DISCUSSION DOCUMENT

Effective Consumer Voice and Participation for New Zealand

A Systematic Review of the Evidence

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for the New Zealand Guidelines Group
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I communicated with a large number of people in New Zealand and overseas and thank them for participating. Special thanks to people who provided documents and read sections of the report, or the whole report, and made comments while it was under production.
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 (Marmor and Morone 1980; Sylvan and Legge 1989; 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.

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xiv Effective Consumer Voice and Participation for New Zealand
Introduction

This report provides the first New Zealand review, based on experience within New Zealand and overseas, of consumer participation in the health sector. It is designed to be the first stage in a process towards the establishment of some form of network or entity that would strengthen consumer voice in New Zealand. The report will review the literature, describe what is being done in New Zealand and overseas, and outline some ways forward for New Zealand. These will form the basis of discussion for a proposed national hui to debate and reach consensus about the way ahead.

The report was commissioned by the New Zealand Guidelines Group (NZGG) which has a particular interest in consumer participation. The NZGG board includes consumer representation and all guidelines development teams have consumer involvement. NZGG, from time to time, has provided consumer training. It is closely involved in the international Cochrane Collaboration which has a Cochrane Consumer Network.

NZGG was approached by the Women’s Health Action Trust, when I was Executive Director of that organisation, to pilot a Consumer Networking Project, which would have involved networking activities to strengthen the consumer sector. This proposal grew out of my experience at a national workshop for Independent Practice Associations organised by the Health Funding Authority, held in Wellington in 1998. I was invited to speak on the topic of consumer involvement and also to run a workshop.

What was clear from this experience was that while providers were being expected to involve communities, there was little guidance or infrastructure to enable this to happen. Each Independent Practice Association was having to invent the wheel for itself. A proposal was taken to the Health Funding Authority to establish a consumer project with a searchable database of New Zealand consumer groups, guidelines for involvement, examples of good practice, bulletin board and so on. Funding seemed imminent until the enthusiastic CEO shifted to another role in the health sector.

There were repeats of this experience over the following years, as potential champions moved around a constantly reconfiguring health sector. One obstacle was the lack of any kind of national consumer networking to enable Women’s Health Action to have the consumer support to set up the project. At the same time, a number of projects amply demonstrated the need. When Women’s Health Action sought to provide a consumer voice in the project to establish a Trans-Tasman Therapeutic Goods Agency (the Consumers’ Health Forum of Australia was already involved), it was required to show a consumer mandate and this had to be constructed from scratch.

Through all this the NZGG was a staunch ally, believing that there needed to be an organised approach to build the capacity of the consumer sector. Indeed, these requirements emerge from this report. The need for ‘champions’, the need to build consumer capacity and the need for supporting infrastructure are shown to be critical to effective consumer participation.

Finally, the NZGG commissioned this report, the basis of which is to provide the evidence and experience underpinning the good idea.

The purpose of the report was to review the work around consumer participation in New Zealand, scope the current situation in New Zealand, review the international literature, look at overseas models of consumer bodies and networks, outline the benefits and achievements of networks, discuss the need for a network or similar body in New Zealand, identify the roles it could play and the gaps it could fill. Finally options for New Zealand would be described.
The report is written from a consumer perspective. As will be noted later, most of the literature found is not written by consumers, but largely by social scientists and academics, and most of the policy is written by governments. Taking a consumer perspective means trying to identify the consumer viewpoint in the subject under discussion. It also means adopting a critical perspective, since a certain amount of the activity in this area is generated by government policy.

The report covers New Zealand consumer activity, but does not include activities amongst Maori as it is intended that this be addressed separately. It provides an overview of the disability sector as it relates to the health sector in particular.

Structure of the Report

This report is organised in three parts:

Part 1 is the results of a review of international and New Zealand literature on consumer voice and consumer participation in the health sector.

Part 2 is a report on the status of consumer participation in the health sector in New Zealand. It is divided into three sections looking at health, mental health and disability. This part looks at

- the strategic framework around consumer participation, describing the relevant New Zealand legislative and strategic documents
- key government offices and agencies, and activities being carried out by these agencies
- the consumer sector, its current configuration and activities.

Part 3 is a report on consumer participation in a number of countries: Australia, United Kingdom, Canada, USA, Europe, and international groups. Each country report is divided into government sector and consumer sector. Lessons for New Zealand are drawn from each country.
1. Literature Review on Consumer Participation in the Health Sector

1.1 METHODOLOGY AND RESULTS

Methods

A number of methods were used to obtain relevant papers and information. These were:

3. A systematic search of electronic databases Medline, Embase, CINAHL, PsycINFO up to end of 2003. Search terms are in Table 1. The search strategy is in Appendix 2.


5. A search of the Cochrane Library.


7. An approach to people involved in relevant fields, government agencies and consumer organisations in New Zealand and overseas. This included email dialogue, telephone interviews and face-to-face interviews. The people contacted and their organisations are listed in Appendix 4.

8. A hand-search of literature held by Women’s Health Action Trust.

9. A request for information through the Public Health Association email list.

The literature that was collected using these methods formed the basis of all three parts of this report.

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<th>Table 1: Search Terms</th>
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For the search strategy, see Appendix 2.

Inclusion and Exclusion Criteria

The focus of the review was consumer voice or consumer participation in high-level policy setting and health decision-making. Because of the paucity of papers specifically on this topic, some papers were included which dealt with consumer involvement in policy setting and decision-making at a lower level, where consumers were representing consumers collectively as opposed to making decisions about their own care.

Papers were excluded if they dealt only with:

- Consumers involvement in decisions about their own treatment
- Self-care or self-management programmes
- User satisfaction surveys and other passive feedback processes
- Provision of information to consumers
- Consumer involvement in teaching students or training health professionals
- Systems for complaints about medical treatment by consumers
- Consumer involvement in research
- Carers or caregivers.

Literature reviews were included even if these were not systematic reviews. Informed review papers or opinion pieces by consumers and others were included, classed as ‘expert opinion’.

Evidence Tables, References and Appendices

The evidence table can be found on the NZGG website at: www.nzgg.org.nz/guidelines/0086/050511_Consumer_Report_Evidence_Tables.pdf.

The table is not organised according to any rigorous methodology as the nature of the literature did not make this worthwhile. The wide-ranging nature of the papers resulted in quite lengthy explanations under the ‘results’ column. Policy papers and ‘how to’ papers are not included in the evidence tables but are listed in the references.

References for the books, reports, and papers used in this report are listed at the back of this report. Where information was obtained from web sites, and it was not in the form of stand-alone papers, it is not referenced in the text. A list of web sites used in this report is given in Appendix 3. Interviews and communications were carried out with a large number of people. However, information taken from these interviews is not referenced in the text. Interviews were not formally structured and people interviewed were not offered the opportunity to correct information, which would have been necessary had quotes been used and referenced to particular individuals. A full list of all those with whom communications were had is contained in Appendix 4.

Results

The search of databases identified 2338 citations:

Embase (824 citations)
PsycINFO (63)
Review of the abstracts identified 60 papers as pertinent, and a further 140 papers were identified through the methods listed as 2-7 in the Methods section above.

Two systematic reviews were found: one, Crawford et al (2002), on the involvement of patients in the planning and development of health care; the second on involving consumers in the delivery and evaluation of mental health services (Simpson & House 2002). No randomised controlled trials were found.

Three important reviews were available from Australia. The Consumer Focus Collaboration funded 22 community, primary care and hospital-based projects as part of the Consumer and Provider Partnerships in Health Project (CAPP5). These projects were reviewed to establish common lessons, including barriers and enablers of participation (Consumer Focus Collaboration 2003). The second review was a literature review of primary care consumer participation initiatives covering community health, general practice and the Australian Coordinated Care Trials (National Resource Centre for Consumer Participation in Health 2002). Even before this, a similar project had been carried out on involving consumers in improving hospital care (Draper 1997).

A recent UK document Patient and public involvement in health: the evidence for policy implementation [Department of Health & Christine Farrell 2004] contained summaries of two significant studies: one of consumer and public involvement in primary care (Harrison et al 2002) and the second on the meanings and motivations of citizen involvement (Thompson et al 2002), which provided a rare perspective on the views of the public and consumer organisations. Both of these studies were accessed in their entirety. Another important resource that emerged late in the preparation of this report was a UK Commission for Health Improvement report on patient and public involvement which followed over 300 inspections of health agencies (Commission for Health Improvement 2004).

Most papers found during this review were individual case studies or case reports of participation. These broadly covered the following areas:

- Independent advocacy by consumer organisations or movements, such as the women’s health movement or HIV/AIDS activists
- Participation in particular services, such as hospital services, primary care or community mental health services
- Reports of consumer participation mandated by government policy or legislation, such as Community Mental Health Centers and Health Systems Agencies in the USA, Community Health Councils, Primary Care Groups and Primary Care Trusts in the UK, and community service centres in Canada
- Experiments with forms of consumer participation such as health panels and citizens’ juries
- Consumer participation in clinical governance, guideline development, Cochrane reviews and so on
- Reports of workshops and conferences.

A large number of other papers examined features of participation, such as characteristics of membership of consumer representatives, selection processes, motivations of people involved, barriers and enablers of participation, education and training, conceptual frameworks, and theories of participation.
There were also a number of review articles which addressed the question through a discussion of the evidence, although this was not usually canvassed in a systematic way. Some of the most thought-provoking papers were more in the nature of opinion pieces. The few papers by consumers tended to be in this form.

Finally, there was a significant body of policy documents, guidelines and general ‘how to’ documents from a number of countries including New Zealand that were included in this review, particularly Parts 2 and 3 which examine past and current activities in New Zealand and overseas.

Limitations in the Literature

Range and methodologies

A recent review of the literature on involving consumers in research noted that the literature on consumer participation is extensive but that there is

‘no conveniently appraised and systematically synthesised summary or a widely agreed characterisation of the diverse methods for consumer involvement or their evaluation. This literature was therefore dismissed for being potentially overwhelming and in need of a systematic review independent of this project’ (Oliver et al 2004, p 2).

This project found a similarly vast and diverse literature when looking more widely at consumer voice in the health sector; however, dismissing it was not an option!

The Australian Consumer Focus Collaboration (2001) notes that as consumer participation is an emerging area, there is no agreement as to methodologies for research:

‘The reported research does not often use methodologies such as randomised trials and systematic reviews which are typical of more established research areas in the health field: rather, descriptive studies and process evaluations are more common’ (p 8).

Applying a rigid methodology to this project, such as, for example, the SIGN system would indeed have reduced the literature to an inadequately small pile. Consequently, this review took a broader approach by including particular works that might not have utilised a rigorous methodology but which were relevant to the topic.

In conducting a rare systematic review of involving patients in the planning and development of health care, Crawford et al (2002) noted that they found some of the most informative literature in grey literature but that this was hard to find. This review found the same thing. Some of the most provocative and intelligent discussions of the subject are to be found in literature that is outside the usual parameters of scientific databases and literature. In reviewing citizen involvement in health care, Thompson et al (2002) observed that there was likely to be a gap in information created by not accessing books and reports published by consumer groups. This review uncovered a few such works but there will be many more in documents such as organisational newsletters and other consumer publications that were not identified by the methods used.

Lack of studies of high-level involvement

Oliver et al (2004) found that:

‘the literature is most advanced for consumer involvement in evidence-based decision-making for personal healthcare, where there are well-established methods for
consumer involvement and its evaluation and a growing collection of systematic reviews of impact’ (p 2). Thompson et al (2002) noted the ‘small amount of literature on citizen involvement in national policy development’ (p 10).

This review found the same pattern: there is a well-developed literature on self-management and joint decision-making between the individual consumer and healthcare provider, but diminishing quantity as one moves into the realms of consumers as a group or collective interest participating in the development of health policy.

**Countries with a strong research base**

Some countries, notably Australia and UK, have deliberately funded research, so that a great deal of the literature emerges from these two countries. In Australia there was an explicit policy of funding research and evaluation of innovative participation projects that occurred through the Consumer Focus Collaboration from 1999–2002. Consequently, Australia has a firm basis from which to carry out further participation projects. Even in that country, there is very little research or evaluation of consumer voice at a Commonwealth level and this is true of all other countries studied.

The Australian approach contrasts starkly with the absence of such documentation in New Zealand, the only possible exception being the mental health area where there have been some reviews and reports, mainly carried out for the Mental Health Commission. Very few evaluations or research emerged from New Zealand. There is no government or academic policy or research unit devoted to consumer participation and it is not a focus of funding for the Health Research Council (HRC). Currently there is only one HRC-funded study underway, of Maori consumers.

**Lack of consumer involvement in participation research**

In all countries studies of consumer participation were overwhelmingly designed and carried out by health and social policy researchers, and health professionals, as opposed to consumers alone or jointly. This was true even in Australia. It was rare to find a study that modelled the subject under scrutiny. Interestingly, one of the few such studies that was found was a New Zealand study of mental health services where one of the three researchers was a consumer adviser and the project had a steering group containing a number of consumer representatives (Crowe et al 2001).

This absence of consumer involvement in setting research agendas on participation and taking part in carrying out research led to a serious deficiency: the research questions were limited to those of interest to academic researchers and health and social policy makers. These are not necessarily the questions of greatest interest to consumers or consumer organisations. This creates a major distortion in the literature and limits the discussion that emerges from it. Reference will be made in this report to some research questions that could be studied in the New Zealand setting.

It is also clear that consumer organisations have not been supported to document or evaluate their own activities, especially in formats that are accessible through conventional search methods. There is a need for funding to enable organisations to do this. Opportunities for consumer organisations to work with students and researchers in academic and research institutions are also necessary to enable this to happen. This is occurring sporadically, however, these projects are usually learning opportunities for students and lack funding for the consumer partner.

**Lack of private sector/NGO participation documentation**

It is important to note that while consumer advocacy can be directed at either the public or private sectors and non-government organisations (NGOs), participation is occurring almost entirely within the public sector. There is little evidence that private health care providers are joining in the trend for participation. In New Zealand, primary health care providers (who are mostly private sector
providers) receiving government funds, are required to take some steps to involve their clients in governance and other processes. This review did not uncover reports of efforts by private providers in other countries. There are examples of NGO providers who are taking steps to become more consumer-focused (such an example is discussed in the Disability consumers section of Part 2 of this report, see section 2.4 page 81) including involving consumers in decision-making processes, but research in Australia showed that in the disability sector at least, NGOs are performing poorly at participation (Morgan, included in ACTCOSS & HCCA 2003).

1.2 CONTEXTUAL ISSUES IN CONSUMER PARTICIPATION

History and Influences

A number of authors outline the increasing trend for governments to encourage consumer involvement in health care decision-making, planning and policy making, both as individual consumers or potential users of services, as citizens and as organised groups (Charles & De Maio 1993; Bowl 1996; Crawford et al 2002; Thompson et al 2002). Crawford et al (2002) note that involving consumers ‘is becoming less discretionary and more compulsory’ (p1263), but it would be a mistake to think that the genesis of the current trend lies entirely with governments.

Governments are finally responding to demands that have been made by grassroots activists for at least 30-40 years, although the way they are responding may not entirely correspond to what consumer movements have been seeking.

Social movements

The current interest reflects a social trend, apparent since the 1960s, to uphold the human rights of individuals and groups and for citizens to have more say in their lives. The health consumer movement emerged in the context of broad social movements such as the civil rights, anti-racist and indigenous rights’ movements, anti-war movements, youth and student movements, psych survivors and disability rights movements, gay liberation and the women’s movement (Dwyer 1989; Charles & DeMaio 1993; Rodwin 1994; Bastian 1998).

Groups of citizens, usually organised through identification with a particular population group, social movement, locality, social or health need, have sought greater autonomy in general, and a larger say in health in particular. These groups mounted a challenge to governments and professional groups to have a voice in formulating health and social policies, professional regulation and service planning (Dwyer 1989; Rodwin 1994; Thompson et al 2002).

These movements seeking social transformation had

‘... one overwhelming agreement and value shared by all the new movements; they were singularly unimpressed by hierarchical organization, with its deadening ability to deny democratic and popular control. In creative opposition to traditional hierarchical forms new flat forms of organizing were developed and maintained through the often chaotic vitality of participatory democracy’ (Rose 1990, p 217).

In this way these social movements foreshadowed the current mainstream interest in methods of participatory democracy.

The women’s health movement is frequently cited as the first significant voice to challenge the health sector since the rise of modern medicine (Dwyer 1989). It has been described as a ‘mega-movement’ with numerous ‘waves’ dating back to the popular health movements of the nineteenth
century. It predated other prominent consumer movements such as the patients’ rights and disability movements and advanced ‘a broader, more extensive critique of mainstream health care’ (Zimmerman & Hill 2000, p 771). This critique involving identifying and scrutinising the power holders in the health sector, including governments, health professions, health industries, especially the pharmaceutical industry, research, funding, and policy bodies on national and international stages. The issue of power was central to this critique in a way that is rarely mirrored in current discussions of voice and participation.

The women’s health movement challenged the prevailing biomedical paradigm and medical hegemony, claiming that women should control and define their own bodies and what they did with them. Particularly in the areas of reproductive control and maternity, women’s health activists achieved sweeping changes (Rose 1990). Quality of care was the fundamental objective of the women’s health movement, not just in terms of safety and efficacy but also in terms of the social acceptability (woman-centredness) of care. Rodwin (1994) argues that the women’s health movement and the disability rights movement were the most successful of the social movements because they had a clear, continuous and concentrated constituency. Many of the issues that concerned the women’s health movement had flow-on effects for consumers as a whole: these included the partnership model of health-care, greater observance of health consumers’ rights, particularly informed consent, a holistic approach to health care, access to information, reform of decision-making structures and a voice in the design of the health system. Zimmerman and Hill (2000) state that ‘the women’s health movement anticipated many of the problems and issues that policy analysts and decision-makers are wrestling with today’ (p772).

People’s experiences and stories were the basis on which these movements constructed their knowledge, actions and political goals, as opposed to scientific knowledge or social policy. Some social movements promoted self-help, most notably the women’s and gay liberation movements, the disability movement and mental health activists. Croft and Beresford (1993) point out that ‘services’ such as gay switchboards, rape crisis, women’s centres and mental health ‘drop in’ centres, emerged from activist movements, not a social policy tradition. In examining the successes of the women’s health and disability rights movements, Rodwin (1994) says that one common element is ‘the idea that professionals – be they doctors or quality assurance specialists – are not always the only or the best judges of what is in the interests of the groups they serve. The people who receive the service can and often do identify quite significant problems that the experts overlook’ (p 166).

Interest in alternative health

Increasing interest in the use of complementary and alternative health practices and therapists by the public has also likely been a factor in government adoption of policies for inclusion, although it is rarely mentioned in the literature. This trend reflects consumers’ desires for less invasive forms of treatment and a more holistic approach to health care, sometimes called the social model of health. The challenge posed by the popularity of alternative health, has made health professionals realise that the prevailing biomedical model needs to be ‘humanised’ to remain competitive and acceptable to consumers.

Community development and primary health

The people-led calls for inclusion in health sector decision-making included a social critique of the traditional medical model and calls for a more community-based primary health care model that were supported by the Alma Ata Declaration (WHO & UNICEF 1978), the Ottawa Charter (WHO 1986) and the WHO’s Health for All by the Year 2000. Over the last two to three decades there has been more interest in prevention and managing chronic health problems, both approaches
requiring a more community-focused approach (Thompson et al 2002). Community-controlled services have been sought by particular groups, especially mental health consumers and indigenous groups, including New Zealand Maori.

**Public health and social inequalities**

More recently, the concept of public health has broadened from the traditional focus on hygiene and communicable disease to emphasise social inequalities as causes of disease. There has been increasing recognition that the dominant medical model of health care has failed to deliver improvements in the health of populations that are deprived according to socio-economic and cultural factors (Beaglehole & Bonita 1997; Howden-Chapman & Cram 1998; Howden-Chapman & Tobias 2000; Minister of Health 2000; National Resource Centre for Consumer Participation in Health 2002). Governments have become willing to look at alternative health service delivery approaches, including those led by indigenous peoples and minority ethnic populations. The understanding that factors external to both the health sector and individuals profoundly influence health status has reinforced calls to involve communities and the public in health decision-making. Transforming services so that they are more acceptable and accessible to the people for whom they are intended requires those people to have a say in service design.

**Inquiries into medical failures**

Inquiries into bad medical practice have also fuelled the call for greater participation in some countries, especially New Zealand, Australia and the UK. Recommendations from inquiries have called for greater scrutiny of medical processes and services to provide greater protection for patients in the health sector. The concept of informed consent has gained greater prominence, carrying with it the need for a partnership approach to individual healthcare and attention to consumers’ rights and health information needs. Calls for professional and systems accountability have included notions that consumers should be involved in setting standards, monitoring and scrutiny (Committee of Inquiry 1988; Crowe et al 2001; National Consumer Council 2002b; Thompson et al 2002; Commission for Health Improvement 2004).

**Consumers’ access to health information**

Any discussion of spurs to public participation would be deficient if it did not include the role of various communication media. From the 1960s there had been a practice for consumer health movements to use their own media to directly impart to the public information formerly sacrosanct to professionals. Consumer groups have created their own consumer health information, publishing pamphlets, books, magazines and so on (Boston Women’s Health Book Collective 1971; Calvert 1982). This trend was exponentially enhanced by the popularisation of the worldwide web. Medical power to some extent rested on a monopoly on information. Now health consumers can easily and directly access information, including the results of medical research, within the privacy of their own homes. Despite wide variations in quality, the internet has played a leading role in empowering consumers and democratising healthcare.

**Market approaches to health care**

The trend to greater participation was set back by the period of market-led health sector restructuring which occurred in many countries in the 1980s and 1990s. Private sector corporate ideology and practices were introduced into the health sector at the expense of democracy. The notion of consumer sovereignty proposed that consumers were best placed to make choices to maximise their welfare. They would influence health care by ‘shopping around’ for services and providers and ‘exiting’ services that did not meet their needs.
The introduction of corporate management styles into health services often brought managers into conflict with medical power, and in some cases managers used consumer participation to reinforce their position. In other cases, managers who had come out of the private sector had little understanding of public sector accountability to the public and the need to involve communities and consumer organisations in health sector planning. Private sector business experience was the principle competency sought for members of public sector governance boards during this period. Competition allowed privatisation and notions of commercial secrecy to impede public scrutiny. Funding to consumer groups was increasingly tied to compliance with outputs set by the state. Consumer organisations were either weakened or ‘trod water’ during this period of market-led restructuring (National Resource Centre for Consumer Participation in Health 2002). The ideology which was fundamental to corporate-style managerialism has even become a prerequisite for consumer organisations, which often struggle with the separation of governance and implementation.

The shortcomings of the market approach for consumers have been well documented (Seale 1993; Calnan 1995). Consumers are not well placed to achieve quality in health care through their own purchasing choices because of imbalances in power and access to information. ‘Exit’ from services as a central aspect of choice is not possible in public services, unless consumers can afford private services and these provide the services needed. Consumer satisfaction surveys widely replaced more substantive consumer input and methods of consultation often approached consumers as individuals, as opposed to providing opportunities for consumers to meet and share views. Consultations or surveys of consumers were largely about hotel aspects of health care such as cleanliness and the quality of food, rather than more substantive issues around quality of care (Seale 1993; Lupton et al 1995; Calnan & Gabe 2001; Cawston & Barbour 2003).

In recent years, there has been a move away from the market model, although not entirely. Many aspects of the market model have become embedded in the system. It still plays an important role in concepts such as consumer information, choice and redress (Cawston & Barbour 2003). Saltman (1994) makes the interesting argument that choice is not just an individualistic act in markets but part of a broader notion of citizenship, whereby citizens contribute to the whole by their acts. The women’s health movement used the concept of ‘choice’ as an organising tool to bring about significant change. An example of this is maternity services, where women achieved more control in childbirth and a more humane approach by making the way they gave birth a political act.

New frameworks for participation

With the retreat from the market approach, there has been a rekindling of interest in consumer participation. In part the renewed attention is a reaction to the loss of democracy that occurred during the market period, as well as the loss of accountability with appointed business-oriented boards. The concept of participation is no longer part of people-led broad social movements, as these are less in evidence than they were 25 years ago, nor are they overtly part of a community development approach.

Recent arguments in favour of consumer participation tend to rest more on notions of participative democracy, active citizenship, social cohesion and civil society, than a restatement of people power. These arguments about participation and inclusion are emerging from postmodern theoretical frameworks which are far removed from the radical activist roots of the social movements of the 1950s and 1970s. In some countries, greater consumer involvement is being led from the top rather than the grassroots. However, it is interesting to note that the New Zealand Primary Health Care Strategy (Ministry of Health 2001a) has adopted the definition of primary health care to be found in the Alma-Ata Declaration of Primary Health Care which supports a community development
model (WHO & UNICEF, 1978). It is not clear whether this framework is well understood by more recent players in the health sector.

**Loss of social learning**

It is worth noting, that the seminal work on consumer participation was published in 1969. The widely referenced paper by Sherry R. Arnstein, *A ladder of citizen participation*, argues that ‘citizen participation is a categorical term for citizen power’ involving a redistribution of power so that those who previously didn’t have it, share it to enable significant social reform and a more equal society (Arnstein 1969, p 216). Her ladder of citizen participation demonstrates that much of what passes for participation today is at the low end of participation or ‘non-participation’ (see Figure 1).

Arnstein’s analysis remains cogent today and is a reminder of the social learning that was lost during the periods of health care reform of the 1980s and 1990s. Jewkes and Murcott (1998) make the observation that the development of new health policy around participation fails to draw on existing bodies of critical literature. Some of the most recent policy developments are relatively simplistic compared to the sophisticated analysis to be found in older literature which was grounded in the experience of broad and powerful social movements and models of community development.

**Growing health care costs**

A more recent driver of participation is growing health care costs, the development of expensive health technologies and the health needs of an ageing population. Governments have shown interest in engaging consumers in debates around spending on health, rationing, and health care priorities. Governments hope that by involving communities, they will gain greater acceptance of and support for potentially unpopular decisions about where health dollars are directed (Milewa et al 1999; Hogg 1999).

**Evidence-based health care and quality**

Other pushes have come from the evidence-based and quality ‘movements’ that have been initiated by progressive people in the system but which have sought to include consumers to a greater or lesser degree. Australian developments have very much occurred within the quality framework. Consumers have sought to broaden the narrow notion that quality is about safety, to include concepts of acceptability and responsiveness to consumer needs (Consumers’ Health Forum of Australia 2003). The Cochrane Collaboration, an international initiative, has modelled consumer involvement through the activities of its review groups, the establishment of the Cochrane Consumer Network and the inclusion of consumers on the governing body. Evidence-based practice has appealed to consumers as it provides an objective basis for shared decision-making in health care that mitigates against the doctrine of ‘clinical freedom’ and it provides a trusted basis for developing consumer health information. It is no accident that many of the most active Cochrane consumers have come out of the women’s health movement.

Consumer participation is not a new idea, but recent developments represent a sea change in official attitudes. What is new is that some governments now have policies and even law to include consumers. The notion of consumer voice in the health sector is increasingly being mainstreamed, although as we shall see through this report, there is no consensus in New Zealand or anywhere else on many aspects of participation.
Terminology

A number of terms are used in the literature to identify non-medical people with an interest or involvement in the health sector. These terms vary according to who is speaking, and there are differences between countries. In the literature, there is rarely a discussion as to why a particular term is used or what it means in the context of the particular report. Even when terms are defined, there is no agreement about definitions. The diverging terms illustrate the many different philosophies that are brought to the discussion of participation. Bastian (1998) makes the point that the terms in themselves derive from differing beliefs about the nature of people’s relationships with the health care system and that they are highly contested:

‘Often, people seek to declare their own stance (or to depict that of others) in their choice of word for members of the community. This is evident, for example, when managers start referring to ‘customers’ to encourage a more market-oriented consciousness within a service. Or when people assert that consumers should be called ‘citizens’ to locate the debate firmly in the arena of rights and/or democratic participation. It is evident, too, when people reject the term ‘consumer’, seeing the word as solely applicable to a market-oriented view of the world’ (p 4)

A discussion of terms provides a useful introduction to differing theories and viewpoints about the place of health care consumers in society.

Terms for non-medical people can be broadly organised into two categories. Those which apply to individuals actually engaged in using health services, and those which apply to members of the public with an interest in the quality of the health system. The first group comprises non-aligned individual users of services, and the second a consumer or public constituency that may or may not be organised. It must be stressed that these terms are not mutually exclusive.

Terms for individuals using services:

Patient is the traditional term for a person who is ill and receiving a medical service. It is considered to be an out-dated term by many consumers and consumer organisations, as it denotes passivity. It is also considered inappropriate for well people using health services, such as women during pregnancy and childbirth or well people using screening services. However, some organisations for people with chronic illnesses still use the term ‘patient’, especially in Europe. ‘Patient’ is widely used in the UK. In discussing a UK national seminar on involving consumers in guidelines development, Duff et al (1996) report that seminar participants thought the term ‘patient’ covered ‘people actively receiving care as well as potential patients, or those with chronic conditions’ (p109). It is unlikely that consumers in countries such as New Zealand and Australia would agree with this definition. Recent policies in the UK have enshrined ‘patient’ as the official term for people actually using services and what would be called consumer organisations in Australia, Canada, the USA or New Zealand, are called ‘patients organisations’ in the UK.

Clients and customers are market terms that appeared during the 1990s period of health sector reform, often introduced by managers. The term ‘client’ is used by some individual consumers, especially in the mental health and social services area (see Geller et al 1998), but ‘customer’ has never been widely adopted.

Users of services is another term found in research and policy documents that is not used by consumers or many consumer organisations. Calnan (1995) prefers the term to ‘consumer’ as ‘unlike consumers of other commodities, those seeking medical care are constrained by their lack of knowledge of choices available and are dependent on professional expertise’ (p 17). Bastian
(1994) points out, the term implies a person actually using a service, whereas consumer movements are often about accessibility to services. Terms for members of the public with an interest in the quality of the health system:

**Lay person** is a term usually used to denote someone without professional qualifications who participates in a health committee or process, but Charles and DeMaio (1993) point out that health care managers and government administrators are not professionals but are part of healthcare institutions. They argue that a distinction can be made between producers (direct and indirect) of health care and those who do not. In New Zealand, the standard for ethics committees includes retired health professionals as lay persons.

Sometimes the term ‘lay person’ is used to mean a person without a financial vested interest in health care decision-making outcomes. The lay person is inevitably non-aligned and lacks accountability to any constituency, even the one she or he is expected to represent. The absence of this constituency means that the lay person frequently lacks expertise and is commonly in danger of cooption (Federation of Women’s Health Councils of Aotearoa/New Zealand 1992; Bastian 1999).

The use of the term ‘lay person’ was historically the favoured approach of health bureaucracies and professional colleges. The people were usually shoulder-tapped on the basis of a social relationship with someone in the health agency. Sometimes well-known personalities such as journalists or upstanding citizens such as ministers were asked. Bastian (1999) criticises the concept as individualistic and about paternalistically ‘doing good for others’. The concept was largely superseded by the emergence of articulate consumer health movements which never applied the term to themselves.

The concept of ‘lay person’ is considered to be out-dated but is still occasionally used in research and policy documents. Bastian (1999) believes that as governments and health bureaucracies have adopted the practice of consumer participation, there has been a return to the concept of the ‘eminent lay person’. The concept of the ‘lay person’ is close to the ‘non-aligned consumer’ who is sought by some governments.

**Consumer** is the term preferred and widely used by consumer health organisations in Australia, USA, Canada and New Zealand. ‘Consumer’ began to be widely used in the 1980s and was viewed as a more active term than ‘patient’. Geller et al (1998) argue that a key feature of consumer is the notion of ‘empowerment’. Some writers equate consumers with ‘consumerism’, or individual choice within markets (Calnan and Gabe 2001). While the term ‘consumer’ has a specific meaning in the context of markets, its meaning to consumer organisations is wider. Rodwin (1994) notes that applying the concept of consumerism to medical care emphasises that health care is a service like any other; it challenges the expert model of health. It conveys the idea that consumers can and do make rational decisions based on having appropriate information available to them (Draper 1997).

Bastian (1998) states that the consumer movement ‘has reclaimed this word and argued that its meaning is now a wide one, encompassing all those people who use, are affected by, or who are entitled or compelled to use health care services’ (p 4). Ard and Natowicz (2001) argue that there are many different types of consumers ‘such as those who have a clinical condition or who are otherwise directly affected by a clinical condition and those who are not directly affected but may be professional advocates or lobbyists for consumer interests’ (p 789).

Consumer movements tend not to make a distinction between consumer advocates and consumers in general and in this sense ‘consumer’ denotes the collective identification of those who are politically organised with those whose interests they seek to advance. McGowan (in ACTCOSS & HCCA
October 2003) agrees that ‘consumer’ has a political dimension: ‘health consumers are users of health services who primarily identify as consumers, and who are accepted by other consumers to speak on their behalf’ (p 8).

A consumer representative is ‘a committee member who voices the consumer perspective and takes part in the decision-making process on behalf of consumers. They are accountable to the organisation they represent and refer back to their constituency. However, sometimes the term is used inappropriately to refer to consumers who do not have such a constituency’ (Consumer Focus Collaboration 2000b, p 4).

A similar definition is given by the Consumers’ Health Forum of Australia: ‘A consumer representative is someone nominated by and accountable to an organisation of consumers’ (Draper 1997 p 11).

Draper (1997) says that the importance of the consumer representative is their commitment to ‘representing not just their own perspective or experiences, but taking steps to establish what other consumers think, representing their point of view, and being prepared to be accountable for the positions they take’ (p 11). The Women’s Health Action Trust (2000) says that consumer representatives cannot be individuals with a professional role in the health system, such as health professional, provider, social worker or paid advocate. Thus, the key qualities of consumer representatives are their selection by a consumer organisation, their commitment to representing their constituency, their accountability back to a consumer organisation and their independence from the health system.

The New Zealand Ministry of Consumer Affairs approach differs from this international understanding of the consumer representative. It says it is ‘a generic term which includes the term layperson’ (Ministry of Consumer Affairs 2003, p 37). Although the Ministry’s research found that in all cases consumer representatives were expected to provide more than their own personal views, and represent consumers’ interests, it does not expect consumer representatives to be selected by or accountable back to a consumer organisation. Instead, they need only have ‘a track record of achievements for the community’ and ‘be respected for their integrity in the community they have worked in and will represent’ and have ‘broad community networks they consult regularly’ (Ministry of Consumer Affairs 2003, p 42).

Ex-patient and survivor are terms used by some activists in the mental health area which, in the form of the former, ‘proactively dissociates then from their former status’, or, in the form of the latter, ‘attributes strength to them despite that status’ (McLean 1995, p 1053).

Citizen is a term to denote members of the public in relationship to the state, nation or other political entity. Because citizenship confers democratic rights, the term citizen implies status, responsibility and the ability to have a say. It is particularly used in the UK by policy makers and researchers. Other countries tend to prefer the term ‘the public’ except when specifically talking about democratic rights. Calnan (1995) says the term defines people ‘by their status in the community’ and argues that as citizens have wider concerns than users of services: ‘citizens’ views encompass not just what individuals require for themselves and their families, but their broader concerns about what form of health care they want for society as a whole’ (p 17-18).

People (or more descriptive terms such as men, women, older people, young people) is favoured over ‘citizens’ by consumers and consumer organisations as being less formal and recognising that people lead lives that are broader and more social than that implied by citizenship. However, as Bastian (1994) points out, the generic ‘people’ does not work as an adjectival term in the same way as consumer (people’s organisation, and people’s representative, for example).
Community is a widely used term with diverse meanings. It is used to describe populations, people living in particular geographical locations, people with a ‘community of interest’, or more loosely as the public (Jewkes & Murcott 1998). Rose (1990) explains that ‘community’ usually has some association with new social movements and some form of ‘solidarity arrived at primarily through shared close geographical location, or to denote a solidarity derived from a common interest’ (p 211). In the 1970s and 1980s it had prominence as part of the ‘community action’ and ‘community development’ ethos which evolved into health promotion. This was not community in a grassroots sense, but a term used by policy-makers for a specific approach to foster community organising and action around issues such as urban redevelopment or healthy lifestyles. In the New Zealand health sector, community is currently also used to include primary health care.

In this review, consumer will be the primary term used, although other terms will be used when discussing particular countries or specific papers where these terms are more accurate.

**Defining Consumer Organisations**

Consumer organisation is an important term in the context of this report but few studies or reports address its meaning The Consumer Focus Collaboration (2003) defines a consumer organisation as:

‘…a group made up of consumers of health services whose main objectives are to work together to support its members and represent their views, and which is independent of professional, commercial and government interests in its decision making. Consumer organisations include self-help groups and advocacy organisations that may be organised around a specific disease, a specific health service or concerns about the health system overall. They may be active from local through to national levels’ (p ix).

What constitutes a consumer organisation is contested in the consumer sector, where there are differing opinions as to whether a consumer organisation is defined by its history, purpose, structure, including governance and style of decision-making, categories of membership, whether professionals can have a role, whether families and carers can be equal members and whether providing services means the organisation has become a ‘provider’. Some groups have taken the view that the governance body or executive committee should be entirely composed of consumers. But there are some organisations that to all intents and purposes look like a consumer organisation which have one or two nurses or doctors on the governing body.

Membership and elections are seen by others as hallmarks of consumer organisations, but some consumer organisations have a trust structure and no paid membership, while others are loosely organised collectives where everyone is part of decision-making. Later in this report, in section 3.4, page 151, the ‘high-profile lobbyists’ found in the USA will be discussed. These are clearly consumer organisations but they do not have a voting membership. The history of the way the group has emerged might demonstrate a community mandate. However, some groups have been formed or fostered by health professionals or governments, but may have developed into autonomous groups.

Functions of the group might be another defining characteristic, with advocacy and support the two key features although an individual group might perform only one of these. More problematic is the level of government funding for services a group receives. Some groups overseas will not accept funds from government, or they limit the proportion of funds received from this source. In New Zealand, it is hard for groups to exist without some level of government funding. Some New Zealand groups have received funding for advocacy, but recent draft policies of the New Zealand Government make it uncertain whether this will continue. In the mental health and disability areas
there are groups which are wholly funded by governments that regard themselves as consumer organisations. Is there a level of funding or purpose of the funding which enables the group to remain as a consumer organisation rather than being redefined as a service provider?

Another funding issue is receipt of funds from health industry sources, such as grants from pharmaceutical companies. These companies have targeted consumer groups in New Zealand and overseas, but it raises questions of the independence of the group, especially if the group does such things as endorsing company products.

This report has made an attempt to address the question with the key features that have been identified, and the questions that arise, summarised in Table 2.

For the purposes of discussion, this report proposes that a consumer group needs to meet the following criteria:

- The purpose of the group is to work for the benefit of health and/or disability consumers. This usually involves advocacy on health issues or support or both.
- The governance of the group should be through a committee, board, council, collective or similar structure that is comprised wholly or almost wholly of health consumers (professionals should not be more than 1 or 2 and should exhibit a consumer-focused approach).
- The group should be a legal entity with a constitution.
- The history of the group should demonstrate that it emerged through consumer organising. If the group was initiated by health professionals or government, it should be able to demonstrate that it has moved to an entirely health or disability consumer-focused position and meets other criteria.
- Full membership should be confined to consumers or consumer organisations.
- The group should have regular contact with the consumers it represents, either through a membership or through opportunities for the community of interest to meet with and have a dialogue with members of the governance body. It should also be able to demonstrate other ways it interacts with consumers.
- If the funding of the group includes monies from government, health industry or health professional groups, the groups must be able to demonstrate measures that it has taken to ensure the source of funding does not influence the policies of the group.
- A consumer organisation can provide services for consumers but must be able to demonstrate that it meets the other criteria and has other activities besides service provision.
<table>
<thead>
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<th>Features</th>
<th>Questions</th>
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| Governance body made up of consumers | 1. Does this have to be wholly consumer? What about boards that mix consumers and others (Family? Members of the public?)  
2. Groups that include one or a small number of professionals?  
3. What about organisations that are flat and more collectively organised, that conflate governance and action?  
4. Does the governance body have to be elected? |
| Group initiated by consumers      | 1. What about groups founded by or whose inauguration is promoted by professionals, government, university, local body or corporate interests?  
2. Groups that were founded by consumers/families but which have become corporatised? |
| Membership made up of consumers  | 1. Some trusts and other entities are not necessarily membership organisations.  
2. Can membership be individual or as groups?  
3. What does membership entitle you to?  
4. Can membership be both formal, as in an incorporated society, and more informal, as in a collective or federation of groups? |
| Formal, legal entity             | 1. Does the group have to be a charitable trust, or incorporated society?  
2. What about more activist, informal groups, which come together around a political agenda or specific issue? |
| Responsive to consumers          | How does the organisation establish relationships with the people it purports to represent?                                                                                                                    |
| Accountable to consumers         | How does the organisation report back to consumers? How do consumers have a voice?                                                                                                                     |
| Any paid staff are consumers     | Do staff have to represent the constituency, or can there be others brought in for management or professional skills?                                                                                       |
| Source of funding                | Many groups receive all or most funding from gov’t for services. Other funds eg membership, sponsorship, public sector or private philanthropic grants, are difficult to achieve and may be insufficient to support an organisation. Is there a proportion of gov’t income beyond which the organisation becomes a service provider? What about health industry funding? Does the group disclose such funding and ensure it doesn’t affect policy? |
| Provide advocacy on behalf of consumers as a group |                                                                                                                                                                                                            |
| Provide support for consumers    |                                                                                                                                                                                                            |
| Provide information for consumers |                                                                                                                                                                                                            |
| Provide services to consumers    | How are ‘services’ defined? When does a consumer organisation providing services become a ‘service provider’?                                                                                           |
| National group                   | Does this eliminate iwi or locality-based groups, or interest groups organised around an issue?                                                                                                          |
Meaning of Voice and Participation

Definitions
The move towards greater consumer voice on health has taken different forms in different countries. There is no consensus as to what ‘voice’ means. Similarly there is no agreement as to what ‘participation’ means. The concepts have multiple meanings (Charles & DeMaio 1993). Many writers over many years have drawn attention to this inherent problem when addressing the issue of participation (Dwyer 1989; Bowl 1996).

