

Effective Consumer Voice and Participation for New Zealand: A Systematic Review of the Evidence

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Executive Summary

Purpose

The purpose of the project was to:

1. To strengthen the consumer sector in New Zealand
2. To improve participation of health and disability consumers in decision-making within the health sector.

The report provides an evidence-based summary of:

- international and New Zealand literature on consumer voice and consumer participation in the health sector
- current consumer participation activities in the health sector in New Zealand
- international models of consumer bodies and networks.

The report was commissioned to inform consumers, policy makers/funders and health care providers, so that options for active health consumer participation can move forward.

Key points from the report

- In New Zealand community involvement in health is a very long-standing tradition
- New Zealand lacks a strong national consumer voice and there is no organised system of networking or sharing information within the sector or for government agencies or providers to engage with consumers
- There is some evidence, particularly from Australia, the UK, and the USA, that consumer participation can lead to improvements in health services
- Independent advocacy is another form of participation that can occur alongside involvement in the health sector
- A strong consumer sector needs government support and acknowledgement
- Participation should be a partnership at every stage. Only through power-sharing will participation deliver the benefits which everyone in the health sector hopes for
- The Consumers' Health Forum of Australia provides a good model for a national consumer body
- An alternative model would be a consortium approach, with representatives of disability and mental health national bodies combining in some way with health consumers

Introduction

Over the past ten years there has been an increasing number of calls for public and private agencies in the health and disability sectors to engage with consumers and to involve consumers in their decision-making and/or governance. This is the trend in many countries and has a number of roots, including the social movements of the 1960s and 1970s, the community development approach to health, concerns about the limits of representative democracy, policies of devolved decision-making, recognition that health status is influenced by socio-economic factors, inquiries into the abuse of patients' rights, and, not least, the emergence of strong health and disability consumer movements.

Each country has gone down this route in a different way, related to the configuration and ownership of the health system, political will, socio-cultural traditions, and historical events. In New Zealand community involvement in health is a very long-standing tradition with many major health services initiated from outside government. The more recent policy of community involvement began in the 1980s, with Area Health Boards, and has been in and out of fashion since then, with successive major restructurings of the health sector, based on dramatically different ideologies about health care delivery.

Unlike some other countries such as Australia, New Zealand lacks a strong national consumer voice and there is no organised system of networking or sharing information within the sector. There are no national mechanisms whereby Government and health agencies can easily engage with the consumer sector and there is haphazard communication of opportunities for consumers to participate in health sector decision-making and policy development. There is also duplication of effort as individual agencies establish discrete databases and methods of communication.

This report incorporates three separate parts:

Part 1: A literature review on consumer participation in the health sector

Part 2: A report on current consumer voice and participation activities in New Zealand

Part 3: International developments in consumer participation

Part 1: Literature Review on Consumer Participation in the Health Sector

New Zealand and overseas literature on independent consumer advocacy and consumer participation within the health sector was examined. The literature review found a large but very disparate literature on consumer participation, lacking an agreed methodology, with most of the literature produced independently of the consumer sector and primarily by social scientists (often reflecting their interests).

A variety of rationales for consumer participation was identified including citizen participation rights, empowerment of consumers, enhancing accountability, legitimating decisions made by managers and health professionals, along with commonsense arguments that involving consumers will lead to more responsive and acceptable services and improve the quality of health care.

There is some evidence, particularly from Australia, the UK, and the USA, that consumer participation can lead to improvements in health services. Some of the strongest evidence

comes from the mental health sector. The Australian trials of partnerships between providers and consumers were mostly positive experiences that had long-lasting effects. In the UK, audits have found that while there is a great deal of activity, little of this has entered the corporate bloodstream. There is a paucity of evidence about the participation of consumers in decision-making and policy setting, especially at a high level. Very often, participation occurs at some distance from the important decision-making processes and structures, at the periphery of the system. There is little evidence so far, that consumer participation activities lead to a redistribution of power or resources.

