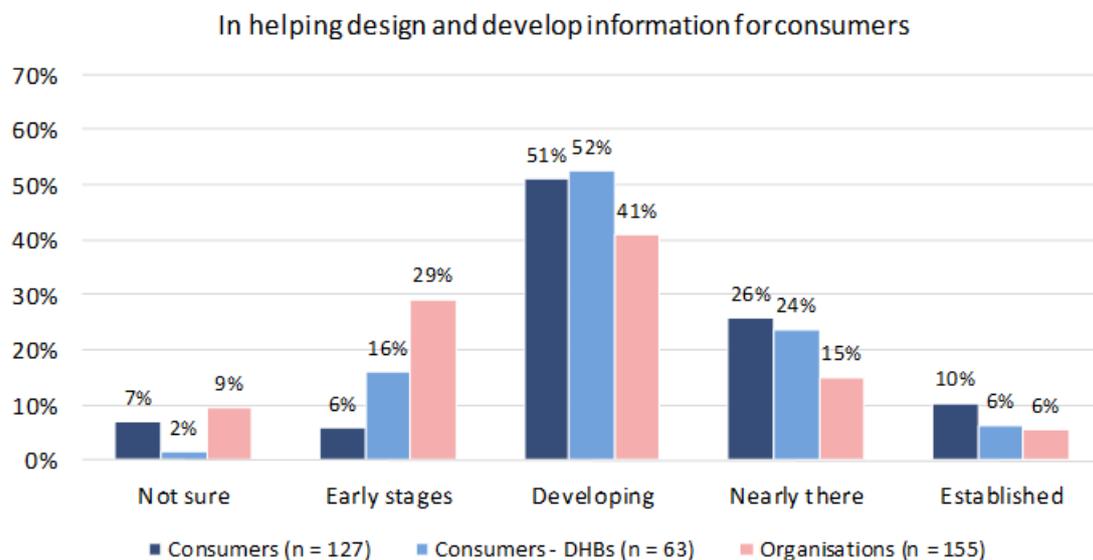


Figure 10: Views about consumer engagement in developing information in their organisation (Source: Organisation and consumer representative surveys)

Examples of consumer engagement in co-design of information include their involvement in:

- the development of information pamphlets (what to expect when receiving treatment, how to avoid risks related to surgery, etc), correspondence (eg, about appointments) and feedback forms

Consumer consultation helped improve advice on eczema

In a provincial area there used to be mixed messages between what Doctors said, what was written on the script and information given by pharmacists on the treatment of eczema. A co-design approach was taken to develop consistent, and consumer friendly, messages to support eczema treatment. All pharmacists in the area signed up to this, and there are videos and resources for doctors to use as part of the consultation. An action plan has also been developed, which is very simple and has all the instructions that are needed, eg, how to apply the ointment, wash the baby, etc.

- improving signage within a health organisation
- the redesign of a website.

Co-design of new website – Counties Manukau Health

Consumer engagement helped to shift the orientation of Counties Manukau Health’s website so it focused on what mattered to patients and consumers; things like visiting hours, parking and direct links to hospitals. *‘It’s now about the people, and less about the DHB’.*

<http://countiesmanukau.health.nz/for-patients-and-visitors/>

4.2.2. Co-design of health services

Fewer, although still the majority of surveyed consumers (83 percent) and organisations (75 percent) thought it was very important to involve consumers in co-design of health services (Figure 11).

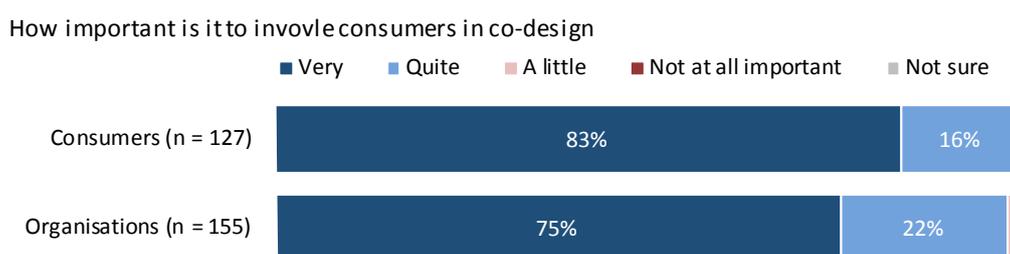


Figure 11: Importance in engaging consumers in co-design of health services (Source: Organisation and consumer representative surveys)

The majority of stakeholders considered their organisation to be ‘developing’ (50 percent) or better (28 percent ‘nearly there’) for consumer engagement in co-design of health services. There were some differences between the groups. Over one-quarter of consumers thought consumer engagement in co-design of health services in their organisation was in the early stages. This increased to one-third for consumers who were answering about a DHB. Analysis of the interviews and open-ended responses in the surveys suggests this may in part reflect a lack of clarity on what is meant by ‘co-design’ of health services.

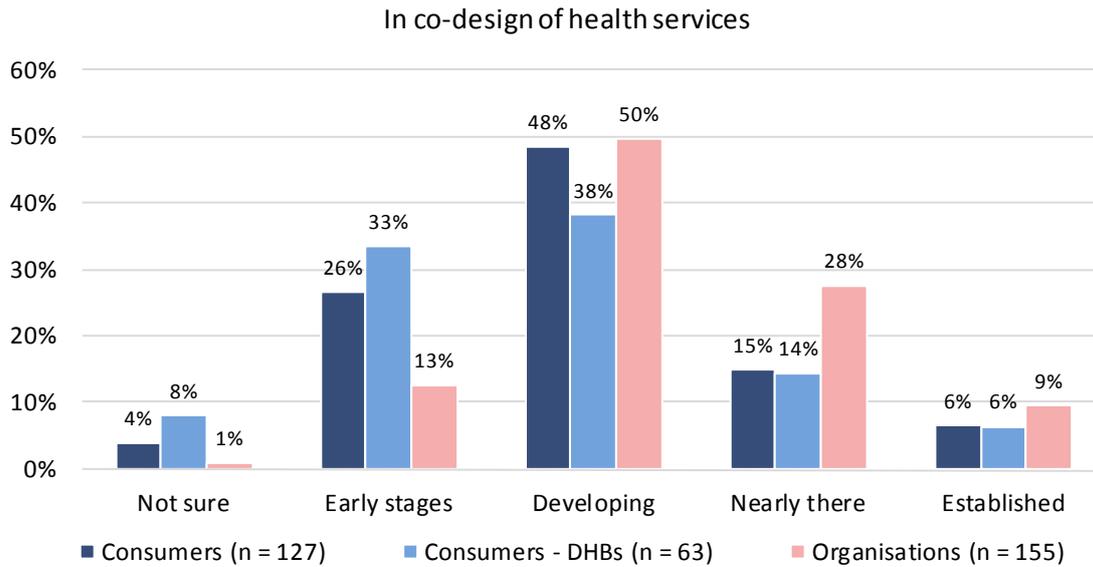


Figure 12: Views on consumer engagement in co-design of health services in their organisation (Source: Organisation and consumer representative surveys)¹⁰

Examples of consumer engagement in co-design of services include their involvement in:

- changing visitor policies
- shaping the design of wards and new buildings/infrastructure (eg, car parks)
- service models
- defining clinical care pathways.

Consumer engagement in clinical care pathways

In one provincial DHB, consumers who have had recent experience of a service are interviewed individually by an ex-clinician to understand their perspectives on the health care they received and what could have been improved. The one-on-one engagement helps to include the voices of people who may find more collective forms of engagement challenging. The consumers' recent experiences also help to ensure the information is relevant to practices. Combined, the individual stories help to contribute a broader consumer perspective.

4.3. Consumer engagement in governance/leadership

Consumer engagement is more than just a set of activities; it involves a cultural shift so consumers are involved at all levels of health care, from the design and delivery of information and services to influencing the organisation at the governance level.

¹⁰ Consumer representative survey results shown for all respondents and the subset answering about a DHB.

Of all the areas assessed, the biggest difference between organisation stakeholders and consumer representatives was in their views of how important it is to involve consumers in governance of organisations that develop policies or provide health care (eg, as board members). Consumers were more likely to rate their engagement in governance as ‘very important’ (83 percent) compared with organisations (66 percent), although the majority of both still thought consumer engagement in this area was important (Figure 13).

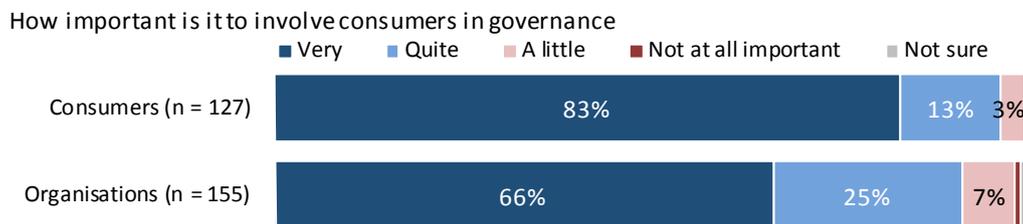


Figure 13: Views on the importance of consumer engagement in governance/leadership (Source: Organisation and consumer representative surveys)

Consumer representatives at governance/leadership levels can contribute at a more strategic level, drawing on ‘learned’ experience (often from other leadership roles), as well as lived experience. A greater ability to provide representative advice is needed at this level. The volume and complexity of information that needs to be absorbed for consumers to be effective in this role requires different skills. The time commitment also increases, as well as the length of engagement. Some consumers were not interested in a governance or leadership role.

There was recognition that more is needed for board chairs and consumers to support consumer engagement at the governance level, and of the importance of engagement at this level, as illustrated in the quotes below.

We know we need to develop governance systems and steering groups; they are not developed yet. Organisation DHB – interview

We aren’t going to change the culture if there are not consumers leading and standing by us in the change. Organisation DHB – interview

Consumer representatives and organisation stakeholders had similar views about the extent to which consumer engagement in governance had evolved in their organisation (Figure 14).

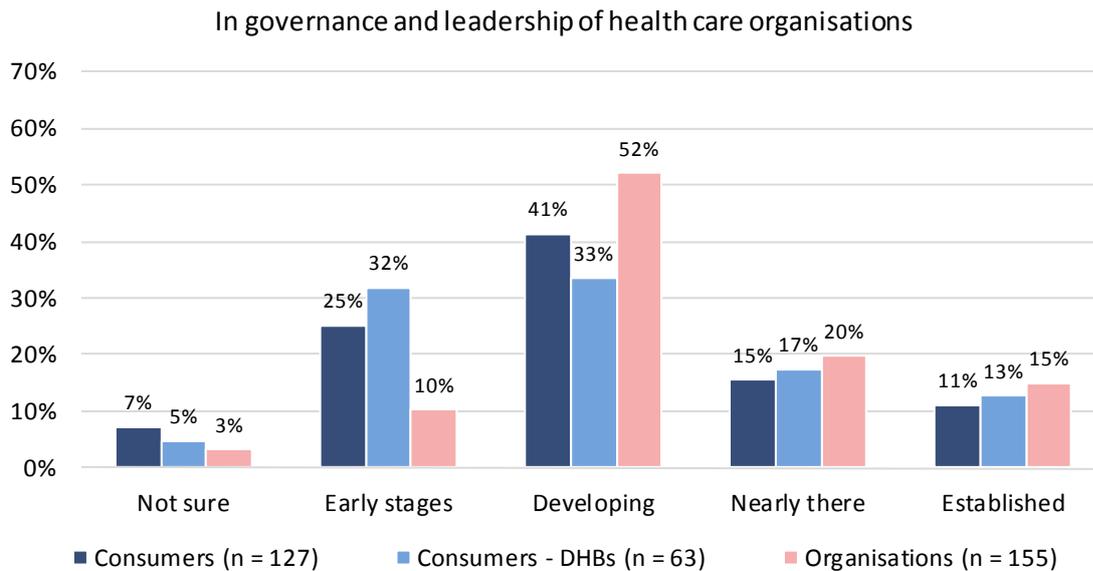


Figure 14: Views on consumer engagement in governance and leadership in their organisation (Source: Organisation and consumer representative surveys)¹¹

Differences between consumer representatives and organisation stakeholders could to some extent reflect different perceptions of what constitutes consumer engagement in governance and leadership (eg, is having one consumer representative on the board sufficient?)

Being a consumer representative at the governance/board level can be challenging, as illustrated in the quote below.

I felt really out of my depth. I felt that everyone else had a big organisation behind them, but you're on your own. Consumer representative – interview

The role of the chair was seen as important, to role model commitment to consumer engagement to staff, as well as providing support to consumer representatives.