The Consumer Focus Collaboration defines consumer participation in a way that confines it to participation in existing health structures:

‘The process of involving health consumers in decision-making about their own health care, health services planning, policy development, setting priorities and addressing quality issues in the delivery of health services’ (Consumer Focus Collaboration 2003).

Bichmann et al (1989) take another approach when defining ‘community participation’. They see it as a community action process. They place no emphasis on ‘involvement’ in an existing institutional framework, but see participation as a more autonomous process. To them participation occurs within community organisations and society at large:

‘Community participation is a social process in which specific groups with shared needs living in a defined geographical area actively pursue identification of their needs and take decisions and establish mechanisms to meet them’ (p 468).

The World Health Organisation (WHO) definition of community involvement in health similarly refrains from restricting involvement to participation in existing structures. Its definition places participation at a number of levels, including creating the social conditions that enable communities to lead healthy lives: Participation is tied to ‘rights’ and emphasises action:

‘A process whereby people…exercise their right to play an active and direct role in the development of appropriate health services, in ensuring the conditions for sustained better health and in supporting the empowerment of communities for better health development’ (WHO cited in Cawston & Barbour 2003).

Currently there is no agreed definition of participation from a consumer perspective, or even examples of suggested definitions. However, the outcome of a workshop in Australia, suggests that consumers might see participation as part of activism by which consumers seek the power to reach social justice goals (ACTCOSS & HCCA 2003). Consumers might prefer the WHO definition to those commonly adopted by health policy-makers.

‘Voice’ differs from participation in being overtly more autonomous. ‘Voice’ contains the meaning of being heard but does not prescribe how or where. It presupposes organisation, and contains the ideas of collectivity and identity. Saltman (1994) describes ‘voice’ as ‘forums for verbal participation’ (p 206). It is unlikely that consumers would define voice this narrowly, but would likely include independent advocacy as a means of strengthening consumer voice. Voice can be heard on a march, through media, lobbying and many other means besides participation.
Frameworks for Voice/Participation

Many writers have attempted to provide a framework within which to measure and discuss consumer participation. Most use a framework of rungs of a ladder or levels that show that much of what passes as participation, falls at the passive or tokenistic levels of participation (Charles & DeMaio 1993). Bastian’s approach (1996) provides levels of participation but these are based on the process, as opposed to the degree of power sharing. Johnson & Bament (2002) base their system on forms or methods of participation. Most models are based on a concept of ‘empowerment’ with methods tested against the degree of control over decision-making that consumer participants have. Saltman (1994) argues that ability to control resources is the key dimension:

‘it is budgetary authority and resource allocation that are the only practical surrogates for power. To become empowered, therefore, patients have to wrest substantial control over these two financial mechanisms away from managers as well as from physicians’ (p 205).

Bichmann et al’s framework (1989) is diagrammatic and asks a number of questions about process as a way of measuring participation.

The most enduring framework is Sherry’s Arnstein’s Ladder of Citizen Participation (Arnstein 1969; Figure 1). Most other frameworks are simply variations of this ladder (Charles & DeMaio 1993; National Resource Centre for Consumer Participation in Health November 1999). Arnstein rates participation according to the degree of power and control consumers have.

Arnstein sees participation as about power and power-sharing. She makes the point that those not holding power and those holding it are not homogenous groups, and that each will contain a host of divergent viewpoints. She also says that there are more than eight rungs: ‘In the real world of people and programs, there might be 150 rungs with less sharp and “pure” distinctions among them. Furthermore, some of the characteristics used to illustrate each of the eight types might be applicable to other rungs. For example, employment of the “have-nots” in a program or on planning staff could occur at any of the eight rungs and could represent either a legitimate or illegitimate characteristic of citizen participation. Depending on their motives, power-holders could hire poor people to coopt them, to placate them, or to utilize the have-nots’ special skills and insights’ (p 217-18).
Saltman (1994) expands the bottom rung of manipulation to include customer relations, token consumer representation on committees, emphasising patient satisfaction within the existing resource allocation structure and even formal advisory groups such as community health councils in the UK, and officially appointed ‘patient representatives’ such as the Swedish ombudsman.
The National Resource Centre for Consumer Participation in 1999 used a modified version of Arnstein’s Ladder to conduct a needs assessment of consumer participation throughout Australia. Each agency, from Commonwealth Government, state governments, peak service providers, service providers, peak community and consumer groups, and consumer groups was assessed using the typology of the ladder. This enabled the resource centre to present a kind of status report on what was happening in participation and to identify areas for improvement.

An interesting example of a different way of expressing levels of participation is the example given by Health Canada (Health Canada 2000). It provides five levels from low to high level of public involvement showing the increasing engagement of participants as higher levels of participation are reached. This is shown in Figure 2.

Figure 2: Health Canada’s Public Involvement Continuum (Health Canada 2000)

1.3 TYPES OF VOICE/PARTICIPATION: INDEPENDENT CONSUMER ADVOCACY

All activities to enhance consumer voice are aimed at influencing decision-makers and influencing and changing the configuration, quality, acceptability and accessibility of services (Lupton et al 1995).

‘Voice’ or ‘participation’ activities can be divided into two major types:

- Independent consumer advocacy
- Participation within the health sector.
This report will primarily be directed at the second of these types. Reasons for this are the lack of literature on the former, at least by using conventional means of searching, and the need, within the New Zealand context, for enhancement and encouragement of the latter. However, there will be a brief discussion of independent advocacy to illustrate the strengths of this method and so as to avoid the conclusion that there is only one way of strengthening consumer voice.

**Independent consumer advocacy**

Independent consumer advocacy refers to actions and activities that are autonomously initiated by consumers. One aspect of this is ‘direct action’. Independent consumer advocacy overlaps significantly with participation within the health sector and participation can be initiated by consumer organisations to achieve what are often quite major shifts in social attitudes and practices.

‘Inside’ or ‘outside’ the system: the example of the women’s movement

It may be useful in approaching this topic to apply a structural analysis tool from the feminist movement, one of the major social change movements of the last century. Feminists of the ‘second wave’ made a distinction between working ‘inside’ or ‘outside’ the ‘system’. Working outside the system meant using strategies such as protest to draw attention to inequities built into the mainstream of society, including the institutions of the state: government, church, business and so on. The strategy involved promoting change by building a groundswell of popular support, using methods such as the media, legal challenges, lobbying decision-makers and influencing elections. This radical stream of the feminist movement borrowed from radical movements elsewhere, including opposition to the Vietnam War, anti-Imperialist movements in countries such as those in South America, student movements, anarchism and workers’ movements. Tools included traditional tools of the left, such as marches, pickets, and so on, and creative direct actions such as street theatre, ‘zap’ actions, and sit-ins.

Working outside the system also included other autonomous but less confrontational actions, such as establishing services, producing alternative sources of information and education through newsletters, broadsheets, workshops, meetings and consciousness-raising. The slogan ‘knowledge is power’ was at the heart of such actions. By sharing information activists sought to empower individuals and validate life experiences by showing that these were shared by the constituency.

The other stream of feminism was characterised by working inside the system to attempt to affect change, and women espousing this route were termed ‘systems feminists’ or ‘reformist’. Thus feminists sought to be involved within government structures, and to establish and take part in advisory committees, select committees, women’s ministries and the like. Reformist women did not seek to overthrow or reshape social, political and economic institutions, but to ‘feminise’ them by including women. The goals were equality, inclusion, and greater power for women, but this was seen as being advanced by enabling women to compete on equal terms with men.

Strengths of remaining ‘outside’

This analysis is useful when approaching the current question of how to give greater voice to health care consumers in determining the kind of health system we have. In a world that has left behind the great populist social movements of the 1960s and 1970s, it is not a distinction often heard. Almost the entire literature that is available to examine the question of enhancing health consumer voice is focused on consumers moving ‘inside’ the system, predicated on being ‘invited’ in. ‘Voice’ is collapsed into participation or involvement in existing structures.

History shows us that campaigns that develop outside the health sector may be necessary to achieve some consumer goals, because, at least in the formative stages there is little support from within the
system. Dwyer (1989) makes the point that successful public policy initiatives often arise from outside the health system but do not meet with official support once they have been initiated. She says that this form of participation ‘often relies on autonomous movements and can involve tough adversarial campaigns’ (p 61).

Particularly in the 1960s and 1970s, health consumer advocacy often took place outside the health sector, using the direct action strategies of rallies, marches, pickets, public meetings, and media coverage of issues and events. Much of this style of advocacy sought to mobilise public support and sympathy, so as to legitimate the ‘cause’ and provide a mandate. An example of this is the abortion campaign in New Zealand and elsewhere (Hughes 1993). White (1999) says it is consumers’ position as ‘outsiders’ that is the source of their influence: ‘To advance their own agenda, lay actors with particular health-care concerns typically have to empower themselves by organizing, advocating, and taking independent media or political action from their position at the periphery of the health-care system. As outsiders, they can confront insiders in oppositional ways that are not possible when they have been joined in an asymmetrical relation of dependency’ (p 477).

Because, currently, participation still leaves considerable power to refuse to listen in the hands of ‘insiders’, Rose (1990) argues that it is premature to dismiss the importance of confrontation and conflict, especially for oppressed groups, for whom they may be sources of self-affirmation.

Berry (1981) warns of the danger of consumer groups that engage with the system being coopted, and says the only effective counter to cooption is to provide ‘a credible threat that the group is willing to forsake good relations and “go public” when the occasion warrants. A group may even have to burn a bridge and then rebuild it’ (p465). He argues that advocacy groups should aim at being ‘institutionalised’ in policy-making. He does not mean ‘cooption’ by this term but that the group ‘is one that is regarded as a legitimate and recurring actor by agency officials’ (p 464). He acknowledges that cooption is a risk but believes there is more to be gained than through conventional participatory routes. To be successfully institutionalised, Berry says there are three goals for groups:

- Identify and cultivate allies in the bureaucracy
- Become a reliable source of information and specialised data that officials can’t get any other way
- Prove to officials that its active opposition to agency policy can be politically damaging.

Berry says that ‘aside from political support, information is the only other thing of value [the group] has to offer’ (p 472). Groups that do their homework and present highly specific research-based studies and policy solutions stand a better chance of exerting influence. Other research conducted by Berry, and cited by him, shows that public interest groups with ‘high’ information capability are much more likely to be consulted by people in government than groups with a ‘low’ capability. Groups need to create sound political reasons for an agency to accommodate its interests. Using the media as a ‘third party’ in disputes shows officials ‘the weapons that can be used against them’ (p 474).

Role of alternative models

All major social movements have modelled alternatives to mainstream institutions in some way. Self-help, information exchange, and alternative services, conceptually reject the notion that consumers are reliant on professionals or mainstream services (McLean 1995). In the women’s health context, feminist health centres, menstrual extraction, and home birth provided methods of avoiding medicalised forms of health care (Zimmerman & Hill 2000). Establishing battered women’s refuges
and rape crisis centres established services that had no mainstream equivalent as the issue of violence against women was not recognised in official discourses.

The women’s health movement also used publication as a tool for social change. For example, in the USA, the Boston Women’s Health Book Collective published *Our Bodies Ourselves* (1971) both as a challenge to the conventional medical model of health care and to empower women by providing them with an alternate source of the information for which doctors were gatekeepers. In New Zealand, the first self-help book for women, *Healthy Women: A self-help guide to good health*, was published in 1982 (Calvert 1982), much of the information having first emerged as articles in the feminist magazine *Broadsheet*.

**Doing both together**

Working ‘inside’ or ‘outside’ the system are frequently adopted simultaneously by consumer organisations. In New Zealand organisations such as the women’s health councils, actively campaigned to be part of advisory mechanisms within Area Health Boards and the structures that followed. The first such council, the Auckland Women’s Health Council, established 1988, was formed partly to progress the issues raised in the Cartwright Inquiry, but also to argue that under the community-development approach of Area Health Boards, women should be involved in service development groups and other policy and planning mechanisms. Women’s health organisations argued strongly for consumer involvement on committees, such as ethics committees, and engaged with formal institutions to become involved in health professional training, systems for complaints and medical discipline.

**Lack of Literature**

The absence of reports on the role of independent advocacy is the result of consumers’ lack of resources to evaluate or even record their campaigns, and the difficulty of winning mainstream funding to do so. If reports exist, they are unlikely to be found through a formal search of mainstream databases. However, web sites for organisations were also searched and key informants in the consumer sector were asked if evaluations/research on their initiatives existed and very little emerged.

When these campaigns are recorded, it tends to be in the form of articles in organisational newsletters or books, rather than through the academic literature. In the New Zealand context, examples of this are *Save the Midwife* (Donley 1986), which describes the campaign to establish independent midwifery in New Zealand, and *The Unfortunate Experiment* (Coney 1988). The latter describes how a women’s health advocacy group worked both inside and outside the system to achieve major reforms in health consumers’ rights. The media was used to expose an unethical experiment at National Women’s Hospital in Auckland and then to gather public support to hold an inquiry. The group then successfully worked through the formal Cervical Cancer Inquiry process to argue for reforms in patients’ rights, complaints systems, medical school training and ethics procedures.

The compilation *Unfinished Business: What happened to the Cartwright Report* (Coney 1993b) is an analysis, largely from the perspective of consumers, of the success of efforts to ensure that the recommendations of *The Cervical Cancer Report* (1988) were implemented. This provides detailed examples of the obstacles faced by consumers when attempting to achieve this through participation on health committees, covering ethics committees, treatment protocols, and cervical screening. A further series of papers examining implementation of the report in the following years can be found at [www.womens-health.org.nz/cartwright/cartwright.htm](http://www.womens-health.org.nz/cartwright/cartwright.htm). Other overseas examples recording
consumer advocacy inside and outside the system are to be found in Patient No More: The politics of breast cancer (Batt 1996) and Dwyer (1989).

The option of providing alternatives as a means of enhancing health consumer voice is not well covered in the literature. In the very few circumstances that consumers win mainstream support for providing services, it does not usually involve a major diversion from the norm. Studies of consumer-controlled organisations in mental health have suggested that they can replicate attitudes and practices that consumers are seeking to replace (O’Hagan undated). In a study of a consumer run community resource centre for psychiatric survivors in the USA, Mclean (1995) found that having consumers as staff did not automatically empower users of the service, as staff took on characteristics of providers. Newly appointed staff lacked the political philosophy of the founders and there were constraints imposed by funders. However, in a recent international study tour, Crooks and Banks (2004) provide a number of examples of successful consumer-led mental health services and conclude that developing organisational values, governance, adequate funding and workforce development are the ingredients for success.

Other examples of autonomous advocacy

This brief outline has concentrated principally on the women’s health movement, but similar histories can be found in the mental health, disability and AIDS areas. For a good description of the Australian AIDS consumer campaign in the 1980s and 1990s see Canavan (2004). Canavan argues that a strong campaign for more recognition could be mounted because the sector most affected – gay men - was already mobilised politically through the gay and lesbian liberation movements. As with the women’s health movement, Canavan describes how the AIDS Coalition To Unleash Power (ACT UP) used “specific, highly political and extremely visible direct actions […] media, public art, political demonstrations and even civil disobedience to force issues like access to treatments, public hospital under-funding, and the need to reform and speed up drug approval times into the spotlight.” ACT UP also worked tirelessly to convince government, researchers and industry that HIV positive people should play a role in decisions affecting their own health (Canavan 2004, p 18).

Rodwin (1994) provides another case study of the disability rights movement which successfully pushed for independent living outside of institutions to enable people with disabilities to gain control of their lives. In the course of this campaign, says Rodwin, the disability rights movement changed the way we think about people with disabilities. Instead of professionals being regarded as the best people to decide what people with disabilities need, people with disabilities argued for the ability to make their own decisions and be given the dignity of risk.

Although this discussion is cursory, these cases provide some examples of the achievements of independent consumer advocacy. There is no literature comparing the efficacy of independent advocacy vis à vis participation. We need to recognise that in examining the evidence or the literature around health consumer voice, we are examining a pre-limited range of experience and possibilities. Some other ways of doing things are not on the radar. This report must proceed within those constraints, but recognising that they exist.
1.4 TYPES OF VOICE/PARTICIPATION: CONSUMER PARTICIPATION WITHIN THE HEALTH SECTOR

Consumer Participation: Rationale

A wide range of reasons are given for enhancing consumer participation in health care planning and policy development (See Table 3). Many of the rationale are not evidence-based, but are more in the nature of ideological beliefs, rights-based explanations or pragmatic approaches to a variety of problems. Florin and Dixon (2004) characterise most of them as ‘assumptions’. In Table 3, only the third category, ‘Better decisions or services/policy improvements’, has some evidence base.

The rationale for participation has largely been developed by people inside the system, that is policy makers, social scientists, managers and providers, rather than consumers. There have been few systematic attempts to establish the rationale for consumer participation by consumers or as a partnership between the various stakeholders in health. What is known about consumer views is discussed in the section on ‘Consumer motivations for participation’, see section 1.3, page 31.

Organised consumers have sought participation, but there has not been a dialogue, shared decision-making or negotiated agreement with governments and providers. In many instances, governments or services have decided to pursue consumer participation, but then have unilaterally decided when to do it, and the methodology to be used. In most countries, there has been very little ‘walking the talk’, in other words, modelling participation at all stages of the process, from agenda setting to practice. This is particularly true in the UK, where participation has been shaped to fit the prevailing ideology of the day (Milewa et al 1998).

Milewa et al (1998) studied National Health Service (NHS) health authorities and found that there is ‘very little consensus on the precise purpose of engaging local populations’ and ‘a lack of synchronicity between the political-administrative institutions of debate and change and corresponding social constituencies’ (p 510-15). Without some explicit cross-sector consensus as to what the purpose and goals of consumer participation are, there is a great deal of room for misunderstanding, confused and uncoordinated approaches, and potential for disappointment. Indeed, given that there is scepticism and disapproval in some quarters, there is a danger that consumer participation may live out a self-fulfilling prophecy of failure. Consumer participation is in danger of being treated as all things to all people.

The rationale for participation can be broadly divided into three categories based on those used by Dwyer (1989):

- Redistribution of power and resources and intrinsic benefit
- Legitimation and compliance
- Better decisions or service/policy improvements.

Redistribution of power and resources and intrinsic benefit

Arguments that fall under this category relate to the social benefits that are seen to accrue to participation. Participation is seen as a citizenship right, and as a way of overcoming the perceived deficiencies of representative democracy, such as low voter turn-out, poor representation and a lack of representativeness (Harrison & Mort 2000). Linked to this is the idea of ‘active citizenship’: the process of participation is the implicit benefit and end in itself rather than any goal or defined outcome, except perhaps a more socially cohesive society (White 1999). Participation can build...
social capital by developing a more informed, engaged and democratically able society. It reflects a broad trend towards devolution of decision-making as close to the people affected by it as possible (Charles & DeMaio 1993). Croft and Beresford (1993) argue that the concept of citizenship can legitimate the concerns of marginalised groups, such as people with disabilities, ethnic minorities and poor people.

The need to make the medical profession and the state more accountable for their actions and for resource allocation is emphasised by others (Calnan & Gabe 2001). Charles and DeMaio (1993) see participation as a response to a loss of faith in the legitimacy and superiority of professional knowledge as the key determinant of health care decision-making. The public wants to determine what is in their own best interests. In this way consumer participation is a response to the traditional paternalism of the medical profession. It confers at least equal status on the experiential knowledge of the consumer compared to the technical knowledge of the health professional.

**Legitimation and compliance**

Governments have sought participation to gain the support of the public for difficult rationing decisions and major shifts in the policy orientation of the health sector. As health technology becomes more sophisticated and costly, governments have to make decisions about priorities. In general there has been a wish to shift resources from hospital-based treatment to prevention and primary care, and to reallocate resources to those with poorer health status and less access to health care. Major ideological shifts in the organisation of health care, such as the proposal for managed care-style health care delivery in New Zealand in the late 1980s and 1990s, are often accompanied by attempts to enlist public support. Involving the public in these decisions is seen as a means of negotiating consensus and consequent support for policies (Dwyer 1989).

The medical profession has historically contested the shape of the health system with governments. When seeking change, governments can enlist the power of public voice to counteract this, sometimes by establishing community structures and devolving some power to them (Grant 1989). Morone argues that the call for participation is not so much one of ‘empowering an oppressed group but subordinating a dominant one’ (quoted in Charles and DeMaio 1993).

There is also a complex set of motivations which emerges from the development of managerialism in the 1980s and 1990s. Rationale for the introduction of managers into public health service structures were to increase efficiency, mitigate doctors’ control over resources and increase the influence of local populations (although there is little evidence that the latter eventuated) (Milewa et al 1998). Various authors outline how managers enlisted consumers to bolster their authority when dealing with clinicians, sometimes quite cynically. White (1999) believes participation is ‘not about empowering consumers and communities or about turning them into decision-makers, but rather, it is about empowering existing decision-makers’ (p 475).

Later, consumer participation has been seen as a means of counteracting the power of the managers themselves. In their study of user group involvement and professional and managerial responses, Harrison and Mort (2000) found that ‘many respondents … described how they used such groups in both short-term tactics and longer-term strategies. The former is neatly summed up in the phrase “[playing the] user card” spontaneously employed by several respondents; it refers to the use of user group opinion to buttress one or other manager’s or professional’s or their institution’s preferred course’ (p66). A recent example of this in the New Zealand context was the organised strategy by pharmacists to enlist consumers and consumer groups to oppose three-monthly dispensing that was being proposed by PHARMAC.
Better decisions or service/policy improvements

This is the everyday commonsense approach to participation which sees it as about improving decision-making. This argument recognises that consumers have special knowledge and expertise deriving from their experience of using services, either individually or collectively. Consumers bring grassroots and community views and preferences to the table to add to the technical skills brought by others. O’Keefe and Hogg (1999) describe this information as ‘crucial for the planning and monitoring of services; but [which] is not being accessed through other communication systems’ (p252).

Underlying many of the rationale contained within the category of better decisions or service improvements is a concern with quality. A desire to improve the quality of services lies behind many of the actions taken as part of independent advocacy. For many consumer organisations, working with service providers or policy-makers is aimed at the same goal. Improving quality is a particular theme in the Australian policy context around participation. For example, a recent inquiry by the Victorian state government described the rationale for community and consumer participation within the broader context of quality:

1. ‘Quality and accessibility of the public health system is of considerable concern to the community that utilises the system. The involvement of the community in policy planning is valuable in terms of democratic participation and in improved social cohesion and health outcomes;

2. Recent reports suggest that increased community and consumer participation supports effective system-wide planning and improvement in health care quality and safety; and

3. Individuals have a recognised right to participate in decision-making about their own health care’ (Family and Community Development Committee, Parliament of Victoria 2004).
Table 3: Rationale for consumer participation

<table>
<thead>
<tr>
<th>1. Redistribution of power and resources and intrinsic benefit (Dwyer 1989)</th>
<th>2. Legitimation and compliance (Dwyer 1989)</th>
<th>3. Better decisions or service/policy improvements (Dwyer 1989)</th>
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<td>• Social trend towards greater citizen democracy</td>
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<td>• Observance of human and citizens’ rights</td>
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<td>• Accountability of the medical profession and the state to populations</td>
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<td>• Empowerment of consumers</td>
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<td>• Strengthen voice of disadvantaged</td>
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<td>• Increase mutual learning of public and government</td>
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<td>• Increase community access to information and knowledge about health and health services</td>
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<td>• Governments engage directly with consumers, rather than rely on providers</td>
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<td>• Devolved decision-making</td>
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<td>• Adoption of community development model, Alma-Ata Declaration, Ottawa Charter, WHO ‘Health For All’</td>
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<td>• Build positive relationships with the public, increase confidence and trust</td>
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<td>• Contribute to social capital.</td>
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<td>• Involving consumers in decisions, especially prioritisation decisions, will lead to community compliance</td>
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<td>• Educate the public about resource constraints</td>
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<td>• Act as a balance to well-organised professional, industry and government groups</td>
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<td>• Support management decisions, empower existing decision-makers</td>
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<td>• Counteract influence of managers</td>
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<td>• Voluntary contributions of labour and finance.</td>
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<td>• More closely align policy and services with needs of populations</td>
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<td>• Decisions are better when made by those closely affected</td>
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<td>• Services will be more acceptable</td>
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<td>• Improve quality of services</td>
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<td>• Improve feedback on the effectiveness of policies and services</td>
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<td>• Provide greater consumer choice</td>
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<td>• Utilise community skills and knowledge</td>
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<td>• Incorporate the power and richness of lay people’s conceptions of health and illness</td>
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<td>• Identify possibly controversial aspects of an issue and help bring together different points of view</td>
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<td>• Represent differing cultural values in decision-making</td>
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<td>• A more wholistic approach, considering the whole person</td>
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Consumer Motivations for Participation

A few papers have examined the question of what consumers seek to achieve through participation. Bastian (1998) says that in participation consumers have sought to ‘re-personalise’ health care and rescue it from the biomedical model. The subjective individual experience was swamped by the pre-eminence of objective medical science.

This question was studied at a workshop in ACT, Australia, sponsored by the Health Care Consumers’ Association of ACT, Disabled People’s Initiative, ACT Council of Social Services and the Australian Council for Rehabilitation of Disabled. The workshop was attended by a large number of consumers, including both health and disability consumers (ACTCOSS & HCCA 2003). This workshop found that the meaning of participation was very broad. Those listed below have been categorised according to Dwyer’s criteria (1989). It can be seen that none of the goals fall within Dwyer’s category of ‘Legitimation and compliance’.

Redistribution of power and resources and intrinsic benefit
- Human rights
- Social justice
- Accountability
- Community development
- Build capacity
- Networking
- Powerful form of social change activism
- Empower consumers to have control over their lives
- Value knowledge, experience and diversity
- Put consumers at the centre.

Better decisions or service/policy improvements
- Consumers involved in every aspect of operations from governance to day-to-day management
- Provide ‘expert’ feedback and advice
- A multi-layer, multi-aspect process involving people having a say
- Consumers as part of the solution
- Give direction to planning and delivery of services
- Make sure policy reflects real life
- Cultural change in the health system (ACTCOSS & HCCA 2003).

This workshop went further than most of the sources cited in Table 3. For this group participation could achieve social justice and social change goals and was seen as being “about “power”, and in this sense it is a very political process/movement. It can be a very powerful source of social activism” (p 4).

This review uncovered only one study that compared the goals of consumers compared to others involved in participation projects. Harrison et al (2002) compared people within Primary Care Trusts (PCT) in the UK with informants drawn from voluntary, community, patients’ or residents’ groups (non-PCT respondents). Both groupings concurred that motivations for patients and the public who got
involved were personal experiences or civic obligation/altruism. There was agreement that voluntary and community groups wished to achieve community aims, meet local needs and reduce health and other inequalities. However, only non-PCT groups had the aim of establishing better and more transparent working relationships with PCTs. Non-PCT respondents also saw success as achieving ‘demonstrable changes in services’ or ‘health improvement’ whereas PCT respondents gave highest ranking to receiving patient and public feedback.

There may be somewhat of a mismatch between consumers’ goals and those of health professionals and administrators involved in such processes. Consumers may have higher expectations of making a difference by participating. As we shall see in the discussion of barriers, professional scepticism and attitudes surface repeatedly as barriers to effective participation.

Motivations of voluntary consumer group members

A major British study by Thompson et al (2002) examined the motivations of voluntary consumer group members who got involved in participation. They found several major motivating forces: a belief in participation from a rights and influence perspective, altruism, and social and emotional benefits of participation.

The pre-eminent motivation was altruism. Participants would not accept poor services and they were not deterred by low standards, lack of opportunity and obstructions. They sought and demanded participation. Their concerns and approaches were collective and they sought gains that were larger than their individual interests. While a personal experience may have prompted their involvement, they wanted to ‘help others’ and ‘prevent what happened to me happening to someone else’. They wanted to ‘leave a legacy’ and influence services for the benefit of others (p 144). They held a set of beliefs about collective action and their right to participate in the affairs of the State. They did not regard participation as the only advocacy role they could play but saw it as a prerequisite to other roles they might play. Consultation and other traditional forms of involvement were viewed with a great deal of cynicism. Many other roles including direct action were seen as ways of having an influence.

There was a highly consistent belief that people had more power as a group than as an individual to change or influence a ‘mega structure’ such as a health service. They thought there was more clout in numbers to make decision-makers listen. The freedom to ‘just get on and do it’ and not battle with health bureaucracies was believed to be an advantage of an organised group (p 168). Their own resources enabled them to set their own priorities and fund their own research to develop their own evidence base. They were wary of becoming too integrated into the government health system. They believed that any movement or group needed effective spokespersons to get their message across and to represent them at meetings with particularly powerful people such as MPs.

Having a national network or organisation was perceived to have great advantages in getting their ‘voice’ heard and having the ‘clout’ to influence service and policy. National networks also enabled groups to gather and disseminate information much more easily. Members of groups believed that they had accumulated a lot of ‘on the ground’ knowledge and expertise in their fields and this gave them a more ‘rounded view’ (p168).

‘They also wanted to affect public and professional attitudes, especially those who came from groups concerned with disability, mental health, and older people. They wanted to make these groups more visible and make it easier for people in these groups to have a voice. People from minority ethnic groups also became involved because they believed it was important to ‘speak up’ for their minority community’ (p148).
Interest of non-aligned consumers in participation

This study also examined the views of non-aligned individuals. Consumer involvement was viewed positively by most, although middle-aged men in particular, were more likely to feel that decisions should be made by professionals and that citizens had so many different opinions that it would complicate matters to involve them. Young people and young men in particular were relatively apathetic, and often expressed a feeling that the public was powerless. They did not respect politicians or policy-makers.

Although there was overall support for public involvement, there was not a great deal of enthusiasm for their own involvement at the policy and planning level. There was increasing disinterest the less local the service became. Most saw hospitals as too large to deal with and they felt hopeless or despondent about achieving influence at a national level. Those not part of voluntary groups lacked motivation to be involved at the national level.

In an Australian study, Johnson and Bament (2002) found a similar lack of enthusiasm among members of the public and users of hospital services. They found a pattern of ‘significantly higher level[s] of interest in participating in ways that require low levels of commitment and involvement…The results also identify that as the involvement and commitment levels required of each method of participation increased, interest in being involved amongst participants greatly decreased’ (p 203). Passive methods were preferred, such as satisfaction surveys and giving feedback over the phone. There was some interest in ‘one-off’ methods such as focus groups and public forums. Less than 10% were interested in participating in ongoing processes such as a hospital committee. By contrast members of consumer organisations showed a high level of commitment to ongoing processes. In her review of participation, White (1999) also reported that ‘lay actors do not appear to be interested in playing a sustained, decisive role with respect to most health-care issues, although they are more willing to be consulted’ (p 471).

Similarly, Harrison et al (2002) found that informants outside PCTs (mainly patient, voluntary and community groups) were sceptical about the feasibility of being able to persuade ‘healthy people’ to participate.

In examining the views of consumers towards participation, not just in the health sector, the National Consumer Council in the UK (2002a) found people were not particularly interested in getting involved in an issue except where it had personally affected them. They were fatalistic and believed involvement would not make a difference. There was a low awareness of how to get involved and many believed that public sector organisations and companies made their decisions behind closed doors and only consulted when they had to. Like Johnson and Bament, the National Consumer Council found that people did not aspire to involvement beyond a relatively low level, for example, letter writing, attending a meeting or talking to a community representative, and even then people said they would be unlikely to actually use them.

Experiments with citizens’ juries and other forms of involvement that focus on prioritisation and rationing have found that members of the public are often reluctant to accept a role in making such decisions (Jordan et al 1998). In a study of a citizen jury looking at prioritisation of services, Lenaghan et al (1996) found that the members of the public acting as jurors were nervous about whether they should be involved in decision-making on such matters. They asked why elected or appointed members of boards were not making them and asked whether members of the public were competent to do so in the first place. In a Canadian study, Abelson (cited in White 1999) found that randomly selected citizens were overall the least preferred as decision-makers, even by their peers.
Support for consumer organisations

A national workshop on involvement in the UK found that consumers support consumer groups. They were concerned at the potential duplication when health agencies and governments establish groups that are supposed to provide a voice for the public. Consumer groups were seen as channelling or feeding in the views of the wider public (King’s Fund 2002).

In general, consumers with long-term or chronic conditions or belonging to particular population groups have been at the forefront of efforts to ‘democratise’ the health sector. These groups have frequent contact with health services, providing greater incentives to try and achieve services that are more responsive to their needs.

The literature in this area of consumers’ attitudes to involvement is small, but the information that is available suggests that authorities may be barking up the wrong tree in trying to achieve involvement of consumers at large beyond the levels they wish to be involved. Ironically, members of the public prefer methods of involvement that are considered to be the least effective (Jordan et al 1998).

Clearly, involvement in ongoing policy and planning processes is not a priority for many consumers. There are issues of trust and lack of knowledge that would need to be overcome to foster involvement. By contrast, consumer organisations are highly motivated to be involved and are supported by consumers.

1.5 CONSUMER PARTICIPATION: OUTCOMES AND LIMITATIONS

Outcomes and Effectiveness

Despite the very large literature, several writers note the lack of focus on the outcomes and effectiveness of participation (Simpson & House 2002; Crawford et al 2002). Without setting the outcomes sought, it is difficult to measure effectiveness. According to White (1999):

‘the vast and eclectic literature on participation displays a common feature: a singular lack of concern with outcomes or the effectiveness of participation’ (p 466).

In the context of the contemporary interest in evidence-based practice, White describes the lack of concern with outcomes as ‘odd’:

‘It raises the following question: why are governments and other authorities determined to invest and reinvest in consumer and community participation in spite of the relative lack of evidence, one way or another, regarding its impact’ (p 466).

She concludes that it is because participation derives its value from its utility to administrators.

Similarly, a number of writers note that much of the activity has not been evaluated (Kelson 2001b; Coulter & Elwyn 2002). The Australian National Resource Centre for Consumer Participation in Health (November 1999) observed that;

‘consumer participation has not been adequately evaluated which means there is limited evidence about its effectiveness. There is also limited process evaluation of consumer participation strategies which means that learning in this area is not always available to those wanting to implement participatory processes’ (p 2).

White (1999) points out that because the literature lacks a common conceptual or theoretical basis, it is impossible to compare or pool results. It is not a lack of conceptual frameworks that is the problem, but the plethora of frameworks, although most are not applied to empirical studies. There is
also no agreement about the meaning of key terms and categories, such as consumers/patients/users or community. For example, during the Oregon attempt to debate ‘core services’, almost 70% of the people in ‘community consultations’ were health care providers.

There is also an issue about the timeframe in which change can be discerned from participation activities. Rochefort et al (1998) examined the involvement of communities in policy development in health and mental health in the USA and Quebec. They say that governments can effect major long-term change in policies and practice by forming alliances with community-based actors. For example, the shift of mental health care from institutions to the community in these two countries would not have been possible without the support and advocacy of the community. The authors say that involvement of communities can bring about transformative change: ‘Community policymaking often seems to occur where the task entails confronting powerful institutions and interests associated with the status quo, as, for example, with a health care system dominated by hospital facilities, or a municipality run by a political machine. Alternative interests are identified and promoted by the policy, and an alliance between government and these interests is built to counter established powers’ [p 560].

While the community is slow-acting, it can cultivate or legitimate fundamental shifts in policy. The authors say that this particular capacity of the community has not received a great deal of attention in the literature.

Some authors contend that focusing on outcomes is not a reasonable thing to do. Democracy (and patient and public involvement) can be valued for their own sake, as expressions of political self-development, rather than their efficacy or efficiency (Harrison et al 2002). Although there is a relative lack of information on consumers’ views on this exact point, it seems unlikely that consumers would value participation for its intrinsic benefit, without believing that it will lead to concrete outcomes. The views described in the section on ‘Consumer motivations for participation’, (see section 1.3, page 31) show that consumers do have expectations of outcomes. Indeed the reluctance of consumers to get involved is often based on concerns about tokenism and a lack of sincerity among other stakeholders. Consumers do have other options around strategies they can utilise to have a voice, so it seems unlikely they would wish to invest their time and effort in activities that only have an existential benefit.

Berry (1981), White (1999) and others point out that despite the enduring popularity of participation programmes, there are numerous reports of projects that have had minimal effect. In Quebec, local community health and social service centres failed to deliver on the promise because doctors organised boycotts and set themselves up in competition (Godbout 1981; White 1999). In the UK, Community Health Councils were constrained by limitations placed on their roles by government (Lupton et al 1995). Checkoway (1982) describes how attempts by consumers to have a strong voice on Health Systems Agency boards in Illinois were defeated by well-organised professional interests who were able to mobilise superior resources to defeat consumer action.

What distinguishes the above examples is that they occurred in highly contested settings, in which, despite support for participation, it was opposed by other powerful interests.

Consumer and Provider Partnerships in Health Projects

The experiences of Australia offer the best evidence of what can be achieved in supportive settings. Australia has enjoyed Commonwealth and state government support for participation, thus creating a climate in which participation is expected and valued, and it is resourced. The CAPPS programme was set up jointly by the Consumer Focus Collaboration, a government agency, and the Consumers’ Health Forum of Australia (Consumer Focus Collaboration 2003).
The 22 CAPPS projects all consisted of groups of consumers or communities working with providers in partnership to achieve goals they had set. The partnership approach would place these projects at the top end of Arnstein’s Ladder of Participation. The settings varied from acute hospital services to community-based services. The projects involved people and services in rural, remote and socio-economically disadvantaged areas and a range of population groups. The projects were aimed at:

- New ways of seeking feedback and improving communications, particularly with consumers who are not readily reached by services. Factors affecting this were cultural diversity, geographic location, and stigmatisation of consumers because of the nature of the health condition
- Providing information or treatment tools
- Education of health professionals and/or consumers
- Development of consumer participation mechanisms
- Involving whole communities in planning and service delivery
- Documenting experiences of involving consumers.

Many of these projects were focused on process rather than health outcomes. An example of this was the Alice Springs Feedback Project, a partnership between Arrernte and Tangentyre Councils and Alice Springs Hospital which tested and developed culturally appropriate ways of receiving feedback from Aboriginal consumers and Aboriginal consumer groups. This project succeeded in identifying appropriate tools for feedback, an Aboriginal Consumer Advisory Committee was formed to provide regular feedback about services, posters and pamphlets were developed to encourage feedback, and presentations were made to staff about feedback. While this project was notionally about improving consumer feedback processes, the relationships formed must be a precondition for increasing the accessibility of services and enhancing the potential for better health outcomes.

The Epworth Endometriosis project was a partnership between the Endometriosis Association and Epworth Hospital. This surveyed women with endometriosis to find out their information needs, developed resources for women, tested these with women, and prepared information for health care providers, nursing faculties, clinical schools and hospitals.

Although many of the goals of projects were quite modest, they often had additional benefits. For example, the Epworth Endometriosis partnership found when surveying women that they were concerned about long delays after laparoscopy until the consultation appointment when findings and treatment were explained. The doctors in the partnership proposed that when they write to women’s GPs (within one week of laparoscopy), they should also write to the women about what had been found and the treatment given. This was a highly satisfactory outcome for the Endometriosis Association and the women attending the hospital.