Research suggests that consumers view the health sector as powerful and difficult to change and that there is some scepticism about participation based on previous experiences, rather consumers believe that by organising collectively, they have the best chance of effecting change. The evidence shows that unlike consumers who belong to organisations, non-aligned consumers are not highly motivated to take part in ongoing participation activities and that they see organised consumer organisations as appropriate to provide a voice for consumers. Independent advocacy is one way of strengthening consumer voice allowing consumers to set and advance their own agendas, and can lead to profound policy shifts. Few studies of independent advocacy emerged in the literature search, however this report does cite some examples, such as the Cartwright Inquiry in New Zealand and HIV/AIDS campaigns overseas.

Some writers emphasise that participation and partnership require power sharing, but that those in the system find it hard to give up control. They question the wisdom of consumers putting so much effort into participation, given the insubstantial evidence of positive outcomes. Some community activists believe that the trend for involvement has depoliticised organised collective advocacy and led to an increased emphasis on individual service delivery rather than system change. Nevertheless, consumers are strongly in support of participation as one means of reaching their goals, but a significant shift in approach is needed. So far participation has largely been occurring on terms set by non-consumers. Participation should be a partnership at every stage. Only through power-sharing will participation deliver the benefits which everyone in the health sector hopes for.

This report discusses the advantages of drawing consumer representatives from consumer organisations, outlines what is known about training for consumers taking part in participation activities, and lists known enablers and barriers of effective participation. Strong consumer leadership is a facet of successful participation. Consumer organisations are a neglected resource and provide a means of tapping into the collective voices of consumers.

Effective participation requires:

- government support
- strengthening and resourcing of consumer organisations
- a system-wide approach in health sector agencies
- a commitment to acting on results.

Advantages of using organised consumer organisations to provide representatives include:

- They are already up-to-speed, and have skills and experience
- Additional training, mentoring and support can be provided through the group

- They have access to the views of a wide range of consumers through their organisations
- They are accountable back to the group
- Consumers from these groups make efforts to represent the wider consumer constituency
- The back-up of an organised group is necessary to counter-balance existing powerful elites in the health sector.

The Consumers' Health Forum of Australia participation programme is described in some detail as providing a model and some lessons to be learned about participation. In some situations, it is appropriate to involve users of services as well as consumers from groups. These consumers can benefit from the support and expertise of representatives of organisations on the same group.

Part 2: Current Consumer Voice and Participation Activities in New Zealand

The report provides the local background to participation and consumer advocacy and the status of the current New Zealand situation. It outlines the strategic context of the health, mental health and disability sectors, all of which support participation. It describes participation activities going on in each sector, and discusses the consumer sector. This scoping exercise found that both the consumer health and the mental health sectors lack a national consumer body, although mental health consumers are moving in that direction with encouragement from the Mental Health Commission. Disability consumers are also considering a national consumer body, and they already have a national Disabled Persons Assembly, other national consumer organisations based on specific disabilities, and long-established NGO providers who are moving to become more consumer centred.

In health, there are a number of national consumer health groups organised around conditions or population groups and a number of national community-based organisations with a strong focus on health, as well as many lobby groups and local groups. There are also a growing number of national consumer reference or advisory groups attached to government or other independent health sector agencies.

These groups are not coordinated or linked in any ongoing way. There are no organised channels for communicating, such as regular meetings, a national web site, email list, or newsletter. There is no comprehensive database of these groups or any recognised channel for communication between health, mental health and disability consumers. Consequently, there is no easy way for governments or others to tap into the collective views of New Zealand consumers, disseminate information to them or seek informed consumer representatives.

While there are varying degrees of recognition of consumer organisations by government in the mental health and disability sectors, this has not occurred in health where responsibility for participation has been largely devolved to District Health Boards (and to a lesser extent, to Primary Health Organisations). Elected District Health Boards are to some extent seen as the mechanism for providing public input into the health system. There is a formal relationship between the Ministry of Health and some non-government organisations; however, many of these NGOs are service providers. Unlike Australia, where consumer participation activities form part of the accreditation of health providers, and the UK where

health agencies are inspected, audited and scored on their participation performance, there is limited scrutiny of health care providers in New Zealand.