Chairs need to be reaching out and building relationships with their consumer representatives. Because they're the leadership, they're the role model. What they do and how they make the consumer representative feel on the group will make all the difference. Organisation DHB – survey

In some districts, two consumer representatives are placed on governance boards to provide peer support. Both consumers and organisations recognised this as a useful way of providing peer support for the consumer representatives, as illustrated in the following quotes.

[Having two representatives on a governance board] is an example of a structure that can support consumer representatives, so people don't feel alone. Organisation DHB – interview

Have more than one representative – it can be daunting to be the only non-professional at a meeting or on a board. Consumer representative – interview

¹¹ Consumer representative survey results shown twice for all respondents and the subset answering about a DHB.

And for one of the consumers interviewed, peer support was needed to keep them participating at the governance/leadership level.

The other thing that was really helpful was having another consumer to talk things through. Without that I probably wouldn't have continued. Consumer representative – interview

Examples of consumer engagement at the governance/leadership level include:

- consumer representatives on boards
- consumer representatives reviewing papers before they go to the board.

Example: Consumer chair on an alliance governance group

In one district a governance group was chaired by a consumer. The consumer was experienced in governance, having previously sat on other boards. The consumer was able to bring this experience to developing the group members' understanding of what a governance role entailed. Many were service providers with extensive management experience but only limited previous experience of governance roles. As a chair the consumer representative was also seen as independent, impartial, not representing one health professional sector or group and as not competing for funding.

4.4. Consumer's views on their engagement with organisations

Overall, consumer representatives/advisors interviewed or surveyed as part of this evaluation were generally positive about their engagement with health care providers. Most were positive about processes used, felt treated with respect (84 percent) and felt they were listened to (72 percent) (Figure 15). Nearly three-quarters (73 percent) felt their contribution was valued. Overall two-thirds (66 percent) of consumer representative survey respondents felt that things improved as a result of feedback consumers provide.¹²

The notion that what I have to say will have an impact on services and their delivery, that what I have to say as a consumer is valued. Consumer representative – survey

Being in a position to influence change and decision-making that reflects the needs, rights and interests of the consumers to advance the wellbeing of the community as a whole. Consumer representative – survey

¹² Very few (four) disagreed with this statement, but around 16 percent felt unsure or neither agreed nor disagreed (31 percent in total not able to say definitively whether things improved as a result of feedback consumers provide).

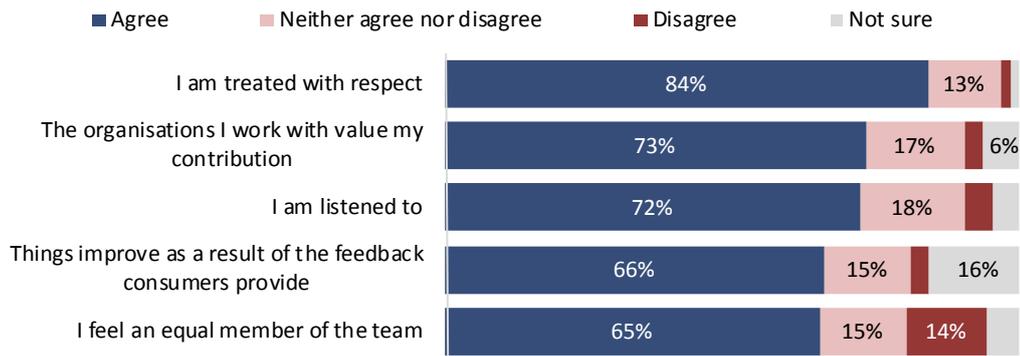


Figure 15: Experiences as a consumer representative/advisor (Source: Consumer representative survey)

4.5. Overview of consumer engagement

Figure 16 summarises the development of consumer engagement at each level: direct care, co-design and governance/leadership, from being aware of it, knowing how to do it, doing it, to it being embedded and part of business as usual. The summary is based on assessment of the quantitative data from the surveys and the qualitative data from the surveys and interviews to illustrate the key themes.

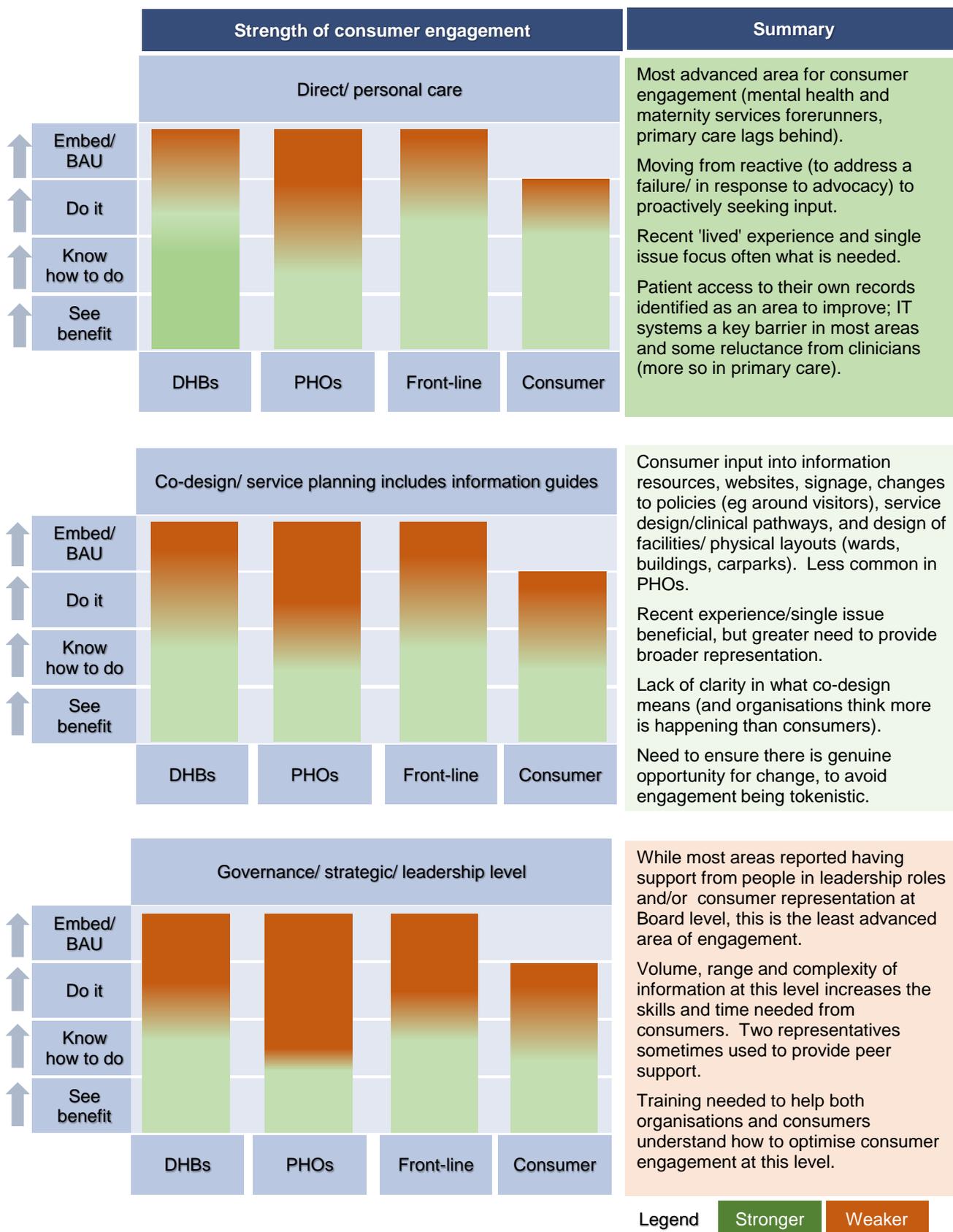


Figure 16: Overview of the stages of consumer engagement

5. How has the PIC programme influenced change?

Key messages:

The Commission is using evidence as a foundation for its work to build consumer partnerships, which helps to build credibility. The Commission is also helping to build the evidence base in this evolving field by evaluating its activities and publishing its findings. The Commission's work to date is well regarded by the sector.

Awareness of the need for, and benefits of consumer engagement have been raised through the Commission's leadership. Resources have been developed and are being used particularly to support consumer engagement in direct/personal care. Health literacy resources were frequently mentioned as useful.

Co-design of information is more common than co-design of health services and wider health environments. The Commission has supported the development of education and training about co-design.

Building effective consumer engagement at the governance level requires more support, for both consumers and organisations. The Commission has developed guidance for board chairs about how to include consumers.

Many stakeholders described a 'sea change' over the past few years where the need for consumer engagement is now recognised – and increasingly valued.

Everyone knows it is important and it needs to happen. There is a collective understanding that it is important. And that matters – when people recognise its value. Organisation DHB – interview

It is not possible to directly attribute changes in attitudes to consumer partnerships in health care to the Commission's activities. The PIC programme has been part of a broader movement that has promoted the need for consumer engagement. (Other influencers locally include the women's health movement, and the work of overseas organisations like the Institute for Health Improvement¹³).

With the women's health movement and consumer engagement, it's part of decades' long changes. Organisation DHB – interview

The evaluation has considered how the Commission's activities has influenced change. It has done this by looking at how stakeholders regard the Commission and how its activities have contributed and are contributing to changes in how organisations and consumers engage.

¹³ www.ihl.org/

5.1. The Commission's leadership is well regarded by sector stakeholders

The Commission's staff and work are well regarded by the sector, as illustrated in the quotes from a consumer, DHB and agency representative below.

We are doing so much more than we were [and] that should be recognised. The work that [the Commission PIC team] did to get everything established should be acknowledged as well – they... got so much done! It's still an area that needs awareness and continues to be an area that the Commission should invest people and resources into. Consumer representative – survey

Overall, the Commission's programme is extremely good. I can't speak highly enough of the Commission's work. Organisation DHB – interview

The Commission has been really good and [PIC manager's] willingness to talk face to face with consumers, and her credibility, due to a clinical background. I admire their work, and they are passionate about it. Organisation Agency – interview

The need for a centralised direction for service/quality improvement was agreed. A question was, however, raised by some DHB stakeholders about the Commission's role, and the potential for tension between an audit function and supporting quality improvement. These are two different roles, and some stakeholders asked for clarification about the Commission's focus.

5.2. The programme's activities are guided by an evidence base

The Commission is using evidence as a foundation for its work to build consumer partnerships. Initial planning and development of the PIC consumer engagement programme was based on a review of evidence confirming the value of consumer engagement.

Developing effective partnerships in health care is an emerging area. The Commission has:

- used existing evidence where available to help inform the development of its activities to support consumer engagement
- contributed to building the body of knowledge by evaluating its activities and publishing information and evaluation findings.

Both are evidenced in the volume of information within the PIC domain on the Commission's website.¹⁴ The latter includes evaluating its own work, from individual events (eg, it sought feedback from attendees at the 'Show and Tell' symposia) to whole programmes of work (eg, the annual survey on consumer engagement; and this evaluation).

The diagram below illustrates how some of the evidence, tools and resources developed as part of the Commission's PIC consumer engagement programme align with the programme's goals (Figure 17).