The review of CAPPS projects concluded that they achieved over and above what they set out to do and that they had ‘positive, long-lasting impact and bring another dimension to our understanding of quality in health care’ (p 51). All found there had been value in working together and wanted to continue the partnership. A striking feature that distinguished these projects from many other participation projects was the joint agenda setting and the willingness of partners to change direction. Bringing consumers into a process where the agenda is already set is the norm in many participation projects, and they do not usually involve whole consumer organisations, but rather one or two consumers. The CAPPS projects identified a range of partnership enablers, many of which are included in the Enablers Section, see section 1.6, page 43 of this report.
Other Australian research

In a study of the evidence supporting consumer participation, the Consumer Focus Collaboration (2001) cited a number of research projects and activities showing that participation could lead to improvements in health services and health status. In particular, they cite the involvement of consumers and families in the implementation of the National Mental Health Strategy and the success of controlling the spread of HIV/AIDS using a partnership approach. One study they cite is a New Zealand report of the establishment of asthma clinics within a partnership framework, with significant Maori involvement in management. This showed a significant reduction in asthma morbidity among Maori, and four key long-term benefits: cultural affirmation, improved access to other health services, a greater sense of control by participants and positive impacts on the extended family (Ratima et al, 1999 in Consumer Focus Collaboration 2001).

Mental health consumers in USA

Geller et al’s (1998) study of consumer participation in the public mental health system in the USA found that there had been a significant increase in consumer participation in the mid to late 1990s. Thirty-nine percent of states addressed consumer empowerment in their statutes and 48% had paid consumer positions in central offices. Most interestingly, there was a positive correlation between the extent of empowerment and the quality of mental health services, as measured by the rating given to the state by the Public Citizen Health Research Group and the National Alliance for the Mentally Ill. While it cannot be said that the relationship was causal, the authors postulated two explanations:

‘One – perhaps the more likely of the two – is that mental health agencies with positively valued practices in other areas have an orientation that predisposes them also to empower consumers. An alternative model posits an optimistic scenario in which mental health agencies that have empowered consumers by employing them in formal organizational roles have been influenced by them and are therefore more likely to engage in more highly rated service delivery practices’ [p 502].

Systematic reviews

The systematic review by Crawford et al (2002) of involving patients in the planning and delivery of services found that few studies have shown that involving patients have improved the quality of care, including acceptability and accessibility of services, and none have shown improvements in consumer health or consumer quality of life, but there are a number of reports that have shown that participation has had an effect.

One weakness of Crawford’s systematic review is that none of the papers emerging from the Consumer Focus Collaboration in Australia was accessed.

The effects found by Crawford et al include the following:

Effects on users

- Several papers note that patients who participate welcome this and that their self-esteem improved as a result of their contribution. Most of the studies involved mental health services, one involved a citizens’ jury. Some studies described consumers’ dissatisfaction with the process.
- Some studies show staff found the process rewarding, others describe difficult relationships between patients and staff.
Changes to services

- The most frequently cited change to services was the production of a new consumer information resource.
- Others described minor changes to services, such as simplified appointment procedures, extended opening times, improving transport to treatment units, and improving access for people with disabilities.
- Several reports describe new services being established such as advocacy, improved employment opportunities, complementary medicines, crisis centres and fertility treatments.
- Two reports describe how involving patients led to the modification or abandonment of proposals to close hospitals.

Other effects

- Some reports noted that organisational attitudes to involving patients improved and in some cases, further initiatives followed.
- Researchers found that involving consumers was used to legitimise decisions whether or not consumers supported them.

Overall impact

- Mixed results were found about the overall impact of involving consumers. A survey of Health System Agencies found that 75% of respondents thought that service quality had improved and 46% said it had improved people’s health. Of 63 consumer participation groups in primary care in the mid-1980s, 52% were able to provide details of at least one change the groups had initiated.
- A study in Stockholm found that following participation, 70% of plans had been implemented.
- A study of mental health forums in the UK found that 39% of concerns raised resulted in a response from providers that was judged acceptable.

The other systematic review of involving users in delivery and evaluation of mental health services (Simpson & House 2002) found that:

- The few comparative studies of users’ involvement indicate that involving users as employees, trainers or researchers has no negative effect and may be of benefit.
- Employees who were or had been users of services spent longer in supervision, in face-to-face contact with clients, or doing outreach time, and spent less time on telephone or office work. They had a higher turnover rate and had less distinct professional boundaries.
- Employing users in case management services did not detrimentally affect clients and clients had some improved quality of life, fewer reported life problems and improved social functioning. In some studies clients of employees who were users took longer before hospital admission and fewer clients needed to be admitted to hospital or stay in hospital was shorter.

Commission for Health Improvement inspections

An interesting example of a systematic evaluation of participation was recently reported from the UK. The now-disbanded Commission for Health Improvement (2004) used inspections (audits) of over 300 NHS trusts as well as other research to examine the impact of the NHS policy of ‘patient and public involvement’. In this case the Commission for Health Improvement identified the goals of this
as improvements in; the quality of decision-making, quality of services, accountability, transparency, openness and relationships between individuals and professionals, organisations and communities.

The Commission for Health Improvement inspects seven components: risk management, use of information, clinical effectiveness, staffing and staff management, clinical audit, education and training, and patient and public involvement. Measurement of public and patient involvement is carried out by looking at the following aspects:

- the range and nature of involvement initiatives
- whether there are plans based on a baseline of needs and organisational priorities
- whether senior management have clear performance processes for the work (accountabilities, clear roles, and responsibilities, reporting and monitoring)
- whether there is organisational support (for example, resources, staffing, training and development)
- that there is integration with other clinical governance work, such as clinical audit
- whether people and groups from diverse communities have been involved.

The commission used a very thorough process. Information was gathered from documentation, site visits, and interviews with stakeholders including patients, carers and the public, community and voluntary organisations, statutory partners and staff. As well, the Commission for Health Improvement carried out a literature review, in-depth studies in two communities, held group discussions in four regions and ran a national stakeholder consultation event with representatives of patient and public interest organisations, trusts, Strategic Health Authorities and national agencies.

The Commission for Health Improvement found that of the seven clinical governance components, patient and public involvement scored lowest compared with other components. Only 8% of trusts scored 3 or 4 (out of a five-point scoring system, none scored 4). Not surprisingly, the Commission found that patient and public involvement was not yet having a major impact on policy or practice: ‘This is despite a plethora of PPI [patient and public involvement] initiatives. It is almost as if there is a brick wall between activities going on and any changes on the ground that happen as a result’

The commission found ‘few successful examples of where PPI had entered the corporate bloodstream’ (Commission for Health Improvement 2004, p 11-12). Further findings of this report will be discussed in later sections.

Similarly, in a study of PCTs, Harrison et al (2002) found that while respondents were committed to the idea of participation, it was not their highest priority when compared with organisational, financial and service development considerations.

They found that participation tended to be defined in terms of activity, rather than purposes or outcomes. The study found that where participation had brought about service changes that would otherwise not have occurred and were observed by those outside the PCTs, it was in the context of an existing community development framework.

There is a great deal of research focusing on the process of participation broadly described as ‘enablers’ and ‘barriers’. These will be discussed in more detail in the ‘Enablers and barriers’ section, see section 1.6, page 43 of this report.
Limitations

As noted earlier, much of the literature on participation is focused on improving processes and testing methods. In general, it uncritically accepts participation as a worthwhile pursuit. However, some writers such as Lupton et al (1995) make an important distinction between participation and influence: ‘just as it is possible for the public to influence decision-making without individuals being directly involved in the process, it is possible for the public to be involved or consulted without its views in the end having any actual influence on the decisions made’ (p 222).

Redistribution of power

The fundamental issue is whether participation involves a redistribution of power.

Cawston and Barbour (2003) point out that there are few examples of consumers gaining greater control over resources or resource allocation. In many instances, community participation results in decreased control with communities being given responsibilities for vanishing external resources in the expectation they will be sufficiently resourceful to themselves step into the gap. Participation is occurring in an environment of finite and constrained resources so that communities do not have the freedom to identify priorities where these are not part of core health services. There are few examples of consumers being able to achieve significant shifts in public spending, as opposed to reorganising the deck chairs.

Similarly, Bowl (1996) examined service user involvement in UK mental health services and also found that there was little evidence of power-sharing. The main function of user committees was to pass information down to users rather than vice versa. Users wanted direct access to decision-making but tended to be placed on occasional working parties, local planning teams and sub-committees. In examining health panels of consumers of mental health and disabilities services in the UK, Harrison and Mort (1998) found that few clinicians took part, rather it was the domain of public relations and communications officers, thus marginalising the decision-making of the groups.

Lupton et al’s study of Community Health Councils in the UK (1995) also found that they were ‘limited to fairly marginal issues such as quality assurance, and that key strategic issues were increasingly taken outside the formal consultative mechanisms. Most felt that their role was to legitimate decisions that had already been taken’ (p 224).

A decade later, the findings of the Commission for Health Improvement (2004) suggest that despite a great deal more experience with participation, and a plethora of guidelines and policy documents, not much has changed. This study found:

‘... good operational work that does not influence decisions. There are also numerous examples of PPI [patient and public involvement] going on in what may be termed “safe” areas, such as having reader panels for patient information leaflets or focus groups on aspects of the ward environment. There are also plenty of examples of patient representatives sitting on steering groups for particular service areas or on projects. But often these project groups sit at the periphery of corporate decision making and people involved may be marginalised or unsupported. The NHS seems to be getting better at finding out what matters to patients, carers and the public – less good at doing things about it. It is having a hard time shifting from “feedback” mode (gathering information about the patient experience) to “influence” mode (sharing a seat at the decision making table with patients, carers, service users and the public)” (p 3).
 Berry (1981) notes that refusal on the part of agencies to give up control contributes to the limited gains of public participation. A number of other authors outline the ways in which ‘the system’ keeps control. Participation is initiated by doctors and managers and in almost all cases they set the agenda (Harrison & Mort 1988). Even when administrators seem to be genuinely seeking public input, they can mould the outcome by overriding what the public says it wants. In the case of the Oregon core services exercise, public debate was redefined as the goal of the exercise, rather than ranking services (White 1999). Milewa et al’s study (1999) found that UK health authority managers had adapted to government requirements for participation by setting up participative structures that enabled them to retain control over key decision-making. White (1999) says it is this aspect of insider control that demarks participation distinctively from autonomous lay action such as advocacy and participation in social movements. In these activities, consumers set their own agendas, use their own resources and expertise and have their own constituencies.

Godbout’s (1981) research of Quebec community service centres led him to conclude that whether consumers can exercise power during participation is dependent on their socio-economic status, whether they are able to mobilise community support, and their relationship with the manager who must implement decisions.

Marmor and Morone (1980) assert that as health markets are inherently unbalanced, mechanisms must be put in place to rebalance power. They advocate two mechanisms: assigning staff to the consumer representatives and allowing external groups to select their representatives.

**Marginal benefits and some risks**

Berry (1981) points to the paradox of the continuing preoccupation with participation when the results have been disappointing. He believes that the benefits that can be gained from participation processes have probably already been gained and that further reforms will produce only marginal benefits and cost-ineffective improvements. ‘For too many activists and scholars,’ he says, ‘their focus remains on reforming citizen participation rather than recognising its limits’ (p 466). He puts this dogged optimism down to advocates failure to see viable alternatives, on the one hand, and scholars, government officials and activists having invested so much in it, they resent the possibility of failure and are determined to make it work.

The Consumers’ Health Forum of Australia has put a huge amount of effort into participation, which is now a major focus for the organisation. As will be discussed in Part 3, the Consumers’ Health Forum has hundreds of representatives on committees of one sort or another. A recent review found that improvements needed to be made to the programme, most of which could be addressed with greater funding (Chalkley Consulting with Artcraft Research 2002). In responding to this, the Consumers’ Health Forum raised important questions about the impact of participation on a consumer organisation and advocacy in general:

‘Consumer groups and other advocacy bodies support increased consultation with individual consumers. However, this increased consultation with individuals has come with a decrease in focus on organised, collective consumer involvement and in the power of consumers working together through consumer organisations to influence the overall health system, and health outcomes. More consumers know more about how a medical service should work for a particular illness, but the number of consumers knowing about the difference between a health system and an illness system or working together to advocate on policy at this level has not increased to the same extent.'
Research in the UK suggests this reduction of collective advocacy has been a deliberate strategy on the part of governments, partially out of a desire to hear from more consumers, and this has, to some extent, depoliticised the organised voices of consumers (Barnes, 1999).

There is an increased emphasis on individual service delivery rather than system change and a loss of focus on public and social health across the health system generally. An illness model dominates health policy in Australia with a strong focus on service delivery to the individual.

These trends in participation present a slight paradox for consumers and organisations concerned to influence both service delivery and health policy. Consumers and consumer organisations are increasingly pushed into commenting on service delivery or existing and inadequate services. Without enabling communities to have a say collectively, or being selective about “which communities” they listen to, government are potentially and inadvertently undermining significant improvements in the wider service system (Consumers’ Health Forum of Australia 2002, p 13-14).

Checkoway (1982) provides an example of a Health Systems Agency (HSA) in east central Illinois in which he himself was involved. Local people threw considerable enthusiasm into getting consumers onto the board, and were recognised nationally as an exemplary group. However, they found themselves outstripped by the powerful professional health interests who had “disproportionate resources, unequal interests, and ongoing organizations” (p 119). This caused the consumers to rethink their investment in participation as the sole route to achieving change:

“In time, however, we were frustrated by the course of events and decided it would be a strategic mistake for us to organize around only health planning without an independent agenda of our own. This decision helped us broaden our concerns and enter a new period of activism at a time when the health planning program itself was in question. It is ironic that the greatest legacy of our local HSA could well have been the formation of a consumer organization made up of large numbers of local consumers who finally outgrew the HSA” (p 121).

Bowl (1996) raises the important issue of whether participating in the system is worth the effort for consumer groups. He asks whether consumers’ interests are best served by becoming involved in departmental structures, or by remaining independent lobbyists.

Despite his personal experience, Checkoway (1982) does not advocate abandoning participation. He says ‘it does not follow that, because participation programs and methods fail to fulfil promise, have shortcomings, and show little association with the quality or import of participation, that these methods lack promise, or that efforts to improve their quality should be abandoned’ (p 307). He advocates continuing with participation, but also using other community tools to have an influence.

The answer given by Berry (1981) is, do both: “Being an “outside” critic has its limitations. It is better to play both sides of the street” (p 474).
1.6 ENABLERS AND BARRIERS

Much of the research on participation has focused on aspects that impede or enable participation. These enablers and barriers of participation are mainly focused on what participants and researchers have identified as necessary to satisfactory processes as opposed to whether they achieve particular outcomes. With the proliferation of participation activities in recent years, a number of major pieces of research in Australia and the UK have provided a strong body of evidence about enablers and barriers. There is considerable agreement in the literature about enablers and barriers.

Nevertheless, there are still gaps in the literature. For example, there is little discussion of the personal characteristics of consumer, provider or other participants that would most enable effective participation. The emphasis is on teaching skills, as if all representatives are born equal. However, some skills may be difficult to teach and many participation processes take fortitude of character.

Enablers

Enablers can be divided into the following categories: government policy support; strong consumer sector; process enablers; and organisational enablers.

Government policy support

- If there is high-level direction or support from government, this can act as a catalyst for change. Government can also provide funding for consumer groups to undertake research, identify and train consumers, act as contact points and liaise with services (Draper 1997; Consumers’ Health Forum of Australia 2002).
- A policy framework is necessary to support participation (Consumers’ Health Forum of Australia 2002).

Strong consumer sector

- Consumer organisations provide the means to develop collective consumer voices. Links to an established organisation provide a valuable resource (Marmor & Morone 1980; Draper 1997; Consumer Focus Collaboration 2003).
- It is necessary to value the voluntary and community sectors. These are often a neglected resource for public involvement work. Public involvement can be taken out into the community, meeting people on their own ‘turf’. Ensuring equitable access for all groups requires strong community links (Anderson et al 2002).
- Consumers’ skills and experience should be valued. Professionals need greater awareness of the community’s ability to act to improve health (Department of Health & Department of Social Welfare 1989; Coulter 1999; King’s Fund 2001; Consumer Focus Collaboration 2003).
- Resourcing consumer organisations, consumer networks and peak consumer bodies enables consumers to participate. Consumer representatives need access to policy research and development from a consumer perspective (Ministry of Health 1995; Draper 1997; White 1999; Women’s Health Action Trust 1999; National Resource Centre for Consumer Participation in Health 2002; Consumers’ Health Forum of Australia 2002).
- Consumers have the final say on who represents them (Department of Health & Department of Social Welfare 1989; Ministry of Health 1995).
• Strong consumer leadership improves the quality and impact of consumer participation (Checkoway 1984).

• Providing consumers with expert knowledge can enable them to overcome information deficits and move to a higher level of decision-making control (Charles & DeMaio 1993).

• Both individual and collective organised consumer voices are needed. There should be communication between individual consumers, consumer representatives and consumer groups (National Resource Centre for Consumer Participation in Health 2002; Consumers’ Health Forum of Australia 2002).

• Consumer representatives put considerable personal time and effort into their roles and this contribution needs to be recognised. Consumer representatives find themselves working with health care providers who are being paid by their employers to work on the same committee or the same project. There should be at least reimbursement for out-of-pocket expenses, and meeting attendance fees. (Draper 1997; Women’s Health Action Trust 1999; King’s Fund 2002; Consumer Focus Collaboration 2003).

• Opportunities and means need to be provided for consumer representatives to work with other consumers and organisations to represent a broad consumer perspective (Draper 1997; Women’s Health Action Trust 1999).

• Especially with marginal groups, contacts may need to be built up over a long period of time (O’Keefe & Hogg 1999).

• Participation is not easy for consumers and they may need support, especially those consumers who have a health condition (Consumer Focus Collaboration 2003).

• Consumers from marginal and vulnerable groups may participate more readily through an organisation independent of the provider (O’Keefe & Hogg 1999; King’s Fund 2002).

Process enablers

• The most effective participation occurs in the context of ‘working relationships’, where there is a dialogue between providers and consumers, and a shift of power between them. Consumers prefer the model of partnership as the way to work. A ‘listening dialogue’ between consumer and hospital staff is better than the model where a ‘messenger moves between the parties’. Messengers can be given a hard time or disbelieved (Draper 1997, p 77). Direct dialogue is important because it engenders ownership of the process at all levels, which is essential to change. Anderson et al (2002) describe the central relationship as a ‘collaborating partnership’.

• Power sharing is necessary to make participation work. Developing trust is important because consumers and providers bring doubts and anxieties to the process (Draper 1997).

• Partnership should involve all the key players. Consumers should have real influence. (Commission for Health Improvement 2004).

• Flexibility and negotiation lie at the heart of public involvement (Anderson et al, 2002).

• A range of ways exist for participation. The structure should be appropriate for the task and the processes should be consistent with the aim (Harrison et al 2002; Consumer Focus Collaboration 2003; Florin & Dixon 2004).

• There should be a shared vision and agreed outcomes before the work is started. Detailed work plans with timelines and identified roles for participants should be developed at the beginning (King’s Fund 2001; Consumer Focus Collaboration 2003).
• Consumers need to be involved from the beginning of a process, not as an ‘add on’ (National Resource Centre for Consumer Participation in Health 2002).
• Protocols, such as mihi and karakia, provide a welcoming environment for Maori consumers (Ministry of Health 1995; Aotearoa Network of Psychiatric Survivors 1996).
• A chair who values everyone’s input, makes sure everyone has access to the same information, builds trust, and deals effectively with conflict is essential for committee processes (Ministry of Consumer Affairs 2003).
• A chair who values everyone’s input, makes sure everyone has access to the same information, builds trust, and deals effectively with conflict is essential for committee processes (Ministry of Consumer Affairs 2003).
• Consumer councils should sit close to corporate decision-making bodies. Too often participation project groups sit at the periphery of corporate decision-making and people involved may be unsupported and marginalised (Commission for Health Improvement 2004).
• High level consumer councils and advisory committees can be effective but only where other participation processes are in place at service planning and delivery level and there are processes in place to consult with consumers (Draper 1997).
• Participation is a continuous process not a one-off event (Draper 1997).
• An iterative relationship between learning and action is needed (King’s Fund 2001).
• Investing time is essential (Consumer Focus Collaboration 2003).
• Participation should occur within a broad social health framework for the health system (Consumers’ Health Forum of Australia 2002).
• The delivery of benefits is important so that participants can see what they are getting for their effort. These benefits may be better services, and also opportunities to ask questions, learn from each other and express a sense of connectedness (O’Keefe & Hogg 1999).
• Getting some runs on the board can be achieved by identifying areas where there is common ground and where problem solving can produce solutions (Draper 1997; Consumer Focus Collaboration 2003).
• The balance of power needs to be continually monitored (Consumer Focus Collaboration 2003).
• There needs to be commitment to doing something with the results and to report back (Draper 1997; Kelson 2001a; Consumer Focus Collaboration 2003).
• The role of particular consumer and provider ‘champions’ as catalysts in the process is critical (Draper 1997; Consumer Focus Collaboration 2003).
• Training and orientation for some of the participants may be needed (Consumers’ Health Forum of Australia September 2002; Consumer Focus Collaboration 2003). Training is discussed in greater depth in the ‘training for consumers and providers’ section on see section 1.6, page 77.
• In partnerships, the representativeness and accountability of the partners is essential (Federation of Women’s Health Councils of Aotearoa/New Zealand 1992; Consumer Focus Collaboration 2003).
Organisational enablers

- A consumer focus needs to be present in organisations’ policies, for example, vision statements (Draper 1997). There should be a rationale and business plan for involvement, with participation built into policy and planning formulation from the start (Commission for Health Improvement 2004).

- Organisations must invest in follow-through to bring about organisational change. Public participation must be systematically linked to internal learning and processes of change. This needs ‘double-loop learning’ to open up organisations to radical change (Anderson et al 2002). The organisation needs to have a culture that values consumer participation and gets and uses consumer feedback (Draper 1997). Participation needs to enter the ‘corporate bloodstream’: it should be integrated with other efforts to improve services and be central to core activities. It should be part of everyday good practice (Commission for Health Improvement 2004).

- Commitment at the top among senior management staff is necessary as well as involvement of staff right across the organisation. Senior management must not only believe involvement is the right thing to do, but see how it can contribute to improving services (Marmor & Morone 1980; Draper 1997; Kelson 2001a; Anderson et al 2002).

- Organisations must tackle real (and imagined) concerns amongst health professionals and staff about the consequences of participation. They should demonstrate the benefits, celebrate success, share good local practice, and create new ‘champions’. Health professionals need clear roles and responsibilities (Commission for Health Improvement 2004).

- There are significant implications for staff recruitment, development and training to develop organisational capacity (King’s Fund 2001).

- Staff that have responsibility for participation need appropriate expertise as a change agent and finder of resources. They should be at a senior level, at the third tier of management at least. The champions of participation within organisations need resourcing and support to prevent them being isolated and over-whelmed (Commission for Health Improvement 2004). Managing consumer participation is a skilled job and those skills need to be present (Draper 1997) Support staff should be under consumer control – selected and accountable to them (Marmor & Morone 1980).

- A dedicated budget is needed (Kelson 2001a).

- Infrastructure for participation should be provided, including office space, equipment and project officers. This applies to the provision of infrastructure for the health institution and the consumer organisations (Consumer Focus Collaboration 2003).

Barriers

Many of the barriers to participation are the mirror image of the enablers. As with enablers, there is a great deal of consistency in what are considered to be barriers.

Government policy

- Lack of high-level leadership, including a lack of commitment within government policy, and a lack of continuity in policy direction, impedes the development of participation. The tendency for government to restructure and to regionalise the health sector is a barrier (National Resource Centre for Consumer Participation in Health 1999).
• Another barrier is government officers who lack skills and knowledge about participation [National Resource Centre for Consumer Participation in Health 1999].
• Poor development of ongoing relationship between government and consumer groups obstructs participation [National Resource Centre for Consumer Participation in Health 1999].

Consumer sector
• Lack of skills, resources and confidence to access information and decision-making are a barrier, as is the technical complexity of many issues. (Ministry of Health 1995; Aotearoa Network of Psychiatric Survivors 1996; Bowl 1996; Bastian 1999; Thompson et al 2002; Consumers’ Health Forum of Australia 2002; Commission for Health Improvement 2004).
• Lack of support and advice, peer review and mentoring adds to a feeling of being isolated (Ministry of Consumer Affairs 2003).
• Anger and frustration within the consumer sector is often based on experiences of previous involvement which has not resulted in action (National Resource Centre for Consumer Participation in Health 1999; King’s Fund 2001).
• Lack of funding means consumers have difficulties networking to strengthen voices and inform others about debates in the health system. Without funding, consumer organisations have difficulty providing training and support for consumers acting as representatives (National Resource Centre for Consumer Participation in Health 1999; Consumers’ Health Forum of Australia 2002; Ministry of Consumer Affairs 2003).
• Users can feel they are not respected, that they are patronised and as if they are there as token representatives of the public. They can feel that they are used as a legitimisation exercise and that the results of participation are not used to influence services. Therefore it is pointless and a waste of resources (King’s Fund 2002).
• Some organisations which claim to represent consumers do not network with others but can act as gatekeepers to participation (National Resource Centre for Consumer Participation in Health 1999).
• A range of practical issues can impede consumers, such as timing of meetings, lack of childcare, lack of or delayed reimbursement of costs and no meeting fees (Aotearoa Network of Psychiatric Survivors 1996; National Resource Centre for Consumer Participation in Health 1999; Bastian 1999; Women’s Health Action Trust 1999; Consumers’ Health Forum of Australia 2002; Ministry of Consumer Affairs 2003).
• Representatives with a chronic or long-term illness which impacts on travelling to meetings can find participation exhausting, but find it difficult to ask for extra help, such as an additional night’s accommodation (Bastian 1999; Consumers’ Health Forum of Australia 2002).
• The stigma of some illnesses or the severity of illness can discourage consumers from participating (National Resource Centre for Consumer Participation in Health 1999; Linhorst et al 2001).

Process barriers
• There is a lack of clarity and little consensus about the purpose of participation (Milewa et al 1998; Carr 2001; Gillespie et al 2002).
• Government agencies wanting to involve consumers find it difficult accessing suitable people (Ministry of Consumer Affairs 2003).
Consumers are more likely to be involved in occasional working parties and sub-committees, but excluded from decisive decision-making roles (Bowl 1996).

Health professionals have the view that participation is about seeking information from consumers rather than a partnership approach to decision-making (National Resource Centre for Consumer Participation in Health 1999).

Being a lone voice on committees is difficult, especially if the matters under discussion are confidential. This is compounded if representatives do not get opportunities to meet with other consumer representatives. Confidentiality can impede consultation with outside groups (Consumers’ Health Forum of Australia 2002; Ministry of Consumer Affairs 2003).

Intimidation, being ganged up on, being treated as an outcast, not being taken seriously, being trivialised, and professionals not recognising that consumers have a valid point of views make contributing difficult for consumers (Ministry of Consumer Affairs 2003).

Consumers are usually a minority on committees and ‘elites’ (whites, men, managers and professionals) tend to dominate, making it difficult for more marginal groups to have a voice (Pinto & Fiester 1979; Cibulka 1981).

Conflicts between health professional groups are difficult for consumers, especially if the chair does not deal with it (Ministry of Consumer Affairs 2003).

Consumers have been used to lobby on professional issues. While these interests can converge with those of consumers, consumers sometimes feel that staff are only interested if the issue is relevant to them (National Resource Centre for Consumer Participation in Health 1999).

- Reporting lines between committees that include consumers and management structures must be clear to prevent users being disempowered by confusion and disappointment at not being able to effect changes (Bowl 1996).

Consumers do not generally organise themselves around health care sectors, which are arbitrary constructs created by governments to meet their own needs (National Resource Centre for Consumer Participation in Health 2002).

Organisational barriers

- Lack of a strategic approach to working with communities impedes participation eg concerning organisational ethos and culture, organisational skills and competencies (Commission for Health Improvement 2004).

- Many organisations are running before they can walk; plans are sometimes not rooted in reality nor linked to operational priorities (Commission for Health Improvement 2004).

- Initiatives are not built on, shared across the organisation, or linked with other improvement initiatives such as clinical audit (Commission for Health Improvement 2004).

- The attitudes and behaviours of managers and health care practitioners were the most commonly mentioned barrier in research of consumer involvement in PCTs (Harrison et al 2002).

- Staff of health agencies often have a limited and overly simplistic view of communities (King’s Fund 2001).

- Racism, paternalism and resistance to power redistribution are barriers (Arnstein 1969; Department of Health & Department of Social Welfare 1989).
• Professionals sometimes feel they are best placed to articulate the views of vulnerable consumers [mental health consumers]. Others see participation as ‘therapeutic’, as part of social rehabilitation (Pinto & Fiester 1979; Bowl 1996).

• ‘Role strain’ as consumers and providers shift from a traditional carer/client relationships to one of equals (Ministry of Health 1995).

• Some professionals fear the consequences of participation: that it will increase consumer expectations, professionalism will be undermined; litigation will increase (National Resource Centre for Consumer Participation in Health 1999).

• Professionals have less belief that participation will improve [mental health] services than consumers (Kent & Read 1998).

• Public involvement is sometimes seen by staff as what ‘other people’ do, for example, nurses but not doctors (Commission for Health Improvement 2004).

• Public service staff are already over-loaded with work and feel under siege (King’s Fund 2001).

• Public involvement in health is chronically under-funded. Funding tends to support projects, but not the development of the infrastructure to support participation. This results in an emphasis on front-end activities, rather than evaluation of results. If health funding is reduced, consumer participation is the first to go (National Resource Centre for Consumer Participation in Health 1999; Anderson et al 2002).

**Barriers for groups from diverse backgrounds**

The National Resource Centre for Consumer Participation in Health (2000) reviewed the literature on participation by groups that were identified by the Centre’s Needs Assessment (National Resource Centre for Consumer Participation in Health 1999) as under-represented in participation activities. These are consumers who are:

• from a range of cultural and linguistic backgrounds
• of Aboriginal and Torres Strait Islander descent
• living with chronic health conditions
• living with a mental illness
• living with a disability
• living in rural and remote areas
• living in poverty
• socially isolated
• young
• older
• of low literacy.

The review was focussed on feedback from consumers which is not central to this review, but as there is no other comprehensive review of participation by consumers from such groups, its conclusions are worth noting here. In fact, many of the findings are consistent with the barriers and enablers identified for mainstream participation. The review found that there were many barriers to participation and that these barriers were common across the groups, rather than being specific to particular types of consumers. These structural barriers to participation were strongly linked to barriers to accessing services. While there have been a great number of projects looking at participation by marginalised groups, there was little evidence that this impacted on broader service delivery. This
lack of impact on service systems and cultures has already been pinpointed as a difficulty with participation involving non-marginalised groups. The key question, this review concludes, is not so much how to seek feedback, but how to ensure it is used to create health care systems that are appropriate and sensitive to the diversity of the communities to whom they seek to provide care.

Many of the barriers in the way of participation by marginalised groups are common to all consumer groups. These will not be repeated here. But there are specific structural barriers for marginalised consumers from diverse backgrounds, including the following:

- Many mainstream organisations do not have systematic and appropriate strategies for including diverse groups.
- Services locate the reason for marginalisation with the consumers, rather than the organisation’s structures and practices.
- Service provider attitudes involving traditional assumptions and stereotypes of particular groups are a key barrier.
- The models of care in services disempower consumers through treating them as dependent, focusing on their disabilities rather than their abilities, failing to respect their rights, and failing to communicate.
- There is a reliance on group specific services which minimises the impact on mainstream services, for example, the existence of ‘Positive women’ groups was used as a reason not to address their needs in mainstream services.
- Work with consumers from marginalised groups is usually a one-off, ad hoc, add-on when funds are available, rather than being part of mainstream practices.

1.7 CONSUMERS: REPRESENTATIVENESS, ACCOUNTABILITY AND EFFECTIVENESS

There are widely varying practices and viewpoints in different countries to the questions of how consumers become involved in participation processes, which consumers are to be involved and what their roles and responsibilities are.

Representativeness
The question of the representativeness of consumers is often raised by health professionals, administrators and policy analysts, both about non-aligned consumers brought into participation processes and representatives of consumer organisations (Bastian 1994; Bowl 1996; Bastian 1998; Jewkes & Murcott 1998; Harrison & Mort 2000; Harrison et al 2002; Cawston & Barbour 2003). Consumers find questions about their representativeness undermining especially as such questions are seldom asked of health professionals (Bowl 1996; Duff et al 1996).

Doctors in particular raise concerns about whether consumers participating in health planning and policy are representative of patients in general (Williamson 1998; Cawston & Barbour 2003). The more experienced and knowledgeable the consumer representatives become, they more they face challenges that they no longer can speak for ‘ordinary’ consumers. Claims are also made that consumer representatives will narrowly focus on their constituencies to the detriment of consumers that are not part of this constituency. Bastian (1998) sees the issue of representativeness as one of control; people in the system raise it to justify their monopoly on choosing representatives.
The issue of representativeness is particularly raised within the citizenship framework adopted in the UK, but it has also been raised within New Zealand. In Australia, the practice of using consumer representatives is well established with the Consumers’ Health Forum of Australia acknowledged by the Commonwealth Government as the legitimate contact point when consumers are sought to act on various national advisory structures (Short 1997).

New Zealand has veered between accepting consumer representatives and consciously opting for non-aligned consumers. This latter concept has much in common with the concept of the ‘lay person’ that was commonplace before the late 1980s, and is still the model used for New Zealand ethics committees. The Ministry of Consumer Affairs nomination system also operates on a non-aligned consumer model. Another trend has been health agencies directly inviting selected individuals for consultation. Even though these individuals are part of groups, because the group is not part of the process, ‘the group itself does not feel represented’ (Aotearoa Network of Psychiatric Survivors 1996 p 6).

White (1999) calls the issue of representativeness a ‘fault line’ in the notion of participation: ‘Lay participants are seen by some to represent some amorphous, undifferentiated “public” or aggregation of individuals, and by others to represent a collectivity, community, or constituency of lay interests’ (p 470).

According to Marmor and Morone (1980), the notion of being able to represent all opinions, interests or social demographics is chimerical:

‘Socially descriptive representation is pernicious because it removes the necessity of recourse to the constituency. The need for formal selection mechanisms and accountability is obviated. Skin color or income, for example, marks a representative as acceptable or not acceptable, regardless of what the constituency thinks. The result is that any member of the group is as qualified a representative as any other. This is a situation that almost begs for “tokenism”’ (p 140).

Harrison and Mort (2000) ascribe the trend to choose representatives according to their demographic or personal characteristics more than their capacity to represent the public as a legacy of the 1990s market approach to health. Governing bodies came to be more and more modelled on boards of directors of commercial organisations, with governance emphasised over representation.

If participation processes are about sharing power and partnership, then it is difficult to see how a sole consumer representative could achieve such equity of influence. The Consumers’ Health Forum of Australia says that while many more committees include consumers than a decade ago, the consumer representative is often alone amongst many health professionals: ‘Hence some representatives feel isolated and limited in the ability to influence committee outcomes’ (Consumers’ Health Forum of Australia 2002, p 13). Both Kelson (2001a) and Duff et al (1996) point to the unfairness of expecting one patient to represent the views of the whole patient population and to be the only participant in a group who is not a health professional. They recommend that in guidelines development, two or three consumers should be included in a group, and that both individual consumers and consumer organisations can be involved. Kelson says that any groups that include consumers should be clear as to whether the consumer is there to provide a personal perspective or to draw on the views of a larger patient network (Kelson 2001a).

The Federation of Women’s Health Councils of Aotearoa/New Zealand (1992) argues that there should be equal consumer and professional members in all groups. A guide to effective participation in mental health services issued by the Ministry of Health (1995) recommended that to avoid
tokenism, 25-50% of committee members should be consumers. This was strongly supported by mental health consumer organisations (Aotearoa Network of Psychiatric Survivors 1996). A guideline for participation developed by the Women’s Health Action Trust (2000) suggests that there are a number of categories of consumers to consider involving: patients/users of health or disability services; caregivers and family/whanau; representatives of organised groups and the public at large.

Studies of the composition of consumers participating in health sector structures commonly reveal that they are likely to be educated and middle class (Jewkes & Murcott 1998). Dwyer (1989) says that it is important not to replicate existing social hierarchies in participation processes. This is another reason to have a number of consumer representatives so that a range of constituencies can be represented.

How people are identified for participation processes (Bowl 1996), accountability and effectiveness are the three central issues that have been identified when addressing the question of representation (White 1999).

Identification of participants

A nominations process where the health agency decides, elections, personal invitations and asking a consumer organisation to send a representative are all methods that are used. Elections are often difficult to organise because the constituency is usually not conveniently identifiable. Where these have been held voter turn out is often low. (Latting 1985). Recent UK experience with Foundation Trusts, where constituents of the service vote for board members, resulted in a very low voter turn-out (Klein 2004).

The nominations and personal invitations processes raise questions of institutional control, accountability and, sometimes, the capability of representatives (Marmor & Morone 1980).

White (1999) and Marmor and Morone (1980) argue in favour of inviting representatives of organised consumer groups to address the power imbalance in health markets between lay actors and organised professional groups. Most people are only intermittently concerned about health; they lack sustained interest. Unless an individual or group has a particular interest, such as a neighbourhood hospital closing, they will be far less intensely interested than well-organised interests whose professional status, working conditions and livelihood depend on the health system. Professionals and managers can count on the resources of their associations or organisations for support, whereas unaligned individuals lack resources and support. Their influence is further neutralised if they must rely on insiders for pertinent information and cues as to issues. White says this explains the preference of administrators for non-aligned people:

‘there is a clear reluctance to bring in outsiders representing concentrated, organized, well-articulated interests, and who have access to outside resources to support them…This is why it is a common strategy for insiders to handpick or coopt known lay actors (typically, concerned citizens with some experience in the health field) as opposed to requesting outside groups with particular interests to delegate representatives’ (p472).

Marmor and Morone (1980) favour selection by the groups themselves, saying that the experience of the community action programmes in the USA showed that this method produced the most able, universally oriented, and least co-optable representatives and the most independent and competent boards.
In Australia the peak consumer organisation the Consumers’ Health Forum of Australia runs a recognised nomination process and selects a suitable person. A similar process is sometimes used in the UK involving the Long-term Term Medical Alliance, and, in Canada, the Canadian Women’s Health Network. These are described later in this report. In the USA, there is a Food and Drug Administration Nominating Group to select consumer representatives for advisory groups.

**Accountability**

Accountability back to consumers or the wider public is at the heart of representativeness. Non-aligned consumers have particular problems in knowing what the issues are for the consumers they are expected to represent and in reporting back to them. Even when representatives expect to be accountable back to the ‘community’, this can still pose difficulties as there are often no existing mechanisms for reaching a wide constituency. It is commonplace for few mechanisms to exist to report back processes and decisions to consumer organisations or the community.

A study of community committees in ‘Health for All’ projects found that many representatives did not report back to the voluntary organisations from whence they came let alone the wider community (Jewkes & Murcott 1998). However, in the cases of community councils in the UK, Pickard (1998) says that ‘they have very consistently tapped into the views of the wider community’ (p 242). In a study of community mental health services in the UK Bowl (1996) found that few user committees in mental health services had minutes and few efforts were made to inform the wider group of decisions or how they could raise issues. There was also little cross-communication between consumers on groups. He recommends that service users on committees need not only to be clear about who they represent but be given the opportunities and resources necessary to develop a dialogue with that constituency.

In this respect the model of the Consumer Representative Program of the Consumers’ Health Forum of Australia provides a means of overcoming the problem of accountability. Consumer representatives have a contract with the Consumers’ Health Forum and this includes formal reporting back at regular intervals. A review of the programme found that representatives were very aware of the need for accountability and valued it (Chakley Consulting with Artcraft Research 2002). Another strategy recommended by the Consumers’ Health Forum is for consumer representatives to focus on how the committee will gather consumers’ views, rather than providing immediate consumer comment. That way consumers can be accountable to other consumers and educate and influence the committee and individual members in their ongoing approach to consumers (Consumers’ Health Forum of Australia 2002).

Latting’s (1985) study of boards of neighbourhood health centres in the USA found that consumers on boards were more likely to be influential if they were formally sponsored by organised consumer groups, regularly attended meetings of their constituency and if they were identified by other board members as having organised group backing. Latting believes that only affiliated consumers should serve on boards, because they are more representative, they have already shown community leadership, and it enhances accountability. Furthermore, this study showed that because of ‘their sense of missionary commitment’ consumer representatives emphasised decision-making by consensus and ‘working things out’ rather than conflict and competitiveness.

In a study of community service centres in Quebec, Godbout (1981) found that if consumers on boards were not ‘well-integrated into the neighbourhood, their capacity for mobilizing neighbourhood elements on their own account is weakened, and this increases their drift towards assimilation into the staff vision of the CLSC’ (p 158).
The issue of accountability becomes acute when serious questions are being considered, such as prioritisation/rationing, funding, and service closure. Citizens’ juries are commonly asked to deliberate on rationing issues, but Pickard (1998) believes they are a particularly flawed model when it comes to accountability because they are:

‘one-off organizations which are disbanded as soon as the four days are over and cannot, therefore, engage in anything approaching an ongoing dialogue with the Health Authority, which appointed them, or with the community from whence the jurors were plucked. By contrast, their permanent remit means that [Community Health Councils] can inevitably be called to account, both to local communities and to the rest of the health service….There is a burden of accountability on the public themselves in their special capacity as a jury, to the wider public on non-jurors — yet the jurors didn’t feel sufficiently involved even to attend the Health Authority public meeting which was convened to discuss the findings of the jury together with plans to consider and eventually implement findings’ (p 241).