Both Australia and the UK have legislation, strategic policy and national guidelines on participation. The New Zealand legislative and strategic framework is patchy and far less rigorous in its application. Champions in government, such as a minister or key government officials, have been identified as an important factor in getting participation off the ground. In New Zealand, the Mental Health Commission and Office for Disability Issues have to some extent played this role, but there is no similar entity in health. Australia and the UK have funded research to provide an evidence base for participation, with certain academic or stand-alone units playing a particular role. There is no parallel for this in New Zealand.

Overall, New Zealand lacks the in-depth policy and infrastructure around participation that exists in countries that have given prominence to consumer participation.

Part 3: International Developments in Consumer Participation

This summary of International models for consumer participation examines consumer participation in Australia, the UK, Canada, the USA, Europe and cross-nationally to see what lessons can be learned to strengthen consumer voice in New Zealand. This was a very large task and the emphasis was on health consumer organisations, although some of the strongest national consumer organisations focus on people with chronic or long-term conditions which includes people with disabilities.

All of the countries examined are exploring various forms of participation in response to the worldwide trend to try and increase the involvement of consumers and the public in health care structures. In most countries this is happening organically and incrementally, often in response to consumer demand, but in the UK the approach is top-down and prescriptive. Legal changes have required the establishment of a plethora of bodies aimed at increasing participation, although most of this is occurring at a local level. Consumers in the UK would have preferred the strengthening of existing community and consumer groups.

In most countries there is formal government support for consumer organisations and some form of dedicated government funding for peak consumer bodies. Efforts to strengthen and support consumer voice have occurred where there is a strong government policy framework, supportive ministers and/or officials, a government office or focal point for promoting participation, a partnership approach between consumer organisations and government, acceptance of advocacy as a role for consumer organisations, and funding for consumer organisations. Some of the most effective models have linkages between consumer organisations and research entities.

While all countries have a range of national health and disability consumer organisations, usually focused on a health condition or population group, only Australia has a single national consumer health umbrella entity as a forum for groups to come together. Only in Australia is consumer participation organised through a consumer body, the Consumers' Health Forum of Australia, although in some countries groups of consumers, such as breast cancer and HIV/AIDS activists, have had an important role in establishing participation activities. The Consumers' Health Forum of Australia also works through partnerships with government and academic entities to continuously improve and strengthen participation activities. In all other countries (including New Zealand), participation is led by federal and state governments, health agencies and health care providers.

Benefits of a National Consumer Body

The literature search identified organised consumer bodies and national bodies in particular as an important means of strengthening consumer voice (Marmorand Morone 1980; Sylvan and Legge 1988; Dwyer 1989; Bastian 1999; King's Fund 2002). In the UK and Canada, the need for a single national consumer health body has been identified through recent research and consultations with consumers and the establishment of such a body is currently being discussed. In The Netherlands a very large and active consumer body for people with chronic illnesses and disabilities has recently been established through the amalgamation of existing groups. The international review showed that a national consumer body can carry out a range of functions that are currently not being provided in New Zealand.

Our history shows that the need for a national body was identified as far back as 1988 and that at that time the Department of Health took some steps to investigate such a development. As will be outlined in this report, this did not come to anything, but over the following years, the need for a national consumer network or focus for health consumers and for mental health consumers has been repeatedly identified. In 2002, the urgent need for national support for consumer participation was identified as part of the Ministry of Health credentialling project. The report to the Ministry of Health (Woodward 2001) noted that in New Zealand *'[c]onsumers lack power because they don't speak with one voice. Developing a national consumer body has the potential to strengthen voice of consumers by addressing common concerns'* (p 14).

The Consumers' Health Forum of Australia provides a good model for a national consumer body, although there are aspects of consumer organisations in Canada, the UK and the Netherlands that could also be incorporated. The forum is a key feature of the Commonwealth Government of Australia's strategy to strengthen consumer participation in the health sector. The forum is an umbrella organisation for consumer organisations, who are voting members, electing a governance board. It has a well-developed consumer participation programme with a database of available consumer representatives, a nominations and selection process, accountability mechanisms, support, mentoring and training in representation.