¹⁴ www.hqsc.govt.nz/our-programmes/partners-in-care/

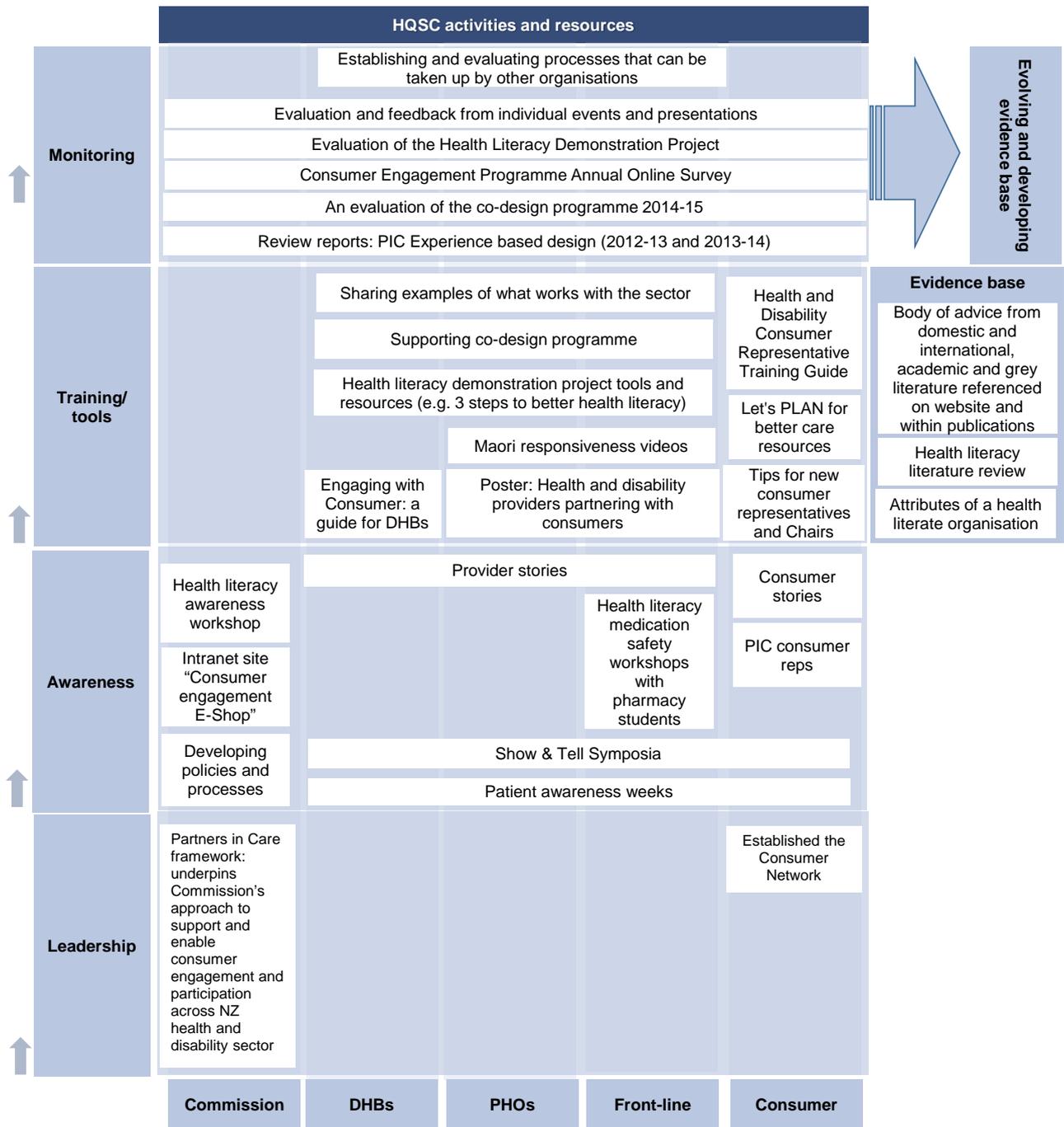


Figure 17: The Commission's consumer engagement activities and resources

5.3. The sector is aware of the Commission’s activities but awareness could be increased

Most organisation stakeholders and consumer representatives included in the evaluation were aware of the Commission’s activities to influence change: just under three-quarters of consumer representative (73 percent) and organisation stakeholder (72 percent) survey respondents were aware of the Commission’s role (in general) in supporting consumer engagement and consumer provider partnerships.

Of those who were aware of this role, nearly all were aware of the Commission’s activities around increasing consumer participation (90–93 percent); and most were aware of the Commission’s work to improve health literacy (83–88 percent) (Figure 18).

Fewer organisation stakeholders and consumer representatives were aware of the Commission’s activities around supporting leadership capabilities for health care providers, (59 percent) and for consumers (52 percent and 56 percent respectively).

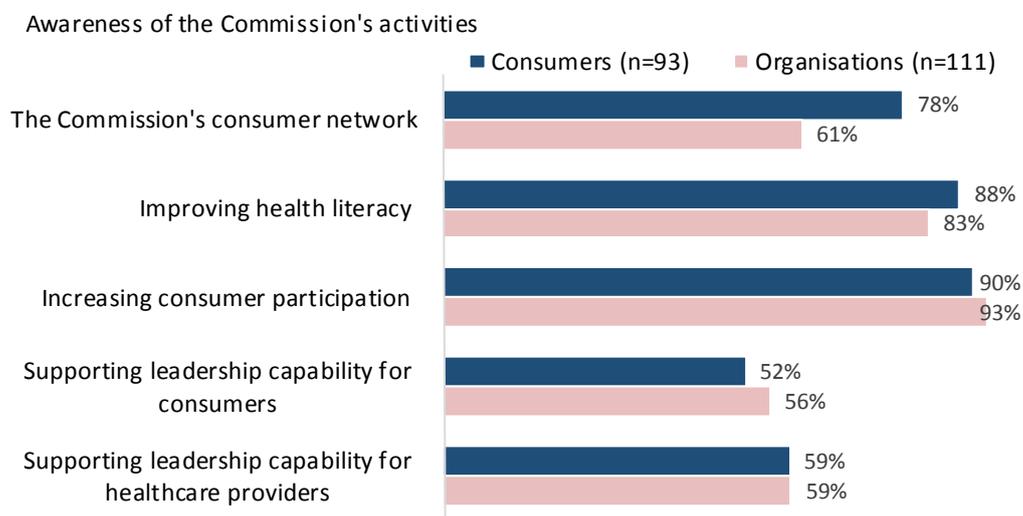


Figure 18: Awareness of the Commission’s activities in supporting consumer engagement and consumer–provider partnerships (Source: Organisation and consumer representative surveys)

Feedback from one interviewed stakeholder noted the potential to increase awareness of the PIC programme through improved promotion, including simplifying the description of the programme as many consumers might not know what ‘partners in care’ meant. Another stakeholder suggested changing the wording from ‘consumer engagement’ to ‘engaging consumers’ would have more appeal.

I think that more clarity around who our customers are and how consumers fit in would be valuable for Commission staff. Commission staff – survey

Maybe for a start we should change from ‘consumer engagement’ to ‘engaging consumers’. [This is a] slight shift in focus from ‘how to get consumers to engage’ to ‘how can we redesign the system to be more engaging’. As with health literacy, it needs to be addressed as a systems issue. Commission staff – survey

5.4. The Commission's activities are raising awareness of the need for change and the benefits of change

Stakeholders considered the Commission has contributed to bringing consumer engagement to the forefront of discussion (or at least higher up the agenda) in the health sector.

Awareness and acceptance of having consumers engaged at all levels has been a huge achievement of the Commission and the resources they provided in creating that guide to working with consumers has been a huge leap forward. Consumer representative – survey

We are working for a common goal... we must all benefit in working together to make our healthcare as open and caring as possible. That we are valued and our worth recognised. How can you help us if we don't tell you how we feel? That we are listened to with respect. That will encourage us to be open with you. And for us to tell you exactly how it is. Together we can do so much more... Consumer representative – survey

One example of the way the PIC programme has raised awareness of the need for change and the benefits of change is through consumer grand rounds – a series of presentations at DHB grand rounds where examples of the value of consumer engagement are provided.

The DHB grand rounds are supported by the development of a booklet – *Engaging with consumers: A guide for district health boards*. The booklet provides an example of how evidence has been used to raise awareness of the benefits of consumer engagement and how to do it. The booklet is available on the Commission's website and has been frequently downloaded.

Example: *Engaging with consumers: A guide for district health boards*

A booklet *Engaging with consumers: A guide for district health boards* was developed to provide DHBs with guidance about consumer engagement and was referred to in a number of interviews.

Engaging with consumers is a wonderful resource; everyone should be given it as part of their orientation to the DHB. Organisation DHB – interview

The guide that they developed for DHBs, they went around to lots of places for advice and had a very good consumer group working on that... They went out into communities to get advice on it. It's a really good document. I have distributed over 100 [copies] and sang its praises. It's a down-to-earth document that's easy to read and tells them where they can go to get other help and advice and guidance. Organisation stakeholder/consumer representative (dual role) – interview

The guide demonstrates a comprehensive and sound evidence base (referencing policy and legislation, and an international body of academic and grey literature). Its development was also guided by a steering group, drawing on input from health care professionals and consumers, and evidencing this in the document through personal stories and quotes.

Providing more resources that help demonstrate the value of consumer engagement was suggested as a way of raising awareness of the benefits.

The Commission could help show the value of doing it in terms of things like cost and resource-saving. Well-designed systems can save money in the long run. If we can win that argument and show it isn't just an extra thing to do but will really improve the service... that would be useful. We've started that, but it could continue to be really strong advocate. Consumer representative – interview

5.5. The Commission has increased sector knowledge about how to change

The PIC programme has increased knowledge about how to change through the development of evidence-based resources to support consumer engagement and the promotion of best practice examples.

The Open for better care¹⁵ campaign has influenced us all. Some of the stories from the adverse events team are good. Overall, HQSC has had a great influence on best practice care which is indirectly about consumers. For the consumer arm, I'm less sure of the influence of the consumer programme at ground level. Organisation DHB – survey

The PIC programme has developed tools and resources to support change. The health literacy medication safety project provides an example where the Commission has followed a systematic and robust process, designing and developing resources to support consumer engagement.

Example: Health literacy medication safety

The health literacy medication safety project included a literature review, evidence-based development of resources, a trial and evaluation of the resources (pilot demonstration project). All were completed by organisations external to the Commission, with expertise in the subject areas. The resulting resources (eg, *Three steps to better health literacy* booklet) have been published on the website, alongside the evaluation report, demonstrating an evidence-based and transparent approach, resulting in the development of tools and resources that can be used by the sector.

¹⁵ www.open.hqsc.govt.nz/open/

The more recently developed *Let's PLAN for better care* resources for consumers demonstrates co-design supported by evidence from consumers.

Example: Let's PLAN

Let's PLAN is a health literacy resource to help consumers prepare for their visit to their GP or other primary care health professional. It was developed because consumers wanted something to help them communicate better with their doctor or nurse, and know more about the medicines they are on. The *Let's PLAN* resource was tested with different ethnic groups and trialled in two PHOs, and considerable changes were made based on feedback from patients, GPs, pharmacists and practice administration staff.

Around one-third of the organisation stakeholder and consumer representative survey respondents had attended a Commission symposium or presentation (Figure 19).

The HQSC sponsor consumers to go to national forums and seminars, and be visible at those. There's one coming up... and there are consumers speaking at it. The HQSC put that together and made sure there was a consumer voice at that conference. Years ago you would not have been able to get a consumer to speak at these events and now it really has changed.
 Organisation stakeholder/consumer representative (dual role) – interview

Only one-fifth of consumer representative survey respondents had attended Commission education and training, but feedback through interviews suggests there is a real need and desire for education and training about consumer engagement. Around half of consumer and organisation stakeholder survey respondents had used or recommended the Commission's website and the *Engaging with consumers: A guide for district health boards* document to support consumer engagement or consumer–provider partnerships.

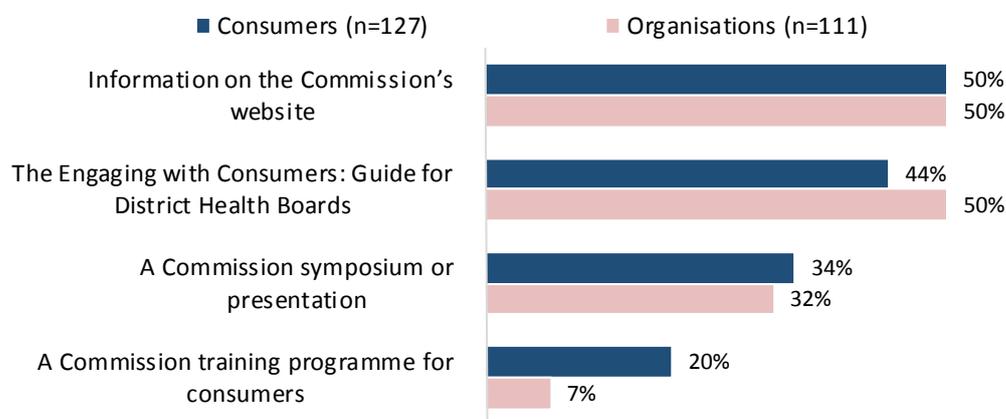


Figure 19: Use of the Commission's tools and resources (Source: Organisation and consumer representative surveys)

Of those who had used the Commission's website, the most commonly used tools (by both organisation stakeholders and consumer representative survey respondents) were: health literacy tools; patient and provider stories; and the checklist to help consumers prepare for a visit to a health care provider (Figure 20).