Effectiveness

There is evidence that using consumer representatives provides more effective participation than using non-aligned consumers. Van Wersch and Eccles (2000) compared the inclusion of various types of consumers on guideline development groups. They found that individual patients, and groups of patients at a one-off meeting participated very little and had difficulty with the technical language. Workshops with patients had more success. These involved training in the technical aspects, but as with earlier method, participants had most comfort with aspects related to consumer education. The final method involved a representative of a major national patient group. This consumer had experience of previous groups, she was used to having discussions with health professionals and was familiar with medical terminology. She felt confident to speak within the group.

A national seminar in the UK on consumer involvement in guideline development provided these benefits for using groups:

‘They have the advantage of working alongside patients who have particular interests or who live with various health conditions. It was felt, therefore, by seminar participants that patient representative groups may have gained an understanding of the experiences and specific needs of patients as a population. The involvement of patient representative organisations may also offer a means to support patients who agree to participate in developing clinical guidelines through their networking activities’ (Duff et al 1996, p 109).

There was similar support from a national workshop in the UK focused on patient and public involvement (King’s Fund 2002). It was felt that instead of establishing new structures [as proposed by the UK government] existing bodies should be built on and developed:

‘It was felt that user-controlled organisations provided a safe space for users to come together, support each other and influence local services. Participants commented that people often felt confident within their own user group but did not feel able to contribute to structures with which they were not familiar. Service user organisations were also able to tap into individuals who were very vulnerable, such as refugees and asylum seekers, who might be frightened of criticising local services’ (p 4).

This workshop also supported national consumer networks that coordinated local groups and played a crucial role in influencing national policy.
Williamson (1999) says that consumer groups’ expertise ‘lies in their detailed knowledge of issues that are of concern to particular groups – as in maternity care’ (p721). Sylvan and Legge (1988) describes how the model of the Consumers’ Health Forum of Australia as a national umbrella organisation allows consumer experiences to be communicated from grassroots to the national health policy level.

White (1999) says the evidence shows that representatives of groups provide the best level of accountability and effectiveness:

‘Collective representation with accountability to an outside constituency, such as an advocacy group or patients’ association is shown to enhance not only democratic process but also the efficacy of lay participation’ (p 470).

Marmor and Morone (1980) say that another advantage of using organised groups is their staying power: ‘Such groups can be expected to pursue the policy through its implementation and administration’ (p129):

‘The very existence of these groups attests to a commitment to improve the life circumstances of some part of their population. Furthermore, they have already paid the cost of organising. We can expect their attention to issues to be high and relatively sustained’ (p 144).

Using the example of the Consumers’ Health Forum of Australia, Dwyer (1989) stresses the benefits of a peak umbrella group for a variety of health consumer groups as it provides ‘a resource base for coordinated policy debate and influence’ and ‘a real challenge to professional hegemony’ (p 61).

1.8 TRAINING FOR CONSUMERS AND PROVIDERS

Lack of training for consumers is commonly identified as a barrier to effective participation, although it has not been subjected to very much research. There is an imbalance in scientific knowledge between health professionals and consumers. The need for training of consumers is commonly seen as the strategy for overcoming this deficit, although White (1999) warns that if training is provided within the system, ‘it is likely to ‘reinforce insider control over the agenda, the flow of information, the deliberation process, and the legitimacy of various opinions and orientations’ (p 472).

Training for providers

The need for training and education of providers and others ‘in the system’ is less well recognised, even though professional/administrator scepticism and attitudes are often identified as a barrier. Some writers have pointed out that this double-standard – only consumers need to be trained to ‘fit in’ – intrinsically illustrates a power imbalance in the participation paradigm. They have suggested that the processes may need to change instead, or, if training is needed, it is ideally provided by consumer organisations (Consumer Focus Collaboration 2003).

The Consumer Focus Collaboration study (2000a) found virtually no studies and no examples of attempts to train health professionals and administrators except for some courses aimed at the individual doctor/patient relationship. Sometimes these appeared to have a wider influence on the culture of the organisation.

Occasionally the need for professional training on consumer participation is recognised. After carrying out over 300 inspections (clinical governance reviews) of NHS services, one of the main recommendations of the UK Commission for Health Improvement was that ‘training and development
needs to be part of enhanced education and training for clinicians and needs to become part of continuous professional development of many staff' (Commission for Health Improvement 2004, p 18). In a national survey of HSAs in the USA, Checkoway et al (1984) found that training for staff in methods of effectively involving the public, along with commitment, was more important than putting more resources into participation.

**Consumer training**

The problem of consumers being over-whelmed or unprepared principally arises when consumers are not part of a consumer group, or the area is particularly technical, for example, research or guideline development. Although seldom identified, the use of consumer representatives (see the ‘Barriers and enablers’ section, see section 1.6, page 43) would go a long way to overcoming this problem. Membership of a consumer group would ensure that the person had experience and access to a source of expertise to have recourse to when needed. The report by Thompson et al (2002) found that consumers from organisations were far more knowledgeable and confident than non-aligned consumers.

Some agencies have tried to provide consumer training, either through a consumer organisation as occurs in Australia through the Consumers’ Health Forum of Australia and the National Breast Cancer Coalition, or through the agency seeking consumer involvement which is the practice adopted by the National Cancer Institute in the USA. In New Zealand, there is very little training, although it has occurred sporadically through the New Zealand Guidelines Group, the Ministry of Consumer Affairs and the National Heart Foundation. Breast cancer organisations are hoping to set up a programme for consumers like the Australian one and are looking for funding. Breast cancer advocacy is the area where most attempts have been made to systematically prepare consumers for participation roles. It is worth observing that breast cancer survivors are a well organised and vocal group internationally, and that they also provide a model of success in establishing close working relationships with health professionals in the area (Liberati 1997).

There are very few studies that look at whether and how training of consumers makes a difference. Davis et al (2001) set up a study to look at the effectiveness of an advocacy training programme and specifically whether the skills of consumer advocacy can be learned and effectively applied after a short course. The programme was based on Project LEAD (Leadership, Education and Advocacy Development) developed in the USA.

Not all the participants in the advocacy training course had had breast cancer (84.3% were survivors). Interestingly most participants were either health professionals (33.3%) or other professionals (37.3%). The study found that participants significantly increased their involvement in advocacy activities as board or committee members, involvement in recruitment for clinical trials and development of patient information, but there was no difference in development of research protocols or design, serving on research review or ethics committees, serving on government advisory committees or various other key advocacy/lobbying activities. No information was obtained about the effectiveness of consumers in bringing about change or having their voices heard around the decision-making table.

Possible reasons for the lack of impact in key advocacy areas could be the inclusion of health professionals among the trainees, and that there was no requirement for participants to be members of existing advocacy groups and that there was no ongoing support for the participants. Many of the participants had no previous experience of activism or involvement with an advocacy group.

The Consumer Focus Collaboration study (2000a) found that a ‘whole of organisation approach to produce sustainable change’ (p 21) is needed to address the systemic issue of organisation attitudes
and culture that impede participation. ‘Mutual learning’ needs to be core business, not an optional extra. The resultant health service will be radically different to mainstream services.

The study identified priorities for future action. These included:

- **Sustainable resourcing** – to document projects and models; evaluate the effectiveness of different projects and models; develop more learning materials and processes; to provide financial support for consumers to participate in these activities; to regularly update the resource guide.

- **Scarcity of education and training for particular groups** – these were health care administrators, consumers and providers from non-English speaking backgrounds and other cultures; rural and remote consumers and providers.

- **Building education and training into participation processes** – learning needs to be built into the planning, service delivery, and evaluation processes. Learning is required for all participants.

- **Cultural change** – one option was to work with organisations also seeking cultural change in healthcare, for example, quality and healthcare standards.

- **Information dissemination** – existing resources were often not being used by providers and web-based indexes and reference sites could help with this, also a national resource centre.

Much of the learning that has been documented through the Australian Consumer Focus Collaboration could provide a basis for such work in New Zealand.

### 1.9 SUMMARY

The literature search resulted in a large number of papers. Most were individual case studies, but there were a small number of systematic reviews and other compilations of evaluations and audits. There is no established methodology for such research and most is focused on process issues as opposed to outcomes. The literature is most advanced for consumer involvement in making decisions about their own health care which was outside the parameters of this report. There is less evidence about consumer involvement in setting policy or planning at a national level. Most of the papers had been written by social scientists and other academics resulting in a literature that is focused on their research questions rather than the priorities of consumers. The search methods that were used found few papers that were written by consumers.

The current international focus on consumer participation has emerged from a background of the social activism of the 1970s and 1980s, and the community development primary health care model that was promoted by the WHO in the 1970s and 1980s. It has been mediated by the market approach to health care that emphasised consumer choice but was damaging to organised collective consumer interests. More recently, concerns about social cohesion and democratic participation have been influential, leading to experimentation with new forms of participation. Inquiries into medical failures have led to calls for more transparency and accountability, and the evidence and quality ‘movements’ have also promoted consumer participation.

‘Voice’ and ‘participation’ can be exercised autonomously through social activism and membership of consumer organisations as well as through engagement with formal structures. Participation inside the health sector can be tokenistic with power imbalances between those within the system and members of the public from outside. The more power is shared, or transferred to consumers, the greater the degree of partnership or citizen control.
Consumer advocates often choose to work outside the system so that they can set and advance their own agendas. Historically many campaigns that have benefited consumers have been conducted outside formal government structures, or at least have started there. Women, psychiatric survivors, people with disabilities, gay men, lesbians and people with HIV/AIDS have all conducted independent campaigns that have both brought about significant change and strongly influenced public attitudes to the various constituencies. Modelling alternative structures or practices is another way that consumers can exercise influence. Overall, this report did not access a great deal of information documenting experiences of working on independent consumer advocacy, mostly because of the search methods used.

Current arguments in favour of participation can be grouped into three broad categories. The first, redistribution of power and resources and intrinsic benefit, sees participation as a citizenship right, a way of overcoming perceived deficiencies in democracy, a means of ensuring greater accountability of those within the system, and as an intrinsic benefit.

The second, legitimation and compliance, argues that people who have been involved are less likely to complain about decisions. Consumers can be expediently used to shore up the positions of those in the system against other powerful groups.

The driving force for consumers is primarily the third category of rationale, better decisions or service/policy improvements. This argues that health services will be more effective if decisions are made by the people affected by them. Participation brings community knowledge and preferences into the decision-making process.

In some countries, a great deal of effort is going into attempting to engage the public at large in decision-making but there is a dearth of evidence that the public wants this. Studies show that the public supports the concept, but is most interested in methods that require low levels of commitment and are at the low end of participation. Some members of the public question whether consumers have the information needed to be involved or they see institutions as too immovable to tackle.

On the other hand, members of established consumer groups are highly motivated and they believe that more can be achieved by acting collectively. These consumer groups are seen by the public as a means of channelling the public’s views.

The considerable literature on participation has demonstrated some benefits, although tangible outcomes can be quite small, such as extended opening times of services. A systematic review found that few studies have shown improvements in quality of care and none have shown improvement in quality of life, but there can be specific effects. A number of studies involving mental health consumers have shown that self-esteem is improved, and where former patients are used as employees, clients had some improvement in quality of life and fewer and shorter hospital admissions. An improvement in health professional attitudes to consumers is reported in some studies and others raise the possibility that ongoing relationships between consumers and providers could deliver long-term benefits.

A series of comprehensive audits in the UK found that it was hard for participation activities to have an impact on the culture of the organisation. Most activities stayed at the margins of decision-making and failed to bring about change.

Some writers point out that a long timeframe is needed to discern change which involves the community, but that transformative change can be achieved when governments and communities act in concert.

The fundamental issue underlying participation is whether it effects a redistribution of power. There is little evidence so far that it does. Currently administrators and others organising participation
activities usually set the agenda, choose the participations and retain the ability to determine whether anything happens as a result. Cooption is a real and present danger when ‘insiders’ retain so much control. This has led to some questioning as to whether consumers should invest so much effort in participation. Experience from Australia, UK and the US has suggested that as participation occurs with individuals, there has been a loss of collective advocacy and the organised voice of consumers has been depoliticised. Consumers need to retain their ability to act as an outside critic while acting within the system.

A large part of the research on participation is focused on enablers and barriers of participation and there is a great deal of consensus about these. The key enablers are:

- government direction, policy, support and funding for participation
- government, consumer and provider ‘champions’ to act as catalysts for change
- strengthening the consumer sector and valuing consumers’ contribution
- power-sharing and partnership between providers and consumers, involving consumers from the beginning of the process, a shared vision and agreed outcomes, an iterative process, and a commitment to do something with the results.
- an organisational culture that values participation, commitment among top management and involvement of staff across the organisation, addressing the concerns of staff and health professionals, and the allocation of expertise and budget.

Key barriers are:

- lack of government leadership and commitment
- consumers’ previous tokenistic experiences, leading to scepticism as to gains that can be made through participation
- attitudes and behaviours of health professionals and managers, resistance to sharing power.

Consumers involved in participation are often questioned about their representativeness. This is raised both about ‘non-aligned’ consumers and representatives of consumer organisations. Choosing individuals because of their demographic characteristics does not ensure representativeness. Similarly it is unfair to expect a single consumer to speak for the diversity of social groups.

A number of writers advocate inviting consumer groups to select representatives, thus ensuring that the most able people are involved, and that they have support and are accountable to the people they represent. There is evidence that consumers with a constituency are more effective and less cooptable. Because health sector interests such as health professional groups are well organised and have a large stake in the sector, representatives need the backing of sustained organised groups.

Training is often presented as a necessary prerequisite for effective participation. The need is usually identified for consumers, but not providers. This illustrates how consumers are expected to ‘fit into’ the system, rather than the health sector reorient itself towards a more consumer-focused approach. Some writers have warned that if training for consumers is provided by the system, it can lead to insider control. Training can be provided by consumer organisations but there is not a lot of evidence that this results in more effective representation. The answer to consumers’ lack of technical skills may lie in the kind of representation programme provided by the Consumers’ Health Forum of Australia, where consumers have the back-up of a consumer organisation. This can only occur if such organisations are resourced for this role.

In conclusion, while participation is complex, and so far has not delivered major benefits to consumers, it is worth pursuing as a strategy for achieving consumer-focused, quality health care. At the same time, consumer organisations should not abandon independent advocacy and they need to
guard against any undermining of their autonomy. 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.
Current Consumer Voice and Participation Activities in New Zealand

2.1 NEW ZEALAND BACKGROUND

The notion of consumer participation in the health sector is not a new one. Many of the building blocks of the New Zealand health system were initiated by the public, as elected stewards or as concerned citizens, in some cases in partnership with health professionals.

Consumers, as users of services and citizens, have been active participants in the wider health sector since the nineteenth century. The female suffragists challenged medical orthodoxy by decrying ‘vivisection’ (surgery) and promoting alternatives, such as hydrotherapy and electric therapy. Health was on the agenda of groups formed in the nineteenth century such as the Women’s Christian Temperance Movement, Young Men’s Christian Association and their female counterparts, and the National Council of Women.

In the early part of the twentieth century the formation of groups such as the Social Hygiene Society (1916) and Royal New Zealand Plunket Society (1907) was prompted by health professionals, but lay women made up the organising committees. These groups established health services that were not being provided by the public health sector and, in the latter case, remain the principle provider of well child services in New Zealand (Coney 1993a).

Consumer-led groups arrive

Towards the middle of the twentieth century, consumers and families started forming their own groups. The New Zealand Family Planning Association was founded in 1936 (as the Sex Hygiene and Birth Regulation Society) by a group of Wellington women who had themselves encountered unhelpful advice from doctors. IHC was started in 1951 by a small group of parents in Wellington, led by Harold and Margaret Anyon. Both these groups have developed into major service providers, in the case of Family Planning, with services now delivered by health professionals.

Parents Centres New Zealand began in 1952 as a ‘natural childbirth’ group promoting home birth and providing innovative antenatal classes. It encountered fierce resistance from the New Zealand branch of the British Medical Association and had to accept medical oversight to enable the classes to continue. Parents Centres ran successful advocacy campaigns to achieve reforms that are now common practice in public hospitals: rooming-in in maternity hospitals, an end to compulsory bed rest after births, the right for children to visit their mothers in maternity hospitals and for fathers to be present at births. Some leading members of Parents Centres ran for elected positions on hospitals boards to advance such issues (Coney 1993a).

The women’s movement of the 1970s and 1980s, in New Zealand and in other Western countries, provided the first major challenge to the medical paradigm (Charles & DeMaio 1993; Saltman 1994). The movement wanted nothing less that the complete reform of medical practice. There were calls for improved reproductive health care, especially access to safe contraception and abortion, choices in childbirth, greater medical accountability and more observance of patients’ rights (Donley 1986; Bunkle 1988). An example of this is the campaign for direct entry midwifery which was led by consumers. Essentially women sought more quality in health care, including improved safety, less medicalisation, more choices and a partnership approach to health care. In New Zealand, the
women’s movement platform was validated through the Cartwright Inquiry of 1987-88, which led to the creation of the position of Health and Disability Commissioner as a watchdog for patients, a nationwide network of independent advocates, regional rather than institutional ethics committees throughout New Zealand, and a national cervical screening programme to be planned and implemented in partnership with consumers (Committee of Inquiry 1988; Coney 1993b).

The mental health movement is another example of a group of consumers who have challenged the quality and content of mainstream services, as former patients or psychiatric survivors. More recently, communities concerned with HIV/AIDS have sought to have a voice in both the prevention of infection and services for positive people.

Maori have challenged both the Western model of medical care and the cultural context around healthcare delivery. They have sought to increase the capacity of Maori providers and for services to adopt a more holistic approach that includes spiritual, mental and emotional, family and community, and physical aspects (Pomare & de Boer 1988). The Maori Women’s Welfare League Rapuora study of the health of Maori women was one of the earliest examples of research which was led by and carried out by the community. The research first began in 1977 and the field work team was made up of League members who were trained for the task. This method ensured a 99% participation rate for this landmark study (Maori Women’s Welfare League 1984).

**Elected representation**

Elected positions on health boards are another means by which consumers have traditionally had a voice in the health sector, but the history of such representation in New Zealand is a chequered one. The Hospitals and Charitable Institutions Act 1885 provided for health boards of citizens, but these were mayors of boroughs and chairs of county councils with others chosen by them. The Hospitals and Charitable Institutions Act 1909 for the first time introduced elections, and this system of governance continued until elected boards were replaced by Crown Health Enterprise boards appointed by Government during the ‘health reforms’ of the 1990s. While elected hospital and Area Health Boards were traditionally dominated by doctors, a concerted campaign by women’s organisations over several decades led to significant changes in the make-up of boards. By 1989 53% of the elected members of Area Health Boards were women, up from 24% in 1968. Social prejudices against women holding public office did not fully apply to health boards which were seen as a legitimate territory for women’s involvement. While some of these successful female candidates were health professionals, elected boards were a means by which lay women in the community could have an influence over health policy and priorities, at least for Pakeha women. Few Maori were elected to boards (Drage 1993).

A corporate approach and health market was pursued in the 1990s and appointed business-oriented boards replaced elected boards. In another round of health sector restructuring, part-elected boards were reinstated by the Labour government in 2001, with the Minister of Health retaining the ability to appoint members to ensure a balance of competencies and adequate representation of Maori on boards.

**Advisory committees**

The practice of including prominent citizens on national and local health advisory committees is a long-standing one, but it was not until the 1980s that consumer representation on advisory committees became more common. Area Health Boards were required to establish community committees and include consumers in service development groups. In the same period, *The Report of the Cervical Cancer Inquiry* (1988) explicitly called for a more patient-centred health system and for consumer representation on committees that were set up. The report required representation of
women on the group establishing the National Cervical Screening Programme and the first standard for ethics committees specified that 50% of positions should be for lay people.

In the wake of the Cartwright Inquiry, consumer organisations initially found it easier to argue for a seat at the table, but the movement towards systematic representation slowed with the adoption of a market approach in the 1990s (Coney 1993b). With the reinstatement of elected members at local levels, emphasis on representation has declined at a national level. As well, there has been the adoption of new forms of representation, such as reference groups and consumer-only advisory groups that have less influence than national advisory committees. There has also been a move away from the concept of ‘representation’ with members of groups often explicitly deemed to be independent of any organisation.

The concept of consumer networks

The late 1980s were influenced by a number of events that led to the first proposal for a national consumer body. These were:

- the experience of the Cartwright Inquiry with its revelations of the extent of medical power and the vulnerability of consumers
- the move to Area Health Boards which had broader responsibilities for health than hospital boards and which were required to have Community Health Committees as standing committees
- the adoption of the World Health Organisation concept of Health for All by the Year 2000 which was underpinned by a community-development model and the belief that health is only achieved with the full participation of the people (WHO & UNICEF 1978).

This confluence of influences provided opportunities for the enhancement of the consumer sector. A number of actions were taken. The Policy and Communications section of the Department of Health commissioned a study to recommend practical ways in which the health system and its workforce could be more responsive to consumers, accountability mechanisms could be improved and consumers could be provided with more support, information and voice.

The ensuing report, Having a Say in Health, followed extensive consultation through the health sector and made a large number of recommendations for complaints systems/disciplinary procedures, partnership relationships, consumer information, community advocates, community committees, ethics committees and a national network for consumers (Nuthall 1988).

Having a Say in Health was issued the month before the release of The Report of the Cervical Cancer Inquiry. It foreshadowed many of the recommendations of that Inquiry, for example, for paid consumer health advocates, independent complaints mechanisms, reformed ethics committees, and a one-stop shop for consumer complaints. Other recommendations for quality assurance, consumer experience surveys and consumer information, were ahead of their time.

Two recommendations are relevant to this report. These were recommendations for community committees and for a national network of consumers. Community committees were to be based on a ward system within Area Health Board boundaries. They were to be made up primarily of lay people with limits on health professionals. Their roles would be to set priorities, provide a voice for local consumers, carry out annual audits of the Area Health Board, and work with primary care providers using a community development model. The committees were based on the Victoria District Health Councils and would have full-time facilitators. In many ways, this model is similar to that currently being pursued in the UK and has some elements of the model being promoted through the New Zealand Primary Health Care Strategy.
The national network of consumers was recommended to address the lack of any national consumer body to respond to issues and provide an independent voice on legislation that would affect consumers, much the same situation that is being addressed in this report. The plan was for the Public Health Association to coordinate the network. It was not intended that the network have an exclusively consumer membership, but that it be an amalgam of consumers, health care providers, researchers and planners. This was the reason for the choice of the PHA as the coordinating body (Nuthall 1988).

*Having a Say in Health* was sent to all hospitals and Area Health Boards as well as others, asking for feedback on the proposals. The Department of Health said it wished to have wide feedback ‘to assist it in its policy development in this area’ (Gibson 1988). To some extent, the recommendations of the report were overtaken by those of *The Report of the Cervical Cancer Inquiry* (1988), but it was not within the brief of the latter report to make recommendations regarding a national consumer body.

A number of attempts were made to inaugurate some sort of national network or organisation. In 1989 Louise Sylvan, then chair of the Australian Consumer Health Forum, was brought to New Zealand by the Department of Health to inform New Zealanders of the work of the Consumer’ Health Forum of Australia and to discuss a similar proposal for New Zealand. Meetings were held in Wellington and Auckland and support for such a unified, representative umbrella organisation was gained. A formal proposal was put to the Director-General of Health asking for funding to establish a national body. However, this was rejected, and, without that critical support, the concept of a national network for consumers lapsed.

A parallel process was occurring concurrently in the mental health area. The Cabinet Social Equity Committee, at the request of the Ministers of Health and Social Welfare, established a National Mental Health Consortium to advise on the establishment of community mental health services. After a period of meetings, consultation and study, the consortium made recommendations which included that the Department of Health fund a Consumer Advisory Network so that consumers could play a role as new structures and services were rolled out. Another recommendation was for the establishment of a national advocacy network for tangata whenua (Department of Health & Department of Social Welfare 1988). In the wake of the Cartwright Inquiry, the position of Health Commissioner was being established and the consortium envisaged that ‘consumer groups would be an integral part of this development’ (p 33). The consortium thought that consumer groups would be part of the patient advocacy service that was being established. The consortium believed that, ‘Every region needs a well resourced consumer group serviced by a Consumer Advisory Network, strong representation on the Regional Mental Health Consortium, and client input at every service outlet supported by the local consumer group’ (p 33).

The recommended Consumer Advisory Network was established as the Aotearoa Network of Psychiatric Survivors, although the expected central government funding did not materialise in the short term. ANOPS struggled with funding, and found it hard to keep a national advocacy focus when most funding was from the northern region for contracted services. ANOPS ceased in 1998.

At that time, the MOH and the Health Funding Authority expressed support for a new national network, but progress has been slow in the intervening years.

The loss of learning that occurred with the era of market-led health care delivery is also mirrored by a loss of learning and consumer capacity that occurred during periods of restructuring. In the late 1980s, the Area Health Boards were required to have standing committees called Community Health Committees. This was greeted with varying enthusiasm by communities in different parts of
New Zealand. In some areas, consumer groups feared that forming these groups would weaken existing community groups, and this did occur in some areas. With the move to Regional Health Authorities Community Health Committees mainly disbanded, but in Wellington region they continued as Community Health Groups elected annually by local communities. In 1997 there were 41 Community Health Groups in the Central Regional Health Authority and two Health Councils. At that time, they were reviewed by the authority which was clearly seeking a more managed form of consultation that met its needs, rather than community empowerment. The groups were costing an average of $3000 each annually, with the total cost to Central of $268,000 (Central Regional Health Authority 1997). Funding to the groups ceased soon after this and most groups folded, although a few, such as the Fielding and Districts Community Health Group still exist.

During the 1990s, there were a number of consumer initiatives by Regional Health Authorities and by the Health Funding Authority. Most of this seems to have been lost during the restructuring that occurred during the establishment of District Health Boards. Key staff left their jobs or were shifted into other positions. Structures and offices that supported consumer involvement were disbanded. Little of this knowledge was transferred to District Health Boards. For example, consumer groups had to remind the Auckland District Health Board during the consultation on their first strategic plan of the existence of earlier extensive consultation on women’s health. Examples of relevant reports that were prepared in pre-District Health Boards years are A review of literature on community consultation processes for the Southern Regional Health Authority (Nuthall 1996), Purchasing and public mandate for North Health (Fraser 1997); Project on the ways to involve the public in the health system for the Central Regional Health Authority (McKinlay Douglas Ltd 1997), Community health groups: discussion document (Central RHA 1997) and Consultation obligations and guidelines for the Health Funding Authority (Health Funding Authority 2000).

The idea of a national consumer body has continued to be raised in the last few years. In 1999, a report by a mental health consumer advisor identified that the need for a national consumer forum still existed. This was particularly evident with the disbandment of Aotearoa Network of Psychiatric Survivors (ANOPS) which stopped operating in 1998. Before this, ANOPS provided a collective national voice for consumers. It also developed a Maori network and made an attempt to establish a Pacific network in Auckland. The report said the roles of a national consumer forum, modelled on the Australian Consumers’ Health Forum, would include advocacy on clinical issues, representation on national advisory committees, development of a national participation policy, participation in research, maintenance of a consumer website, interactions with movements in other countries, recognition as the official ‘lynchpin’ with the Ministry of Health, quality assurance activities, and working with the Health Commissioner on consumers’ rights. It was envisaged that a Maori network work in partnership with the forum and that a structure of regional and local consumer forums underpin the national forum (Mitchell 1999).

The efforts of Women’s Health Action over a number of years from 1996 to gain funding for a national consumer network were briefly outlined in the introduction. At a training workshop for consumers, organised in 1998, participants called for the need for a national network. One participant sought to progress this but there was concern from consumer groups that the source of funding was the Researched Medicines Industry, a pharmaceutical industry body. In 2004, the Foundation of the Blind researched overseas models for some form of national disability consume body (Boyd 2004). Even if it has not been achieved, the concept of a national consumer voice has been identified continuously by New Zealand consumers.
Current situation in New Zealand

One of the terms of reference for this report was to scope the current New Zealand consumer environment to find out how it is organised, what relevant activities and projects are occurring and to identify needs and gaps. This was achieved by using the following sources:

- New Zealand websites which are listed in Appendix 3
- Key informants in both the consumer/community and government sectors. Those contacted are listed in Appendix 4
- Government documents including legislation, policies, strategies, reports, workplans, implementation plans and others of relevance
- Documents such as annual reports and newsletters of government and consumer groups.

A note needs to be made about what constitutes a consumer organisation. A relatively broad definition was accepted in preparing this report. However, organisations simply providing services for consumers were not included, even if not-for-profit, unless there was evidence of some other features of consumer control, such as consumer governance, services provided by consumers for consumers, and/or a history of having been initiated from the community.

The discussion in the section below provides an overview of participation by health and disability consumers in the health and disability sectors. These are covered under three headings:

- health consumers
- mental health consumers
- disability consumers.

At the consumer level, there is considerable overlap between these groupings, as an individual consumer or consumer organisation can have an interest in all three areas, for example, Age Concern and Parent-To-Parent.

As well as these, other government agencies beyond these sectors have taken initiatives to promote consumer participation that are relevant to this report, and these will be briefly discussed.

2.2 HEALTH CONSUMERS

Strategic Framework

In 2000 the New Zealand health sector was restructured into 21 District Health Boards (DHBs). The New Zealand Public Health and Disability Act 2000 provides, under Section 22 (11), objectives for DHBs that include:

- ‘to promote the inclusion and participation in society and independence of people with disabilities’
- ‘to reduce, with a view to eliminating, health outcome disparities between various population groups within New Zealand by developing and implementing, in consultation with the groups concerned, services and programmes designed to raise their health outcomes to those of other New Zealanders’
- ‘to foster community participation in health improvement, and in planning for the provision of services and for significant changes to the provision of services’.
Section 38 (3b) requires DHBs to ‘consult its resident population’ on draft strategic plans or amendments to plans.

The New Zealand Health Strategy [Minister of Health 2000] identifies seven fundamental principles that should be reflected across the health sector including ‘active involvement of consumers and communities at all levels’. The Strategy says that elected membership of DHBs ‘will help ensure democratic participation in the decision-making process’ but ‘this is not a substitute for community, consumer and provider involvement and participation through other mechanisms’ (p 43). DHBs have particular obligations to consult with Maori. A large number of purposes are cited for consultation, including:

- identify and understand different communities’ needs and priorities
- be accountable to users of services
- foster acceptable solutions
- uphold consumers’ rights
- provide opportunities for communities (geographical and professional, and communities with common interests) to participate in development of policy and strategic direction
- build consensus and understanding of issues
- develop a sense of partnership
- shared ownership of solutions (Minister of Health 2000, p 43-45)

A number of other government strategies encourage consumer and community participation, including The New Zealand Disability Strategy: Making a World of Difference Whakanui Oranga (Minister for Disability Issues 2001), The Primary Health Care Strategy (Minister of Health 2001a), He Korowai Oranga Maori Health Strategy (Minister of Health 2002b) and Looking Forward: Strategic Directions for the Mental Health Services (Ministry of Health 1994).

The Primary Health Care Strategy requires Primary Health Organisations (PHOs) to work with local communities and enrolled populations to ensure services are organised around the needs of communities and to include some members of the communities in their governing bodies. As part of minimum requirements set for PHOs, they need to be able to demonstrate ‘that their communities, iwi and consumers are involved in their governing processes and that the PHO is responsive to its community’ [Minister of Health 2001]. PHOs are required to have a community participation policy which sets out the organisation’s position on community participation in governance, strategic planning, service planning, service evaluation and resource allocation [Ministry of Health 2002a].

However, not all government strategies and plans highlight the need to provide opportunities for consumer participation. The Health of Older People Strategy [Ministry of Health 2002b], for example, encourages the facilitation of informed choices by older people and their families, but is silent on the issue of their involvement in decision-making around policy and service planning and delivery, except for a requirement for DHBs to encourage health advocacy structures for older Maori people. The Pacific Health and Disability Action Plan [Minister of Health, 2002a] places greatest emphasis on workforce development for Pacific people which has been identified by Pacific peoples as a priority for their communities.

Another aspect of the regulatory framework that has an influence on consumer participation in New Zealand is the Health and Disability Commissioner Act 1994. This establishes a Health and Disability Commissioner to promote observance of the rights of health and disability services consumers, a national network of independent advocates to assist with low level resolution of complaints and provide a community education role, and to investigate complaints. The Act also provides for the creation of a regulation called the Code of Health and Disability Services
Consumers’ Rights. The Code confers 10 Rights including rights to services of an appropriate standard, to effective communication, to be fully informed, to make informed choice and give informed consent, to support and to complain. It also requires the Commissioner to consult with representatives of health consumers and disability services consumers when preparing or reviewing the Code.

While the Code is principally aimed at an individual consumer’s rights, it creates a national framework and cultural context that gives support to calls for a consumer-centred approach and more effective consumer voice at all levels in the health sector. The Code reinforces that citizens have rights, including the right to a voice, and that consumers should be treated with respect as autonomous human beings.

Government and Health Sector Activities

Ministry of Health

The Ministry of Health (MOH) does not have a strong focus on consumer participation and, apart from the events described above in the late 1980s, never has had. Compared to the mental health and disability sectors (see below), the MOH lacks a framework, policy or commitment around consumer participation. While the New Zealand Health Strategy calls for ‘active involvement of consumers at all levels’ this is not modelled in the MOH. There have been some initiatives and these will be discussed further, but by and large public participation is seen as having been addressed through elected members of DHBs, requirements for consultation by DHBs and requirements for PHOs. In other words, the MOH devolves responsibility to a local level and does not systematically involve consumers in policy or planning at a national level.

The MOH does from time to time involve consumers in committees and reference groups. However, there is no clear policy for including consumers, so that different government services adopt differing approaches. These include shoulder tapping, referrals from various government databases and registers, selection from nominations following public advertising or request to the sector, or request for representative from designated organisations. Consumers participate on different conditions: sometimes they are asked to represent a constituency, often it is explicitly stated that the person is to be ‘independent’, representing only him or herself.

There is usually a single ‘generic’ consumer on a group, an approach that has been criticised by consumer groups and by the MCA (Ministry of Consumer Affairs undated). Many important national committees lack consumer representation at all. Of the eight national committees listed on the MOH website, only one explicitly states it contains consumer representation (New Prescribers Advisory Committee). The National Health Committee includes the CEO of a disability organisation and the National Ethics Committee on Human Assisted Reproduction includes a representative from an infertility society; otherwise there is no consumer representation. The National Screening Unit has a Consumer Reference Group (see below) and other service areas may have consumer representation.

Overall, the approach is haphazard. Certainly there is no sustained pattern of including consumers or policy to support it.

There is a current issue with regard to proposed MOH policies on funding for advocacy/lobbying.
Credentialling project

MOH initiatives around clinical excellence/quality have attempted to include consumers. This was primarily focused on consumer participation in credentialling processes at a DHB level. In 2001, a report was prepared for the MOH, Quality Improvement and Audit Section, Personal and Family Health Directorate of the MOH. This was based on a review of the literature, an examination of overseas models, and interviews with some key informants (Woodward 2001). The report notes that ‘New Zealand lags some way behind other publicly funded health systems’ in terms of consumer participation in health planning and evaluation (p 7). The project had found when trying to promote credentialling to DHBs, they encountered the response that ‘consumer participation has not been an integral part of “the way we do things around here”’ (Ministry of Health (2002c). There were no organisational principles to guide participation processes. The report identified two areas which would enable consumers to participate in the health sector: the development of a consumer-focused culture in provider organisations; and the establishment of a national body to develop strategies to resource and support public participation in health service delivery. It was recommended that the MOH fund a survey of health consumer groups, health NGOs and DHBs to identify the issues to be addressed in developing a central resource to promote participation. The role of a national body was seen as information (clearing house, web site etc), facilitation (research, special projects, public speaking etc) and empowerment (developing guidelines, consumer training, mentoring and support).

As a result of this report, in 2002, a reference group containing a number of health and disability consumers was set up to develop an approach to consumer participation in New Zealand health services. The reference group had two goals: develop a toolkit for DHBs, and develop a national resource for participation. After a number of meetings, a toolkit was issued in 2003 (Ministry of Health 2003a). This provided practical guidance for health and disability support services wishing to involve consumers in credentialling. Involving consumers in credentialling has been promoted to the DHBs by the MOH through meetings with Chief Medical Officers and CEOs, sector meetings, and the use of ‘champions’. It is now a requirement in letters of expectation from the Minister to the DHBs and in the Operational Policy Framework, part of the Crown Funding Agreement. Consumer representatives are trained on the job and so far there is only informal networking between them.

The second task of the reference group – to establish a national consumer resource – was not progressed. The Quality and Audit team in the MOH had hoped to move the consumer participation project beyond credentialling, but there has not been support for it to do so within Government.

Ministry of Health/NGO relationship

The MOH has also formed a MOH/NGO forum to promote stronger relationships between the Ministry and the community and voluntary sector, similar to developments in the Ministry of Social Development (See section 2.2, ‘Ministry of Social Development’, page 73). This is broader than consumer organisations, and the majority are independent community and iwi/Maori service providers operating on a not-for-profit basis. There is a written framework for relations and six-monthly forums are held. The NGO Working Group includes members from mental health, Maori health, Pacific health, public health and disability backgrounds.

Intersectoral Community Action for Health

Another initiative is the Intersectoral Community Action for Health (ICAH) projects funded by the MOH’s Reducing Inequalities Contingency Fund. Pilot projects are being held in four parts of New Zealand. The aim of these is to improve overall health outcomes and reduce inequalities for Maori, Pacific peoples and low-income groups through community-based intersectoral activities (Minister of
While ICAH are not consumer organisations in the usual sense, some do have a strong community base, adopting a community development model.

One example of an ICAH is Porirua Healthlinks Trust, established in 1999, which has a strong community base. The trust has relationships with the Porirua City Council, Te Runanga O Toa Rangatira, Capital and Coast DHB, PHOs and providers and the MOH. The trust board contains a number of community representatives and the management committee has representatives from Porirua City Council and MOH.

Porirua Healthlinks works to a Porirua City Health and Disability Report and Plan that was developed from the community. In the health area, Porirua Healthlinks assists people in accessing services and advocates on behalf of its community to the DHB about issues of concern that have been discussed at community meetings. A recent example is the DHB proposal to charge people attending a new Accident and Medical clinic. Porirua Healthlinks explicitly states that it is not a provider, but seeks to provide leadership, facilitating dialogue, action and coordination amongst the communities and providers of Porirua, and with central and local government agencies that have a role in health.

The trust has an office in Porirua with 4-5 staff and has a number of projects including a health information project, including a database of 1400 services to which people can be referred, and it is currently scoping the development of a website and 0800 number that people can ring for information.

**District Health Boards**

**Elected board members**

Part-elected boards were reinstated by the Labour Government in 2001, and are seen by the Government as a significant mechanism for engaging communities in decision making on funding and services that are responsive to consumers’ needs [King 2004]. Consumers and communities are seen as having a ‘direct involvement in DHB governance by being able to vote or stand as a candidate in DHB elections.’ This mechanism is supposed to ensure DHBs are ‘accountable to the community and are aware of the region’s needs’ (Minister of Health 2003, p 126)

However, the jury is still out as to the extent to which elected members are able to represent and be accountable to their communities. Elected DHB members have dual accountabilities to the Minister of Health and their constituents and there are varying views among DHB members as to their comfort with this situation. Recent research showed that one in five of elected members feel unable to handle this dual accountability. Among appointed members, 58.4% felt principally accountable to the Minister. Just under half of all board members agree they have sufficient autonomy. One quarter felt they were ‘a rubber stamp for management’ (Health Reforms 2001 Team 2003).

**Community involvement in DHBs**

As noted earlier, the New Zealand Health Strategy explicitly states that DHBs should not rely solely on elected members to provide consumer/community input into decision-making but directly encourage consumers to participate. How they do this is essentially left up to DHBs. There are performance indicators for engagement with Maori and Pacific communities but otherwise DHBs are simply required to outline what they are doing in Annual Plans.

DHBs are required to involve communities in the development of their strategic plans. There has so far been no evaluation of how well they do this, but Women’s Health Action, a women’s health consumer advocacy group, surveyed DHBs to find out how they consulted consumers in the preparation of their first strategic plans in 2002. The survey found that most DHBs used traditional
methods of consulting such as a submission process, advertising and public meetings. Of the respondents, only two formally evaluated the process (Khrapko 2002).

It was beyond the scope of this report to investigate the activities of all the 21 DHBs; however some examples can be given. The Minister of Health’s third report on progress implementing the New Zealand Health Strategy mentions that Waikato DHB has established seven Community Health Forums through the region with up to 80 people regularly taking part. The chair of each forum meets with DHB staff and has access to the CEO to discuss issues of local importance. Members of Community Health Forums have also been involved in the establishment of PHOs and are involved in local management groups and PHO governance (Minister of Health 2003).