Bastian (1999) credits the existence of the Consumers' Health Forum of Australia with strengthening the consumer health sector in Australia and encouraging participation. Advantages she cites for the forum are:

- It provides a mutually acknowledged bridge between the government and the health consumer movement
- Regular communication with the political and bureaucratic arms of government has kept consumers' concerns and priorities on the agenda
- It has provided a clear route for forum member organisations to participate in government policy and decision-making processes
- Government has a relatively simple conduit to consumer opinion and can communicate its views and activities to a wide constituency
- The existence of a well-funded health consumer lobby has led to growth in the consumer sector and enabled consumer and community groups to take advantage of the growing interest in participation.

Cross-sector support can also be important in gaining support. In Australia, health promotion, public health and social service agencies advocated to government to support the establishment of the forum. Successful consumer bodies need sustainable funding and to establish stable relationships with government. In addition there needs to be acceptance of the role of advocacy organisations that sit outside government in contributing to civil society.

Options for a National Consumer Organisation in New Zealand

A New Zealand national organisation could operate as an umbrella organisation in a similar fashion to the Consumers' Health Forum of Australia.

It could play the following roles:

- Hold forums and meetings to develop the consumer movement, enabling groups to come together to discuss subjects of interest and establish common positions where possible
- Undertake projects and campaigns on topics of interest to the consumer movement in New Zealand
- Develop a searchable database of consumer organisations to enable consumers, providers and public agencies to contact consumer groups
- Develop a database of consumer groups and consumers who are available for participation activities, seek nominations for specific posts and make selections of the most appropriate people
- Disseminate information and raise awareness about relevant issues, including, posting an electronic web-based bulletin board of notices about events, news, research results, consultation and participation opportunities
- Provide training, mentoring, support, access to information and networking opportunities for people acting as consumer representatives
- Provide opportunities to share learning, and develop the role of successful advocacy and participation in decision-making, policy direction and service planning
- Develop background papers, submissions, guidelines and other policy documents
- Foster and develop partnerships to carry out research on topics identified by consumers to provide an evidence-base for consumer activities. A national consumer organisation would also have a role in disseminating relevant research findings
- Develop partnerships with government and other agencies to deliver programmes and undertake activities to improve the quality of health care and the health and wellbeing of New Zealanders
- Work in partnership with member organisations on national projects and activities.

Other overseas national consumer organisations provide further guidance about the roles of a national body. Desirable features that emerge from these are:

- Advocacy needs to be accepted as a key role of the organisation
- The organisation should take a high-level strategic role
- Annual or biennial meetings of members help to:

- strengthen networks amongst consumers
- foster discussion of current issues
- provide direction to the national committee or steering group
- provide a mandate for ongoing work
- The organisation should adopt the principles of acceptance of differences and diversity, building on shared goals
- There needs to be support for member organisations, including entering into partnerships with them on specific issues. This assists in capacity building.
- The national body should not replace member organisations
- A number of modes of communication need to be used, recognising that member organisations will have differing communication technology and ability
- Linkages with Centres of Excellence or research institutions enable consumers to have input into the research agenda and operate from an evidence base.

An alternative model, recognising that there are already national disability consumer groups, and mental health consumers working towards a national consumer body, would be a consortium approach, with representatives of disability and mental health national bodies combining in some way with health consumers. The current lack of a similar national consumer health group could provide some difficulty with this model.

At this stage it is not known how Maori would wish to be involved. Maori have rarely organised as consumer groups, preferring to organise as iwi, iwi or locality-based provider groups or community of interest groups, such as women or kohanga reo. There are however options for involvement in a single national consumer group or in consortium or partnership arrangements.

Governance structure

Overseas bodies such as the Consumers' Health Forum of Australia tend to be constituted as an incorporated society, with the membership electing a steering group, board or national committee.

Voting members are consumer organisations that subscribe to the goals of the organisation. Non-voting members are individuals and other organisations. This would include individuals providing a consumer perspective in participation activities who are not representing a consumer organisation.