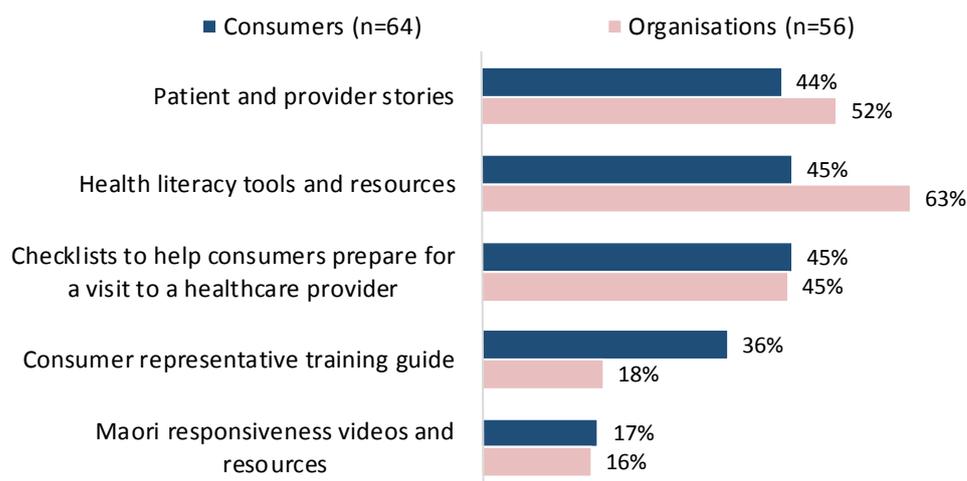


Figure 20: Survey respondents' use of tools and resources on the Commission's website (Source: Organisation and consumer representative surveys)

Several organisations commented that, while there is a wealth of information on the Commission's website, it could be hard to find resources. A dedicated section on consumer engagement could help, as well as identifying resources for organisations and for consumers.

A few commented on the need for the website (and resources, eg, used for Patient Safety Week) to better reflect the ethnic diversity of New Zealand, in imagery and availability of resources in other languages.

What resources are there in the different languages to meet the needs of our consumers? Tongan, Samoan, Chinese, Indian? Partnership is only in English. We need better understanding of different cultures. Consumer representative – interview

5.5.1. The Commission's support for consumer engagement in direct care

Health literacy underpins consumers' ability to engage in direct/personal care.

The focus at the moment is on patient safety and experience of care, how we partner with them and build better health literacy. ... This is a priority area as there is a huge advantage in partnering in decision-making in care. Organisation DHB – interview

One of the main activities through which the Commission has supported direct care is the development of health literacy resources. Approximately one-third of surveyed consumer representatives rated the Commission's activities in improving health literacy and consumer participation as very or quite effective.

Across the stakeholder groups surveyed, health literacy education and training was occurring, but approximately one-third responded it is occurring 'in a limited way'.

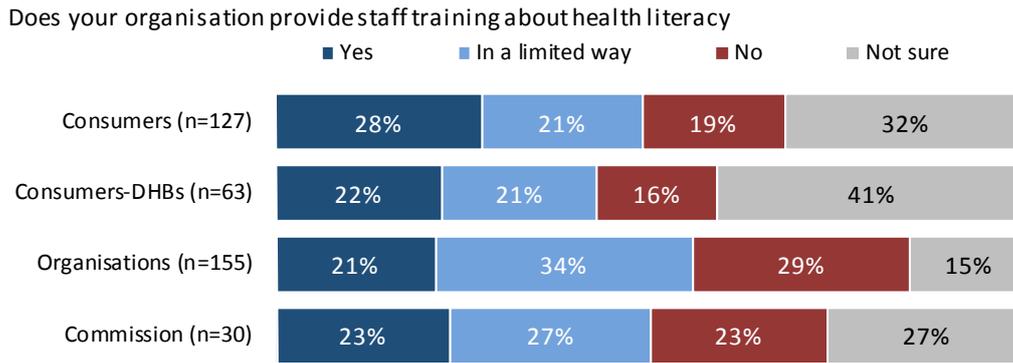


Figure 21: Organisation education and training for staff about health literacy (Source: Organisation, consumer and Commission staff surveys)

5.5.2. The Commission’s support for co-design

Part of the Commission’s PIC programme of work involved funding a co-design programme. The programme, established in May 2012, was designed to provide opportunities for consumers and providers to work together on projects to improve service delivery, using the co-design methodology and tools. Delivery of the programme was based on the principles of the Experience-Based Design (EBD) approach, developed by the National Health Service (NHS, UK) and applied within health care services in England, Canada, the USA and New Zealand.

The principles of this approach stem from the premise that the ‘*experiences of patients, the public and staff receiving or delivering healthcare services are a valuable source of information that can be used to improve safety of care and transform services*’.¹⁶ Involving consumers at a level ‘appropriate to their needs, skills and experience’ is fundamental to the co-design process.

Participants were on the whole very positive about their experience of the EBD programme. They recognised the value in the approach and its potential as an effective way of engaging staff and consumers in improving health care service provision:

*[Participants] said that it [the EBD approach] is a powerful way of understanding consumers’ views and what their experiences of healthcare services are really like. It is an effective way of engaging consumers in healthcare improvement from the outset and provides a powerful method for engaging with, and gaining, staff support.*¹⁷

Stakeholders identified a lack of understanding about what is meant by ‘co-design’– and that it can sound scarier than it is.

How do you get teams and services to start? It seems a big scary thing. Where do you start? ... There are things you can learn, tools you can use, but we try and take it back to basics. It’s a simple human process of engaging, listening, [and] involving. Organisation DHB – interview

¹⁶ Hayward, B. (2015). An evaluation of the co-design programme 2015.

¹⁷ *ibid*

For co-design to be effective, it needs to engage consumers early on, and where there is a genuine opportunity to make changes.

Consumer engagement has to be from the beginning, be genuine, and where there is no end goal already in place. Once there is an end goal, it doesn't matter what the consumers tell you, you're still moving towards that end goal. Being open to consumers means the organisation might change. Organisation DHB – interview.

5.5.3. The Commission's support for consumer engagement in governance and leadership

There was less awareness among organisation and consumer representative survey respondents of the Commission's activities around supporting leadership capabilities for health care providers and supporting leadership capability for consumers (see earlier Figure 18). Of those who were aware of the Commission's activities in this area, fewer than 10 percent of organisation stakeholder survey respondents considered the Commission's work in supporting leadership capability for health care providers to be 'very' or 'quite' effective (compared with 29 percent of consumer representatives, who thought the Commission's work in this area was very or quite effective) (Figure 22).

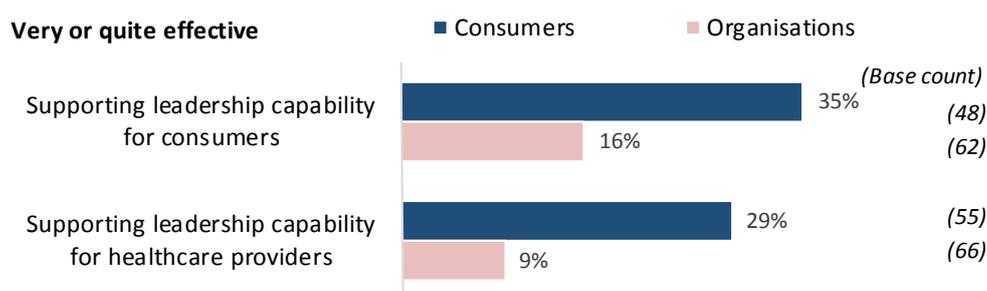


Figure 22: Views on the effectiveness of the Commission's activities around supporting leadership capability (Source: Organisation and consumer representative surveys)

The volume and complexity of reading (and sometimes a lack of lead-in time) before governance meetings was raised as a challenge for some consumer representatives. Some also mentioned not having access to printers, and that they found these types of documents hard to read online.

5.6. The PIC website

The Commission's website is one of the main channels of communication to the sector. The website provides a wealth of resources on consumer engagement in health care. This includes resources and tools developed as part of the PIC programme, specifically: links to other areas of the Commission's work; evaluations of its previous and ongoing activities; research articles from academic and grey literature (New Zealand and internationally); and links to tools, resources and general information of relevance on external websites (including networks and organisations, such as central government departments, health providers, research institutes, university programmes and NGOs).

Referencing the work of others and demonstrating the evidence used to develop resources contributes rigour and credibility to the Commission’s material. It also helps strengthen the overall message. For example:

*The data presented display that patient experience is positively associated with clinical effectiveness and patient safety, and support the case for the inclusion of patient experience as one of the central pillars of quality in healthcare.*¹⁸

Half of the organisation stakeholder and consumer representative survey respondents had used information on the Commission’s website (Figure 19).

Data were provided by the Commission on traffic to the PIC pages of the website. Views of the landing page, ‘about us’ and the workstreams peaked in quarter 3 (calendar year, July–August) 2014, as illustrated below (Figure 23). The ‘news and events’ section saw the greatest volume of traffic in quarter 2 of 2015 (more than trebling the previous two quarters) and ‘publications and resources’ traffic peaked in quarter 3 of 2015. The latter coincides with the publication of *Engaging with consumers: A guide for district health boards*. The quarter preceding this publication saw several news stories about the forthcoming document, during a consultation phase.¹⁹

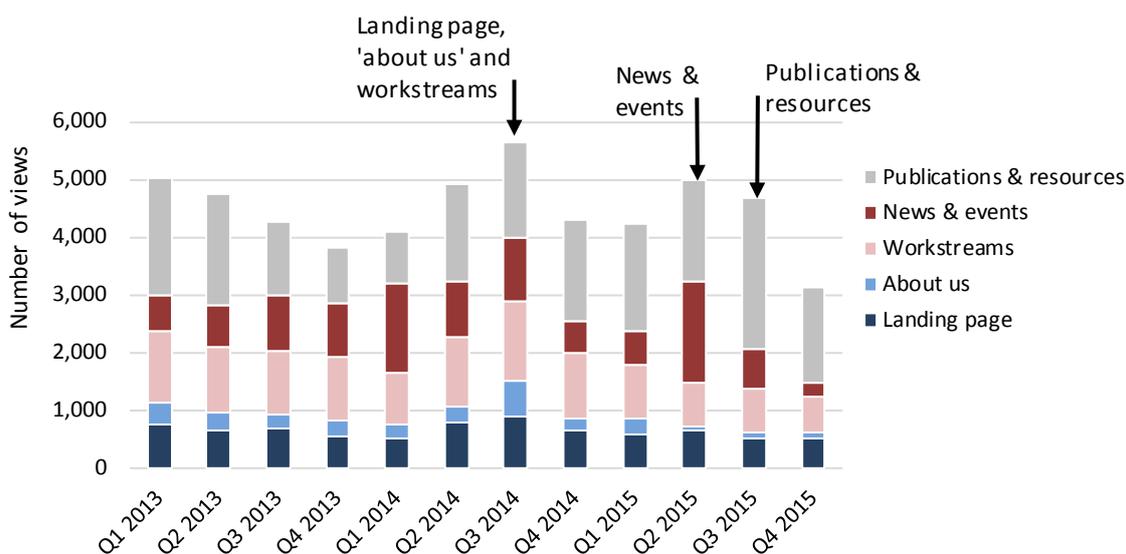


Figure 23: PIC website page views (Source: Commission website statistics)

However, despite the high level of use of the website, the large amount of information made it difficult to find what some users wanted. Commission stakeholders also noted the website is primarily aimed at health care providers and may not be adequately promoted – or tailored – to consumers.

¹⁸ Referenced in: 'Overview of the Commission's Consumer Engagement programme' (powerpoint presentation, October 2014, available at:

[http://www.hqsc.govt.nz/our-programmes/partners-in-care/work-streams/co-design-partners-in-care/#\[RESOURCES\]](http://www.hqsc.govt.nz/our-programmes/partners-in-care/work-streams/co-design-partners-in-care/#[RESOURCES])

¹⁹ <http://www.hqsc.govt.nz/our-programmes/partners-in-care/news-and-events/news-2/news/2080/>

6. The main barriers to consumer engagement

Key findings:

Staff not knowing how to include consumers and lack of consumer understanding about health systems were consistently identified by survey respondents as barriers to involving consumers.

Education and training needs identified included induction, presenting a representative view and working effectively at the governance level (needed for consumers and organisations alike).

Recruitment of consumer representatives/advisors was a challenge for some, especially the need to match consumers' skills, interest and expectations with the type of engagement needed, particularly at the governance level.

More work is needed to reach Māori, Pacific peoples, Asian and other ethnic groups and younger consumers; this could be supported by different models of engagement.

Consumers identified inconsistency in payment and recompense made to consumer representatives/advisors.

In the surveys, respondents were asked about the extent to which different potential barriers made it difficult for organisations to include input from consumers.²⁰ Figure 24 provides a summary of responses. Potential barriers are discussed in more detail in the following sections.