Another example is Waitakere DHB which over a period of 18 months from November 2002 developed a framework for consumer participation and community engagement. This was the work of a Consumer Participation and Community Engagement Leadership Group, consisting of consumers, which met fortnightly and then held a series of public meetings and hui to get input. The framework went to the DHB Board in mid-2003. It stated that engagement had to occur at all levels from that between consumer and doctor/nurse, to engagement with the board. It recommended a Statement of Intent between Waitemata DHB and consumers and communities, community liaison meetings, a one-stop consumer information phone line and that every service area have its own annual community engagement plan. A recommendation was made for a Health Consumer Council (Consumer Participation and Community Engagement Leadership Group 2003). Waitakere also has a Waitakere Health Link community forum (formed in 2001) with an executive committee consisting of eight elected community representatives, five health care providers and Waitakere City Council elected members. This is a partnership between Waitemata DHB, Waitakere City Council, Pasifika Healthcare, Wai-Health and Integrated Primary Care Services Ltd. The forum meets monthly to participate in healthcare decision-making and foster collaborative arrangements (Waitakere Health Link 2003). Waitakere Health Link is mainly a forum for sharing information; it follows an earlier West Auckland Health Forum (1988-95) which was a community development and community-driven forum for local people to raise issues and lobby the Area Health Board. It was considered to be very effective by local communities but did not survive the health reforms restructuring.

**Primary Health Organisations**

PHOs must be able to ‘demonstrate that their communities, iwi and consumers are involved in their governing processes and that the PHO is responsive to the community’. ’Community’ is defined as ‘all individuals that are currently enrolled with that PHO’, but it is acknowledged that there may be other communities of interest within the enrolled population (Ministry of Health 2002a, p 13).

The Minimum Requirements for PHOs do not prescribe any particular way that the community’s voice should be heard at the governing level. Examples are given of the way some PHOs have done this. Most Health Care Aotearoa organisations are governed by a management committee comprising elected representatives and staff representatives. Pasifika Healthcare has a board elected by the community. Ngati Porou Hauora has a board with a majority of community representatives, one from each of seven communities, as well as holding regular hui. However, many Independent Practice Associations have only one or two community representatives on their trust boards and these appointments have usually been made by approaching prominent local citizens (Ministry of Health 2002a).

It is beyond the scope of this report to investigate in detail how PHOs are meeting the requirements; however; there are some initiatives that are relevant to this report.
Funded by the Health Research Council, the Department of Public Health at Wellington School of Medicine and Health Sciences is leading a project to develop measurement tools for assessing community participation in PHOs, to enable comparative assessments of the degree of participation. The project has been developing a theoretical framework drawing on New Zealand and overseas experience before developing a draft measurement tool. The Continuous Quality Improvement tool will then be trialled in 10 PHOs, with a range of governance structures, including elected and appointed boards of trustees and appointed boards of directors. The tool is designed to be used for self-assessment and for review by an external reviewer (Neuwelt 2004).

Another initiative is a series of workshops for PHOs in late 2004 to be organised by the MOH to discuss experiences of community participation.

Ministry of Consumer Affairs
The MCA has a long-standing interest in consumer initiatives. Its initiatives are directed at consumers in all sectors and are not specific to health or disability. In 2002, the Ministry issued a Consumer Representation Study which was aimed at improving the effectiveness of consumer representation (Ministry of Consumer Affairs 2003). It is important because it is the only substantive piece of work of its kind carried out in New Zealand. The writing of the report had involved interviewing a large number of people acting as consumer representatives in a wide range of sectors and officials involved with consumer representatives or in selection processes. Some of the enablers and barriers to consumer participation were included in that section of this report.

- The study identified a number of problems:
- Inconsistent understandings of definitions of consumer roles, especially around ‘representation’
- Officials express doubt about the purpose of representation, especially around the ability of consumers to understand technical areas and whether inclusion of consumers improves decision-making
- There is difficulty locating consumer representatives. This is because officials are not familiar with the consumer sector and the best way to approach it, they lack information about the consumer constituency needed for the particular project, and they wish to have consumers who are not ‘disruptive’. Consumer organisations are reluctant because of poor experiences they had had with previous consultations
- There are practical difficulties for consumers including cost, isolation, minority status, having a diverse constituency, dealing with conflict and lack of a formal consumer representative network. The latter barrier means that consumer representatives have few opportunities to network with others, discuss issues with a mentor, or gain support (Ministry of Consumer Affairs undated; Ministry of Consumer Affairs 2003).

The report suggested a number of remedies for these problems to make representation more effective. The MCA developed two guidelines, one for officials and one for chairs of advisory bodies and boards. These were accepted by Cabinet in 2003 (Minister of Consumer Affairs 2003).

The Ministry also keeps a data base of potential nominees for positions and has 36% success with its recommendations. A Nominations Reference Group consisting of 12 individual consumer representatives is used to identify potential nominees. The MCA writes a letter of support when putting forward a person’s CV.

The MCA also hold a twice-yearly Consumer Network meeting. The Network consists of people who have gained public positions through the MCA nominations process. The Network meets over two days to discuss issues of common concern.
Concerns about the MCA process focus on the lack of transparency in the nomination process, the exclusion of consumer representatives who are not appointed by the MCA route from the network, and the approach of the MCA that consumer representatives are not representative of or accountable to consumer organisations.

Other government nominations databases
A number of other government agencies hold nominations databases. The people on these are not confined to consumers. These are:

- The Ministry of Women’s Affairs Women’s Appointment File
- Te Puni Kokiri
- Ministry of Pacific Island Affairs.

Ministry of Social Development
The Ministry of Social Development has been pursuing a policy to improve relationships with the community and voluntary sectors. A working party produced a report called Communities and Government – Potential for Partnership Whakatupu Whakaaro (Community and Voluntary Sector Working Party 2001). This outlined problems being faced by the community and voluntary sector. In December 2001 the government signalled its intention to commit to a new way of working by signing a Statement of Government Intentions for an Improved Community-Government Relationship. A Community-Government Relationship Steering Group was established to recommend ways that the problems identified in the working party report could be addressed. Its report, He Waka Kotuia – Joining Together on a Shared Journey (Community-Government Relationship Steering Group 2002), produced recommendations for improving relationships between the government and not-for-profit sector. These processes and the Ministry of Social Development initiatives described below are across the entire voluntary and community sector which includes community-based providers of services. The organisations involved in working groups and projects tend to be not-for-profit welfare and social service agencies and iwi/Maori organisations. Consumer health groups have not been represented on working groups and have not been greatly involved in these processes.

Community and Voluntary Sector Office
One outcome of the processes described above was the establishment, in September 2003, of a Community and Voluntary Sector Office within the Ministry of Social Development. This is part of the government’s commitment to strengthening relationships with community, voluntary and tangata whenua organisations. The functions of the office are to provide advice on cross-government policy issues affecting not-for-profit organisations and to enhance the sector’s involvement in government decision-making. The aim of the office is to strengthen the capacity of not-for-profit sector and national networks. The office is similar in structure to the Office for Disability Issues (see page 82). The Community and Voluntary Sector Office reports to the General Manager, Sector Policy, Ministry of Social Development.

The launch of the office also included a new resource for public servants, the Good Practice Participate web site ([www.goodpracticeparticipate.govt.nz/](http://www.goodpracticeparticipate.govt.nz/)) which provides guidelines on how government agencies can effectively engage with community, voluntary, iwi and Maori organisations. The site covers ‘active relationships’, benefits of community participation, formal consultation, partnership, and community representation on boards and committees. This latter section directs people to the MCA guidelines, and nominations services at the MCA, Ministry of Women’s Affairs, Te Puni Kokiri and Ministry of Pacific Island Affairs.
Community Sector Taskforce

The Community Sector Taskforce was set up as a result of work by the Community-Government Relationship Steering Group. It is fostering three pieces of government-funded work, one of which is a series of forums throughout New Zealand in 2004 for community organisations from all sectors. The forums have put forward proposals for greater collaboration in the future including:

- A common declaration or statement of values
- A framework for Treaty-based practice for the sector
- A proposal for a national entity or network to provide ongoing leadership for the whole sector.

While the first two points have been endorsed through the process, participants have expressed a wish to give more detail about the concept of a national entity or network before a mandate is given to go forward.

Another proposal of the Community Sector Taskforce is for strengthened communication across the community and voluntary sector through sustainable information networking processes and systems, including linking and enhancing existing databases and networks, and a ‘clearing house’ for information.

National Consumer Advisory Groups

There are a growing number of national consumer advisory or reference groups in the wider health sector, some of which are required under the New Zealand Public Health and Disability Act. In all the examples listed below, the committee membership was chosen by the entity it is advising, and members do not represent organisations. There does not seem to be a clear definition of what constitutes a consumer, with some members being involved in provider groups. The groups tend to meet three or four times a year and give advice to the entity. The groups’ scope of activities is usually constrained by Terms of Reference that have been established by the entity alone or in consultation with the advisory group. The groups usually give advice to the entity appointing them and are limited in their ability to engage with consumer organisations. There is very little specific research on all-consumer advisory groups, but generally their effectiveness depends on how well linked they are into the agencies decision-making framework, the overall involvement of consumers in the agencies processes (Draper 1997), and on other enablers and barriers identified in the ‘Enablers and barriers’ see section 1.4, page 43.

Accident Compensation Corporation

The Accident Compensation Corporation (ACC) has developed a Code of Claimants’ Rights and in early 2003 the Chief Executive established a Consumers Outlook Group to advise ACC on issues relevant to its delivery of services to claimants. The Consumers Outlook Group’s role is to represent the views of ACC claimants and to assist ACC to develop a more effective delivery of services. There are currently 12 members of the Consumers Outlook Group appointed by the CEO of ACC.

PHARMAC

The PHARMAC Consumer Advisory Committee has ten members and meets about three times a year to provide advice to the Board of PHARMAC on prioritisation of pharmaceuticals, how to improve access to pharmaceuticals, information needs of patients, and responsible use of medicines. The Consumer Advisory Committee was appointed by the Board of PHARMAC following a nominations process. It makes recommendations which are taken to the board by the chair, and the board formally reports back what action it has taken. The committee also takes actions to pursue issues that are within its terms of reference. This can involve writing to government agencies or initiating
discussion on an issue, such as industry sponsorship of consumer groups, through the consumer sector.

Health and Disability Commissioner

The Commissioner has appointed a six-person Consumer Advisory Group that meets three times a year. The group gives advice to the Commissioner on the handling of consumer complaints, improvement of health and disability services, public interest issues where the Health and Disability Commissioner can take a lead, policy issues raised by the Commissioner and promotion and education. The group has been selected to enable perspectives of Maori, disability and health (including mental health) consumers to be included.

National Screening Unit

The National Screening Unit has an 11-member Consumer Reference Group that meets several times a year to provide advice to the National Screening Unit. Some members are also on breast screening, cervical screening, Maori and Pacific advisory groups. The group was selected by the National Screening Unit and the consumer member of a previous screening advisory committee, following a nominations process.

Other initiatives

A number of other government or independent agencies include consumers in their governing bodies or other activities.

The New Zealand Guidelines Group has two consumers on its board (one is a DHB manager) and includes one or more consumers in all of its guideline development groups. There is also specific Maori, Pacific and disability representation on the board.

Standards New Zealand has a consumer on its board and also includes consumers in some of its groups developing standards, but until recently, participation has been seriously constrained by limited funding support for consumers who take part. Consumer organisations can rarely support a consumer representative out of their own funds so that consumers are disadvantaged compared to those representing professional groups or industry. Recently, Standards New Zealand set up a consumer fund to provide travel funding for consumers participating in standards groups.

Consumer Activities

There are a very large number of consumer health organisations in New Zealand, including the following types:

- National organisations
- National networks of groups, or umbrella organisations
- National and local support groups
- Health drop-in centres
- Disease or condition focused groups
- Advocacy groups organised around a local issue, such as the closure of a service
- Groups organised around a defective product or service, eg breast implants or unsafe blood products
- Advocacy groups based on populations, such as women
- Groups based on difficulty accessing a service, such as abortion or home birth
• Information services
• Awareness groups
• Locality-based and regional groups.

None of these descriptions is exclusive of the others. Many groups play multiple roles for their members and the wider society. The groups take a great number of forms including incorporated societies, charitable trusts, and groups that are not necessarily legal entities, such as collectives, drop-in centres or informal support groups.

There is no consistent form of funding for the majority of these groups. Many rely on membership fees, donations, voluntary labour, fundraising activities and grants from government and non-government sources. With both private and public sources of funding, groups have found their ability to attract funds or grants has deteriorated as limited funds have been understandably channelled towards the most disadvantaged groups. Many private philanthropic and government funding agencies have taken the view that consumer health groups should be funded out of Vote:Health. However, neither the MOH nor the various regional health bodies that have existed over the past 20 years have taken responsibility for funding consumer/community organisations. Support tends to be intermittent and most devolved government health bodies are severely constrained by their need to operate within fixed budgets. Constant health sector restructuring has also contributed to difficulties arranging funding. When funding is gained it is usually on a contractual basis tied to specific services. This means that it may not be sustainable or the funds can divert the organisation from its original purpose. Funding for advocacy has become particularly problematic following criticism of some aspects of government contracts with particular health advocacy groups.

Some of the groups have sufficient resources to have an office and paid staff. An example of this is the New Zealand Organisation for Rare Disorders (NZORD). This charitable trust is a large national umbrella group, set up in 2000 following a conference of over 30 rare disease support groups.

Another example is the Women’s Health Action Trust, founded in 1984, which is a charitable trust with offices in Auckland providing advocacy and information for women. The trust has taken a particular interest in consumer participation and has developed guidelines which can be found on its web site (see Appendix 3).

Many groups at a national or local level do not receive funding or it is so intermittent that the group is unable to establish a base or paid staff. An example of this is the Federation of Women’s Health Councils of Aotearoa/New Zealand which at one point had an office and some operational funding but now functions primarily through email and has two unpaid co-convenors.

As well as these groups, there are a number of well-established community-based membership groups that have a strong focus on health. These include Maori Women’s Welfare League, National Council of Women, Parents Centres and Greypower. There is also the Consumers’ Institute of New Zealand which is a generic consumer organisation with an interest in this area. The Consumers’ Institute has a membership and elected board of seven. Its main work is the testing of a wide range of consumer products, and it publishes a widely distributed magazine. Unlike some generic consumer organisations overseas (for example, the UK National Consumer Council), the Consumers’ Institute does not have a strong focus on consumer participation or health services. The institute has representatives on a number of government committees (excluding food safety, the only health committee in 2003 was the Drinking Water Advisory Group) but there is no consumer representation programme to enable members to be nominated for positions (Consumers’ Institute of New Zealand 2004).

The consumer health sector is uncoordinated and fragmented. There is a lack of structural support. No government agency is responsible for supporting the sector, even though such groups are a
critical element in civil society. There are a few government initiatives, outside health, that seek to promote networking and collaboration, however, health groups often find themselves a minority in wider social networks.

There is not even a single good-quality database of consumer health groups. There are a number of listings on government and non-government web sites, but there is no ‘one-stop shop’ for information about groups. Similarly, the distribution of news and information to consumer groups is inconsistent. There is no one agency that is responsible so that information sharing is informal and haphazard.

Networking and cooperation between groups is haphazard. There are few opportunities for groups to get together and discuss areas of common concern at a national level. Some localities or regions do have networks, but this is not consistent across the country. Examples have already been given of community networks in the Waitakere area, and in a few areas, community health groups that were established under the aegis of Area Health Boards still exist. In Auckland, the University of Auckland, School of Medicine hosts a Community Forum for the purpose of involving the community in the training of students and to meet accreditation requirements. The main activity of this is occasional forums rather than ongoing networking.

When issues that concern the consumer sector emerge, networks often have to be put together on a case-by-case basis. For example, over the last several years as the New Zealand government and industry interests have been discussing a joint Trans-Tasman Agency for Therapeutic Products, consumers had to firstly, insert themselves into the process, and then establish a specific network of interested groups to support consumer representation on the working party and work on the issue.

While it is common for at least a single person to be included on government and other groups developing policy, guidelines, standards and providing advice, consumer groups are not consistently involved in the process of nomination or selection. When consumers are selected from groups to act as consumer representatives, there is no organised programme for training and support. A number of initiatives have recognised this for their particular constituencies and are trying to address it.

The New Zealand Heart Foundation is developing a training programme for health advocates who wish to act as consumer representatives or groups specific to heart disease, based on the programme of its UK counterpart called Hearty Voices. It also plans to develop a national network of representatives, providing training and support. The NZGG also provides training on guideline development for all members of guideline teams including consumers, although it is not tailored to consumers.

In the breast cancer area, a loose coalition of breast cancer groups in Auckland has been developing a programme based on the A Seat at the Table project established by the Breast Cancer Network of Australia (see section 3.1, ‘A Seat at the Table’, page 95). The group consulted New Zealand women’s breast cancer organisations and the concept was supported. A proposal has been developed along the line of the Australian project and the group is now seeking funding. They propose a three-day course with training in scientific areas, as well as such things as media training and interacting with government agencies. They are seeking funding for a project manager, who would provide ongoing support for women following their training. One obstacle they have identified is the lack of a clear process for appointing people as representatives on groups.
2.3 MENTAL HEALTH CONSUMERS

Mental health consumers have developed ways of representing consumer interests that are unique in the health sector. Some of the features of the approach are found in the USA and other countries but several key informants believe that New Zealand has moved ahead of some other Western countries.

Strategic Framework

The New Zealand Health Strategy (2000) lists ‘improving the health status of people with severe mental illness’ (p 13) as a priority goal and ‘improving the responsiveness of mental health services’ is listed as a service priority (p 19).

Consumer participation has been on the agenda of the mental health sector for over a decade. In 1989 a group consisting of government, providers, consumers and Maori called the National Mental Health Consortium (Department of Health & Department of Social Welfare [1989] identified six major needs to enable effective participation by mental health consumers. These were: validation, power-sharing, information, participation skills, advocacy and funding. Consumer participation was highlighted in the national mental health strategy, Looking Forward: Strategic Directions for the Mental Health Services (Ministry of Health 1994) and Moving Forward: The National Mental Health Plan for More and Better Mental Health Services. (Ministry of Health 1997).

In 1995 the MOH explored the issue more closely when it issued evidence-based guidelines for effective consumer participation in mental health services (Ministry of Health 1995).

The national mental health strategy requires that the MOH involve consumers in policy and planning, that consumers be involved in regional planning, and in the design and purchase of services, and that providers be able to demonstrate the employment of consumers in services (Ministry of Health 1997).

Two further key documents for the mental health sector are the National Mental Health Service Development Plan called Blueprint for Mental Health Services in New Zealand: How things need to be (Mental Health Commission 1998) and the National Mental Health Sector Standards (2001) developed for the MOH. The blueprint calls for greater opportunities for people with experience of mental illness to take up roles in the mental health workforce as advisers or support people, and for them to receive training. The standards require that consumers are involved at all levels of planning, delivery, implementation and evaluation of mental health services.
Government and Health Sector Activities

Mental Health Commission

The key government agency responsible for mental health services in New Zealand is the Mental Health Directorate in the MOH. However, because of long-term concerns about the quality and accessibility of mental health services, in 1996 the government established a Mental Health Commission. Its roles are to monitor the implementation by the MOH and providers of publicly funded mental health services of the national mental health strategy, reduce discrimination against people with mental illness and ensure the mental health workforce is strengthened (Mental Health Commission 1998).

The Mental Health Commission plays an active role in fostering the inclusion of service users/consumers in policy, planning and service delivery and monitoring progress towards this goal. The Commission sees consumer participation at all levels as a way of ensuring the responsiveness of mental health services to consumers (Mental Health Commission 2000).

Paid consumer advisers

A key strategy that has been adopted for enabling consumer influence in the mental health sector is the paid employment of consumer advisers as part of the mental health workforce. This is seen as both ensuring the responsiveness of services to service users’ needs and assisting in recovery. This strategy developed in an unplanned and organic fashion. There are similar models in other countries, particularly the United States of America. The practice of using consumer advisers developed from the engagement in the late 1980s by the Auckland Area Health Board of the group Psychiatric Survivors to give consumer advice. By the mid-1990s there were paid advisers in Auckland, Mid-Central (Waikato), Wellington and Dunedin, and this has evolved into a nationwide practice. Many NGO providers are now following suit.

A review carried out by the Mental Health Commission in 1999, found that 23 consumer advisers were employed at 13 of the 22 Hospital and Health Services mental health services and seven others were planning to do so (Mental Health Commission 2000). By 2003 all DHBs had at least one paid consumer adviser in mental health services and some had more than one adviser delineated according to service (e.g. forensic, Maori mental health) (Mental Health Commission 2003; Hansen undated).

Since 1999 there have been twice yearly national meetings of consumer advisers from all DHBs constituted as the National Association of Hospital and Health Services Consumer Advisers (NAHHSCA). The purpose of these meetings is to review issues of note, network and support each other, however, not all paid advisers receive funding from their DHBs to attend.

Self-employed, paid mental health advisers or consultants work alongside senior management and/or services and advise on the needs of consumers in planning and delivery of services. They are sometimes involved in advocacy on behalf of individual consumers, but in general work at a systems level. Some have consumer advisory groups or formal links to community organisations; all must find ways of engaging with consumers in the area in which they work. Despite significant growth of paid consumer advisers in a relatively short space of time, there has not been any evaluation to determine how they have impacted on service quality and responsiveness at the patient level, nor how to manage the potential for conflicts.

Reviews in 2000 and 2004 by the Mental Health Commission found that there were variable practices in employment conditions and pay of mental health advisers. There was a lack of clarity as
to roles, limited or absent training and supervision, and the effectiveness of advisers was mediated by the commitment of managers, and staff attitudes. Sometimes lacking support, advisers could become stigmatised and isolated. As consumer advisers are employed by the health services, there could be dual accountabilities to the employer and consumers in the community which sometimes led to criticism from the latter that advisers were insufficiently linked into the community. The Mental Health Commission, in urging service user participation at all levels, warned against organisations being ‘over-reliant on a few paid service user participants. There is a danger that these people will become a service user clique, and that current recipients will be overlooked’ [Mental Health Commission 2002, p 31]

These issues are still current in 2004, and effort is being put into the training and support needs of consumer advisers. The Health Research Council has funding from the MOH for a Mental Health Workforce Development Programme and is currently tendering for training programmes for advisers, including the development of nationally consistent guidelines and job descriptions. It is likely that training will be piloted in one DHB, or there may be two pilots to allow comparisons.

Consumers as providers of services
The Mental Health Commission has also promoted the concept of ex-patients as providers of mental health services. An important example is the Hawkes Bay Light House Trust, the governance body for consumer-run services in that area. This trust has for the past seven years been running a seven-day a week drop-in centre for mental health consumers in Napier and Hastings, funded originally by the Health Funding Authority and now the Hawkes Bay DHB. The Trust has three consumer adviser contracts with the DHB, arguing successfully that these services are best provided independently from the DHB, as well as holding the Like Minds Like Mine destigmatisation contract in Hawkes Bay. Recently the trust has begun providing its own packages of care to enable in-patients and people in community houses to live independently in their own homes. In 2003 the Hawkes Bay DHB established a Mental Health and Addiction Committee as one of its standing committees, with significant consumer, family, Maori and Pacific representation. The DHB has now brought NGO providers into its structures enabling consumer providers to access clinical services as if they were a public provider.

Another example of consumer-provided services is the Wellington Mental Health Consumers’ Union, one of the oldest and largest service user providers of mental health services in New Zealand. It runs three drop-in centres, advocacy services for two DHBs, policy advice services, and provides policy advice for the local DHB.

Other initiatives
Many DHBs also have mental health consumer advisory committees or advisory committees that include consumers and there are other less formal opportunities for consumers to have a say. The MOH includes consumers on some committees, usually selecting these itself, rather than consulting the wider sector or calling for nominations. The MOH does not employ mental health advisers. Dissatisfaction with representation processes at a national level is one of the drivers of the current initiative to form a national network or entity (see below) [Hinds 2004].

Consumer Activities
A discussion paper by the Mental Health Commission concluded that service user participation is not fully integrated into the mental health system and that some organisations do little because they perceive it as too difficult. They noted a tendency to focus on service user participation ‘at the service
or system level, rather than the individual service user’s relationships with mental health workers while they are receiving a service from them.’ (Mental Health Commission 2002, p 5).

The development of the role of mental health advisers is widely acknowledged as having weakened community-based advocacy and self-help groups as experienced, politically aware consumer advocates moved into the mental health workforce, coupled with unreliable funding, and variable management and governance of community organisations. Some consumer organisations belong to Platform, an umbrella body for NGOs providing support services and community development in mental health, but Platform is also open to providers and these make up the majority of members.

A report by Aotearoa Network of Psychiatric Survivors (1996) noted that advocacy was not a major role for New Zealand mental health consumer groups, with the major exception of the Wellington Mental Health Consumers’ Union which was funded by the Health Funding Authority for advocacy. Most groups were mutual support groups although they varied markedly in roles, membership and networking with other groups.

A national mental health consumer network

As noted above, a recommendation by the Mental Health Consortium to establish a national mental health consumer groups was not followed up at that time. To begin to address the lack of consumer-based advocacy, four regional consumer networks, open to individuals and groups, have been formed: Northern (Auckland regional Consumer Network), Midland (Midland Region Consumer Advisory Group), Central (Central Potential), and Southern, based on old Regional Health Authority boundaries. Except for Midland, all of these are funded by the MOH. There has been a national hui and a national steering committee with representatives from the four regions is currently working towards the establishment of a national organisation or network. The aims of a national body at this stage are:

- to provide consumer input and critique into national initiatives by the MOH, Mental Health Commission, Health Research Council and other national entities
- to link up the diverse range of people with mental illness in New Zealand
- to provide comment on national media stories about mental illness and coordinate media responses through the regions (Tovey 2004).

2.4 DISABILITY CONSUMERS

The scope of this part of the project was initially intended to be confined to disability issues as they applied to the health sector. To include the whole disability sector would have widened the scope of the review considerably and the author felt that if this were to occur a person with disabilities should lead such a project.

There has been considerable debate in the disability sector about the policy direction of subsuming disability under health as disability is not seen as a matter of illness or disease. This report does venture more broadly than the health sector to give some idea of relevant initiatives in the wider government and non-government sectors. It is recommended that a future step for this project would be to seek a more in-depth review of consumer participation for people with disabilities.
Strategic Framework

The key policy document for the disability sector is *The New Zealand Disability Strategy: Making a World of Difference Whakanui Oranga* (Minister for Disability Issues 2001) which was required under the New Zealand Public Health and Disability Act 2000. The Strategy was developed after extensive consultation through the disability sector and is the first strategy to address the needs of people with disabilities on a cross-sectoral basis. *The New Zealand Disability Strategy* has 15 objectives a number of which are relevant to the participation of consumers in health policy development and planning. These are:

- Objective 5 Foster leadership by disabled people
- Objective 6 Foster an aware and responsive public service
- Objective 7 Create long-term support systems centred on the individual
- Objective 11 Promote participation of disabled Māori
- Objective 12 Promote participation of disabled Pacific peoples
- Objective 14 Promote participation of disabled women in order to improve their quality of life (Minister for Disability Issues 2001).

Objective 5 requires actions to

5.1 encourage disabled people to take part in decision making as service users, as staff in the delivery of services, and in the governance, management, planning and evaluation within all services that disabled people access;

5.2 assist self-help initiatives, service provision and advocacy organisations run by disabled people for disabled people;

5.3 model the inclusion of disabled people in leadership roles within government departments, in order to encourage leadership by disabled people within all organisations;

5.4 support the development of a leadership development programme and mentoring programme for disabled people

5.5 establish a register of disabled people for government appointments

5.6 make information available to disabled people and their advocacy organisations about how to influence government policy (Minister for Disability Issues 2001, p 23).

Government agencies such as central departments and DHBs are required to develop annual strategy workplans to report what they are doing to implement the strategy.

Government and Health Sector Activities

Office for Disability Issues

On 1 July 2002, responsibility for implementing this strategy was transferred from the MOH to the Office for Disability Issues in the Sector Policy Group of the Ministry of Social Development. The office is required to promote participation and inclusion of people with disabilities with three main roles.

- Lead, monitor and promote the implementation of *The New Zealand Disability Strategy*
- Provide policy advice and lead strategic and policy development across government
• Support the Minister for Disability Issues.

The Minister for Disability Issues reports annually to Parliament on progress in implementing the strategy. In the most recent report the Minister reported a number of initiatives relevant to this report. Some of these are reported below. The Minister reported some progress on Objective 5, but had nothing to report about 5.2, 5.4 and 5.6. Under 5.5, the Minister reported that the Office was working with Te Puni Kokiri, Ministry of Pacific Island Affairs and Ministry of Women’s Affairs to establish a register of people with disabilities available for government appointments (Minister for Disability Issues 2003).

The Office for Disabilities Issues is planning to consult on a proposal to establish a committee or council made up of disabled people and their families/whanau to provide feedback on progress implementing The New Zealand Disability Strategy and to highlight issues of importance to the disability community. The proposal is for a council of around 7-9, but up to 13 members. The office proposes that the disability community choose the members, by way of disability organisations choosing representatives. Suggested members are five from regional groups of Disabled Persons Assembly (DPA), a Maori representative, two parent/carers representatives, one from People First, one from the Association of Blind Citizens, one from the National Mental Health Advocacy Network and one from the Deaf Association of New Zealand. Members would meet four times a year for two days each time and be accountable back to their communities (Office for Disability Issues 2004). This proposal has the support of DPA.

Disability Services Directorate of Ministry of Health

The Disability Services Directorate in the MOH is responsible for policy advice on disability support service matters to the government, and for planning and funding disability support services. Policy is focussed on the support needs of people with long-term physical, sensory and/or intellectual disabilities, especially, since November 2003, those under 65 years of age.

The Disability Services Directorate in the MOH is progressively moving to a more consumer-centred model. It is currently carrying out a consumer participation project around how to consult with the disability community. This is seen as meeting Objectives 5, 6, 11, 12 and 14 of the Disability Strategy. The project is reviewing overseas models, and a New Zealand-wide consultation has been carried out by LIFE Unlimited to find out from people with disabilities and others how they wish to be involved with the Disabilities Services Directorate. While this is about consumer participation, the consultation involved people with a disability, family members/whanau, and some providers of services, mostly those which are consumer-led. It is not looking widely at how people with disabilities participate in the health or other sectors, but specifically at the relationship with the directorate as a funder of services.

In a two-stage project, 32 forums were held throughout New Zealand to seek the views of a cross-section of people in the disability sector. From the feedback draft mechanisms were formulated and this went out for consultation in early 2004. One mechanism is for annual community-based forums at key New Zealand locations, as well as for four hui for Maori in the four MOH regions.

The second is for the establishment of a national body to engage with and give advice to the Disability Services Directorate at meetings twice a year. Three options were considered:

• A group consisting of representatives from geographic areas
• A consumer consortium made up of existing consumer groups
• A disability council similar to the state disability councils in Australia.
The preferred option was the Disability Consumer Consortium. As proposed, this is not made up solely of consumer organisations. It is proposed that it be made up of:

- representatives from existing national disability organisations that largely consist of consumers
- national disability organisations who already provide information and advice to disabled consumers
- additional representation for parents, Maori and Pacific peoples.

The consortium would engage with the Disability Services Directorate in a partnership model to give high level advice and look at the Directorate’s plans such as the Annual Plan (Ministry of Health 2004).

From this a small working group would be drawn to engage with the directorate on a more frequent basis. The directorate would be able to go to this group for policy advice or recommendations for consumer representatives for other projects and processes.

The Disability Services Directorate proposes that the National NZ Federation of Disability Information Centres provide administrative support for the consortium and annual forums. A plan to implement this project is due at the end of June 2004.

DPA has some reservations about this model, particularly what it sees as the ‘reactive character of the proposed approaches to consumer input’, with the consumer body ‘commenting on and responding to ministry plans and initiatives, rather than playing an integral role in the development of ministry thinking and planning.’ DPA is also concerned at the inclusion of a provider group in the consortium (DPA, 29 April 2004).

There is also a project looking at the use and experience of Maori when accessing health and disability support services called the Maori Consumer Research Project: The Participation and Experience of Maori in the Health and Disability Services. This is a joint venture between the MOH, Health Research Council and Accident Compensation Corporation. Fieldwork will commence in mid-2004 (Minister of Health 2003).

One issue for the disability sector is the definition of consumer. Some disability NGOs are very large and receive significant funding from Government to deliver services. Some organisations include in their membership family/whanau as well as the person with the impairment. There is not agreement in the sector as to whether providers of services can also be defined as consumer organisations and whether those including family/whanau are strictly consumer organisations.

Disability Empowerment Advocacy and Support Services

The Secretariat is also funding a pilot project to establish organisations in the Northern region called Disability Empowerment Advocacy and Support Services (DEASS) to assist with advocacy and support to enable disabled people to access services. This project developed out of the experience in the Northern Region locality office of the MOH with the employment of a person with a disability in the Disability Services Directorate team. This was found to have unexpected benefits in increasing the visibility of disability, raising awareness around access issues, and increasing capacity in when and how to engage with the disability community over operational matters. In 2001-02 the locality office began working closely with the Auckland branch of DPA to gain advice over the operational role of the MOH. The benefits of this partnership led to the concept of the DEASS.

Established in 2002, there are currently five DEASS funded by the MOH. There are specific organisations for Maori (Te Roopu Waiora), Pacific peoples (Pacific Islands Advocacy Support Services or PIASS), parents and families and a generic group which includes new settlers and refugees. The fifth is a Tai Tokerau Northland area-based organisation. Each has an office and staff...
made up of people with disabilities, and the governing bodies of these organisations are mainly people with disabilities. Their role is not patient advocacy for individuals, but advocacy on systemic issues. They have a partnership with the Disability Services Directorate to provide advice on operational matters and local policy issues. Features of the partnership include:

- Memorandum of Understanding between MOH and a collective of the five DEASS
- co-leadership in specific projects to develop consumer standards to inform funding decisions
- monthly meetings of all partners
- commitment to the provision of independent advice by DEASS
- understanding by MOH that leadership and capacity of DEASS need to be built.

As DEASS are pilots there has so far not been any evaluation of their effectiveness.

As an example of the range of work undertaken by DEASS, the generic DEASS is managed by the Ripple Trust, a not-for-profit charitable trust with a board composed of people with disabilities. Ripple Trust is managing a project called the VIP Project (Valued, Included and Participating), a three-year process, begun in 2002, of implementing the New Zealand Disability Strategy in the Northern Region Locality of the MOH’s Disability Services Directorate.

Most staff are people with disabilities and a number of contractors are also used. Ripple Trust provides community advocacy on disability issues to Government, but also other agencies, such as service providers, local government and corporations. As well as taking up issues, Ripple Trust provides consumer representation using its staff or contractors.

It determines what issues are through focus groups and individual complaints, although it was set up to deal with these. It runs self-advocacy workshops.

Ripple Trust also provides Disability Impact Training for a range of public sector and increasingly private sector entities. The Trust trains the trainers to work with these entities (Ripple Trust 2004).

Ripple Trust works with the four other DEASS in the Northern Region as a collective.

The PIASS appears to be the first Pacific health or disability consumer organisation. The PIASS model, with its emphasis on the individual needs and rights of people with a disability, is challenging the Pacific traditions of families and elders as the level at which needs are addressed.

Disability has traditionally been invisible in the Pacific community, where it has been seen as bringing shame on families. In assuming a voice for disability consumers, PIASS also challenges the practice of Pacific providers representing communities.

Governance of the PIASS is through a board with a mix of disabled and non-disabled people, and there is also a mix among paid staff. While the philosophy is to try to provide service for disabled people by disabled people, this has not been possible so far. PIASS provides information and advocacy for disabled people and families, awareness raising and training in workplaces. PIASS has a seat on the Taikura Trust Board which provides needs assessment for services in the wider Auckland region.

Other initiatives

In 2003, the MOH commenced funding a comprehensive web site for people with disabilities, caregivers, family/whanau and health professionals. [www.weka.net.nz](http://www.weka.net.nz) provides up-to-date information about what is happening in the disability sector. The website is run by Enable New Zealand, a company which assists disabled people and others in the sector, and the New Zealand Federation of Disability Information Centres.
NGO and Consumer Activities

The disability sector differs from the health sector in that there are a number of very large well-established NGOs providing services for people with intellectual, physical and sensory disabilities. In some cases they are the sole or dominant provider of particular services. Whether these can be considered consumer organisations depends on the criteria that are established for consumer groups. Their histories differ, as do their structures and roles. Most see advocacy for the rights of their constituents among their core roles. IHC, for instance, was founded by parents of intellectually handicapped children. It provides advocacy and support for members and has grown into the largest provider of services to people with intellectual disabilities and their families. It has a membership base which elects a New Zealand Council. Another disability NGO is CCS, which was founded by Rotary. It is the largest provider of support and services to people with physical disabilities. It also advocates on behalf of people with physical disabilities. It has a membership that is not required to have a disability, which elects local executive committees and regional representatives to sit on the national board.

Most of the large disability NGOs who are service providers do not identify as consumer organisations and are not considered to be such by the Disabilities Services Directorate of the MOH or DPA. Traditionally, many have had governance structures consisting of public-spirited citizens and business people as opposed to people with a disability. However, some of these disability NGOs are shifting towards a more consumer-centred focus.

An example of this is the Royal New Zealand Foundation for the Blind which recently symbolically changed its name to Royal New Zealand Foundation of the Blind to reflect a new direction. Under the Royal New Zealand Foundation of the Blind Act 2002 it became a member-driven organisation and the Act provides for it to become an incorporated society at a later date. Members must be legally blind or guardians of vision impaired children. Nominees for the board of directors are not required to be vision impaired or members but currently the board contains a majority of partially sighted and blind people and family members.

The Foundation also has 40 Community Committees and funds and networks with nine consumer organisations, including the Association of Blind Citizens of New Zealand, with 1500 members the largest as well as the oldest disability consumer organisation in New Zealand, Retina New Zealand and Ngati Kapo O Aotearoa. All the organisations are national organisations and most have an office with at least a part-time worker. All rely on a great number of volunteers. Some carry out advocacy, others confine their activities to support. Some, like Retina New Zealand, are linked internationally. Retina New Zealand also has a research fund and student scholarships.

The Foundation is currently reviewing its relationship with consumer organisations to arrive at the most effective model and has examined models of consumer involvement in other countries (Boyd 2004). Since the change in governance in 2003, consumer organisations have had significant input into the strategic direction of the Foundation. Twice a year, the Foundation funds a Consumer Consortium which brings together representatives of consumer organisations.

The example of the Foundation demonstrates the complexity of determining whether an organisation can be defined as a consumer one.

Another example of large disability NGOs moving to a more consumer-centred approach is provided by CCS. CCS recently commissioned a study of the process and goal of community participation and the actual experience of service users of CCS, adults with physical disabilities. This is being carried out by the Donald Beasley Institute with co-investigators who include disability services consumers.
DPA was founded in 1983 as the umbrella group for people with all kinds of disabilities and disability organisations at national and local levels. It provides a collective advocacy voice for people with disabilities as well as providing information and advice on policies, and monitoring of laws, policies and practices. DPA is linked to two international organisations: Disabled Persons International and Rehabilitation International. DPA has 1300 individual members and 350 organisations belong. There is a national office with five paid staff. DPA has a business arm, Maxeq Consulting Ltd, which is able to provide consultants to private and public agencies.

DPA has a number of categories of membership: individual membership is for people with an impairment; family membership is for those with a child under 18 with an impairment; organisations of disabled persons; and organisations for disabled people. The latter are associate members and cannot stand for office in the organisation. DPA has an elected national executive committee and there are also about 40 local branches.

DPA considered the New Zealand Disability Strategy, ‘a landmark success’ and meets with the Minister for Disability every six weeks, as well as having relationships with the Ministry for Social Development and MOH. It provides consumer representatives for various national and regional government committees and processes and provides informal support for people taking on these roles. Regional assemblies meet regularly to network, provide support and mentor people. Most have a representative on the disability advisory committee of their DHB.

As well as DPA, there are a large number of national and local consumer organisations, focused on particular disabilities. Examples of this are Parent to Parent, a national support and information network for parents of children with special needs, and the recently formed People First, a national advocacy organisation run by and for people with intellectual disabilities.

2.5 SUMMARY

The report above has described the history, ongoing activities and new initiatives in the health, mental health and disabilities sectors with regard to consumer voice and participation.

There are striking differences in the way the three sectors have and are developing, and there is little connection between them.

The mental health sector has developed the system of paid mental health advisers that is fairly consistently applied throughout New Zealand, but there is recognition that this cannot substitute for a strong independent consumer sector to provide a voice for people with mental illnesses. Regional consumer networks are developing in an organised way and a national grouping is emerging through this network. In time a strong national voice for mental health consumers may emerge through this development.