The CG-Raad in the Netherlands has a slightly different structure where member organisations send representatives to an assembly at which a governing board is elected.

Any national committee/council/board will require a spread of interests so that there is a representative voice for different ages, Maori, ethnic communities, rural consumers, a range of disability and health consumers, and so on.

Funding options

New Zealand is currently experiencing difficulty with the concept of government funding support for advocacy and lobbying activities, especially those activities that involve government policy. It was clear from the international evidence that this role is largely accepted in the other countries studied. For example, the Canadian Women's Health Network is funded specifically to alert the government to emerging issues.

The Dutch example of the CG-Raad provides a mechanism for separating government funding for advocacy from a direct contractual relationship with the government. The Netherlands Government provides funds to a foundation for health and disability consumers, which then distributes funding to consumer organisations. The current difficulty in New Zealand could also be addressed by instituting funding grants to consumer organisations, as opposed to contracts for services. That way the consumer group has discretion over how it spends its funds and it distances it from government influence.

Funding for a New Zealand consumer organisation body could come from:

- Government
- Contributions from District Health Boards
- Other agencies which would benefit, including Accident Compensation Corporation, New Zealand Guidelines Group (NZGG), Health and Disability Commissioner, National Health Committee, Health Research Council, Human Rights Commission, PHARMAC. These agencies could pay for training and support for consumer representatives to be provided through the network
- Universities and other tertiary organisations could contribute if there was some sort of training or study linkage or internship programme
- Membership contributions
- Sponsorship of particular activities. It will be important for any proposed consumer body to have a clear policy on health industry funding of the body, such as pharmaceutical industry funding
- Contracts to take part in or carry out accreditation, evaluations, training with providers and so on.

Recommendations from the Report

- NZGG to invite consumer health and disability organisations to a national meeting to discuss options for a national consumer focus and seek their support for it. Participants could discuss and decide on their preferences as to the form of the organisation, principles by which to work, rules for membership, the roles of the organisation (using those given here as a basis). They could appoint an interim steering group to take the project forward.
- NZGG to invite someone to visit New Zealand from Australia to further discuss the model of the Consumers' Health Forum of Australia and the relationship with the Commonwealth Government.
- NZGG to advocate to the Ministry of Health with regard to the need for a consumer focus in the Ministry of Health. This could be a dedicated office, portfolio or division. There is also a need for a national policy and framework within which agencies such as DHBs can participate. Advancing this recommendation should await a national hui of consumers, although preliminary discussions could be held with the MOH.
- NZGG to advocate to the Ministry of Health for the need to national policy around consumer participation. This would expand on the *New Zealand Health Strategy* principle for active involvement of consumers at all levels. Advancing this recommendation should await a national hui of consumers, although preliminary discussions could be held with the MOH.
- The option of establishing a foundation or trust to distribute government funding to health and disability consumer organisations should be explored further.
- There is a need for standards, performance measures or similar tools for measuring consumer participation within DHBs, PHOs and other service providers.
- DHBs, PHOs and other service providers should be regularly audited against such standards, similar to the process of the UK Commission for Health Improvement (now the Healthcare Commission). The Commission's framework could be accessed to see if this could be modified for New Zealand. Other tools could also be evaluated.
- NZGG to advocate to the Health Research Council the need for a consumer focus within the priorities of the council. This could develop as a partnership with the peak consumer body.
- NZGG to seek opportunities to promote research and evaluations on consumer participation, for example, the goals and outcomes sought for participation projects, consumer experiences of participation, and so on.
- There is a need to find sources of funding to allow consumer organisations to document (and publish) New Zealand examples of consumer advocacy and participation.
- The UK National Consumer Council *Stronger Voices* training programme for consumers should be assessed (with regard to its acceptability and applicability in New Zealand) as a possible basis for consumer training in New Zealand.
- An in-depth review of the disability sector may be needed as an adjunct to this report

- This report has not canvassed organised activities involving Maori consumers as this is intended to be carried out separately. This should occur before other recommendations are progressed.