The most frequently noted barrier for Commission staff, organisation stakeholders and consumer representatives was 'staff not knowing how to include consumers' (74–77 percent of survey respondents considered this to be a major or somewhat of a barrier). This is captured in the quote below from a DHB stakeholder interviewed.

HQSC is very supportive but the big question is how? We need tangible things like training for consumer representatives, screening, helping them to understand bias, supporting them to participate. Organisation DHB – interview

Finding consumer representatives for committees/groups also showed a very consistent response across the three surveys, with 60–65 percent considering this a barrier.

A substantial number of stakeholders suggested lack of support from boards and senior managers was a barrier to consumer engagement. Some of the other factors identified as barriers are also likely to be influenced by the extent to which senior managers support engagement.

²⁰ For the Commission and stakeholder survey this was organisation-specific (ie, for their organisation); for the consumer representative survey this was based on their general experience (ie, the latter was non-organisation-specific for this question).

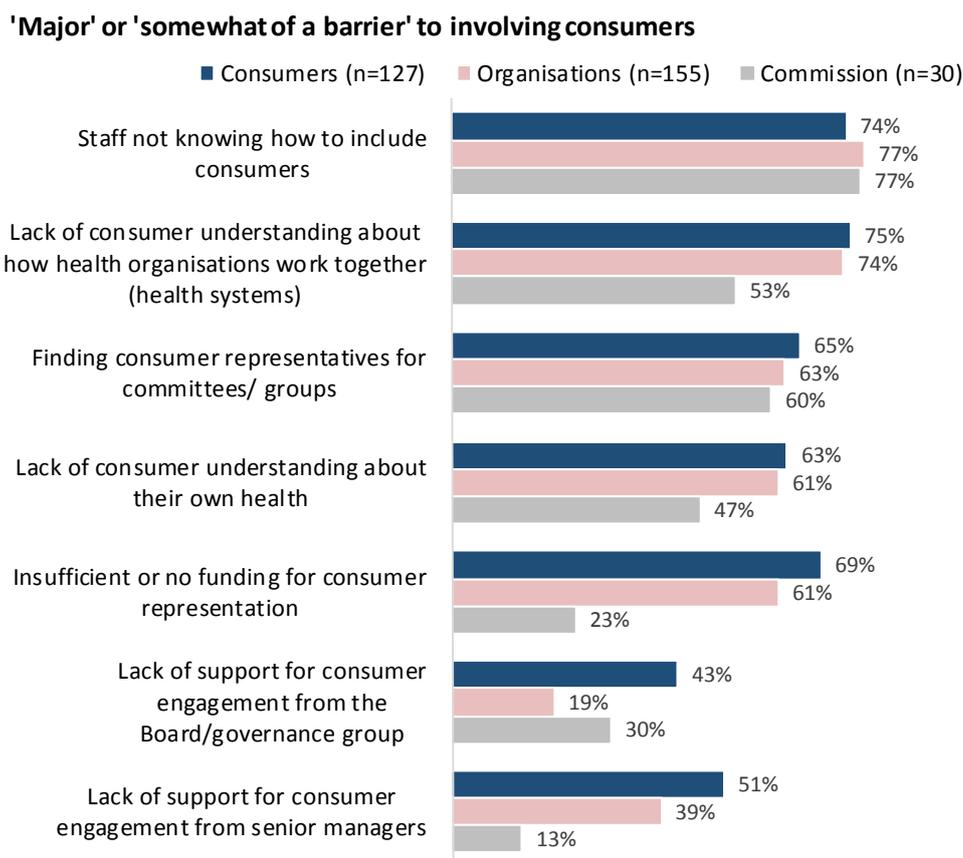


Figure 24: Barriers to involving consumers (showing percentage of survey respondents who considered each factor as a 'major' or 'somewhat of a barrier') (Source: Organisation, consumer representative and Commission staff surveys)

6.1. Finding consumer representatives

Most consumers surveyed were personally invited to become a consumer representative (Figure 25). Approximately equal proportions had heard about the opportunity through an advertisement and been told by someone they knew (29 percent and 30 percent respectively). Other routes included finding out about it through an existing role or through personal experience/interest.

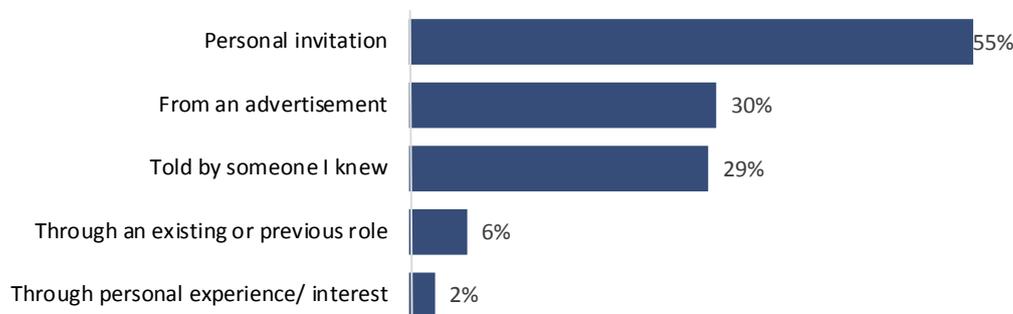


Figure 25: How consumer representative survey respondents heard about the opportunity to become a consumer representative/advisor (Source: Consumer representative survey)

Using personal invitations and existing networks appears to be an adaptive response by health care organisations to help consumer representatives operate effectively in the role and to minimise risks associated with people with 'personal campaigns' or 'bearing grudges'.

There appears to be a 'snowballing' effect in the process of finding and recruiting consumer representatives/advisors; once someone is an advisor for one organisation, they are more likely to work for another. Over half the consumer representative survey respondents were currently a representative/advisor for more than one organisation (Figure 26). Some of the organisations commented on the fact that the same consumer representatives were used in multiple forums, and some comments were made about seeing the same faces again and again.

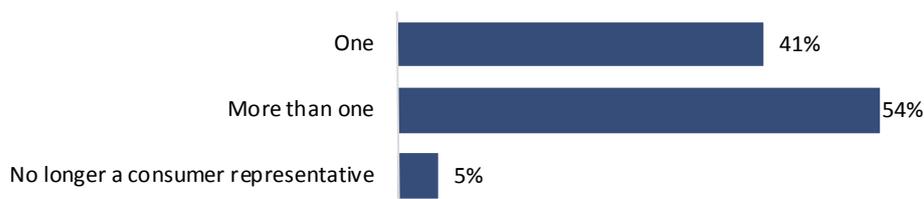


Figure 26: Number of different organisations consumer representative survey respondents represented/adviced (Source: Consumer representative survey)

There was a sense that a reasonable proportion of consumer representatives had been in their roles for several years. This was appropriate for some types of engagement, but less useful when looking at recent experiences of services. To address this, some organisations were planning new ways of seeking consumer input, including using social media platforms to engage more youth.

They [the consumer representatives] don't provide a moving feast, it's a static function, so they are not representative of the wider community. We recognise this, so also have ways of getting dynamic views. We have a youth advisory group and are developing on-line feedback. It helps to keep things fresh. Organisation DHB – interview

In some situations, consumers wanted to engage on a specific issue only. As one of the DHB staff interviewed commented, once action had been taken to resolve the issue, a consumer's interest or confidence to engage can fade. For this reason, the DHB stakeholder commented it was useful to bring:

... a flow of consumers on for shorter, more focused input related to their specific experience, and then allowing them to move on. Organisation DHB – interview

Several consumer representatives noted a practice in the health sector of using staff to act as consumers. While staff may have experienced health care services, they were not seen as being able to bring a 'true' consumer perspective.

In health, one of the barriers is the wide-spread acceptance of medically-trained people as consumers. These are often very useful people, but are not true consumers, even though they use health services. The framework is different, the relationships are different, and the level of understanding is very different. Consumer representative – survey

The need for an independent and skilled group to oversee the recruiting, screening, education and training of consumer representatives was raised by several stakeholders. Some suggested a role for the Commission here, for example, through a register of consumers. Several also mentioned the services provided by Health Link North, which supports the local DHB by recruiting, screening, educating and training a pool of consumer representatives; services that were well-regarded by several respondents.

Health Link North

Health Link North (<http://healthlinknorth.org.nz/>) is an independent, community-driven organisation committed to improving the health outcomes of residents of Auckland’s North Shore and the Rodney District, including South Kaipara. It promotes community participation in health care decision-making and fosters collaborative relationships between health care providers and the community.

6.2. Broad representation of consumers

There was a sense the current pool of consumer representatives was not representative of the wider population. Nearly a quarter (24 percent) of respondents to the consumer representative survey thought there was not an appropriate diversity of consumer representatives.

Just under half the respondents to the consumer representative survey were university educated; stakeholders considered this reflected consumer representation as a whole.

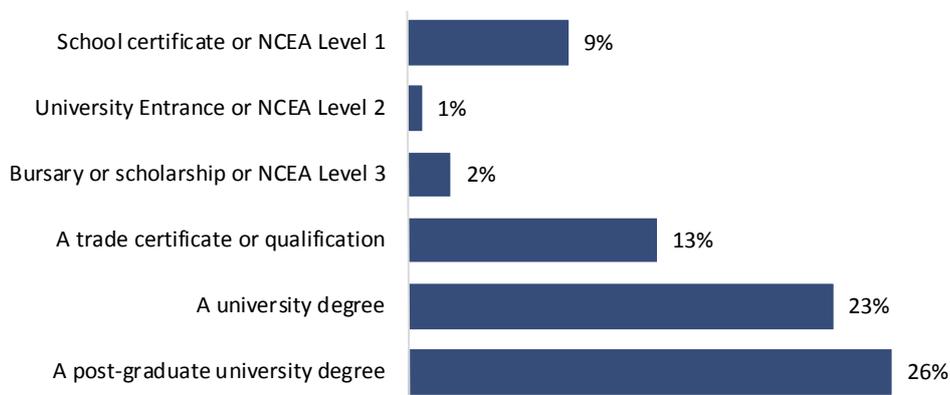


Figure 27: Education qualifications of consumer representative survey respondents (Source: Consumer representative survey)

In many interviews with organisations, staff noted there were additional challenges in finding consumers from Māori, Pacific and other ethnic backgrounds and those living in lower socioeconomic areas.

For Māori, Pacific and other ethnic groups, another barrier to engagement raised was the difference in world views and concepts of health (more holistic compared to a Western biomedical model). The concept of being a ‘consumer representative’ can also be a barrier to participation as it can conflict with cultural and social practices around interpretations of

representation.²¹ There can be an added burden for people feeling they have to represent their entire ethnic group.

Particularly hard thing for me (still) is whether you are a representative and, if so, who are you representing? Or whether you are just there as the non-clinician, as the real person, to ask the questions about how would that feel, what would that mean for somebody? I still feel that depending on the day or the meeting you can sometimes be both. And I think it is particularly hard for Māori consumers because they have to be representative for a whole ethnicity.
Consumer representative – interview

A mix of engagement approaches and multiple levels of consumer engagement are needed particularly to reach disenfranchised and vulnerable groups.²²

While most organisations tried to recompense the costs of participation for consumer representatives/advisors (eg, travel costs), working multiple jobs and/or shift work can restrict participation among people from lower socioeconomic groups. There can also be confidence issues related to differences in education between some consumers and the usually highly educated health professionals and staff.

6.3. Matching consumers' skills and interest to the role

A recent Australian study noted the need to match consumer representatives with suitable roles.²³ The evaluation of the Commission's co-design programme also noted the need to match consumers' skills and interest to the work being undertaken.²⁴

In this evaluation there were several examples given where a mismatch of the consumer to the role could promote frustration, and undermine the engagement approach. The mismatch was heightened at the governance level, where the input needed was at a strategic level. (As noted, there is value in having individual patient stories presented to the board, eg, in videos, but deliberations and decisions need to move beyond individual experiences, and this could be a challenge for some consumer representatives).

Identifying the skill, knowledge and qualifications needed to be more than just a consumer but to have the pre-requisite skills and/or training to understand what governance means in practice. Consumer representative – survey

In some cases, there was a lack of skills and/or understanding of how to operate at a governance level, for consumers and some staff alike.

²¹ Johnson, A (2015). Consumer and Community Engagement in Health Services: A Literature Review to Support the Development of an Evidence Based Consumer and Community Engagement Strategy for the Women's and Children's Health Network, South Australia

²³ Consumers Health Forum of Australia. May 2015. "Unique and essential": A review of the role of consumer representatives in health decision-making. <https://www.chf.org.au/pdfs/chf/Role-of-Reps-Health-Decision-Making-2015.pdf>

²⁴ An evaluation of the co-design programme 2014-15 (prepared by Ko Awatea's Evaluation Officer – Brooke Hayward; available at: <http://www.hgsc.govt.nz/our-programmes/partners-in-care/publications-and-resources/publication/2370/>)

6.4. Payment and recompense

A common principle was that people would not be out-of-pocket. Consumer representatives were usually recompensed for costs (eg, travel, parking) associated with participation. (Recompense in some cases did not always cover the costs of participation, as the amounts set had not been adjusted, eg, for increases in petrol prices.)