At the government level the lead agency in this area is the Mental Health Commission which fosters and encourages the development of consumer participation and has issued a number of helpful reports and guidelines.

The disability sector has a recognised national consumer body in the DPA which also has local groups. There are also organised national groups for people with different types of disability. Some of these are long-standing consumer organisations, but other predominantly service provider NGOs are becoming more consumer focused.
A number of new initiatives have been undertaken by the Disability Services Directorate of the MOH and these have the potential to enhance consumer voices at a local level, especially for specific communities, such as Maori and Pacific, which have not had discrete voices.

In similar fashion to the Mental Health Commission, the Office for Disability Issues is fostering consumer involvement and is currently examining the possibility of a national disability consumer council.

By contrast, the consumer health sector is lagging behind. The mental health and disability sectors have a strong strategic framework, compared to health, where responsibility for engagement with consumers and communities has largely been devolved to DHBs and PHOs. Mental health and disability also have a lead government agency or ‘champion’ which is responsive to and supports the development of the consumer sector.

The health consumer sector is more fragmented and disconnected and more marginal with regard to influencing decision-making.

All three sectors are required to involve consumers as a result of legislative and strategic frameworks. The notion that consumers should be involved in making policy and planning services is more embedded in the mental health and disability sectors compared to health where recognition is intermittent and tends not to be sustained. There is no lead government or non-government agency which has the role of fostering consumer involvement in health.

There is an absence of practical mechanisms for identifying and communicating with consumer organisations. Each agency which wishes to communicate and engage with the consumer sector has to independently establish those links which is both inefficient and ineffective. The only guidelines are those developed by the MCA which, while helpful, are generic rather than specific to the health and disability sectors, and there are philosophical differences in the approach compared to Australia where consumer participation is well established.

A number of government and independent agencies such as ACC, Health and Disability Commissioner, New Zealand Heart Foundation and the New Zealand Guidelines Group are taking steps to include consumers but there is no coordination of these efforts, neither is there any central body to collect and disseminate information about what is going on. There is a similar pattern at the DHB and PHO level, although the PiPCO self-assessment tool project (Neuwelt 2004) is providing some guidance to PHOs.

There is little specific happening for consumers from Maori and ethnic populations. The recently formed PIASS appears to be the first specific Pacific consumer group in the health and disability sectors.

Looking at all three sectors, there is a lack of integration. There is no framework or mechanisms that would allow the sectors to easily communicate, share information or work collaboratively.

In all sectors there is a long-standing lack of resourcing to build the capacity of consumer organisations as a key ingredient in civil society. There are also specific unmet needs, such as training programmes, mentoring and support for people acting as consumer representatives, provision for networking among consumer representatives and consumer organisations, and mechanisms for distributing news and information among consumer organisations.
3 International Developments in Consumer Participation

3.1 AUSTRALIA

Australia is often regarded as the country with the most integrated and comprehensive approach to evidence-based consumer participation and support for a consumer voice at the national level.

The Australian system for consumer involvement has taken a different direction than any other country studied. It provides a strong national framework and evidence-base. The inauguration of the Consumers’ Health Forum of Australia, supported by the Commonwealth Government, and the establishment and funding of national agencies charged with fostering consumer participation with both providers and consumers has legitimated such activities to a degree that has not occurred anywhere else in the world. Participation activities that are still contested in other countries have been mainstreamed; they are increasingly embedded in the health sector. Furthermore, the existence and official support for a peak consumer organisation has validated consumer health organisations at all levels so that they are prioritised in consumer participation. The debates about representativeness that have occurred in other countries do not occur to the same degree in Australia. Involving non-aligned individuals, policies which are actively pursued in some countries, including at times New Zealand, are not part of the Australian scene.

As an example, all Metropolitan Health Service Boards in Victoria have a statutory requirement to establish a Community Advisory Committee. This is based on an acceptance that consumer participation is a democratic right, promotes social cohesion and improves health care quality and safety. The Victorian state government guideline for membership of Community Advisory Committees requires nominations to be sought for members ‘from peak bodies’ as well as advertising. Health care providers can attend meetings by invitation as a resource, but a clear majority at all meetings must be consumer/community members of the committee (Victoria Government Department of Human Services 2000).

Consumers are seen as having a valid role at all levels of the health system in Australia. Most states have a consumer council, advisory committees on specific issues, such as mental health, and there are rural health councils in many states. A strong evidence-base has been developed for such activities. Consumer involvement is not treated as an add-on or afterthought, but is an integral part of the health sector. Demonstrating an organisational commitment to community participation is a requirement of Australian health service accreditation programmes (Consumer Focus Collaboration 2000b).

History


The Whitlam Labour Government of 1972-75 emphasised a community development approach for the health sector. This resulted in the widespread establishment of community health centres in many
states, particularly Victoria, and federal funding support for NGOs. The regime also incorporated the ‘new left’ policy of participatory democracy in public administration (Short 1998; National Resource Centre for Consumer Participation in Health 2002). This direction was reinforced by events at an international level, when the Alma-Ata Declaration provided a framework for achieving this through an enhanced primary health care approach, including community participation.

During the 1960s and 1970s the women’s health movement’s emphasised consumer voice and this was influential beyond women’s health. A self-help movement emerged, particularly for disability and mental health consumer groups, which by 1984 were able to access funding from a Self Help Funding Programme. The Better Health Commission, established by Commonwealth Health Minister Dr Neal Blewett in 1986, recommended that all publicly funded health services be required to meet standards of good practice in community relations and patients’ rights, including involving communities in planning, policy and priority setting (National Resource Centre for Consumer Participation in Health 2002). In the early 1980s, people from the consumer movement, self-help movement and community health movement came together to put forward a proposal for a consumer-oriented health policy analysis and advocacy body. This became the Health Issues Centre in Melbourne.

In 1985 a coalition of nine consumer, community and medical groups petitioned Dr Neal asking for his department to be more accessible and responsive to consumers and to establish formal mechanisms for community participation in the Commonwealth Department of Health in line with the WHO primary health care policy. The Minister established a committee to review the department with four members of the department and four representatives of consumer and community health organisations. The Review Committee consulted widely and in late 1985 reported on the need for ‘a strong community lobby to provide the Department with guidance which would act as a balance to the representatives of the more traditional interest [health professional and industry groups]’ (Sylvan & Legge 1988, p 64). The review also recommended the establishment of an independent national health forum open to all community and consumer organisations, funded by the department.

Consumers’ Health Forum of Australia

A year after the review, 16 consumer and community organisations came together to create the Consumers’ Health Forum of Australia. The role of the forum was to:

- Establish a network of groups
- Improve communication between the community and government department of health and ensure greater access to the department and its decision-making role
- Provide a community voice on health issues and represent those views to the department and the minister
- Develop educational strategies and programmes to enable consumer and community representatives to be effective at advocating their point of view
- Distribute funds for and information about participatory and social action research.

Funding was provided by the Commonwealth Department of Health and the minister, Dr Blewett, instructed his department to consult the Consumer’ Health Forum on any major policy issues. His support is counted to be critical to the creation of the Consumer’ Health Forum. Although a number of health and social service groups supported the establishment of the Consumer’ Health Forum, there was a reaction from some medical groups, such as the Australian Medical Association, about the ‘abandonment of scientific principles in health care and the replacement by humanistic ones’ (Sylvan & Legge 1988 p 66).
Sylvan and Legge (1988) and Short (1998) identify a number of factors that enabled the creation and development of the Consumer’ Health Forum in its first decade:

- Visible social movements seeking participation
- International health policy context favouring a community-based primary health care approach
- Social and policy context that supported inclusion of the community in policy development
- A minister and key public officials who were supportive
- Government desire to move to a more community-based model of health
- Government need for more support for the Medicare scheme
- Consumer lobby could be an ally in reform of health care.

Specific advantages of the Consumers’ Health Forum were:

- Coordination of research and advocacy across consumer, self-help, environmental and welfare networks
- Ability to work intersectorally
- Communication channels from grassroots to national policy making
- A consultative network for developing consumer-oriented policies (Sylvan & Legge 1988).

A strength of the initial Consumers’ Health Forum concept was the relationship between the consumer organisation and research. A similar synergy, although differently organised, will be described in section 3.1 on the Canadian Women’s Health Network, page 146. On its establishment the forum was given a small budget of $AUS 60,000 for grants to consumer and community groups for research and development projects. This unique programme enabled consumer and community organisations to initiate and conduct their own projects according to their own assessment of needs and gaps. As a result, consumer representatives could be properly briefed and knowledgeable in their roles. Groups representing professional, government or commercial interests could not apply (Short 1998).

Between 1987 and 1992, 75 consumer research projects were funded by the Consumers’ Health Forum research development programme. This research underpinned the Consumers’ Health Forum policy advocacy work in Aboriginal health, maternity care, mental health, and aged care. As an example, funding enabled the Congress Alukura, an Aboriginal women’s organisation based in Alice Springs, to come together to a workshop to discuss the notion of ‘borning’ and knowledge of the Grandmother’s Law. Knowledge gained from this workshop and other sources, aided them in gaining government support for an Aboriginal Women’s Health Centre in Alice Springs (Short 1998).

Funding for the Consumers’ Health Forum research programme ceased in 1992 after a government review of community funding led to much reduced core funding for the Consumers’ Health Forum and many other major health and community organisations. Short explains that the programme was never popular with the National Health and Medical Research Council, some of whose funding was shifted to the forum, and because the forum developed its own ethical guidelines for research. The public sector was coming under the influence of managerialism which raised concerns about untied money going to community organisations, and the lack of direct accountability to the minister. There were also arguments within the Commonwealth Government that all research should be rationalised under one entity.

After the Howard Government came to power, it commissioned a Coopers and Lybrand review of funding of national secretariats of community organisations. From 1997, in line with corporatist and
new public sector management approaches, portfolio funding to national secretariats was much more closely linked to measurable outcomes relevant to provision of health and family services in the community. Increasingly the Consumers’ Health Forum funding was devoted to consultations with government about its programmes. Short sees this as demonstrating the shift from the community development to the managerialist approach to consumer participation in health policy development (Short 1998). Reports from the Consumers’ Health Forum make repeated mention of reductions in funding through the 1990s (Consumers’ Health Forum of Australia 2002). This has followed a shift in focus at a Commonwealth level from hospital care to primary health care. Many of the consumer participation activities in Australia were initially focused on hospital services.

Currently the Consumers’ Health Forum is almost entirely funded by the Department of Health and Ageing through the Community Sector Support Scheme. Funding is for governance, management and support staff, office costs, policy input, the representatives’ programme and communications such as the web site.

Membership of Consumer Health Forum of Australia
The Consumers’ Health Forum is governed by a Governing Committee which is elected by members from national, state and local consumer organisations. Current committee members include representatives from groups representing the following: state consumer councils, seniors, people with disabilities, rural consumers, breast cancer survivors, mental health survivors, social services and ethnic communities.

There are currently over 100 member organisations of the Consumers’ Health Forum. Voting members are organisations (not individuals) that meet the following criteria:

- They represent the interests of consumers on health matters rather than professional, provider or commercial interests
- Their membership is open to consumers or consumer organisations
- They can elect consumers or consumer organisations to the governing body of the organisation
- They fully support the aims and objectives of the Consumers’ Health Forum.

Associate members are organisations or individuals with an interest in consumer health issues. They cannot vote or participate in the formal mechanisms the Consumers’ Health Forum uses to consult while developing consumer policy.

Quality Use of Medicines Program
A major recent project of Consumers’ Health Forum is the Community Quality Use of Medicines Program. The forum has been advocating for such a programme for Australians for some time and recently the Commonwealth Department of Health and Ageing determined that a programme would be instituted to be managed by the National Prescribing Service, a not-for-profit independent organisation that provides services for all those involved in the prescribing process. On advice from the forum, the National Prescribing Service has established a management committee to oversee and guide the programme that is predominantly comprised of consumers which were selected through Consumers’ Health Forum processes.

The Consumers’ Health Forum also has a role in networking through communities to raise awareness of individuals and organisations, providing input into the development of appropriate testing methodologies for educational and information resources relating to consumer use of medicines information. The Consumers’ Health Forum’s involvement will be evaluated and used as a basis for decisions about funding after the end of 2005 (Consumers’ Health Forum of Australia 2004).
Since its formation the role of the forum has shifted from a community development model, based on its ability to commission research and development at the grassroots, to one where the major role is providing representatives for government advisory and consultative processes.

**Consumer Representation Programme of the Consumers’ Health Forum**

The most significant activity of the Consumers’ Health Forum is the Consumer Representatives’ Program. Australia is the only country in the world where representation is under the control of a consumer organisation. The programme provides for the selection, training and provision of consumer representatives to over 230 Department of Health and Ageing committees and working groups with a health remit. Short (1998) describes the system as “a “one-stop consultation shop” for the Commonwealth Department of Health and Family Services [now Health and Aging]” (p142). The forum advertises vacancies through its newsletter and interested applicants must be nominated through a member organisation of the Forum. A sub-committee assesses and selects from the applications. They are offered training, ongoing support and networking opportunities by the Consumer’ Health Forum. This large amount of activity, which is driven by the demands of health agencies, consumes a much bigger proportion of organisational resources than the Consumers’ Health Forum originally planned (Consumers’ Health Forum of Australia 2003).

The system of representation in Australia is different from that of New Zealand, where representatives are commonly not required to be part of a consumer organisation. The MCA nominations and representation programme specifically seeks people who do not represent organisations to serve on committees. In Australia, the principal of consumer representatives being accountable back to consumers through the Consumers’ Health Forum is well established and supported by the Department of Health and Ageing, although there have been difficulties putting this into action because of limited resources. Accountability back to consumers is reinforced by representatives being required to sign an agreement with the forum requiring them to do such things as regularly report back to the Consumers’ Health Forum (see [www.chf.org.au/consumer_reps_program/chf_agreement.asp](http://www.chf.org.au/consumer_reps_program/chf_agreement.asp) for a sample agreement). In New Zealand, where contracts exist, these will be with the government body, thereby implying a form of accountability to the government. This difference in approach reflects the existence in Australia of a national consumer body with responsibility for supplying trained representatives to government committees.

The Consumers’ Health Forum has developed considerable expertise in running a consumer representation programme and has published a number of very useful reports which explore what is needed to run a successful programme. They provide a very helpful resource for the formation of any similar scheme in New Zealand (Consumers’ Health Forum of Australia 2002; Consumers’ Health Forum of Australia 2003).

The Consumers’ Health Forum sought an independent review of the Consumer Representative Program which identified a number of problems and stresses, mostly the result of inadequate funding:

- Inadequate funding meant there was only one full-time staff member to manage the programme, including the nominations process, support, training, briefing and feedback for consumer representatives.
- The service is a low cost one with the cost of each committee member approximately $427 per annum compared to a minimum of $6000 for a comparable service in the private sector.
- The Department of Health and Ageing’s support for consumer representation is ad hoc. The department had no protocols or processes to ensure consistency in approach to such matters.
as remuneration, or timeframe for reimbursing expenses. This imposes a financial burden on representatives.

- There was a lack of clarity about responsibilities of consumer representatives to report back to the forum.
- There was a lack of face-to-face meetings with other representatives or the forum, because the organisation lacked funds.
- Lack of funds also meant the forum was unable to provide specialist advice on particular technical areas, such as pharmaceuticals (Chalkley Consulting with Artcraft Research 2002).

The evaluation made a number of recommendations including that:

- The Department of Health and Ageing appropriately resource the services it wished the Consumers’ Health Forum to provide
- The Department of Health and Ageing develop a policy and protocols on consumer representation to cover such things as how to find accountable consumer representatives, consistent sitting fees, and so on
- The Department of Health and Ageing develop training and information for committee secretarial staff
- The Department of Health and Ageing fund the Consumers’ Health Forum to provide training for consumer representatives including a training package for trainers, a resource kit for consumer representatives, training workshops in states and territories, and at least annual workshops for representatives
- With appropriate funding, the forum could strengthen its accountability procedures (Chalkley Consulting with Artcraft Research 2002).

The Consumers’ Health Forum addressed these and other issues by holding a workshop which was attended by around 50 consumer representatives (Consumers’ Health Forum of Australia 2002). Workshop participants effectively endorsed and fleshed out the findings of the external review and identified benefits, challenges and fundamentals for good practice in consumer representation. These were aimed at:

- Achieving a broader level of representation
- Improving the quality of representatives
- Achieving more effective involvement of consumers in improving the health system and influencing health outcomes.

As a result of the external review and the workshop the Department of Health and Ageing increased funding to the Consumer’ Health Forum to progress the actions identified at the workshop, particularly to increase training and support for consumer representatives. Among the improvements are the following:

- The Consumer’s Health Forum has updated its policy guiding the Consumer Representatives’ Program
- A new remuneration policy was developed to be used for secretariats including consumer representatives on committees
- Report-back mechanisms for consumer representatives have been improved
- The Consumers’ Health Forum improved its training and resource materials (Consumers’ Health Forum of Australia 2003).

Workshop participants also identified that the proliferation of consultation with individual consumers had distorted the focus of the forum. There had been:
‘a decrease in focus on organised, collective consumer involvement and the power of consumers working together through consumer organisations to influence the overall health system and health outcomes. More consumers know more about how a medical service should work for a particular illness, but the number of consumers knowing the difference between a health system and an illness system or working together to advocate policy at this level has not increased to the same extent’ (Consumers’ Health Forum of Australia 2003, p 13).

Thus, to some extent, participation had deskilled and depoliticised the forum. Despite these difficulties, the forum programme is more developed than any other elsewhere in the world and provides a good model, tested by experience, for New Zealand to consider. It would be worthwhile inviting a key person from the Consumers’ Health Forum to come to New Zealand to discuss this at some point.

The programme stills faces challenges in attaining sustainable funding.

**A Seat at the Table programme**

This consumer representation programme is an initiative of the Breast Cancer Network Australia, which is a major national group for breast cancer survivors with 100 member organisations and 9000 individual members. Breast Cancer Network of Australia is funded by fund-raising, pro-bonos and sponsorship, with an occasional contribution from the Office of the Status of Women.

A Seat at the Table is designed to place women and families who have been affected by breast cancer around the table when decisions are being made about policies and services. There are a number of components of the programme:

- A process for nominating, selecting and supporting women on committees. All nominations are assessed by the programme manager and the final selection is made by a panel who decide by consensus
- A secure database of consumer representatives used by Breast Cancer Network Australia to select candidates and monitor activity
- Guidelines and resources for consumer representatives
- Guidelines, resources and procedures for organisations requesting Breast Cancer Network Australia representatives
- Training for consumer representatives including participation in a Breast Cancer Advocacy and Science Training Programme
- A resource guide on the model that can be used by other groups.

Representatives are required to ‘speak for a defined group of consumers rather than express their personal opinions…. Breast Cancer Network Australia has a structure of support and consultation in place to assist its representatives and they are accountable to Breast Cancer Network Australia.’ (Breast Cancer Network Australia website). There has not been any formal evaluation of the ‘A Seat at the Table’ programme.

Breast cancer groups in New Zealand have been trying to establish a similar scheme in New Zealand.

**Consumer Focus Collaboration**

The Consumer Focus Collaboration was established in 1997 to strengthen the focus on consumers in health service planning, delivery, monitoring and evaluation. It was established on the recommendation of the Taskforce on Quality in Australian Health Care to progress work on
consumer issues in acute medical care. It was a national body with representatives from consumer, professional and private sector organisations, and all health departments.

With the Commonwealth Department of Health and Aged Care, the Consumer Focus Collaboration developed a Consumer Focus Strategy which funded projects to promote, integrate and disseminate information to increase consumer involvement in the health care system. Projects included:

- the establishment of the National Resource Centre for Consumer Participation in Health – see below
- the development of a series of publications
- the CAPPS programme which gave 22 small, time-limited grants to partnerships of consumers and health care providers to demonstrate good practice in consumer participation in all aspects of health planning, delivery, monitoring and evaluation. All the projects are documented and there is an important overview document summarises the evidence from these projects (Consumer Focus Collaboration 2003).

The Consumer Focus Collaboration was a three-year project which ended in 2001, with the National Resource Centre for Consumer Participation in Health taking over the role of distributing the publications developed by the Collaboration.

National Resource Centre for Consumer Participation in Health

The National Resource Centre for Consumer Participation in Health was set up by a consortium of the Health Issues Centre, the Women and Children’s Hospital, Adelaide, and La Trobe University in Victoria, funded by the Commonwealth government. Its role is to assist organisations to improve their strategies for involving consumers in their services and practices by providing advice and evidence-based strategies. The centre is not a consumer organisation and it was intriguing to note that consumers are frequently not involved in projects, such as literature reviews, or, where they are, they are very much in the minority.

The National Resource Centre provides easy access to published research and projects about:

- Different methods for obtaining consumer feedback, associated tools and their cost
- Different strategies and approaches to consumer participation
- Associated organisational change processes.

There is a huge and impressive range of documents available on the National Resource Centre for Consumer Participation in Health website some of which were developed by the Consumer Focus Collaboration. Around 5,000 visitors (counted as people who go beyond the homepage) visit the website monthly (National Resource Centre for Consumer Participation in Health 2004). The papers cover such things as:

- Guidelines for running workshops for consumers
- Payment for consumer representatives
- Evaluations of projects
- Resources for organisations wishing to involve consumers
- Communicating with consumers through health information
- Self-assessment tools for services
- Literature reviews
- Education and training for consumer participation.
The centre also provides training on consumer participation, project work, consultancies, and a telephone advisory service.

Commonwealth funding for this service including the web site ran out in June 2004. The Centre is seeking new funding and so far has had limited funding promised from New South Wales and South Australia. In the meantime the Centre is providing a limited number of services (National Resource Centre for Consumer Participation in Health 2004). (Note: This service closed on 1 October 2004.)

Implications for New Zealand

Potential benefits

Getting started

• The support of key government ministers and/or officials is an important element in strengthening the voice of consumers nationally.
• Cross-sector support that is wider than consumers is helpful in gaining support for a national consumer body.
• Health policy that adopts a social model of health and a community development approach provides the context for strengthening consumer voice.
• The government has funded research into participation and created centres of excellence that disseminate information to provide a strong evidence base for participation. There is a partnership approach between these agencies and consumers.
• There are evidence-based guidelines for participation that assist health agencies in setting up programmes and processes.
• The government funds a peak consumer body to strengthen the consumer sector and as a focal point for consumers.

What a ‘peak’ consumer body can achieve

• The Consumers’ Health Forum provides a model for New Zealand, especially in terms of roles, structure and membership.
• The linkage between research and consumer voice provides an evidence-base for practices in consumer involvement.
• There are clear advantages in having a peak national consumer organisation in terms of influencing government, promoting consumer issues and negotiating with government on behalf of consumers.
• A national consumer organisation provides an efficient and effective means by which government can engage with and involve consumers.
• An adequately funded national consumer body can provide a comprehensive high quality consumer representation programme.

What an effective ‘peak’ consumer body needs

• Sustainable funding is critical to the continuance of consumer organisations and the quality of their work, as well as agencies supporting consumer participation.
• Stability in terms of ongoing government support.
• Acceptance of the role of advocacy.

Needs of representation programmes
• An effective consumer representation programme has complex needs, including selection, training, support, resource development, opportunities to network, succession planning and accountability processes.

• Nominations processes must be transparent, fair, and democratic. Even then it is difficult to involve groups which are disadvantaged because of socio-economic status or illness.

• For effective representation, a government health agency needs to be committed to consumer representation, have policies and protocols, staff training, resource and remunerate consumers and evaluate regularly.

Potential pitfalls

• Funding and government demands can distort the priorities of consumer organisations. There is a tension between funding sources and autonomy.

• The growth in consumer representation practices has coincided with a loss of collective consumer advocacy.

3.2 UNITED KINGDOM

Government Activities

More than any other country, the UK has attempted to involve the public, as citizens and as patients, in health care decision-making. Since the mid-1970s, a variety of means have been used to systematically foster involvement in an organised and relatively prescriptive way. What distinguishes the UK system is its top-down, nationalised approach, requiring local trusts, consumer organisations and communities to fit in to a prescribed design (Milewa et al 1998).

Efforts have also been distinguished by periodic major shifts in policy, driven from a national level, and relatively few attempts to evaluate effectiveness.

There is not the room here to go into the history of public participation in the UK, but Hogg (1999) argues that the recent direction of the UK Department of Health grew out of initiatives of Community Health Councils that were created as statutory bodies in England and Wales in 1974.

Pickard and Smith (2001) distinguish two types of lay involvement that have occurred in the UK. Firstly, the consumerist framework that relates to market relationships as found in the private sector. This emphasises the rights of consumers to access, choice, information and complaint in relation to specific services. The focus is on the patient, consumer or carer. Initiatives within this framework include the Patient’s Charter, complaints procedures and Patients’ Participation groups which centre around general practice.

The second framework is the citizenship or democratic approach that relates to people as citizens and taxpayers with rights to access healthcare, but also duties to participate or contribute collectively to society. Mechanisms that can be placed within this framework are Local Voices, Citizens’ Juries and Community Health Councils.

Both frameworks continue to co-exist in the UK health system. Patient and citizen involvement are central to the most recent NHS reforms and modernisation process. The reforms build on earlier policies that emphasised the importance of involving patients and the public in decision-making about the shape of services they receive (Department of Health 1997). The Inquiry into the Bristol
Royal Infirmary gave additional impetus to these developments (Department of Health 2001b), in a similar way that the Cervical Cancer Inquiry led to reforms in patients’ rights in New Zealand.

The new UK reforms, brought in by the Health and Social Care Act 2001, are designed to integrate the views of patients and citizens through every level of the NHS, bringing the patient voice ‘inside’ the NHS as opposed to keeping it ‘outside’ (Department of Health 2001b). The Department of Health believes these changes will:

- Strengthen accountability to local communities
- Speed up change
- Create patient responsive services (Department of Health 2003a).

Patient and citizen involvement will be delivered through a multi-tiered, highly structured framework to develop a ‘patient centred service where patients are seen as active partners in their care’ and local communities are involved ‘in the design, delivery and development of local services’ (Department of Health 2001a, p 12). PCTs are seen as the leaders in the reorientation of the NHS and the main place for consumer voice is at this level. This devolved approach has some similarities to the current round of New Zealand reforms except that it is a more prescribed and integrated approach and it requires citizen involvement by statute, as opposed to by policy and encouragement as occurs in New Zealand (National Health Service 2003).

Individual consumer-focused initiatives

Four recent examples of individual consumer-focused innovations are:

- Expert Patients Programme (EPP)
- Complaints Advocacy Service (CAS)
- Patient Advice and Liaison Service (PALS)
- Providing choices for patients in the NHS. This will not be discussed further in this report but further information can be found in Building on the Best, Department of Health UK (2003b).

Expert Patient Programme

The EPP (Department of Health 2001c) is a NHS-based training programme that provides opportunities for people with long-term chronic health conditions ‘to take effective control over life with a chronic condition’ by using their own skills, information and professional services (www.expertpatients.nhs.uk/about_whatpatient.shtml). The rationale for the EPP is the acknowledgement that the predominant pattern of disease in the 21st century is of chronic rather than acute disease. Unlike many of the other period innovations made by the NHS, there is a strong evidence-base for this approach as research in a number of countries including UK, USA and New Zealand over two decades has shown that people can improve their health and quality of life through self-management skills.

Much of this research can be found on the Stanford Patient Education Research Center web site at http://patienteducation.stanford.edu/main.html which is linked to the Expert Patients’ Programme

EPP is being introduced over a six-year period. In the pilot phase between 2001 and 2004 local programmes will be evaluated. This work is being carried out by a number of centres, including a major study by the National Centre for Primary Care Research and Development with the Universities of York and Manchester. Results are expected in 2005. A small multi-disciplinary Implementation Group within the NHS is managing the pilot programme implementation. Interestingly, this group contains no consumer representatives, although the Long-term Medical Conditions Alliance is playing

New Zealand Guidelines Group
an important role in the project. There is more about this in the Long-term Medical Conditions Alliance see section 3.2, page 104.

Between 2004 and 2007 it is intended to mainstream EPP through NHS services, PCTs and patient organisations and to establish a National Coordinating and Training Resource (Department of Health 2001c).

There have been criticisms that the EPP will only reach a minority of patients who have the personal resources to access the programme. Surveys of doctors show that many have reservations, especially as they fear articulate patients will take up more time. Actual randomised controlled trials have shown a reduction in visits of 42-44% and improved use of self-management behaviour such as exercise (Shaw & Baker 2004).

Patient Advice and Liaison Service

Patient Advice and Liaison Service (PALS) is a new initiative for NHS trusts to:

- provide on-the-spot advice and help for patients, carers and families about services
- refer patients with complaints to CAS
- act as a catalyst for change and improvement in services by providing reports to trusts, clinical governance and quality departments
- support all staff to develop a PALS culture.

The Department of Health intends to evaluate PALS.

Complaints Advocacy Service

Another initiative for individual patients is the new CAS which will provide advice and support for people wishing to make formal complaints. Provision of CAS is being contracted to voluntary sector providers and it is intended that these will be managed by the Commission for Patient and Public Involvement in Health.

Citizenship initiatives

Other UK government initiatives fall within the citizenship or democratic framework and are of most interest in this report. These are:

- Commission for Patient and Public Involvement in Health (CPPIH)
- Forum Support Organisations (FSO) originally called Local Network Providers
- Patient and Public Involvement Forums (PPIF)
- Primary Care Trusts and Foundation Trusts
- NHS Live, a year-long programme, launched in July 2004, to run projects to involve patients in redesigning services. This is run in partnership with private sector sponsors, including a number of pharmaceutical companies. It will not be discussed further in this report.
- National Institute for Clinical Excellence (NICE) Patient Involvement Unit (PIU)
- Government advisory committees.

The Department of Health initiated a research programme to inform these developments called Health in Partnership. The findings of the 12 studies were not available until after the structures described above were established. The majority focus on patient and carer involvement in decisions about their own care. Four studies focus on public involvement in service planning and delivery. They are discussed in the section above (Department of Health & Christine Farrell 2004).
Commission for Patient and Public Involvement in Health

Consumer health organisations played a big part in advocating for the CPPIH. They argued that there must be a national body to enable consumer influence in policy-making at a national level (National Consumer Council 2002b). The CPPIH emerged from the recommendations of a study group set up by the NHS that included the Long-term Medical Conditions Alliance (LMCA), Patients’ Forums and the College of Health. CPPIH is designed to provide ‘a national means of ensuring the consistency and effectiveness of patient and public involvement across the country’ (Department of Health 2001b p 12).

CPPIH was established in January 2003 to give the public a voice in decisions that affect their health, and the health of their local community. It is described as an ‘independent non-department public body’ funded by the Department of Health, reporting to the Secretary of State. There are 10 commissioners, a chair and a chief executive. The commissioners come from diverse backgrounds including academia, social services, NHS trusts, and a minority from patient organisations.

The Commission has responsibility for producing and implementing standards and quality control for Patient and Public Improvement Forums. The CPPIH will collect information from the PPIF and making recommendations to the Secretary of State for Health and other bodies. It will also report to the Secretary of State for Health on how well the new system for patient and public involvement is working.

The CPPIH has contracted nine regional centres (Strategic Health Authorities) to manage Forum Support Organisations who support PPIF. There are actually four layers in the framework, CPPIH, Strategic Health Authorities, Forum Support Organisations, and PPIF.

Forum Support Organisations

FSO are voluntary and community not-for-profit organisations who will support the development of two or more PPIF. They will be contracted to the CPPIH to provide, training, knowledge, management and administrative support, independent of the NHS but they will report to a regional centre. They are also to help forums communicate with each other and external organisations, ensure information and support from the CPPIH is available to forums, help them monitor NHS services, and assist them to take an active role in local decision-making in health.

Patient and Public Involvement Forums

PCTs already have consumer representatives on their governance boards but this new initiative sets up separate forums called Patient and Public Involvement Forums. There are some 571 PPIF, one for each PCT and NHS trust in England.

The PPIF replace 184 Community Health Councils that were formed under the 1973 reorganisation of the NHS. The role of Community Health Councils was to support individual patients and complainants, monitor local services and represent consumer views to health authorities so that these views could be taken into account in the design of health services (Butler 2003; Seale 1993).

Every health authority had a Community Health Council but they encountered a number of problems: their role was never clear and was regularly altered; budgets were small; their right to be consulted was limited; and their existence was tentative as successive governments suggested they were unnecessary and even tried to disband them. In the late 1980s, Community Health Councils lost the right to attend meetings of boards of local health authorities. A review by Lupton et al (1995) found that there was widespread view that Community Health Councils influence was mainly limited to fairly marginal issues, such as quality assurance, and that their role was ultimately to legitimate

The PPIF are to be the ‘new independent voice for patients and the public’ (Commission for Health Improvement 2001). They will be made up of local people and will monitor and review day-to-day service delivery by the NHS trusts and PCTs from a patient perspective, including seeking the views of consumers. They will have legal powers to inspect premises, make reports and recommendations and refer matters of concern to other agencies including the CPPIH and the National Patient Safety Agency. They are able to have a non-voting representative on trust boards.

**Primary Care Trusts and Foundation Trusts**

Primary Care Groups were expected to transform into PCTs by 2004, with a dominance of lay members on the board, however, the executive committee of each trust has a majority of professional members. PCTs are required by legislation to involve and consult with patients, carers and the public – not just when major change is proposed, but in the development of programmes and service delivery (Commission for Health Improvement 2004).

Foundation Trusts are a new innovation. The first 10 Foundation Trusts came into being on 1 April 2004. These are hospitals that are ‘independent public benefit corporations’. They are not subject to the same financial and operational constraints as other hospitals within the NHS, being able to make decisions locally and borrow from the private sector. The Secretary of State is unable to intervene in the running of a trust unless it is failing. www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicy/SecondaryCare/NHS.

Foundation Trusts are another tool by which the government hopes to deliver ‘decentralisation and democracy’ (Klein 2004, p1332). Governance of Foundation Trusts is through a board of governors most of whom are elected by ‘members’. Members are local people who have registered and are then entitled to vote for governors to represent the public and patients. They are legal owners of the trust. The model is similar to that of a friendly or mutual aid society. Staff also elect some governors.

**National Institute for Clinical Excellence Patient Involvement Unit**

This initiative predates the latest round of NHS reforms. The National Institute for Clinical Excellence (NICE) was established in 1999 to promote clinical excellence and effective use of resources in England and Wales. It has a close relationship with the New Zealand Guidelines group. NICE develops evidence-based guidelines for providers, patients and carers and has a policy to include at least two consumers on each guideline group. Since 2001 NICE has funded a Patient Involvement Unit (PIU). The role of the unit is to advise on and support patient involvement in the development of NICE guidelines and audit products (Kelson 2001b).

This is the first time that a systematic approach to patient/carer involvement in guideline development has been attempted in England and Wales. The PIU and NICE intend to work with patient organisations and patient representatives to evaluate the effectiveness of their processes. (Kelson 2002).

The role of the PIU is to provide advice to guideline and audit teams; advise NICE Guidelines Advisory Committee; identify patient and carer organisation stakeholders for individual guideline and audit topics; provide advice and support to patient and carer organisations interested in contributing to NICE processes; facilitate interaction between NICE and patient/carer organisations; and review NICE processes from a patient/care perspective. The PIU suggests methods for patient involvement to collaborating centres; assists with identification and nominations for potential patient/carer participants; and provides advice, support and training to patient/carer representatives. Specific
functions include identifying patient/carer organisations that NICE will invite to register as a stakeholder; for each guideline topic, facilitate a patient/carer meeting for registered stakeholders; support the nomination process; and provide training (Kelson 2001b).

Although NICE decisions are based on evidence provided by clinicians, researchers and ‘patient experts’, they are set against a background of social values and judgements. This is the role of the NICE Citizens’ Council which has 30 members drawn from varying sections of the population. It brings the views of the public to NICE decision-making. The council meets twice a year in 3-day sessions and members deliberate on questions put to them by the NICE Board. These meetings are open to the public. The NICE Citizens’ Council had its first meetings during 2003 and there has been some criticism of the type of questions that it is being asked to address (Dolan et al 2003). The Citizens’ Council is not representative of consumer organisations and has no role in its own right.

NICE also has a Partners’ Council that includes 10 ‘patient advocates’ – these are mainly representatives from consumer organisations such as the National Consumer Council and the Long-term Medical Conditions Alliance (see below). The Partners Council meets annually to review the NICE annual report and is a source of advice for NICE.

Government advisory committees

The Department of Health includes patient and consumer representative organisations on committees and working groups, especially those involving policy reforms. The NHS Information Authority runs a public reference group which is a virtual group of around 500 individual consumers who contribute in many ways, including taking part in consultations, surveys and focus groups, testing products and services, critiquing external communications, sitting on boards and advisory groups and so on. An evaluation on the impact of the public reference group by the National Consumer Council found that the group was valued and used by staff, but there needed to be more formal acknowledgment and support for the group (National Consumer Council 2002b).

Consumer Activities

As a strongly nationalised health system, with universal access to free health care, much of the attention of consumer organisations in the UK has been on improvements in the NHS, particularly at a trust level. There is a wide range of disease-focused consumer organisations, but much of the energy of potential consumer organisers has gone into the Community Health Councils, and will probably continue to be directed at the PPIF and Foundation Trusts. Whereas in most Western countries, women are strongly organised around their particular health needs, apart from maternity, women in the UK have only recently begun to network at a national level.

The voice of consumers is not strong at a national level, and consumer input into public structures diminishes as the health sector hierarchy is ascended.

Consumer organisations have generally not supported the major restructuring that is occurring. Apart from the EPP and the CPPIF, it has not been driven by consumer organisations. When the King’s Fund held a workshop for health and social care service user organisations in 2002, there was a great deal of suspicion about the changes and participants made a number of points about the government model:

- Users of services, especially marginal groups, supported the use of existing consumer organisations as their voice as opposed to new statutory bodies. More support should go to existing consumer organisations as opposed to new statutory bodies. People were confident with existing user groups.
Consumers were worried PPIF would not represent local communities as existing appointments by NHS tended to favour the middle class.

There was a need for national networks of consumer groups to coordinate views and influence national policy.

Experience had shown that consumer views were often not respected or taken notice of. There needed to be a culture change and more support and training for staff in the NHS to be more responsive to consumers (King’s Fund 2002).

The main national consumer organisations in the UK are the LMCA, the Patients’ Forum, the Patients’ Association and the generic consumer organisations, such as the National Consumer Council. New Zealand does not have any parallel for the Patients Association. This has a national office and a Council of Trustees elected by members. The current president is a former ‘Agony Aunt’ and nurse. Anyone can become a member and the most recent appointments of trustees were of non-consumers: a consultant physician and a practising dental surgeon. The Patients’ Forum is a network of national and regional health groups who make up members who can vote for a management committee. Providers can be non-voting members.

Long-term Medical Conditions Alliance

Founded in 1989, the LMCA is the largest consumer health group in the UK and is similar in structure to NZORD. It is an umbrella group for 116 national voluntary organisations with long-term medical conditions. There are about 500-1000 other similar groups that are not part of the LMCA. Other bodies and corporate supporters can be associated members. There are around eight staff and a board of trustees that selects new trustees.

The LMCA provides services and support for members and provides a public voice for consumers with chronic illnesses in partnership with its member organisations. In its method of working, it does not seek to replace its constituent organisations, but works in partnership with appropriate organisations on particular tasks. Although not well resourced, the LMCA is funded by government (45%), subscriptions, private grants, and corporate sponsorship, including pharmaceutical industry sponsorship. A recent Annual Review of the organisation applauded the current enthusiasm for patient involvement, but noted: ‘now we need the funding base of voluntary sector organisations to catch up with these expectations!’ (Long-term Medical Conditions Alliance 2002).

LMCA provides representatives for consultative committees, such as the NICE Partners Council, General Medical Council Patient Reference Group, and a number of NHS bodies. The organisation has a policy on the method for appointment of representatives, which are drawn from the LMCA Board, staff or member organisations. The organisation keeps a database of prospective representatives and the selection is made by the director and policy officer.

The LMCA plays a very sophisticated and strategic role, concentrating on engaging with and influencing the Department of Health and NHS at the highest level. It has been adept at identifying and pursuing key goals for its members. During 2003 it put a great deal of energy into successfully gaining recognition of the needs of people with long-term conditions in the development of the National Service Framework. It positioned itself by gaining representation on the External Reference Group advising the department on the framework. In addition, a policy analyst from the department was seconded to the LMCA to help engage voluntary organisations in the development of the new framework standards. She led consultations throughout the country and the findings were able to be fed into the development of the framework.

The LMCA played a lead role in the genesis of the EPP. This initiative provides a successful example of the role consumer organisations can play in leading and modelling innovative developments in the
health sector. The LMCA developed a programme of lay-led ‘self-management’ which was carried out through the Living Well project. The LMCA was contracted to act as the interim EPP national resource providing support to PCTs and EPP trainers until the scheme was established. Ultimately, LMCA has been successful in convincing the Department of Health that the rolling out of EPP would succeed only if it was done in partnership with voluntary organisations representing patients with long-term medical conditions. Since November 2003, Jane Cooper, the LMCA’s director of self-management has been working two days a week with the EPP, focusing on enhancing the partnership with the voluntary sector and the development of a good infrastructure.

In 2003 the LMCA distributed over 20,000 self-management resource packs, organised and ran the first assessor training course with the EPP. The NHS was next awarded a contract with the NHS Information Authority to look at the feasibility of delivering self-management online.

The LMCA credits part of its success to the good relationship it has established with Harry Clayton, director for patients and the public in the Department of Health, who oversees the EPP. The LMCA says Mr Clayton is ‘wholeheartedly committed to patient organisations playing a central role in the EPP as it moves towards “mainstreaming” of self management in the NHS’ (Long-term Medical Conditions Alliance 2002, p 11).

Training for consumer representatives

Training for consumer representation is provided by several organisations. The British Heart Foundation started providing training in mid-2003. The programme is called Hearty Voices and it aims to have a nationwide network of trained representatives. One-day training sessions are held in different parts of the UK and there are staff to provide ongoing support. In November 2003, the British Heart Foundation held its first National Patient and Carer Conference.

The National Consumer Council has a particular focus on health and runs a training programme for consumers and consumer representatives called Stronger Voice. This programme trained over 400 Community Health Council representatives and is now involved in training people for PPIF. A programme specifically adapted for the forums was piloted in 2002.

- The course involves 15 hours of training in five sessions:
- Why representatives are important – what is a consumer, why do people need to be represented, the role of a representative
- Being a representative – the role, skills and knowledge participants need, who they represent and their relationship with the provider
- Knowing your group and allies – building understanding of the groups the person will be working with
- Skills and knowledge – how to identify the needs and concerns of consumers, prioritise issues, how to effectively raise these at meetings, how meetings work
- Developing your strategy – setting realistic goals and planning a course of action.

Stronger Voice is a toolkit that can be used by local trainers, who undergo an induction course and are licensed. Currently this course is not available outside the UK but because of requests (including this one!) the National Consumer Council has decided that it will be possible to license someone to run the courses in other countries. More information is available on the National Consumer Council website: www.ncc.org.uk/SV_Main/index.htm.

Another initiative worth noting is the Health Voice Network which is a web based networking tool for consumers, organisations and staff working in health. It is particularly focused on community involvement in health. It is funded by the Department of Health (50,000 pounds) and managed by
the UK Health for All Network. There are 1200 members. An evaluation showed that participants particularly valued the ability to post questions by email and receive response from others in the network. Members did not value as highly other aspects of the network including the website and newsletter. Lack of time was given as a reason for not using the website [Siddiquee 2003; Close & Newey 2004].

Analysis of Consumer Participation in the UK

Public involvement in the NHS decreased in the post-War period until new policies were adopted in the 1990s, particularly as a result of the election of the Labour Government in 1997 (Florin & Dixon 2004). This latest round is the most radical and far-reaching and current changes are seen to be addressing a long-standing ‘democratic deficit’ in the NHS (Klein & New 1998).

Criticisms of the approach include:

- The lack of clarity and consensus around what patient involvement means, and whether the current policies will meet the desired objectives
- The potential for duplication and divided accountability as providers are ultimately accountable to the Secretary of State, but are expected to be responsive to local forums
- The need for democracy to be balanced by fairness and equity; it remains to be seen whether local democracy can achieve this [Klein & New 1998; Florin & Dixon 2004].

In developing a more patient-centred NHS, the emphasis is on mandating public involvement, but there is little attention to changing the culture, attitudes and behaviours of managers and health professionals, even though these have been persistently identified as barriers to consumer participation (King’s Fund 2001; King’s Fund 2002; Gillespie et al 2002).

Primary groups do not have to become PCTs until 2004, so it is too early to say whether the muted lay voice found on the earlier entities is remedied by the increase in lay members of PCT boards (Pickard & Smith 2001). Likewise, the CPPIH was established in January 2003 and PPIF were formed on 1 December 2003, so it is too early to say whether the UK approach will make a positive difference. The Commission for Health Improvement, which monitored the implementation of patient and public involvement, was wound up on 31 March 2004 and its functions were taken over by the Healthcare Commission. The Commission for Health Improvement was able to inspect health services and assess the quality of care including what they were doing in patient and public involvement. Its reports showed that while there was a great deal of activity, it was having a limited influence on policies and the learning was not being shared within or across organisations (Commission for Health Improvement 2002; Commission for Health Improvement 2004).

The sheer scale of the change means that it will take some time to become fully functional. The restructuring wound up the 30-year-old system of Community Health Councils before the new system was up-and-running and there have been criticisms of the loss of capacity and personnel that accompanied the changeover. The timeframe is short, and there does not seem to have been a great deal of thought given to the training needs of the thousands of people taking on new roles or to the accountability mechanisms for people who are expected to represent communities. People interested in being on PPIF registered their interest as individuals and there have been predictable arguments in local areas about whether to prefer ‘pure consumers’ not attached to organisations as opposed to nominations from consumer organisations. There is plenty of scope for wide variations to emerge in the makeup, functioning and roles of the PPIF, Foundation Trusts and FSOs.

The approach being taken by the Department of Health is very structured and prescriptive, but this does not necessarily mean that there is clarity about roles and the interfaces between a multiplicity of
agencies. It is not clear either whether there is any built-in monitoring or evaluation of the new structures although there is a Performance Improvement Framework for patient and public involvement (NHS 2003).

Other criticisms have centred around issues of under-funding of the CPPIH, duplication of roles and responsibilities and the choice and location of organisations given the role of FSOs (Butler 2003b; Muir 2003; Secretary of State for Health 2003).

In April 2004, the chair of the largest PPIF, the London Ambulance Service patients’ forum, complained that there was a lack of resources, facilities and infrastructure. There have been complaints that the FSOs have refused to make public the membership of PPIF. Many PPIF are not up to strength because of difficulties recruiting members. Eventually it is proposed to have 5,720 members – at least ten members per forum (Gould 2004).

The National Consumer Council (2002b) has made a number of recommendations to try to ensure that the CPPIH and PPIF are effective, including adequate resourcing, consumers to be involved in defining measures and standards against which the new NHS will be judged, clarification of the roles of ‘lay’ people, consumer involvement not to be ‘tacked on’ but to happen from the beginning (p 9).

In May 2004, 900 PPIF members from all over England took part in 25 regional events organised by the CPPIH to discuss the Department of Health’s consultation document Choosing Health. Recommendations that emerged from the forums were for bans on smoking in public places and tobacco advertising, use of alcohol taxes to fund health initiatives, nationally consistent sexual health education in schools, a shift towards prevention in health services, and for people to take more responsibility for their own health, with Government providing information and support. There was nothing new about the results of this consultation, and the exercise seemed to be more of a public showcase for the possibilities of PPIF.

Concerns have been raised that the elected boards of Foundation Trusts may duplicate the role of the PPIF and that in some areas, the role of the PPIF may be made redundant. As an experiment in democracy, the experience of Foundation Trusts so far, although short, is not reassuring. In one election, only 2% of the eligible population registered as members and only 1% voted. Similar disinterest has been shown at staff elections where the turnout has been less than 10%. Only specialist hospitals have been able to attract a large and active community (Klein 2004).

It also remains to be seen what affect the PPIF and Foundation Trusts will have on existing consumer organisations. With so many positions to be filled, the new structures may drain talent from existing community organisations, and undoubtedly their time will be devoted to making the new system work.

It is clear that the model has not been sought by consumer organisations and the option of strengthening existing patient/consumer organisations has not been considered, but it is the preferred option for consumer organisations.

The overall picture that emerges from the UK is one of frustration, scepticism and in some areas, apathy (King’s Fund 2002; Klein 2004). Others argue that the experiment needs time. Florin and Dixon (2004) describe the changes as piecemeal and disparate and point to the lack of an evidence base for many of the new methods. There is limited partnership or consumer participation at the national level to provide consumer input into macro policy. This is only occasionally remarked on (King’s Fund 2002; Lapsley 2004) and confirms the impression that the consumer voice in the UK is quite muted the higher one goes up the hierarchy. At the national level there is a reliance on elected members of Parliament to provide democracy and accountability.
This observation must be tempered by the success of the LMCA in engaging at the national level and in succeeding in establishing a rare example of partnership between national health policy-makers and the consumer sector.

**Implications for New Zealand**

Despite the rhetoric of local control, how this is occurring in the UK is very centrally driven and proscribed. The NHS is unique amongst health care systems in the Western World in that it is predominantly funded from taxation and is the direct responsibility of central government. While this has some similarity to New Zealand, in this country primary health care has traditionally been organised as private businesses and private insurance plays a significant role. The recent round of restructuring being carried out by the Labour Government is modelled to some extent on the NHS model. The New Zealand devolution model has similar ideological roots to the ‘local democracy’ model of the UK. New Zealand PHOs have similarities with UK PCTs, but it remains to be seen how much the overlay of not-for-profit will alter the ethos of primary health care in New Zealand. Neither is there any parallel for the elected DHBs in the UK model.

The UK has a much more public service culture in health so that it is possible to carry through radical changes in policies and structures. Consequently, the restructuring, while interesting as an experiment in democratisation, does not seem to offer many lessons for New Zealand. Indeed, it is notable that when consumers have been consulted about the government model, they have said they would prefer greater recognition of existing consumer organisations and strengthening these at a national level, rather than the establishment of new statutory bodies.

**Potential benefits**

**Government roles**

- The UK demonstrates a high degree of government commitment to participation and to providing consumer-centred health services. It is prepared to countenance major changes in the way health services are delivered.
- While responsibility for participation is devolved, there is central oversight of progress. The inspection function of the Commission for Health Improvement has provided a way of auditing health service providers to measure the degree to which they are implementing consumer participation.
- These inspections provide baseline information against which progress can be measured, and they allow learning to be shared across the health sector. They also provide accountability to the public for the effort they put into participation.
- A national body has been given responsibility for ensuring that patient and public involvement occurs in a way that ensures effectiveness.
- The government funds research into consumer participation and distributes the results.

**Consumer experiences show that:**

- Government programmes can be delivered in partnership with voluntary agencies.
- Partnership is more likely when there is a ‘champion’ in the system with whom to establish a good relationship.
- There is a need for a national consumer body to coordinate consumer organisations and strengthen consumer voice at the national level.
• Modelling innovative practices within the consumer sector can lead to their adoption through the health sector.
• The National Consumer Council Strong Voices consumer representative training package and infrastructure should be investigated further to ascertain whether it would provide the basis for a similar training programme in New Zealand.
• The structure and method of working of the Long-term Medical Conditions Alliance provides some model features for a New Zealand umbrella organisation:
  • Representatives for external committees are drawn from both within the LMCA structures or from member organisations using a published policy. Interested people can put their names on a database for selection. They report back and are provided with support.
  • The LMCA works in partnership with its own constituent groups on particular projects, providing opportunities for them to take leadership roles
  • It adopts a high-level strategic role in campaigns it conducts while providing a great deal of practical support for constituent groups.

Potential pitfalls
• A prescriptive, government directed approach to involvement may not guarantee success and may weaken the consumer sector.
• Partnership and participation needs to happen at all levels of the health system, not just at the devolved level.
There is no national body for health and disability consumers in Canada, although some major
groups are currently discussing this with Health Canada, the government health agency. The other
relevant government agency is the Office of Consumer and Patient Involvement (OCAPI).

Government Activities

Office for Consumer and Public Involvement

The Office for Consumer and Public Involvement (OCAPI) is part of the Health Products and Food
Branch (HPFB) of Health Canada. The initiative is designed to support and encourage effective
public involvement to enable Health Canada to deliver programmes, launch new initiatives and
build public trust. OCAPI provides information and opportunities for Canadians to be involved in
decision-making regarding priorities, policies and programmes. The HPFB focuses on food, nutrition,
biologics, gene therapy, therapeutic products, and natural health products.

In 2002, to increase transparency and involve the public, the HPFB established a Public Advisory
Committee to provide advice from a consumer perspective on issues as requested by HPFB. The
Public Advisory Committee is to provide guidance to OCAPI and the HPFB related to planning and
managing public involvement activities and to advise on effective communication with the public.
Committee membership is wider than consumers. It is made up of health professionals, alternative
therapists, academics, community-based lay people, ethnic representatives and others. HPFB also
intends establishing regional citizen forums or networks.

OCAPI and Health Canada have issued a number of valuable documents providing policy and
guidance on public involvement. The Public Involvement Framework and Guidelines (Health Canada
2000) give detailed guidelines on the rationale and conceptual framework for public involvement,
and details of how to develop and implement a public involvement plan.

Canadian Health Network

This is an online health information service run as a partnership between Health Canada and major
Canadian health organisations.

Women’s Health Bureau

Since 1996 Health Canada’s Women’s Health Bureau has managed a Women’s Health
Contribution Program which supports community-academic partnerships in research and information.
The Bureau was established in 1993 to expand Health Canada’s capacity in women’s health and
provides a good example of collaboration between government and NGO/consumer sectors that
supports a national consumer voice in health. The strategic framework is the Women’s Health
Strategy released in 1999 on which the Bureau reports twice-yearly.

The Bureau is policy-focused and takes a whole-of-Government approach. It works with other parts of
Government to promote policies and programmes that address women’s health and to further
understanding of gender as a variable in health. It maintains relationships with other federal
departments, provincial governments and outside organisations at the domestic and international
levels.
It also administers a Women’s Health Contribution Program which ensures high quality information is available and builds capacity in women’s health. This funds:

- Four multidisciplinary Centres of Excellence in women’s health which operate partnerships between academics, policy-makers and consumer organisations
- The Canadian Women’s Health Network which disseminates research findings and other information (see below)
- Other initiatives such as working groups.

Consumer Activities

The issues of main interest to Canadian consumer groups centre on the impacts of healthcare reform and pharmaceutical issues, including direct-to-consumer advertising of pharmaceuticals. Although there is no national health consumer body, there are a number of large consumer organisations and networks including Consumers’ Association of Canada, Best Medicines Coalition, and the Health Charities Council of Canada. Some of these are discussed below.

Best Medicines Coalition

The Best Medicines Coalition (BMC) is an alliance of major chronic-illness health groups formed in 2000. The BMC mission is ‘people-centred access to the best medicines for all Canadians’ (website). Goals include encouraging active participation of citizens in all aspects of decision-making in access to best prescription pharmaceuticals, accelerating reform of Canada’s drug safety and review system and advocating for access to best medicines.

Member organisations include the Cancer Advocacy Coalition of Canada, Canadian Breast Cancer Network, Canadian Diabetes Association and the Association for the Fifty-Plus. Membership is not confined to consumers, as members can be individual consumers/patients, advocates, national health or disease-related organisations, academics or health care providers. BMC holds regular meetings of a Steering Committee which consists of representatives of organisations. There are also biennial national summits which are attended by delegates from consumer and patient organisations, government, voluntary associations and industry. The national summits provide an opportunity for diverse groups to meet and have an input into the policies and priorities of the Coalition.

In 2002 BMC developed a partnership and relationship with Health Canada and OCAPI. BMC members took part in a workshop to develop a Patient Involvement Strategy for the HPFB of Health Canada.

Similar to New Zealand, patient/consumer engagement is not organised or fostered in a consistent way in Canada. The need for a model was the major focus at the 2004 Best Medicines Coalition 3rd Annual Summit. While the Summit did not seek to reach a single position, there was support for enhancement of the role of OCAPI as a one-stop shop providing criteria for selecting consumer representatives, a database of potential representatives, and training for representatives. Several workshops saw the need for an advisory committee to OCAPI to make this happen (Best Medicines Coalition 2004).

The BMC includes the pharmaceuticals industry in some of its activities, such as summit planning. It supports the federal government position of controlling direct-to-consumer-advertising, although it believes that there must be a balance between direct-to-consumer-advertising and education.
The coalition is funded from a range of sources including the private sector, funds from participating groups, Health Canada and unconditional funds from the pharmaceutical industry.

The BMC develops position papers which are supported by participating groups and other disease-state groups. The coalition provides representatives for committees convened by government and other agencies. Support and expenses are provided and training is planned for the near future.

**Consumers’ Association of Canada**

This is an independent, not-for-profit organisation with a national membership. The Consumers’ Association of Canada is an information and advocacy organisation that makes submissions and represents consumers on a number of national committees. It is interested in a wide variety of consumer issues, including health. In 1988 it created a Health Council to address current health issues and develop Consumers’ Association of Canada policy. It has a voluntary chair and membership from across the country. Consumers’ Association of Canada is a strong supporter of a publicly funded health care system and has been mainly concerned with the provision of health care, especially primary health care, and home-based care.

**Canadian Women’s Health Network**

The Canadian Women’s Health Network provides an interesting model for a New Zealand network. The context of the need for the Network was cutbacks in government spending on health and social services and a move to more community-based services which impacted particularly on women as carers. Proponents of the network believed it would increase understanding of the health care system, reduce isolation of groups and ‘transform anger into creative action’. They acknowledged from the beginning the difficulty of networking in Canada ‘with its vast geographic distances, linguistic, cultural and regional diversities’ (Winnipeg Consultation Organizing Committee 1994, p 11).

The network’s gestation was lengthy. It took over 10 years to build the network, with a nationwide survey carried out to gauge the level of support. Progress was slow in the early years because of a lack of funding. The project received a boost in 1989 when Health Canada provided funding for three years to move the project forward. Finally, a national consultation meeting was held in 1993. Women representing over 70 organisations from every province and territory attended and agreed to form the network. They adopted a slogan for a network: ‘Unity with diversity and support without interference’. A Coordinating Committee was formed made up of regional representatives and women representing specific sectors (disability, immigrant etc) and a report of the consultation was published. The Coordinating Committee’s task was to finalise a mission statement, establish funding, develop an action plan to bring back to groups, network and monitor health policies (Winnipeg Consultation Organizing Committee 1994).

Basic values and operating principles were arrived at. These included a woman-centred philosophy; holistic view of health; recognition of diversity; functioning bilingually; support for the principles of Canada’s Health Act; recognition of healthcare as a fundamental human right. The goals of the network are to:

- facilitate communication among groups and individuals and foster change through education, research, health promotion and advocacy
- advocate for change in women’s health policies and practices, especially for those groups whose health status is most at risk for reasons of economics, class, race, geography, age, disability or sexual orientation
- maintain up-to-date databases of women’s health issues and resources
• provide a forum for critical debate
• play a ‘sentinel role’ by articulating emerging women’s health issues
• facilitate networking between women’s health community and academic researchers
  (Canadian Women’s Health Network 1999).

The network has built national and regional links among organisations and women who care about
women’s health. It works closely with the Centres of Excellence for Women’s Health to promote
communication, information sharing and networking among individuals and groups. This relationship
provides an evidence-base for activities but the Network also uses research and information from
grassroots organisations to inform its policies and platforms.

The membership of the network is made up of individuals, groups, organisations and institutions
concerned with women’s health and is not exclusive to consumers. There is a Board of Directors
made up of women of all ages bringing their perspectives as indigenous women, immigrants and
refugees, women of colour, lesbian, French Canadians, and women with disabilities. These are
selected at the AGM following a nominations process.

When Health Canada or other government agencies ask for consumers for committees the
appropriate person is chosen from the board or staff or from an extensive database of individuals
and organisations.

The network receives small amounts of funds from donations, membership fees and grants for
projects, but the Women’s Health Bureau funding is the mainstay and supports the core business of
the network. The network says this relationship does not interfere with its independent advocacy as it
has a mandate to critique government policy, and the Women’s Health Bureau also has a role to
provide policy advice on gender to the rest of Health Canada.

Implications for New Zealand

Potential benefits

Good ways that national consumer bodies can operate.

• The BMC practice of holding a biennial summit provides an opportunity for members to
  network and provides direction for the BMC steering group
• Partnership with the government strengthens BMC’s voice and ability to have influence
• Some key features of the Canadian Women’s Health Network could be applied to the
  establishment of a generic consumer health network in New Zealand:
  • The policy of ‘unity with diversity and support without interference’ enables the network to
    speak with one voice on key issues but not interfere with others’ actions where there is not
    agreement
  • The network will not replace the work of organisations in representing their members
  • Integration/partnership with the Centres of Excellence in Women’s Health enables the
    network to participate in setting research agendas, encourages consumers to participate in
    research projects and provides an evidence-base for Network policies and practices. Evidence
    from the grassroots is also integrated into this approach
  • The government strategic framework and relationship with the Women’s Health Bureau
    provides government support and stability
  • Advocacy is accepted as a key role for the network. The network is expected to highlight
    emerging issues
• Partnership with the Canadian Health Network enables good quality women’s health resources to be available online
• Communication within the network uses a number of different forms to firstly, keep pace with technological change, but, secondly, recognise that there are barriers to accessing the technology, and there are language barriers and literacy difficulties for some women (Canadian Women’s Health Network 1999; Canadian Women’s Health Network 2003).

3.4 UNITED STATES OF AMERICA

Government Activities

In 1974 a system of regional planning bodies called Health Systems Agencies (HSAs) was brought into being by the National Health Planning and Resources Development Act (PL 93-641). HSAs could be private not-for-profit corporations, units of local government, or public regional planning bodies. At least half of the governing bodies had to be consumers of health care who were representative of people who resided in the region. The system owed its genesis to the social activism of the 1960s and 1970s especially consumer health organisations representing poor people, ethnic minorities, women, elderly people and workers. These groups demanded equal access in health care (Grant 1989).

The HSA system was designed to give consumers a voice in the formulation of health policies. While it went some way to achieving this, consumer members of HSAs faced the problems of lack of community resources and lack of expertise, compared to the strength of healthcare providers. Health care is only intermittently important in people’s lives, so representation was of most interest to those active in public affairs rather than actual consumers of health services. Providers of services, however, have an abiding full-time interest in healthcare, and possess resources and specialist knowledge of the system. HSAs also lacked sufficient powers. They could not directly require changes in health care delivery, but only make recommendations to the state agency. The HSA system was unable to rebalance consumer interests with those of health professionals and managers. The political climate was changing in the 1980s towards less government and returning power to the states and the private sector (Marmor & Morone 1980; Grant 1989; Seale 1993). The HSA system was dismantled in 1986 and consumers lost the federal mandate to be involved in health planning. The following decade saw the growth of Health Maintenance Organisations and managed care that provided few opportunities for consumers to participate in health policy and planning (Grant 1989).

Given that the USA is the home of markets and consumerism, it is perhaps surprising that more official effort is not put into encouraging consumer participation into health policy and planning. The repeal of PL 93-641 means that there is no federal mandate for consumer involvement. Consumer power seems to be confined to shopping around for the right health plan.

In this policy vacuum, the two agencies that have made the most progress are the Food and Drug Administration (FDA) and the National Cancer Institute and this has come about through challenges and protests by breast cancer and HIV/AIDS activists. Apart from this, there does not appear to be a concerted effort to involve consumers at a federal level around consumer participation. It was beyond the scope of this report to examine participation at the state level, although some comment is made on what is happening in mental health.
Food and Drug Administration

The FDA provides a comprehensive programme to include consumers in its evaluation of drugs and therapies, although consumers do not always have the same powers as scientific members of advisory groups.

Several times a year, the FDA holds a meeting for a nominating group and a consortium of consumer organisations, which reviews the qualifications of consumer candidates and puts forward potential consumer/patient committee representatives to the FDA.

There are 30 FDA Advisory Committees, 18 device panels and eight chartered subcommittees. Consumers are usually represented on these committees by technically qualified health professionals with links to consumer advocacy groups. Patient representatives are sometimes included on the committees and may be voting or non-voting members (Rados 2004).

The FDA distinguishes between consumer representatives, who may not be consumers, and patient representatives. Patient representatives will usually be a person with a history of the disease, for which a new treatment is sought, or a caregiver or member of a patient group. Patient representatives routinely sit on committees reviewing products and therapies for the diagnosis and treatment of HIV/AIDS and cancer, and, on a case-by-case basis for products and therapies relating to other serious and life-threatening diseases, for example, arthritis, diabetes, hepatitis B, hepatitis C, lupus, polio and so on. Patient representatives on committees reviewing oncologic therapies and products are usually voting members; patient representatives on other committees, such as the Antiviral Drugs Advisory Committee, are usually non-voting members.

The Office for Special Health Issues provides orientation and training on an individual basis and opportunities are provided for the person to speak with other patient representatives and observe meetings before they assume the role. Meetings are usually open to the public and sometimes attended by hundreds of people, with national press coverage.

The Office for Special Health Issues has a Cancer Liaison Programme with a permanent staff who work closely with cancer patients to recruit, select and train patient representatives for cancer-related advisory committees. It also provides a Cancer Drug Development Patient Consultant Programme which trains cancer patient advocates who serve as patient consultants in the pre-approval clinical trial stage of cancer drug development. The patient consultant provides advice to the FDA and to the drug sponsor on such things as trial design, and recruitment strategies.

The inclusion of consumers is credited with transforming criticisms that the FDA was too slow in approving drugs for such life-threatening illnesses as AIDS, into ardent supporters for the high levels of protection that the FDA provides (Holston 1997). In recent years consumer organisations have been advocates for the FDA against attacks to diminish its powers by the Bush administration and Congress.

National Institutes of Health

NIH Director’s Council of Public Representatives (COPR)

The Council of Public Representatives (COPR) is a statutory federal advisory committee made up of members of the public which advises the National Institutes of Health (NIH) on issues related to:

- Public input and participation in NIH activities
- Public input and participation in setting research priorities
• NIH outreach programmes and efforts.

COPR is made up of 21 people who were chosen by the NIH Director after an application process. Although there are a number of consumers and family members of patients there are also educators, health professionals, scientists and academics. It meets twice yearly and takes part in a range of outreach activities.

National Cancer Institute

When the National Cancer Institute (NCI) appointed a Director’s Consumer Liaison Group in 1997 this was described as the first such high-level consumer organisation. The group’s roles are to help set research priorities, create a forum for exchange of ideas between the scientific and advocacy communities and assist in developing processes and criteria for identifying consumer advocates to serve on advisory committees. While most members are cancer survivors, many also hold positions on NGO and cancer advocacy groups that are not strictly consumer organisations, and there are also health professionals on the group.

The NCI also has a Consumer Advocates in Research and Related Activities (CARRA) programme which recruits consumers to form a ‘ready and waiting’ group who are available to participate in a wide range of NCI activities on an ‘as needed’ basis. Currently there are 220 members in the CARRA programme. They receive orientation on the NCI and the roles and responsibilities of CARRA and additional training for each task they undertake.

Other national institutes include consumers on advisory committees from time to time. There does not appear to be any consistent way in which this occurs.

Consumer Activities

Rose (1990) argues that the impact of the major social movements of the 1960s and 1970s persisted in the USA whereas it diminished in countries such as the UK because the USA has such a strong cultural commitment to democracy. The USA is more tolerant of debate and conflict and thus could accommodate new forms of advocacy. As will be clear through this section, the USA enjoys forms of consumer advocacy that are not found in countries such as Australia and the UK. These organisations have a national profile and voice and they attract significant private funding support. They are independent of government and have maintained a position ‘outside’ the system; they use legal avenues and they do not position themselves as ongoing participants within the system. They do take part in government hearings (such as the FDA public hearings on pharmaceuticals – there is no equivalent in New Zealand) and committees, but this involvement is balanced by high profile public activism.

Current major issues for consumer organisations in the USA centre around the need for extended or universal healthcare, the role and activities of the pharmaceutical industry, greater federal funding for research and the availability of information about physician and hospital performance.

A particular issue in the USA context is industry funding of consumer organisations. Among disease-specific groups, virtually all the bigger ones, and even small ones with a national agenda, are funded by the health industry.

Despite the existence of an extensive consumer sector, there is no national health consumer body and there are no moves afoot to form one. There is an existing National Health Council, which is represented on the board of the International Alliance of Patients’ Organisations, but it is not specifically a consumer group. It is primarily focused on encouraging volunteerism and charitable giving, and its members include voluntary health agencies, professional associations, NFP
organisations and business and industry groups including a large number of pharmaceutical companies. Some of these are represented on the board.

The USA consumer health sector consists of a very large number of groups at state and federal level, including nationally-prominent consumer advocacy groups. Examples of these are the large umbrella organisations such as the National Breast Cancer Coalition and the National Women’s Health Network, and high-profile lobbyists, such as the New York-based Centre for Medical Consumers and the Washington-based Public Citizen Inc. There is a very long-established National Consumers League, similar to the New Zealand Consumers’ Association, which campaigns on a number of consumer issues including health care and medicines. There are also groups that sound like consumer groups but which turn out to be commercial entities or strongly ideological lobbyists. An example of the first is the Patient Advocacy Coalition Inc which provides litigation services for consumers, and an example of the latter is the National Consumer Coalition whose mission is to promote a market economy.

The scale of the largest umbrella organisations is enormous and they have clout to match their size. The National Breast Cancer Coalition is a membership organisation with a network of 600 organisations and 70,000 individuals. It relies heavily on individual donors as it has a policy not to accept government money or more than 15% of its budget from companies that profit from the screening, diagnosis and treatment of breast cancer. It is highly effective at using mass media, influential sponsors, and imaginative campaigns to raise awareness and bolster its influence. It focuses on research (the National Breast Cancer Coalition has succeeded in increasing federal appropriations for breast cancer research six-fold), access to treatment and high quality trials, and increasing the influence of women living with breast cancer. A major feature of the National Breast Cancer Coalition’s campaigns has been its call for breast cancer advocates to be ‘at the table’ where decisions are being made about funding.

High-profile lobbyists

The high-profile public interest lobbyists are a unique form of consumer organisation, largely only found in the USA. These are non-profit consumer advocacy or lobby organisations that run high-profile campaigns and use legal challenges. They do not have a membership and voting processes to elect their boards, and rely on private donations for funding. They are quite small entities but are well-known and effective in advancing their issues. In New Zealand, Women’s Health Action was partly modelled on the Public Citizen group, describing itself as a public interest, consumer advocacy group in women’s health.

The Centre for Medical Consumers (founded 1976) is active in New York State and makes national efforts to improve the quality of health care. As well as private donations and newsletter subscriptions, it is supported by the Judson Memorial Church. The Centre for Medical Consumers works to raise public awareness about quality problems in the American health care system, to ensure institutions and professionals are held accountable for the quality of care through strong enforcement of laws and regulations, to press for evidence-based medicines, to critique misleading drug advertisements, to push for greater consumer voice in decisions that affect quality of care, and require that decisions of managed care organisations are open to appeal.

Public Citizen was founded by Ralph Nader in 1971 to represent consumer interests in Congress, the executive branch and the courts. It has had a strong interest in the safety of drugs, medical devices, healthcare and food, and has a Health Research Group as part of the organisation. The Deputy-Director of the Public Health Group has developed health activist courses which are taught at medical and public health schools around America. Public Citizen has a membership which receives
a number of benefits, but which does not vote. The organisation will not receive funds from corporates, health professional groups or government.

The Boston Women’s Health Book Collective (now known as Our Bodies Our Selves or OBOS) is another uniquely American phenomenon. Originally formed as a feminist collective of women, they published in 1970 the first mass market self-help health book for women, Our Bodies Our Selves (now available in such countries as Armenia, Russia, Senegal and Serbia). They are recognised internationally. Today, they continue to publish and to promote their concepts of informed health consumers as catalysts for social change, women as their own health experts, women’s right to know and protecting the normality of women’s life events such as childbirth. A current project is Public Voice which aims to magnify the voice of the women’s health movement through working with the media, coalition building, networking, participating in government technical advisory committees, and public speaking. The aim is ‘to keep the broader consumer and feminist perspectives in focus within the environment in which market-driven messages predominate’. The group now describes itself as a ‘non-profit, public interest, women’s health education, advocacy and consulting organisation’. There is a board of directors and paid staff but no membership.

Mental health network

In the mental health sector a federal law in 1986 required states to do mental health planning and include various stakeholder groups including consumers and parents. Councils now exist in every state and must have at least 50% consumers and family members. They review community mental health plans, monitor and evaluate mental health services and advocates for adults and children with mental illnesses.

The National Association of Mental Health Planning and Advisory Councils is a network of advocates, parents and consumers involved in state mental health planning and advisory councils. There is a board that is elected by the membership. The National Association of Mental Health Planning and Advisory Councils provide technical support, information sharing and a national voice on mental health planning issues. It also promotes self-help for mental health consumers.

Implications for New Zealand

Potential benefits

At government level

• A project team or similar entity within government agencies helps ensure consistency and comprehensiveness in the approach to consumer representation.

At the community level

• Stand-alone campaigning advocacy bodies that are independent of government can be very effective at raising awareness and advocating for consumer interests.

• Well-resourced consumer organisations can successfully drive consumer participation programmes; especially if they have a specific rather than generalist focus (breast cancer rather than all consumer issues).

• The National Association of Mental Health Planning and Advisory Councils model is a more formalised version of what is occurring in New Zealand in the mental health sector with paid consumer advisors. It could also provide a model to enable consumers on DHB committees, community committees, and consumers involved in governance for PHOs to come together to
discuss areas of interest and represent the interests of consumers otherwise isolated within their own areas.

- The funding base in the USA is not replicable in New Zealand because the population available for subscriptions and donations is so much greater in the USA and there are also a number of private philanthropic trusts. New Zealand groups are much more likely to be dependent on public funds. Health industry funds are not as available in New Zealand compared to the US. The lack of such funding ensures that New Zealand groups are not compromised by industry influences. This situation may change as health industry groups make more funds available for patient groups.

### 3.5 THE NETHERLANDS

The Netherlands Government has made support for organisations representing the chronically ill one of the cornerstones of its health policy. It aims to prevent discrimination against the chronically ill and encourage positive discrimination. To achieve this it funds a number of consumer organisations.

**Nederlandse Patienten Consumenten Federation, Netherlands Patient/Consumer Federation**

This federation of groups was founded in 1992 to work for improved access to and quality of health care, offer information to patients and defend their rights. The group promotes the common interests of patients to government, policy-makers at national, regional and local levels, professionals organisations and health insurance companies. It develops ‘platforms’ of policies with its members. In 1998 the group took up the issue of waiting lists and published waiting times on its web site. It is primarily government-funded.

There are 18 member groups which are national networks focused on a disease (e.g. cancer) or common interest. These represent two million members. The office in Utrecht has 45 staff.

In addition there are 28 Regional Patients and Consumers Platforms that work at regional or local level. These groupings have formed themselves into a national platform, the LOREP, that is represented on the national Consumenten.

**Dutch Council of the Chronically Ill and Disabled (CG-Raad or CG-Council)**

This council was formed in 2001 through the amalgamation of GehandicaptenRaad and Werkverband Organisaties Chronisch Zieken (United Patients’ Organisations of the Chronically Ill) or WOCZ. It includes 150 organisations, mostly national organisations of people and parents of people with a chronic illness or disability, but also regional and local organisations. Altogether these organisations cover 300,000 members. There is a General Assembly which is the policy-making body of CG-Raad. It is made up of representatives from member groups. The General Assembly appoints a board for CG-Raad.

The council is an advocacy organisation and also provides support to member organisations. It works at a high level seeking alliances with sympathetic groups and agencies. The council works more widely than health and takes an active part in national politics in order to influence politicians and ministers. It lobbies through letter writing, lobbying, submissions and taking part in national debates, and through the media it seeks to create ‘a strong, convincing and emancipated image’ of people with disabilities. It negotiates with research institutes and agencies involved in areas such as transport for influence policy and planning at an early stage. There is also a wide range of services, such as training, legal assistance, information line, library, and conference rooms.
The office in Utrecht has 60 staff members. CG-Raad is funded through a foundation for patients, the disabled and elderly people that receiving funding money from the Dutch Government.

Before the amalgamation, WOCZ was credited with putting people with long-term medical conditions on the political agenda. It achieved changes in taxation and payments for drug treatment, and health care is said to have become more responsive to people with long-term conditions. Training for health professionals by consumers has been instituted.

Implications for New Zealand

Potential benefits

At government level

- Government policy to support consumer organisations improves their capacity and effectiveness.
- Embedding consumer perspectives in policy improves their acceptance and legitimates the need for organisations to advocate on behalf of their members
- Core policy to include consumers legitimates the need for funding
- An independent funding foundation can distribute government funds to consumer organisations, thus putting funding at some distance from political influence
- Specific consumer funding creates stability for organisations.

3.6 INTERNATIONAL AND CROSS-NATIONAL CONSUMER ORGANISATIONS

There are a number of consumer groups that cross national boundaries and while international organisations were outside the remit of this report, some of these are outlined briefly so as to provide a more complete picture of consumer organisations.

Consumers’ International

Consumers’ International is a generic consumer organisation with a focus on health, especially patients’ rights, the right to health care and pharmaceutical products.

The organisation is governed by a board of directors, elected by full members at the World Congress every three years. Full members are independent consumer organisations with a national presence who are active across a range of issues. They must be independent of party politics and not funded by corporations. Consumers’ International membership is over 250 organisations from 115 countries. The only New Zealand members are the Consumers’ Institute of New Zealand and the Ministry of Consumer Affairs. The head office is in London and there are regional offices in Malaysia, Chile, Zimbabwe and London.

New Zealand does not seem to be well linked into this organisation as the information about patients’ rights in New Zealand on the web site was seriously out of date. It predated the promulgation of the Code of Health and Disability Consumers’ Rights in 1996.

International Alliance of Patients’ Organisations

IAPO is a global alliance of consumer health organisations founded in 1999, based in The Netherlands. The focus is on people with chronic illnesses, syndromes, impairments and disabilities. The goals of the alliance are to create active partnerships between consumer organisations,
strengthen the voice of consumers internationally and build alliances with health professionals, policy makers, academics, researchers and health industries.

Full members are patients’ organisations and there are a few New Zealand members including Arthritis New Zealand. Associate members are health care NFP organisations. However, it is not clear how patient organisations are defined as some member groups are open to health professionals and industry. There are currently 102 full members and 10 associate members. The members elect a governing board of five. Current chair is Albert van der Zeijden whose background is with CG-Raad. Other board members come from the USA, Uruguay, and the UK.

IAPO networks with its members, and holds a searchable directory of consumer groups. In February 2005 it will hold the first global assembly of patients’ groups in the UK.

IAPO has struggled to gain sustainable funding. Its initial funding came from a consortium of pharmaceutical companies and currently most of its funding is provided by pharmaceutical and other health industries. Current major ‘Industry Partners’ are Johnson & Johnson, Medtronic Foundation (medical technology), Merck & Co, Novartis, and Pfizer.

European Patients’ Forum

Twelve pan-European patients organisations formed this group in 2003 in response to calls by the European Commission and other EU institutions to have a single pan-European patient body for consultation purposes.

The main objectives include:

- To exchange information and points-of-view between pan-European patients’ groups in the area of EU health policy and initiatives
- To share health experiences and examples of good practice to strengthen consumer voice
- To offer the views of patients through a broad, representative and independent patient group resource
- To provide a forum for patients’ organisations to develop a common position on health policy and to lobby on behalf of those organisations
- To be the first point of reference for EU and other European institutions when seeking the views of patients and patient groups
- To cooperate in joint projects.

At the inaugural meeting in January, members elected an executive committee. Members must be pan-European groups which meet a number of criteria including having:

- membership in more than half of the member states of the EU
- an elected governing body
- accountability to members and consultation processes in place
- disclosure of their sources of funding and available audited accounts.
Cochrane Consumer Network, CCNet

The Network started in 1993 and became a Cochrane entity in 1995. The Network is accountable to the governing body (board) of The Cochrane Collaboration (called the Steering Group) for both structure and performance.

The purposes of the Network are to:

- Represent and provide a consumer viewpoint in the development of systematic reviews, including prioritisation of titles
- Support consumers and their interests in The Cochrane Collaboration
- Provide support, information and networking for consumers working within Cochrane entities, such as review groups, fields and centres
- Increase awareness among Cochrane entities of the benefits of involving consumers
- Provide mechanisms of accountability for consumers in the Collaboration
- Raise awareness about the place of evidence-based practice and the work of The Cochrane Collaboration in communities and among consumers outside the Collaboration
- Disseminate summaries of information obtained about healthcare interventions through the Cochrane review process
- Develop evidence-based consumer health information to enable consumers to make informed health care decisions.

Membership is free and is open to all consumers or consumer organisations. Supporting members are health professionals or researchers interested in consumer participation and the health of people in developing countries. There are members from over 50 countries. The Network is governed by an international council, with members drawn from specific regions, and there are two representatives on the Steering Group. Members are encouraged to form geographical satellites as a way of facilitating local effectiveness.