However, there was a lack of consistency in payment for consumer representatives. Consumers on the Commission's Consumer Network are paid, guided by the State Services Commission Fees Framework.²⁵ Consumer representatives in the mental health sector and maternity services also tend to be paid (but with variations in the amounts). Remuneration was more common for consumers at the governance level and not common at the direct care level of engagement (reflecting in part the level and time commitments associated with engagement).

For some consumers, the amount paid to them was recognised as nominal, but they were happy to contribute as a form of service to the community.

Although financial compensation does not adequately reflect the time I put in I am happy about the remuneration as I view the job as a part of my service to the community. Consumer representative – survey

A minority of the consumer representatives wanted a more formal employment relationship, given the importance of the role and the hours spent working. Potential disadvantages to formal arrangements were that an employment relationship could reduce a consumer representative's independence. Motivation could also shift from a focus in improving health care to financial.

Payment or not, being valued mattered.

I would do this if there was no financial recognition. However, it is great to be valued and that your time and energy is recognised. Consumer representative – survey

A few felt the amount (and type) of payment reflected a lack of valuing of the consumer. Lack of consistency in compensation could make joint meetings with consumers across a DHB and regionally uncomfortable for staff and disheartening for representatives, as the differences could make lower/unpaid individuals feel less valued. The lack of consistency was also raised as an equity issue by some consumers and DHB staff.

... although organisations are keen on consumer engagement they are not prepared to fund it. For example, to pay their consumers a decent amount. Giving grocery and petrol vouchers in my opinion is patronising and is not full partnership. Consumer representative – survey

²⁵ www.dPMC.govt.nz/cabinet/circulars/co12/6

6.5. Education, training and support

6.5.1. For consumers

Fewer than two-fifths (38 percent) of consumer representative survey respondents had received education or training as a consumer representative/advisor.

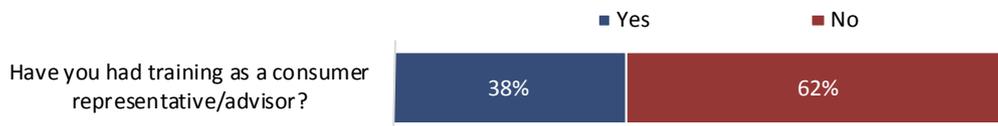


Figure 28: Education or training received by consumer representatives (Source: Consumer representative survey)

Of consumers who had received some education or training (48), most (58 percent) found it very useful. Education and training topics included:

- purpose of the role and expectations
- communication (effectiveness, how to engage different clients)
- about the health system (structure, policies, procedures)
- leadership and governance
- advocacy.

Four mentioned specifically having undertaken Health Quality & Safety Commission PIC education and training modules.

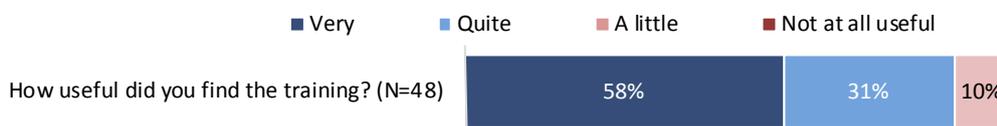


Figure 29: Usefulness of education or training received by consumer representatives (Source: Consumer representative survey)

The need for education and training for consumers to support them in their role as representatives was frequently raised, most often when starting (induction), how to provide 'representative' views and how to operate effectively at the governance level.

There seemed little in the way of formalised induction processes for new consumer representatives, although some groups tried to ensure new representatives received mentoring from a longer-standing member. Several representatives reported feeling 'thrown in at the deep end'.

The following quotes illustrate these points.

I was literally thrown in at the deep end and had to work out what I would do myself. Consumer representative – interview

Provide education on how to engage consumers so they are positive regarding involvement and are not just coming to the table with their own personal health agendas. Organisation DHB – survey

Provide better training for representatives including information about organisational structure and any changes, committees and their roles, role of the representative, relationship between hospital and other Health Providers. Consumer representative – survey

As part of its role in building sector capacity and capability, the Commission seeks to support health providers to provide education and training on consumer engagement for consumers and staff. Education and training about consumer engagement was being provided, but across most stakeholders this was seen to be occurring ‘in a limited way’ (Figure 30).

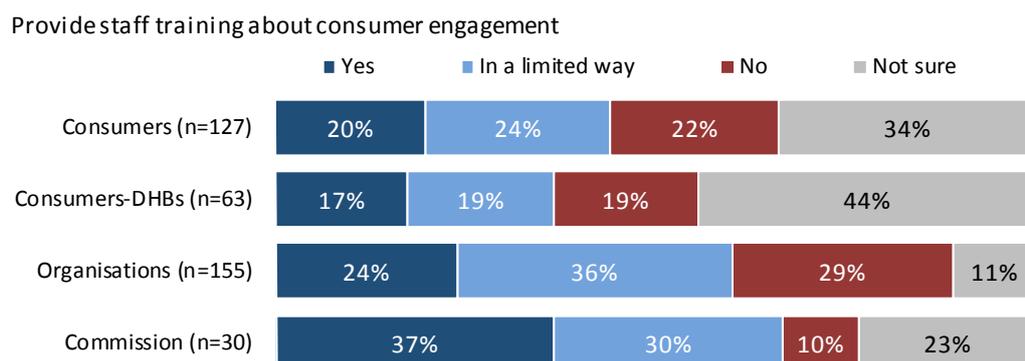


Figure 30: The extent organisations provide education or training to staff about consumer engagement (Source: Organisation, consumer and Commission staff surveys)

6.5.2. For staff

At the direct care and co-design level, a barrier to consumer engagement raised is that some clinicians think they are already working in partnership with consumers. Other barriers include a concern that consumers do not understand what they need, or what is safe for them, as well as a lack of education and training, time pressures, a desire not to become involved in a patient’s emotional state, and a fear of losing control or power.²⁶

Some staff were also unfamiliar with working at a governance level, or at knowing how to work effectively with consumers at this level of engagement.

6.6. Overview

Figure 31 provides an overview of the different characteristics of consumers that are important to consider when matching consumers to different types of roles. In interviews, consumer representatives and organisation stakeholders described problems that arose when there was a mismatch between consumer and provider expectations of the partnership.

²⁶ Coulter, A. 2012. Leadership for Patient Engagement. London: The King’s Fund. URL: www.kingsfund.org.uk/leadershipreview.

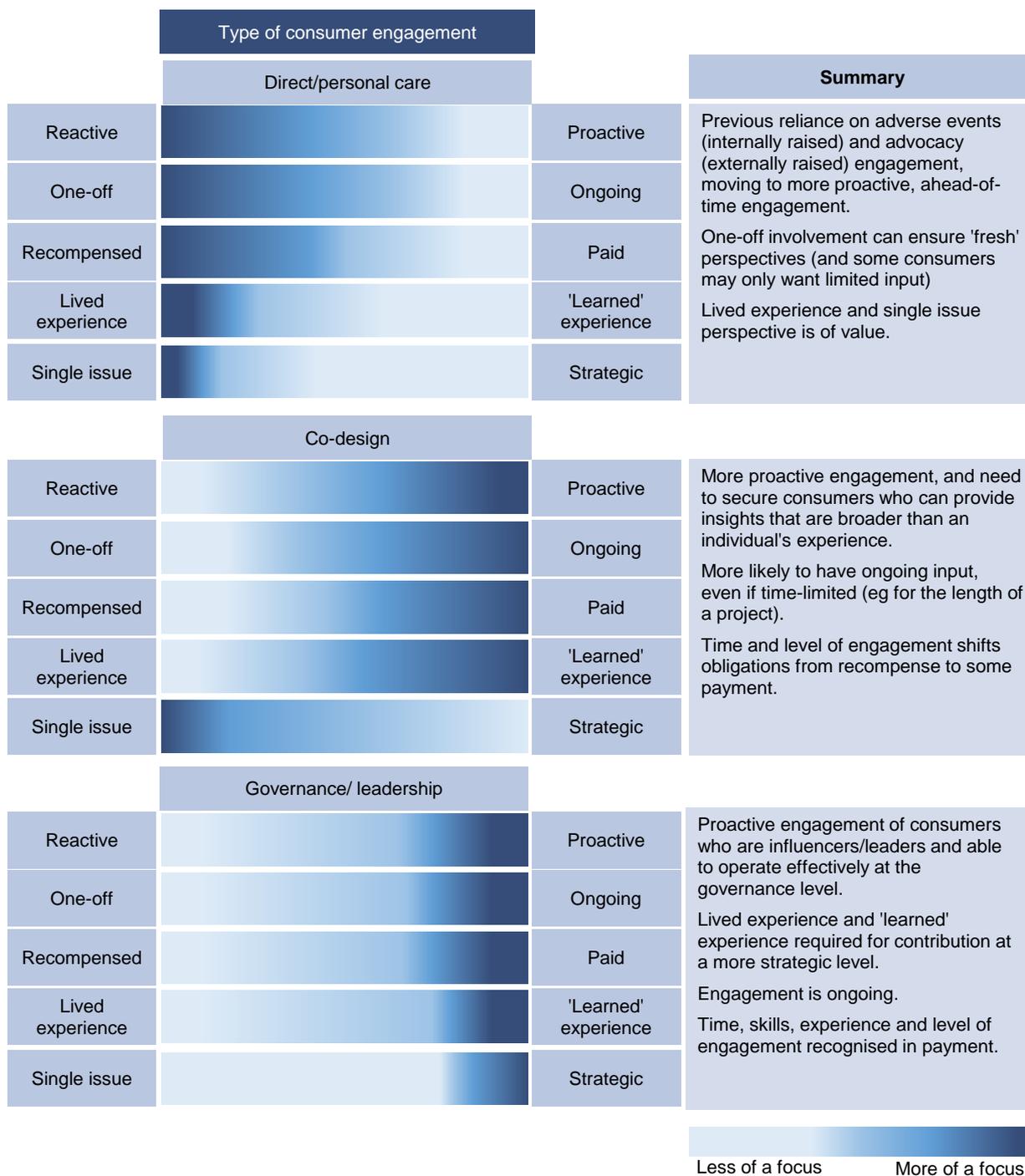


Figure 31: Overview of the characteristics of consumers that contribute to effective engagement

7. Remaining gaps in consumer engagement activities to achieve the PIC programme framework's aims and objectives

Key findings:

Generally, the Commission's PIC programme covered the main activities required to bring about sector-wide change in consumer engagement.

However, stakeholders identified some gaps in consumer engagement activities to achieve the PIC programme's framework and aims. These included:

- expanding the focus of the programme to include primary care
- assisting with understanding how to recruit and engage consumers and in particular how to involve harder-to-reach groups
- supporting staff engagement at a practical level
- enhancing the leadership within organisations that is essential to achieving change.

7.1. Build consumer engagement in primary care

The Commission has focused much of its efforts to date on consumer engagement with DHBs. The need to expand into the primary sector was raised several times. Consumers tend to have more contact with the primary health sector, which increases their ability to improve the services used by the majority of the population at any given time.

Work is also needed at the interface between primary and secondary care to help make the system easier for consumers to engage with, and to navigate.

A lot has been done by the Commission to support health literacy between professionals, and between professionals and consumers. What's needed now is support to navigate the health system, for example, between professionals and primary and secondary care. There is a role for the Commission to make changes at this system level. The whole system should be designed around working well for the consumer. The organisation-by-organisation focus of the Commission is needed, but now it needs to take systems approach. Organisation Agency – interview

7.2. Increase the focus on vulnerable groups

The need to better engage with vulnerable populations was raised as an area for future development by consumers and organisations. These populations have a higher risk of poor health outcomes, so helping services be more aware of and responsive to their needs could lead to better health outcomes (and likely reduce avoidable costs associated with delayed treatment). This was an area where leadership from the Commission was sought.