The Network of over 300 members is not funded by the Collaboration and has continually struggled to find funds for its work; it operates within the Cochrane policy of not receiving health industry funding. There is an annual meeting at the time of the annual Cochrane Colloquium at which the management team are appointed, elections are held as required, and policy is discussed. The Network is currently developing an active, truly inclusive network approach. This includes the development of a new web site (http://www.cochrane.org/consumers), where relevant documents and newsletters can be accessed, and a moderated e-mail discussion list that also serves to keep members informed.
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# APPENDIX 1: ABBREVIATIONS

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
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<tbody>
<tr>
<td>ACC</td>
<td>Accident Compensation Corporation</td>
</tr>
<tr>
<td>BMC</td>
<td>Best Medicines Alliance (Canada)</td>
</tr>
<tr>
<td>CAPPS</td>
<td>Consumer &amp; Provider Partnerships in Health Project (Australia)</td>
</tr>
<tr>
<td>CARRA</td>
<td>Consumer Advocates in Research and Related Activities (USA)</td>
</tr>
<tr>
<td>CAS</td>
<td>Complaints Advocacy Service (UK)</td>
</tr>
<tr>
<td>CCS</td>
<td>Crippled Children Society</td>
</tr>
<tr>
<td>CG-Raad</td>
<td>Dutch Council of the Chronically Ill and Disabled</td>
</tr>
<tr>
<td>CHC</td>
<td>Community Health Councils (UK)</td>
</tr>
<tr>
<td>COPR</td>
<td>Council of Public Representatives (USA)</td>
</tr>
<tr>
<td>CPPIH</td>
<td>Commission for Patient and Public Involvement in Health (UK)</td>
</tr>
<tr>
<td>DEASS</td>
<td>Disability Empowerment and Advocacy Support Services</td>
</tr>
<tr>
<td>DHB</td>
<td>District Health Board</td>
</tr>
<tr>
<td>DPA</td>
<td>Disabled Persons Assembly</td>
</tr>
<tr>
<td>EPP</td>
<td>Expert Patients Programme (UK)</td>
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<tr>
<td>FDA</td>
<td>Food and Drug Administration (USA)</td>
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<td>FSO</td>
<td>Forum Support Organisations (UK)</td>
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<td>HPFB</td>
<td>Health Products and Food Branch (Canada)</td>
</tr>
<tr>
<td>HSA</td>
<td>Health Systems Agency (USA)</td>
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<tr>
<td>IAPO</td>
<td>International Alliance of Patients’ Organisations</td>
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<tr>
<td>ICAH</td>
<td>Intersectoral Community Action for Health</td>
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<td>IHC</td>
<td>Intellectually Handicapped Children</td>
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<td>LMCA</td>
<td>Long-term Medical Conditions Alliance (UK)</td>
</tr>
<tr>
<td>MCA</td>
<td>Ministry of Consumer Affairs</td>
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<tr>
<td>MOH</td>
<td>Ministry of Health</td>
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<tr>
<td>NCI</td>
<td>National Cancer Institute (USA)</td>
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<tr>
<td>NGO</td>
<td>Non-government organisation</td>
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<td>NHS</td>
<td>National Health Service (UK)</td>
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<tr>
<td>NICE</td>
<td>National Institute for Clinical Excellence (UK)</td>
</tr>
<tr>
<td>NIH</td>
<td>National Institutes of Health (NIH)</td>
</tr>
<tr>
<td>OCAPI</td>
<td>Office for Consumer and Public Involvement (Canada)</td>
</tr>
<tr>
<td>PALS</td>
<td>Patient Advice and Liaison Service (UK)</td>
</tr>
<tr>
<td>PCT</td>
<td>Primary Care Trusts (UK)</td>
</tr>
<tr>
<td>PHO</td>
<td>Primary Health Organisation</td>
</tr>
<tr>
<td>PIASS</td>
<td>Pacific Islands Advocacy Support Services</td>
</tr>
<tr>
<td>PIU</td>
<td>Patient Involvement Unit (NICE – UK)</td>
</tr>
<tr>
<td>PPIF</td>
<td>Patient and Public Involvement Forums (UK)</td>
</tr>
<tr>
<td>WOCZ</td>
<td>Werkverband Organisaties Chronisch Zieken (United Patients’ Organisations of the Chronically Ill)</td>
</tr>
</tbody>
</table>
APPENDIX 2: SEARCH STRATEGY

Database: MEDLINE <1966 to September Week 4 2003>

1. consumer$.tw. (15107)
2. patient$.tw. (2275425)
3. (public or community).tw. (187268)
4. expert patient$.tw. (29)
5. lay person$.tw. (300)
6. people$.tw. (88287)
7. user$.tw. (36283)
8. (citizen$ or person$).tw. (218427)
9. or/1-8 (2619239)
10. (patient cent$. or patient center$).tw. (1937)
11. patient care planning.sh. (24235)
12. physician-patient relations.sh. (39986)
13. (professional adj5 patient$ adj5 relations$).tw. (290)
14. (doctor$ adj5 patient$ adj5 relation$).tw. (2251)
15. (health adj15 personnel adj15 patient$ adj15 relation$).tw. (41)
17. exp Nurse-Patient Relations/ (18813)
18. or/10-17 (83937)
19. 9 and 18 (38336)
20. exp Consumer Participation/ (18874)
22. (goal setting adj15 (consumer$ or patient$)).tw. (144)
23. ((consumer$ or patient$) adj3 (involve$ or input$)).tw. (25883)
24. ((patient$ or consumer$) adj3 represent$).tw. (10230)
25. or/20-24 (54246)
26. 19 and 25 (2918)
27. partners$.tw. (22566)
28. consultation.mp. (16289)
29. [consultation or participation].tw. (55914)
30. decision making.sh. (38754)
31. consumer advocacy/ or patient advocacy.sh. (23410)
32. or/27-31 (136122)
33. 19 and 32 (5161)
34. (governing board or leadership or trustees or decision making organisational).sh. (16940)
35. (organisation or organization).mp. (98675)
36. organization.tw. (98639)
37. collaboration.mp. (12274)
38. network.mp. (49910)
39. group.mp. (81663)
40. council.mp. (11068)
41. (collaborat$ or network$ or council$ or forum$).tw. (1232196)
42. Health Administration/ or Consumer Participation/ or Social Values/ or Health Planning/ or Health Systems Agencies/ or Community Health Services/ or Community Health Planning/ or regional Health Planning/ (63161)
43. or 34-42 (1398097)
44. 26 or 33 (6924)
45. 43 and 44 (1685)
46. exp Delivery of Health Care/ (408083)
47. exp Health Services/ (836299)
48. exp mental health services/ not mental hygeiene services.mp. [mp=title, abstract, cas registry/ec number word, mesh subject heading] (44338)
49. exp Disabled Persons/ (30444)
50. or/ 46-49 (1089801)
51. 45 and 50 (1593)
52. exp Evaluation Studies/ (470726)
53. monitor.mp. (38246)
54. audit.mp. (9608)
55. (monitor$ or audit$).tw. (275147)
56. feedback.tw. (31851)
57. consumer satisfaction.sh. (11964)
58. exp health services research/ (47624)
59. survey.mp. (126780)
60. exp Data Collection/ (629505)
61. or/52-60 (1414401)
62. 51 and 61 (625)
### APPENDIX 3: WEBSITES USED

<table>
<thead>
<tr>
<th>Website</th>
<th>Organisation</th>
<th>Country</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td><a href="http://www.moh.govt.nz">www.moh.govt.nz</a></td>
<td>Ministry of Health</td>
<td>NZ</td>
<td></td>
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<tr>
<td><a href="http://www.moh.govt.nz/ngo">www.moh.govt.nz/ngo</a></td>
<td>Ministry of Health</td>
<td>NZ</td>
<td>MOH &amp; community and voluntary sector, including links to groups</td>
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<td><a href="http://www.nhc.govt.nz">www.nhc.govt.nz</a></td>
<td>National Health Committee</td>
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<td><a href="http://www.moh.govt.nz/mentalhealth">www.moh.govt.nz/mentalhealth</a></td>
<td>Mental Health Directorate, MOH</td>
<td>NZ</td>
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<td><a href="http://www.mhc.govt.nz/">www.mhc.govt.nz/</a></td>
<td>Mental Health Commission</td>
<td>NZ</td>
<td></td>
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<td><a href="http://www.odi.govt.nz">www.odi.govt.nz</a></td>
<td>Office for Disability Issues, part of Ministry of Social Development</td>
<td>NZ</td>
<td>Responsible for implementation of Disability Strategy</td>
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<tr>
<td><a href="http://www.community.net.nz/links/">www.community.net.nz/links/</a></td>
<td>Dept of Internal Affairs</td>
<td>NZ</td>
<td>Resource to help NZ communities Links to community groups</td>
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<tr>
<td><a href="http://www.community.net.nz/Hottopics/CSTaskforce/">www.community.net.nz/Hottopics/CSTaskforce/</a></td>
<td>Community Sector Taskforce</td>
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<td><a href="http://www.goodpracticeparticipate.govt.nz">www.goodpracticeparticipate.govt.nz</a></td>
<td>Site to help NZ government servants engage with community, voluntary, iwi and Maori organisations</td>
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<td>Guidelines for participation</td>
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<td><a href="http://www.consumeraffairs.govt.nz/">www.consumeraffairs.govt.nz/</a></td>
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<td><a href="http://www.acc.co.nz/claimscare/cons-outgrp/">www.acc.co.nz/claimscare/cons-outgrp/</a></td>
<td>Consumers Outlook Group of ACC</td>
<td>NZ</td>
<td>ACC consumers advisory group</td>
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<td><a href="http://www.enable.co.nz">www.enable.co.nz</a></td>
<td>Enable NZ</td>
<td>NZ</td>
<td>Company to assist people with disabilities and manage MOH funding</td>
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<tr>
<td><a href="http://www.weka.net.nz">www.weka.net.nz</a></td>
<td>NZ disability information website</td>
<td>NZ</td>
<td>Maintained by Enable NZ and the NZ federation of Disability Information centres</td>
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<td><a href="http://www.dpa.org.nz">www.dpa.org.nz</a></td>
<td>Disabled Persons Assembly</td>
<td>NZ</td>
<td>Umbrella group for disability organisations</td>
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<td><a href="http://www.ripple.org.nz">www.ripple.org.nz</a></td>
<td>Ripple Trust</td>
<td>NZ</td>
<td>NFP organisation which provides services for people with disabilities in the Northern Region</td>
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<td><a href="http://www.platform.org.nz">www.platform.org.nz</a></td>
<td>Platform NGO Support Services and Community Development in Mental Health</td>
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<td><a href="http://www.ihc.org.nz">www.ihc.org.nz</a></td>
<td>IHC</td>
<td>NZ</td>
<td>Service provider for people with disabilities</td>
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<td><a href="http://www.ccs.org.nz">www.ccs.org.nz</a></td>
<td>CCS</td>
<td>NZ</td>
<td>Service provider for people with disabilities</td>
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<td><a href="http://www.mnzfb.org.nz">www.mnzfb.org.nz</a></td>
<td>Royal New Zealand Foundation of the Blind</td>
<td>NZ</td>
<td>Service provider for blind people</td>
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<td><a href="http://www.peoplefirst.org.nz">www.peoplefirst.org.nz</a></td>
<td>People First</td>
<td>NZ</td>
<td>Organisation for people with intellectual disabilities</td>
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<td><a href="http://www.abcnz.org.nz">www.abcnz.org.nz</a></td>
<td>Association of Blind Citizens</td>
<td>NZ</td>
<td>Largest national consumer organisation for blind people</td>
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<td><a href="http://www.deaf.co.nz">www.deaf.co.nz</a></td>
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<td><a href="http://www.hearing.org.nz">www.hearing.org.nz</a></td>
<td>Hearing Ass Inc</td>
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<td><a href="http://www.parent2parent.org.nz/">www.parent2parent.org.nz/</a></td>
<td>Parent to Parent</td>
<td>NZ</td>
<td>Support for parents who have children with special needs</td>
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<td><a href="http://www.breastcancer.nzco.net">www.breastcancer.nzco.net</a></td>
<td>Breast Cancer Network of NZ</td>
<td>NZ</td>
<td>Network of breast cancer survivors</td>
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<td><a href="http://www.nzbc.org.nz">www.nzbc.org.nz</a></td>
<td>The NZ Breast Cancer Foundation</td>
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</tr>
<tr>
<td><a href="http://www.nzord.org.nz">www.nzord.org.nz</a></td>
<td>NZ Organisation for Rare Disorders</td>
<td>NZ</td>
<td>Umbrella group for many disease groups, good contacts list</td>
</tr>
<tr>
<td><a href="http://www.consumer.org.nz">www.consumer.org.nz</a></td>
<td>Consumers’ Institute of New Zealand</td>
<td>NZ</td>
<td>Generic consumer organisation</td>
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<td><a href="http://www.womenshealth.org.nz">www.womenshealth.org.nz</a></td>
<td>Women’s Health Action Trust</td>
<td>NZ</td>
<td>Women’s health group with strong consumer focus</td>
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<td><a href="http://www.allergy.org.nz">www.allergy.org.nz</a></td>
<td>Allergy New Zealand</td>
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<td>NFP consumer group</td>
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<td><a href="http://www.alzheimers.org.nz">www.alzheimers.org.nz</a></td>
<td>Alzheimers New Zealand</td>
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<td><a href="http://www.arthritis.org.nz">www.arthritis.org.nz</a></td>
<td>Arthritis Foundation of New Zealand</td>
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<td><a href="http://www.coss.net.au/directory/ac-oss/orgname.index.html">www.coss.net.au/directory/ac-oss/orgname.index.html</a></td>
<td>Directory of organisations in Australia</td>
<td>Australia</td>
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<td><a href="http://www.health.gov.au/pq/consumer/cfc.htm">www.health.gov.au/pq/consumer/cfc.htm</a></td>
<td>Consumer Focus Collaboration</td>
<td>Australia</td>
<td>Commonwealth govt project to foster consumer focus in health sector, now completed</td>
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<td><a href="http://www.consumersonline.gov.au">www.consumersonline.gov.au</a></td>
<td>Consumers Online</td>
<td>Australia</td>
<td>Australian federal govt one-stop shop for consumers</td>
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<td><a href="http://www.health.gov.au/pq/consumer/capps.htm">www.health.gov.au/pq/consumer/capps.htm</a></td>
<td>Consumer and Provider Partnerships in Health Project</td>
<td>Australia</td>
<td>Documented projects to demonstrate good practice in consumer provider partnerships</td>
</tr>
<tr>
<td>Website</td>
<td>Organisation</td>
<td>Country</td>
<td>Comment</td>
</tr>
<tr>
<td>-------------------------</td>
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<td>-------------</td>
<td>-------------------------------------------------------------------------</td>
</tr>
<tr>
<td><a href="http://www.chf.org.au">www.chf.org.au</a></td>
<td>Consumers’ Health Forum of Australia</td>
<td>Australia</td>
<td>National consumer health body</td>
</tr>
<tr>
<td><a href="http://www.healthissuescentre.org.au">www.healthissuescentre.org.au</a></td>
<td>Health Issues Centre</td>
<td>Australia</td>
<td>Non-govt health policy centre</td>
</tr>
<tr>
<td><a href="http://www.participatelnhealth.org.au">www.participatelnhealth.org.au</a></td>
<td>National Resource Centre for Consumer Participation in Health</td>
<td>Australia</td>
<td></td>
</tr>
<tr>
<td><a href="http://www.latrobe.edu.au/cochrane">www.latrobe.edu.au/cochrane</a></td>
<td>Cochrane Consumers and Communication Review Group, in School of Public Health</td>
<td>Australia</td>
<td></td>
</tr>
<tr>
<td><a href="http://www.hcc-wa.global.net.au">www.hcc-wa.global.net.au</a></td>
<td>Health Consumers Council of West Australia</td>
<td>Australia</td>
<td></td>
</tr>
<tr>
<td><a href="http://www.bcna.org.au">www.bcna.org.au</a></td>
<td>Breast Cancer Network of Australia</td>
<td>Australia</td>
<td></td>
</tr>
<tr>
<td><a href="http://www.bcna.org.au/projects/seat_table_overview.htm">www.bcna.org.au/projects/seat_table_overview.htm</a></td>
<td>BCNA A Seat at the Table project</td>
<td>Australia</td>
<td>Organised consumer representation and training programme</td>
</tr>
<tr>
<td><a href="http://www.actcommunity.org">www.actcommunity.org</a></td>
<td>Health Care Consumers’ Association of the ACT</td>
<td>Australia</td>
<td></td>
</tr>
<tr>
<td><a href="http://www.cppih.org/">www.cppih.org/</a></td>
<td>Commission for Patient and Public Involvement in Health</td>
<td>UK</td>
<td>National body fostering patient and public involvement through local trusts</td>
</tr>
<tr>
<td><a href="http://www.chi.nhs.uk">www.chi.nhs.uk</a></td>
<td>Commission for Health Improvement</td>
<td>UK</td>
<td>Disbanded 31/3/04</td>
</tr>
<tr>
<td><a href="http://www.healthcarecommission.org.uk">www.healthcarecommission.org.uk</a></td>
<td>Healthcare Commission</td>
<td>UK</td>
<td>Launched 1 April 2004 with task in quality improvement in NHS</td>
</tr>
<tr>
<td><a href="http://www.legislation.hmso.gov.uk/si/si2003/20032123.htm">www.legislation.hmso.gov.uk/si/si2003/20032123.htm</a></td>
<td>Health Department</td>
<td>UK</td>
<td>Patients’ Forums regulations</td>
</tr>
<tr>
<td><a href="http://www.doh.gov.uk/healthinequalities/">www.doh.gov.uk/healthinequalities/</a></td>
<td>Health inequalities website</td>
<td>UK</td>
<td></td>
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<tr>
<td><a href="http://www.doh.gov.uk/involvingpatients/">www.doh.gov.uk/involvingpatients/</a></td>
<td>Dept of Health</td>
<td>UK</td>
<td>Information on patient &amp; public involvement</td>
</tr>
<tr>
<td><a href="http://www.natpact.nhs.uk">www.natpact.nhs.uk</a></td>
<td>National Primary &amp; Care Trust development Programmes</td>
<td>UK</td>
<td></td>
</tr>
<tr>
<td><a href="http://www.expertpatients.nhs.uk/">www.expertpatients.nhs.uk/</a></td>
<td>Expert Patients Programme</td>
<td>UK</td>
<td>Govt self-management programme</td>
</tr>
<tr>
<td><a href="http://www.nice.org.uk">www.nice.org.uk</a></td>
<td>National Institute for Clinical Excellence</td>
<td>UK</td>
<td>Guidelines development</td>
</tr>
<tr>
<td><a href="http://www.thepatientsforum.org.uk">www.thepatientsforum.org.uk</a></td>
<td>The Patients Forum</td>
<td>UK</td>
<td>Network of national &amp; regional patient health organisations</td>
</tr>
<tr>
<td><a href="http://www.patientsassociation.com">www.patientsassociation.com</a></td>
<td>The Patients’ Association</td>
<td>UK</td>
<td>Consumer health organisation</td>
</tr>
<tr>
<td><a href="http://www.avma.org.uk">www.avma.org.uk</a></td>
<td>Action Against Medical Accidents</td>
<td>UK</td>
<td>Consumer organisation</td>
</tr>
<tr>
<td>Website</td>
<td>Organisation</td>
<td>Country</td>
<td>Comment</td>
</tr>
<tr>
<td>---------</td>
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<td>---------</td>
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</tr>
<tr>
<td><a href="http://www.mooreadamsoncraig.co.uk">www.mooreadamsoncraig.co.uk</a></td>
<td>Moore Adamson Craig Partnership</td>
<td>UK</td>
<td>Research, policy and training in user involvement in health. Did reports that led to latest NHS model</td>
</tr>
<tr>
<td><a href="http://www.ncc.org.uk">www.ncc.org.uk</a></td>
<td>National Consumer Council</td>
<td>UK</td>
<td>Generic consumer group with focus on health and representation training programme</td>
</tr>
<tr>
<td><a href="http://www.partnerships.org.uk/guide/frame.htm">www.partnerships.org.uk/guide/frame.htm</a></td>
<td></td>
<td>UK</td>
<td>NGO guidance on partnerships</td>
</tr>
<tr>
<td><a href="http://www.hft.org/">www.hft.org/</a></td>
<td>Help for Health Trust</td>
<td>UK</td>
<td>NHS sponsored site about quality information for consumers</td>
</tr>
<tr>
<td><a href="http://www.kingsfund.org.uk">www.kingsfund.org.uk</a></td>
<td>King’s Fund</td>
<td>UK</td>
<td>Research of consumer involvement</td>
</tr>
<tr>
<td><a href="http://www.napp.org.uk">www.napp.org.uk</a></td>
<td>National Association for Patient Participation</td>
<td>UK</td>
<td>Promotes the role of patient participation in general practice</td>
</tr>
<tr>
<td><a href="http://www.collegeofhealth.org.uk">www.collegeofhealth.org.uk</a></td>
<td>College of Health</td>
<td>UK</td>
<td>Now folded</td>
</tr>
<tr>
<td><a href="http://www.patientsassociation.com">www.patientsassociation.com</a></td>
<td>The Patients’ Association</td>
<td>UK</td>
<td>National consumer network</td>
</tr>
<tr>
<td><a href="http://www.bhf.org.uk">www.bhf.org.uk</a></td>
<td>British Heart Foundation</td>
<td>UK</td>
<td>Runs the Hearty Voices project</td>
</tr>
<tr>
<td><a href="http://www.which.net">www.which.net</a></td>
<td>Consumers’ Association</td>
<td>UK</td>
<td>Generic consumer organisation</td>
</tr>
<tr>
<td><a href="http://www.healthvoice-uk.net">www.healthvoice-uk.net</a></td>
<td>Health Voice Network</td>
<td>UK</td>
<td>E-based resource for those involved in PPI</td>
</tr>
<tr>
<td><a href="http://www.shapingourlives.org.uk">www.shapingourlives.org.uk</a></td>
<td>Shaping Our Lives, National User Network, National Institute for Social Work</td>
<td>UK</td>
<td>National network being established for user organisations, expanded into health from social services, emphasis on mental health and disability</td>
</tr>
<tr>
<td><a href="http://www.hmca.org.uk">www.hmca.org.uk</a></td>
<td>Long-term Medical Conditions Alliance</td>
<td>UK</td>
<td>National umbrella group for patient organisations</td>
</tr>
<tr>
<td><a href="http://www.ippr.org.uk">www.ippr.org.uk</a></td>
<td>Run by Institute for Public Policy Research</td>
<td>UK</td>
<td></td>
</tr>
<tr>
<td><a href="http://www.healthinpartnership.org">www.healthinpartnership.org</a></td>
<td></td>
<td>UK</td>
<td>Research project supporting patient &amp; public participation</td>
</tr>
<tr>
<td><a href="http://www.dpp.org.uk">www.dpp.org.uk</a></td>
<td>Doctor-Patient Partnership Board</td>
<td>UK</td>
<td>UK education charity working with PCOs &amp; public</td>
</tr>
<tr>
<td><a href="http://www.ex.ac.uk/folk.us">www.ex.ac.uk/folk.us</a></td>
<td>Folk.us site</td>
<td>UK</td>
<td>Lay involvement in health research</td>
</tr>
<tr>
<td><a href="http://www.guardian.co.uk">www.guardian.co.uk</a></td>
<td>Guardian newspaper</td>
<td>UK</td>
<td>Stories about problems with patients’ forums</td>
</tr>
<tr>
<td>Website</td>
<td>Organisation</td>
<td>Country</td>
<td>Comment</td>
</tr>
<tr>
<td>---------</td>
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</tr>
<tr>
<td><a href="http://www.canadian-health-network.ca">www.canadian-health-network.ca</a></td>
<td>Canadian Health Network</td>
<td>Canada</td>
<td>Health Canada site with information and links to groups for the public.</td>
</tr>
<tr>
<td><a href="http://www.hc-sc.gc.ca/english/women/cwh.htm">www.hc-sc.gc.ca/english/women/cwh.htm</a></td>
<td>Health Canada Women’s Health Bureau</td>
<td>Canada</td>
<td>Govt agency that supports &amp; funds centres of excellence and Women’s Health Network etc.</td>
</tr>
<tr>
<td><a href="http://www.cwhn.ca/">www.cwhn.ca/</a></td>
<td>Canadian Women’s Health Network</td>
<td>Canada</td>
<td>Govt-funded network of women’s organisations.</td>
</tr>
<tr>
<td><a href="http://www.bestmedicines.ca">www.bestmedicines.ca</a></td>
<td>Best Medicines Coalition</td>
<td>Canada</td>
<td>National umbrella consumer organisation.</td>
</tr>
<tr>
<td><a href="http://www.consumer.ca">www.consumer.ca</a></td>
<td>Consumers’ Ass of Canada</td>
<td>Canada</td>
<td>Information about health committee, submission.</td>
</tr>
<tr>
<td><a href="http://www.cmhta.ca">www.cmhta.ca</a></td>
<td>Canadian Mental Health Association</td>
<td>Canada</td>
<td>Advocates for mental health patients, governing body contains health professionals, separate committee for consumers.</td>
</tr>
<tr>
<td><a href="http://www.fda.gov/oc/advisory">www.fda.gov/oc/advisory</a></td>
<td>Food &amp; Drug Administration advisory groups</td>
<td>USA</td>
<td></td>
</tr>
<tr>
<td><a href="http://deainfo.nci.nih.gov/ADVISORY/boards.htm">http://deainfo.nci.nih.gov/ADVISORY/boards.htm</a></td>
<td>National Cancer Institute Director’s Consumer Liaison Group</td>
<td>USA</td>
<td></td>
</tr>
<tr>
<td>Website</td>
<td>Organisation</td>
<td>Country</td>
<td>Comment</td>
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<tr>
<td>------------------------------------------------------------------------</td>
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<tr>
<td><a href="http://la.cancer.gov/carra/about_carra.html">http://la.cancer.gov/carra/about_carra.html</a></td>
<td>Consumer Advocates in Research and Related Activities</td>
<td>USA</td>
<td>NCI programme to involve consumers in its daily activities</td>
</tr>
<tr>
<td><a href="http://www.health.gov/healthypeople">www.health.gov/healthypeople</a></td>
<td>Healthy People 2010</td>
<td>USA</td>
<td>Government community development/health promotion initiative</td>
</tr>
<tr>
<td><a href="http://patienteducation.stanford.edu/">http://patienteducation.stanford.edu/</a></td>
<td>Stanford School of Medicine Patient Education Research Centre</td>
<td>USA</td>
<td>Research &amp; evaluation patient self-management programmes</td>
</tr>
<tr>
<td><a href="http://consumerinterests.org/">http://consumerinterests.org/</a></td>
<td>American Council of Consumer Interests, ACCI</td>
<td>USA</td>
<td>Academics &amp; professionals involved in consumer &amp; family economics</td>
</tr>
<tr>
<td><a href="http://www.citizen.org/hrg">www.citizen.org/hrg</a></td>
<td>Public Citizen and Health Research Group</td>
<td>USA</td>
<td>Advocacy group</td>
</tr>
<tr>
<td><a href="http://www.consumerfed.org">www.consumerfed.org</a></td>
<td>Consumers Federation of America</td>
<td>USA</td>
<td>Education and advocacy on consumer issues including healthcare</td>
</tr>
<tr>
<td><a href="http://www.prairenet.org/cchcc">www.prairenet.org/cchcc</a></td>
<td>Champaign County Health Care Consumers</td>
<td>USA</td>
<td>Advocacy around access to health care</td>
</tr>
<tr>
<td><a href="http://www.consumerwatchdog.org">www.consumerwatchdog.org</a></td>
<td>Foundation for Taxpayer &amp; Consumer Rights</td>
<td>USA</td>
<td>California-based NFP citizen organising and training</td>
</tr>
<tr>
<td><a href="http://www.nwhn.org/">www.nwhn.org/</a></td>
<td>National Women’s Health Network</td>
<td>USA</td>
<td>National organisation advocating for women’s health</td>
</tr>
<tr>
<td><a href="http://www.patientadvocacy.net">www.patientadvocacy.net</a></td>
<td>Patient Advocacy Coalition Inc.</td>
<td>USA</td>
<td>Independent source of information and advocacy for health care consumers in Colorado</td>
</tr>
<tr>
<td><a href="http://www.namhpac.org">www.namhpac.org</a></td>
<td>National Association of Mental Health Planning and Advisory Councils</td>
<td>USA</td>
<td>Includes consumers</td>
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<tr>
<td><a href="http://www.medicalconsumers.org">www.medicalconsumers.org</a></td>
<td>Center for Medical Consumers</td>
<td>USA</td>
<td></td>
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<tr>
<td><a href="http://www.stopbreastcancer.org">www.stopbreastcancer.org</a></td>
<td>National Breast Cancer Coalition</td>
<td>USA</td>
<td>Activist umbrella group</td>
</tr>
<tr>
<td><a href="http://www.patientpowernetwork.org">www.patientpowernetwork.org</a></td>
<td>Aims to make health care more accountable to patients, a project of FACCT: Foundation for Accountability</td>
<td>USA</td>
<td>Funded by managed care and pharmaceutical industry</td>
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<tr>
<td><a href="http://www.ourbodiesourselves.org">www.ourbodiesourselves.org</a></td>
<td>Boston Women’s Health Book Collective</td>
<td>USA</td>
<td></td>
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<tr>
<td><a href="http://www.nclnet.org">www.nclnet.org</a></td>
<td>National Consumers League</td>
<td>USA</td>
<td>Includes safety of medications</td>
</tr>
<tr>
<td><a href="http://www.nationalhealthcouncil.org">www.nationalhealthcouncil.org</a></td>
<td>National Health Council</td>
<td>USA</td>
<td></td>
</tr>
<tr>
<td><a href="http://www.nlembassy.or.kr">www.nlembassy.or.kr</a></td>
<td>WOCZ Association of Organisations of the Chronically Ill</td>
<td>Netherland ds</td>
<td></td>
</tr>
<tr>
<td>Website</td>
<td>Organisation</td>
<td>Country</td>
<td>Comment</td>
</tr>
<tr>
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<tr>
<td><a href="http://www.npcf.nl">www.npcf.nl</a></td>
<td>Nederlandse Patienten Consumenten Federation</td>
<td>Netherlands</td>
<td></td>
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<tr>
<td><a href="http://www.cg-raad.nl">www.cg-raad.nl</a></td>
<td>Dutch Council of the Chronically Ill and Disabled</td>
<td>Netherlands</td>
<td></td>
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<tr>
<td><a href="http://www.europeanpatientsforum.org">www.europeanpatientsforum.org</a></td>
<td>European Patients’ Forum</td>
<td>Europe</td>
<td>Recently formed organisation of pan-European organisation</td>
</tr>
<tr>
<td><a href="http://www.pickereurope.org">www.pickereurope.org</a></td>
<td>Carry out research, educational work, evaluate health services throughout Europe ‘through the patients’ eyes’</td>
<td>Europe</td>
<td>Board contains medical people and patients orgs</td>
</tr>
<tr>
<td><a href="http://www.cochraneconsumer.com">www.cochraneconsumer.com</a></td>
<td>Cochrane Consumer Network</td>
<td>International</td>
<td>Now goes to website below</td>
</tr>
<tr>
<td><a href="http://www.informedhealthonline.org">www.informedhealthonline.org</a></td>
<td>Health Research and Education Foundation</td>
<td>International</td>
<td>Offshoot of Cochrane Collaboration, run from Melbourne</td>
</tr>
<tr>
<td><a href="http://www.cochrane.no/consumers/">www.cochrane.no/consumers/</a></td>
<td>Cochrane Consumer Network</td>
<td>International</td>
<td></td>
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<tr>
<td><a href="http://www.bcaction.org/Pages/LearnAboutUs/PreventionFirst.html">www.bcaction.org/Pages/LearnAboutUs/PreventionFirst.html</a></td>
<td>Breast Cancer Action</td>
<td>USA/Canada</td>
<td>Prevention First Campaign: A Coalition of Independent Health Organisations</td>
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<tr>
<td><a href="http://www.consumersinternational.org">www.consumersinternational.org</a></td>
<td>Consumer International CCI</td>
<td>International</td>
<td>Have a health programme</td>
</tr>
<tr>
<td><a href="http://www.patientsorganizations.org">www.patientsorganizations.org</a></td>
<td>International Alliance of Patients’ Organizations (IAPO)</td>
<td>International</td>
<td>Global alliance representing patients</td>
</tr>
</tbody>
</table>
## APPENDIX 4: INDIVIDUALS/ORGANISATIONS CONTACTED

### New Zealand

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
<th>Country</th>
<th>Topic discussed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doug Banks</td>
<td>The Light House</td>
<td>New Zealand</td>
<td></td>
</tr>
<tr>
<td>Gillian Bohm</td>
<td>Ministry of Health</td>
<td>New Zealand</td>
<td></td>
</tr>
<tr>
<td>Hilary Boyd</td>
<td>Policy &amp; Planning Advisor RNZ Foundation of the Blind</td>
<td>New Zealand</td>
<td></td>
</tr>
<tr>
<td>Phillida Bunkle</td>
<td>Health advocate and board members, New Deal for Communities, Fulham, UK</td>
<td>New Zealand</td>
<td>NZ history and UK</td>
</tr>
<tr>
<td>Vicki Burnett</td>
<td>Paid mental health consumer adviser</td>
<td>New Zealand</td>
<td></td>
</tr>
<tr>
<td>Leanne Catchpole</td>
<td>Waitakere DHB</td>
<td>New Zealand</td>
<td></td>
</tr>
<tr>
<td>Kylie Clode</td>
<td>Disability Policy Manager, Disability Services Directorate, MOH</td>
<td>New Zealand</td>
<td></td>
</tr>
<tr>
<td>Susie Crooks</td>
<td>Whatever it Takes, Lighthouse Trust</td>
<td>New Zealand</td>
<td></td>
</tr>
<tr>
<td>Fiona Doolan</td>
<td>Heart Foundation, Cardiac Rehabilitation Consultant</td>
<td>New Zealand</td>
<td></td>
</tr>
<tr>
<td>Jacinta Fa’alili</td>
<td>Pacific adviser, Health Research Council</td>
<td>New Zealand</td>
<td></td>
</tr>
<tr>
<td>Jo Fitzpatrick</td>
<td>CEO, Women’s Health Action Trust</td>
<td>New Zealand</td>
<td></td>
</tr>
<tr>
<td>John Forman</td>
<td>New Zealand Organisation for Rare Disorders</td>
<td>New Zealand</td>
<td></td>
</tr>
<tr>
<td>Fiona Gordon</td>
<td>Research Coordinator, Public Health, Health Research Council</td>
<td>New Zealand</td>
<td></td>
</tr>
<tr>
<td>Camille Guy</td>
<td>Vice-President, Retina NZ</td>
<td>New Zealand</td>
<td></td>
</tr>
<tr>
<td>Lesley Harwood</td>
<td>Adviser, Ministry of Consumer Affairs</td>
<td>New Zealand</td>
<td></td>
</tr>
<tr>
<td>Kate Hirst</td>
<td>MOH, Manager of disability consumer consultation project</td>
<td>New Zealand</td>
<td></td>
</tr>
<tr>
<td>Tricia Irving</td>
<td>Skylight Trust</td>
<td>New Zealand</td>
<td>Support for children &amp; families coping with loss</td>
</tr>
<tr>
<td>Merian Litchfield</td>
<td>Litchfield Healthcare Ass, Centre for Rural Health, Christchurch Medical School,</td>
<td>New Zealand</td>
<td>Research on rural communities</td>
</tr>
<tr>
<td>Pat Neuwelt</td>
<td>Public health registrar, Dept of</td>
<td>New Zealand</td>
<td></td>
</tr>
<tr>
<td>Name</td>
<td>Position</td>
<td>Country</td>
<td>Topic discussed</td>
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</tr>
<tr>
<td>Sue North</td>
<td>Advocacy Liaison Coordinator, ACC</td>
<td>New Zealand</td>
<td>Supports Consumers</td>
</tr>
<tr>
<td>Mary O’Hagan</td>
<td>Commissioner, Mental Health Commission</td>
<td>New Zealand</td>
<td></td>
</tr>
<tr>
<td>Dennis Paget</td>
<td>President Marlborough Greypower, Former health spokesperson, member Health Committee</td>
<td>New Zealand</td>
<td></td>
</tr>
<tr>
<td>Elizabeth Powell</td>
<td>MOH, Primary Care</td>
<td>New Zealand</td>
<td></td>
</tr>
<tr>
<td>Jim Primrose</td>
<td>MOH, Primary Care</td>
<td>New Zealand</td>
<td></td>
</tr>
<tr>
<td>Tina Reid</td>
<td>Federation of Voluntary Welfare Organisations/ Community Sector Taskforce</td>
<td>New Zealand</td>
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<tr>
<td>Barbara Robson</td>
<td>Co-convenor Federation of Women’s Health Councils of Aotearoa/New Zealand, member Taranaki DHB, Chair Disability Committee</td>
<td>New Zealand</td>
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<tr>
<td>Maire Russell</td>
<td>Research fellow, Health Service Research Centre Victoria University</td>
<td>New Zealand</td>
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<tr>
<td>Robyn Shearer</td>
<td>Programme Manager, Mental Health Workforce Development Programme, Health Research Council</td>
<td>New Zealand</td>
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<tr>
<td>Judy Small</td>
<td>Policy Analyst, Office for Disability Issues, Ministry of Social Development</td>
<td>New Zealand</td>
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<tr>
<td>Alison Taylor</td>
<td>CEO, Mental Health Foundation</td>
<td>New Zealand</td>
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<tr>
<td>Gera Verheul</td>
<td>CEO, Ripple Trust</td>
<td>New Zealand</td>
<td>Disability Empowerment &amp; Advocacy Support Service in Northern Region of MOH</td>
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<tr>
<td>Rod Watts</td>
<td>Manager, Planning &amp; development, Disability Services Directorate, MOH</td>
<td>New Zealand</td>
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<tr>
<td>Wendi Wicks</td>
<td>Disabled Persons’ Assembly</td>
<td>New Zealand</td>
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<tr>
<td>Donal Wineera</td>
<td>Project manager, Porirua Healthlinks</td>
<td>New Zealand</td>
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<tr>
<td>Pauline Winter</td>
<td>Pacific Business Development Trust, formerly CEO Workbridge</td>
<td>New Zealand</td>
<td>Involvement with Pacific health and disability issues</td>
</tr>
<tr>
<td>Gillian Woods</td>
<td>New Zealand Breast Cancer Network</td>
<td>New Zealand</td>
<td>Re training programme</td>
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**Overseas**

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<thead>
<tr>
<th>Name</th>
<th>Position</th>
<th>Country</th>
<th>Topic discussed</th>
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<tbody>
<tr>
<td>Barbara Bourrier La Croix</td>
<td>Canadian Women’s Health Network</td>
<td>Canada</td>
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<tr>
<td>Mona Dupre-Ollink</td>
<td>Outreach Coordinator, Canadian Women’s Health Network</td>
<td>Canada</td>
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<tr>
<td>Jane Hamilton</td>
<td>Coordinator Best Medicines Coalition</td>
<td>Canada</td>
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<tr>
<td>Name</td>
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<tr>
<td>Helen Hopkins</td>
<td>CEO CHF Australia</td>
<td>Australia</td>
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<tr>
<td>Alison Hopkins</td>
<td>Health of Connections Team National Consumer Council</td>
<td>UK</td>
<td>Re Stronger Voice</td>
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<tr>
<td>Marcia Kelson</td>
<td>Patient Involvement Unit, NICE</td>
<td>UK</td>
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<tr>
<td>Kathy Kovacs Burns</td>
<td>Best Medicines Coalition</td>
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<tr>
<td>Shannon Little</td>
<td>Communications Office, Public Citizen, USA</td>
<td>USA</td>
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<tr>
<td>Suzanne McGregor</td>
<td>Hearty Voices</td>
<td>UK</td>
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<tr>
<td>Katherine Murphy</td>
<td>Director Communications, Patients’ Association</td>
<td>UK</td>
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<tr>
<td>Maryann Napoli</td>
<td>Center for Medical Consumers USA</td>
<td>USA</td>
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<tr>
<td>Cynthia Pearson</td>
<td>National Women’s Health Network</td>
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<tr>
<td>David Pink</td>
<td>CEO, Long-term Medical Conditions Alliance</td>
<td>UK</td>
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<tr>
<td>Emma Reeves</td>
<td>Senior Coordinator, International Alliance of the Chronically Ill</td>
<td>International</td>
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<tr>
<td>Terri Smith</td>
<td>National Programme Manager, Breast Cancer Network of Australia</td>
<td>Australia</td>
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<tr>
<td>Fiona Tito</td>
<td>Research School of Social Sciences Law, former board member, Consumers Health Forum of Australia and part of Consumer Focus Collaboration</td>
<td>Australia</td>
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</tr>
<tr>
<td>Albert Van Der Zeijden</td>
<td>Vice Chair, CG-Raad (Netherlands) and Chair, International Alliance of the Chronically Ill (International)</td>
<td>Netherlands</td>
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<tr>
<td>Janet Wale</td>
<td>Cochrane Consumer Network (CCNet)</td>
<td>International</td>
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