I think we miss out on feedback from a huge chunk of the population... Those are the people who don't fill in questionnaires and feedback forms. If we're really serious about improving [services] for those who possibly are the more expensive ones, who have more adverse

outcomes, [then] we have to go out into the community properly and pay them for their time... The Commission could lead the way and demonstrate that this is one way of doing it. My experience of people in DHBs is that they have no idea, absolutely no idea, of how to engage. Consumer representative – interview

7.3. Help support staff engagement approaches

The King's Fund found that engaging staff and patients is essential in making change and improving health care systems.²⁷

Engagement in healthcare involves one group that is far more powerful than it thinks – doctors – and another that is far less powerful than it should be – patients. Engagement with both is central to improving patient care.²⁸

The theme of engaging staff also emerged as part of the evaluation, as illustrated in the quote below. It also captured another theme, that the positive side of consumer and staff engagement can often be lost when the focus is solely on avoiding the negative.

Also need to think about staff, for example, their job satisfaction and joy at work through consumer engagement. There is a tendency [in consumer engagement] to focus just on the negative, like serious adverse events. Commission staff – interview

Sharing successes of consumer engagement is also part of building staff engagement.

*I think we are making progress. As someone who is helping lead the work in this DHB I would appreciate a training day with other DHB leads where we can share ideas, successes, challenges and have some training provided by HQSC. **It feels very much as though we are pioneers in a new frontier of health without a map at times.** [emphasis added]. Organisation DHB – survey*

7.4. Leadership

The King's Fund has identified three sets of skills that go into successful leadership of health improvement: service-specific knowledge, improvement know-how, and change management skills – the third of which includes engaging with both staff and patients (and their representatives).²⁹

Consumer representatives surveyed were more than twice as likely as organisation representatives to rate a lack of support for consumer engagement by the board/governance group as somewhat or a major barrier (43 percent compared to 19 percent; Figure 32). Consumers were also much more likely to say it was a major barrier (13 percent compared to 2 percent for organisations).

²⁷ The King's Fund. 2012. Leadership and engagement for improvement in the NHS: Together we can. London: The King's Fund. p.1

²⁸ Ibid. p.12.

²⁹ Advancing Quality Alliance as cited in: The King's Fund. 2012. Leadership and engagement for improvement in the NHS: Together we can. London: The King's Fund. p.10.

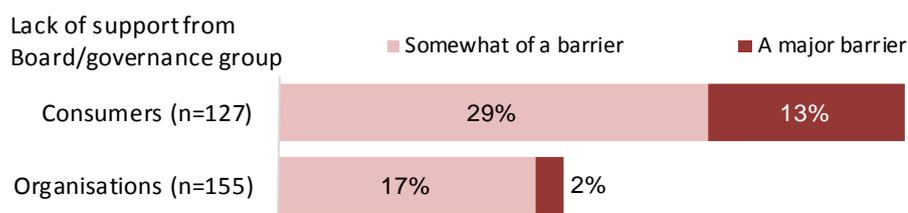


Figure 32: Lack of support for consumer engagement from the board/governance group (Source: Organisation and consumer representative surveys)

Over one-third of both consumer representatives (37 percent) and organisations (35 percent) thought a lack of support for consumer engagement by senior managers was somewhat of a barrier (Figure 33).

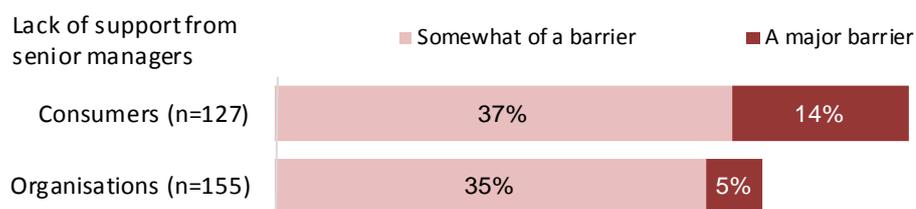


Figure 33: Lack of support for consumer engagement from senior managers (Source: Organisation and consumer representative surveys)

The need for support from senior managers was raised by several consumer and organisation stakeholders, and the types of support are captured in the quote below.

Representatives need to be well supported and resourced in their roles in order to make a difference and to sustain the challenges of the role. Consumer representatives are contractually responsible to their manager while they remain ethically and morally responsible to the people they represent. This can create a tension which needs to be well understood and supported by management. Organisation DHB – survey

Several of the organisation stakeholders felt that the idea of consumer engagement was supported, but other priorities (and often those with accountability measures) took precedence.

Lack of support for consumer engagement from senior managers in my view is not so much because of lack of buy-in, as I know they support the concept. In my opinion it is because they do not see it as a work priority for them and so it is not progressed and staff are not made accountable. Organisation DHB – survey

A few of the organisation stakeholders commented on what appeared to be a gap between the level the Commission operated at and the ‘on-the-ground delivery’ of health services. Greater visibility and leadership at the operational level was suggested, for example, having Commission staff providing expert advice or peer review on plans.

HQSC could work more directly with the DHBs. The risk at the moment is that the HQSC is seen as too far removed from the ground floor... [Commission staff] could work with DHBs and show what consumer engagement looks like as national leaders in this work. They could be available to help us. This could be by teleconference in project meetings, or being available to give expert advice when needed, or commenting on an implementation plan. This would also ensure a level of oversight and national consistency. Organisation DHB – interview

8. What are the key and emerging areas for future focus?

The first years of the PIC programme have raised awareness of the need for change and promoted the benefits of change by highlighting the advantages of consumer engagement. The PIC programme's evidence-based resources and tools, and best practice examples of how change can be achieved have helped some organisations to make changes.

There was recognition among many of the stakeholders that while good progress has been made, there is still a long way to go. Organisations are at different stages on a pathway to effective consumer partnerships: a continued focus on awareness-building is necessary for some in the early stages of development whereas others would benefit from more guidance about how to engage consumers. Some have well developed consumer engagement in direct/personal care and may benefit most from more advice about how to include consumers in governance.

In looking ahead, it is helpful to consider the shifts in attitudes that are required to build partnerships with consumers as a change management process with different activities needed at different stages in the process.

There are many different models of change and all have similar elements. The Prochaska and DiClemente model of change³⁰ has been extensively used to understand change for individuals in a health promotion context. For organisations the ADKAR³¹ approach sets out five steps to change as:

- **A**wareness of the need to change
- **D**esire to participate and support the change
- **K**nowledge of how to change (and what the change looks like)
- **A**bility to implement the change on a day-to-day basis
- **R**einforcement to keep the change in place for example by monitoring progress and providing feedback.

The model is described as being most effective when changes for organisations and individuals (in a health context staff and consumers) move in parallel. Communication is essential in progressing the different stages of change.

Figure 34 is an adaptation of the ADKAR change model. The green shading shows aspects that are better developed, and the red those less developed in consumer engagement.

But the gap is 'how'? We don't know how to do it. Organisation DHB – interview

The initial focus of the PIC programme was on building awareness, providing leadership to facilitate change and innovation in developing evidence-based tools and resources to support change.

³⁰ http://stepupprogram.org/docs/handouts/STEPUP_Stages_of_Change.pdf

³¹ <https://www.prosci.com/adkar/adkar-model>

Looking ahead, the different stages of development of organisations, suggest extending the focus of the Commission's role to develop and provide more information that is focused on how to partner with consumers, while continuing to promote awareness and influence organisations in early stages of developing consumer partnerships.

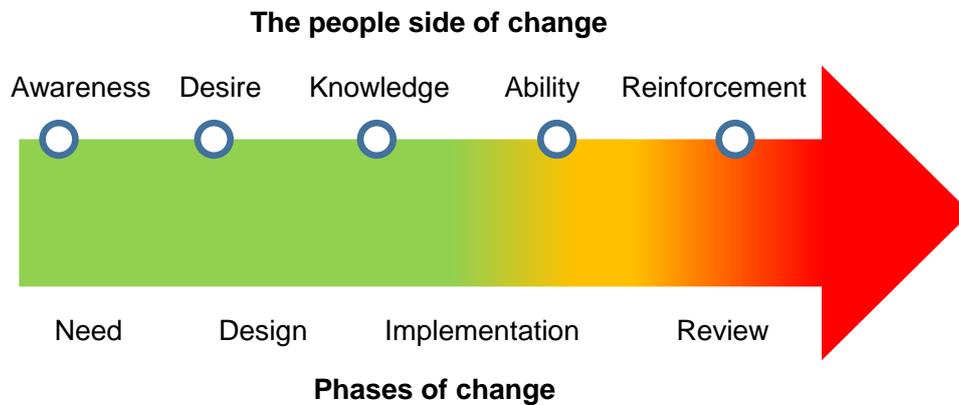


Figure 34: Stages of change – an adaptation of the ADKAR model

Potential areas for future focus raised in this evaluation are considered in the context of the Commission's role as an influencer.

8.1. Overview of next steps

The PIC programme's limited resources were noted by internal and external stakeholders. Some commented that the programme budget is unlikely to change substantially. Therefore, a Commission-wide focus on how best to use the resources available is the next step. The importance of involving consumers in decisions about the next steps was highlighted.

No need for further advocacy. It's the 'how' [to involve consumers] now and not the 'why'. Do you put your energy into helping the 'how'? Commission stakeholder

Suggestions arising from the evaluation for the future focus of the PIC programme are summarised in Table 1. The Commission cannot achieve these changes alone and needs to further influence other agencies and organisations to assist. Given the importance of consumer engagement across the sector, cross-agency funding is suggested.

Table 1: Potential activities for future focus

Building awareness and reach
<ul style="list-style-type: none"> <p>Enhance the Commission’s role as an influencer – the PIC team is small and must continue to actively build a network of influencers including the Commission’s consumer network, the Commission’s staff, and other Agencies and organisations. The Commission’s own team provide a workforce that can influence others as part of business as usual. More promotion of PIC and education and training available would better equip staff as potential champions.</p> <p>Connect and influence – the Commission could extend its effectiveness by more actively influencing others to increase their focus on consumer partnerships and align their strategic planning, and expectations of providers to the PIC programme. eg, Setting expectations for consumer engagement in contracts. Commission staff suggested using/better using existing contacts.</p> <p><i>Commission has a clinical leads network that meets four times per year. Maybe we need to have a half day workshop on consumers and consumer engagement and how to influence organisations.</i></p> <p><i>Need to target the four DHB regional groups to set consumer engagement as a priority and spread good practice.</i></p> <p>Continue to communicate the benefits – the Commission could also continue to profile the benefits of consumer engagement and consider more formal communications strategies targeting different groups (consumers, health professionals and organisations).</p> <p><i>[Need to] tap into healthcare worker engagement [including] job satisfaction and joy at work through engagement with patients and families. [This is] another message to engage clinicians with.</i></p> <p>Promote the inclusion of consumer engagement in health professional education and training – building awareness and skills in consumer engagement during undergraduate education is an effective way of achieving a shift in attitudes. Professionals can also be upskilled through their continuing education programmes.</p> <p><i>It’s a new paradigm for some senior clinicians... the College can be a powerful way to get that message across.</i></p> <p>Enlist community support – community organisation(s) with experience in implementation could to help support the Commission’s work, and better bridge the gap of moving from theory to practice.</p> <p>Extend awareness and reach to primary care – stakeholders noted the importance of extending the focus of the PIC programme to include primary care. The Commission has started to do this.</p>

Building the knowledge about how to make changes

- **Guidelines about 'how to do' consumer engagement** – many stakeholders wanted more information about how to engage with consumers. There is already a wealth of information on the Commission's website. A more active focus on building awareness of the information, and making it easier to navigate the website might help.
- **Consumer engagement quality advisors** – personal advice and feedback on progress is very important. Developing the quality and risk managers as consumer engagement advisors or developing a consumer engagement quality expert in each district may help to progress change. An independent consumer engagement quality expert role has worked well in other Commission programmes and would also be a way to influence primary care.
- **Continue to share information about what works** – while good work is being done there was a feeling that it is not being shared, leading to duplication of work. There was also a real interest in finding out what others had done to advance consumer engagement, with a particular focus on the practical steps of how to do this well. Part of this could involve connecting up existing consumer networks to facilitate the exchange of ideas as well as build peer support.
- **How to gain broader consumer representation** – broadening the range of consumer representatives to include a greater mix of Māori, Pacific and Asian peoples, and younger consumers is important. The Commission could help provide examples of different engagement approaches and strategies to help expand thinking about what consumer representation is and how it can be done, particularly to reach disenfranchised or vulnerable groups.

Improving the ability to change – by removing barriers

- **Best practice** – continuing to develop best practice policies and guidance would help provide consistency to consumer engagement across organisations
- **Education and training** – was requested frequently by consumers and organisations stakeholders. Topics included all aspects of consumer engagement. The Commission is not a training provider but as the 'go-to' organisation may need to lead the development of an education and training programme and selection of providers.
- **Consumer register** – several organisation representatives wanted to be able to access a register of potential consumers, with information on skills, experience and interest to help match them to particular roles. (This would also be supported by clearer definitions of roles and expectations).
- **Consumer recruitment** – providing support to find new consumer representatives, and to have some form of quality assurance process in place (ie, checking

suitability for the role).

- **Influence employers** – to build consumer engagement skills into staff job requirements. And to set clearer expectations for consumer representatives/advisors about role requirements, particularly for representation on governance groups.
- **Guidelines about consistency in compensation** – one aspect of consumer engagement where consistency is required is the way consumers are compensated for their contribution. Differences in compensation between consumers and others underpins different perceptions of the value of consumer's contribution.

Consumer engagement is a subject on everyone's plate now, just at different stages....As consumer engagement grows, there is a question about creating a resource that is accessible to support it. Consumer representative – interview

- **Incentivising change** – targets focus activity and drive results in the health sector. The (current) absence of a target related to consumer engagement means other areas (with targets and accountability reporting) can be prioritised ahead of this work.

Hate to say it [but] targets work. They help middle management [who] need a clear direction on measurement and what we are trying to achieve. Organisation DHB – interview

Reinforcing change

- **A target or quality marker** – to support consumer engagement was seen as a way of ensuring work was prioritised.

What is the measure that tells us we are getting some traction?

- **Embedding into 'business as usual'** – by having a requirement for consumer engagement built into policies, processes and practices. This includes in staff education and training, performance development, planning, purchasing and implementation of services, and monitoring and accountability reporting.

Establish an effective consumer advisor council at a high level within the organisation and require all projects to include a plan for consumer engagement. Set up policies and procedures that support consumer engagement as a key domain of quality and require managers to monitor them. Provide compulsory staff training. Develop a consistent remuneration policy for consumers. Organisation DHB – survey

Have some accountability set up for consumer engagement via management objectives, so there is more visibility, conversation and action planning around this. Organisation DHB – survey

Appendix 1: Programme logic model

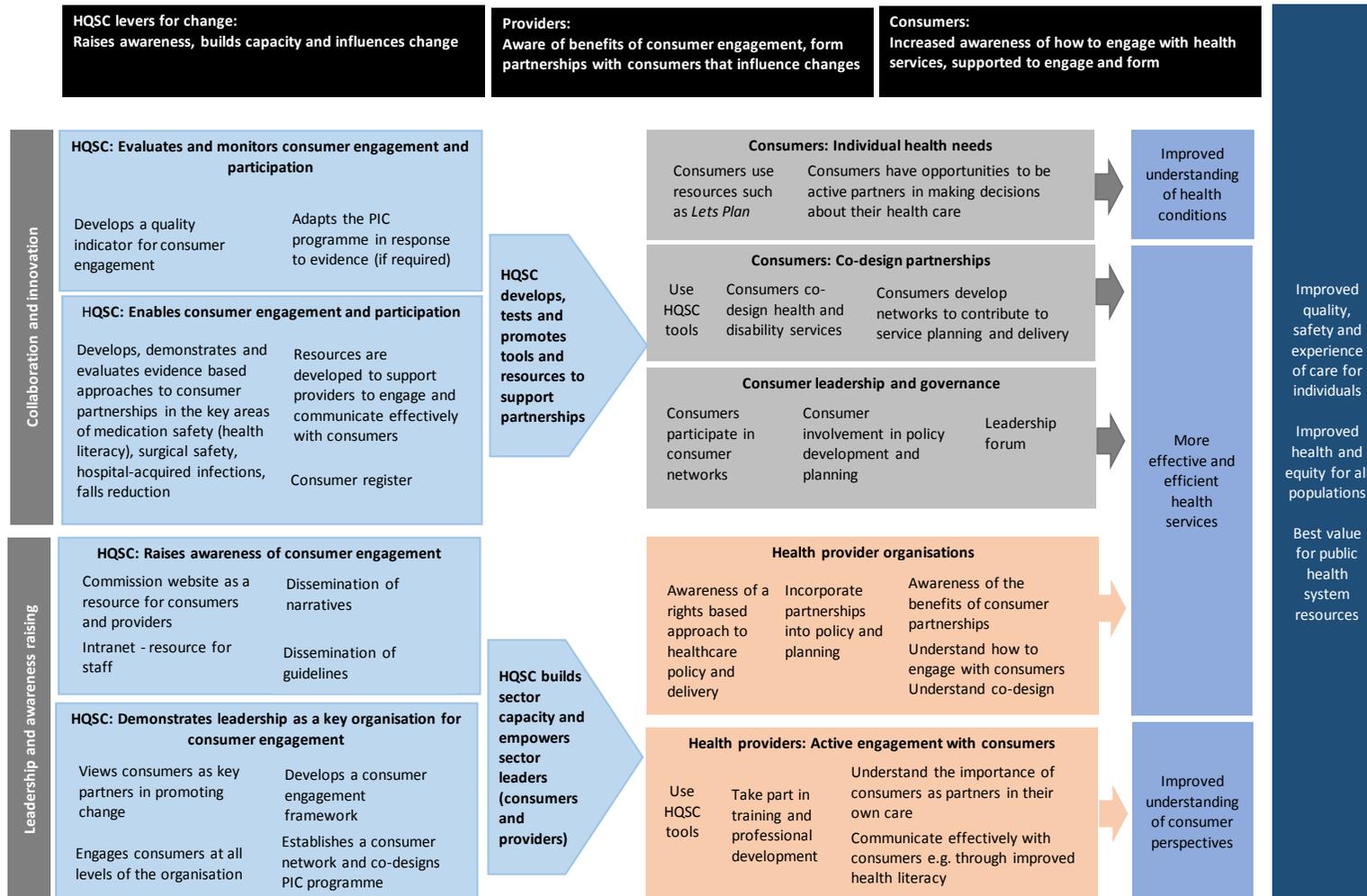


Figure 35: Programme logic model

Appendix 2: Evaluation framework

An evaluation framework linked to the logic model was developed in consultation with the Commission. It sets out the evaluation questions and sub-questions, measurable indicators and data sources for each evaluation question.

Table A1: Evaluation framework

Evaluation questions	Indicators/Comments	Data sources
What was done?		
Is the PIC programme a comprehensive and coherent approach to consumer engagement?	Overview of Commission activities in the key theme areas of leadership and awareness raising, collaboration, innovation Identification of any gaps	Document review Website review Interviews Surveys
What resources have been developed to support provider engagement with consumers?	Resources have been developed with a health literacy focus Examples of resources and how they have been used Commission staff use of resources Stakeholders views on resources	Review of resources Interviews – all groups Surveys – all groups
How was it done?		
What strategies and approaches did the Commission use and why?	Strategies and approaches to influence other organisations The programme's activities have been guided by an evidence base	Document review Interviews Surveys
What were the reasons for any changes in planned activities?	Project reports describe implementation learnings	Project reports Website review
How well was it done?		
Is the Commission seen as a key organisation for consumer engagement in relation to health quality	Commission staff consider consumer engagement a priority Commission policies and practices reflect the importance of consumer	Document review – Performance Improvement Framework (PIF),

and safety?	<p>partnerships</p> <p>Stakeholders consider the Commission's leadership effective</p>	<p>policies, annual surveys</p> <p>Commission staff survey</p> <p>Interviews</p> <p>Stakeholder survey</p>
Has the Commission established an effective consumer network?	<p>Consumer network is established and reflects diversity and skill mix</p> <p>Consumers on the network consider their input is valued</p> <p>Retention of consumer network members</p>	<p>Consumer network interviews, survey</p> <p>Commission interviews, survey</p>
Are consumers supported to participate as partners?	<p>Consumer partnership is demonstrated in the Commission's key areas of medication safety, surgical safety, hospital-acquired infections and reducing falls</p> <p>Consumers participate in leadership forum</p>	<p>Consumer interviews and survey</p>
Do key stakeholders know about the PIC programme?	<p>Stakeholder awareness of the PIC programme</p> <p>Stakeholder awareness of resources</p> <p>Examples of how PIC information and resources have been used</p>	<p>Interviews</p> <p>Survey</p> <p>Website review</p>
How well did the Commission collaborate with stakeholders?	<p>Examples of collaboration</p> <p>Stakeholders consider collaborations are effective</p>	<p>Project reports</p> <p>Project evaluation reports</p> <p>Interviews</p>
How effective has the Commission been in developing provider leadership?	<p>Examples of partnerships</p> <p>Attendance at workshops about co-design</p>	<p>Interviews and survey of providers</p> <p>Review of workshop attendance data</p>

How did the Commission demonstrate innovation?	Examples of innovation across key theme areas	Interviews Surveys
What has contributed to the programme's successes?	Examples of activities, approaches, resources etc that have contributed to successes	Interviews Surveys
What challenges have been encountered and how are they being addressed?	Examples of challenges – within Commission's scope Examples of challenges encountered within organisations, provider groups, consumers	Interviews Surveys
What difference has the PIC programme made?		
How successful has the programme been in influencing change?	Commission staff assessment of leadership and achievements Stakeholder attitudes to consumer engagement in direct care, service delivery, governance Examples of successes – take-up of health literacy resources, examples of consumer participation at all levels Examples of changes in systems to facilitate consumer engagement Examples of how consumer engagement has made a difference	Interviews with consumers Online survey of consumer network Document review Review of annual surveys
Did the programme result in any unintended consequences?	Examples of unintended consequences	Survey Interviews Document review – project evaluations
To what extent did the programme represent good value for money?	Consumer and provider examples of value for money Literature	Survey Interviews Review of project evaluations

What are the key and emerging areas for future focus?

<p>What are the remaining gaps in consumer engagement activities to achieve the PIC programme framework's aims and objectives?</p>	<p>Activities and key theme areas are linked to the logic model to identify any gaps</p> <p>Stakeholders' examples of activities and gaps</p> <p>Stakeholders describe potential to strengthen the Commission's leadership</p>	<p>All data sources</p>
<p>What should happen next?</p>	<p>Identified gaps</p> <p>Stakeholder's views on future focus considered in the context of what has been achieved and identified gaps</p>	<p>All data sources</p>

Appendix 3: Evaluation participants

Comparison of consumer representatives, organisation stakeholders and Commission staff survey responses.

In the analysis below the consumer representative/advisor survey responses have been broken down to show all responses (which reflect a mix of organisation types – see Table A2) and those that relate to DHBs specifically, where applicable.³²

The organisation stakeholder survey responses were predominantly (86 percent) from DHB employees, so these have not been separated.

In all comparisons, the small sample size of the Commission staff survey (n=30) should be noted and small counts (percentages) treated with some caution.

For context, the organisation types and DHB areas represented in the consumer representative and organisation stakeholder surveys are shown below.

Table A2: Organisation types represented by consumer and organisation stakeholder survey respondents*

Organisation types represented	Consumer representative survey ³²		Organisation stakeholder survey	
	Count	Percent	Count	Percent
DHB	63	50	134	86
NGO/Not for profit	32	25	7	5
Central government	17	13	2	1
Primary health	10	8	10	6
Other	5	4	2	1
<i>Total</i>	127	100	155	100

³² Organisation stakeholders represented only one organisation in the survey (their employee). Consumer representatives could represent more than one type. The counts shown in Table A2 show which organisations were represented in consumer representative survey responses where the question asked about one organisation type only.

Table A3: DHB areas represented by survey respondents (Source: Organisation and consumer representative surveys*)

DHB area	Consumer survey	Consumer survey - DHB respondents*	Organisation survey
Auckland	 2%	0%	 10%
Bay of Plenty	 6%	 8%	 6%
Canterbury	 20%	 14%	 6%
Capital and Coast	 13%	 11%	 12%
Counties Manukau	 5%	 2%	 14%
Hawke's Bay	 7%	 10%	 2%
Hutt Valley	 4%	 5%	 1%
Lakes	 2%	 2%	 6%
MidCentral	 5%	 6%	 6%
Nelson Marlborough	 2%	 5%	 2%
Northland	 2%	 3%	 15%
South Canterbury	 4%	 5%	 1%
Southern	 2%	 2%	 1%
Tairāwhiti	 2%	 3%	 6%
Taranaki	 8%	 10%	 7%
Waikato	 3%	 5%	 1%
Wairarapa	 3%	 3%	 1%
Waitemata	 4%	 3%	 3%
West Coast	 6%	 5%	 1%
Whanganui	 1%	0%	 1%
Total respondents	127	63	155

* DHB area representation in the consumer representative survey responses is shown twice. The first shows all consumer representative survey respondents. The second relates only to the consumer representatives who were answering about a DHB when asked questions about a specific organisation type.