

FEEDBACK, PARTICIPATION AND CONSUMER DIVERSITY

A LITERATURE REVIEW

Produced by the National Resource Centre for
Consumer Participation in Health

A Consumer Focus Collaboration publication

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The Commonwealth Department of Health and Aged Care has funded a range of projects to strengthen consumer participation in health through its Consumer Focus Strategy. These projects are overseen by the Consumer Focus Collaboration, which is made up of consumer organisations, professional organisations, Commonwealth, state and territory health departments, and private sector representatives. The Collaboration works to increase effective consumer participation at all levels within the Australian health care system.

Projects funded through the strategy are intended to promote, integrate and disseminate information and increase consumer involvement in health service planning, delivery, monitoring and evaluation. The Consumer Focus Collaboration publication series documents these projects.

A wide range of organisations participate in the Consumer Focus Collaboration, representing a broad range of views and interests. Consumer Focus Collaboration publications do not attempt to reflect all of the views of the individual organisations and jurisdictions represented on the Collaboration. However they do demonstrate the shared perspective on strategies for building a strong consumer focus for national action on quality and safety.

For information on the availability of the publications, contact the Information Manager, National Resource Centre for Consumer Participation in Health, ph: (03) 9479 3614, free call 1800 625 619, or check the web site (<http://nrccph.latrobe.edu.au>).

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Foreword

Building a safe, high-quality health care system means that people managing and working in the system need to work together with consumers and the community to achieve sustainable improvements and maintain public confidence in the system.

The Consumer Focus Collaboration publication series provides practical tools to support consumer and health care providers to achieve this goal. These tools have been developed through projects funded by the Commonwealth Department of Health and Aged Care.

The Consumer Focus Collaboration, established in 1997, has played an important role in taking forward work on consumer participation at the national level. The Collaboration is a national body with representatives from consumer, professional and private sector organisations, and all health departments. Its aim is to strengthen the focus on consumers in health service planning, delivery, monitoring and evaluation in Australia.

The Collaboration is taking the lead in fostering an active partnership between consumers of health care and those who provide that care.

The resource guides, reports and issues papers that make up the publication series have been designed to provide health care consumers, service providers and managers with ideas and information about how to work together in partnerships.

Strengthening the voice of consumers in the health system requires a multi-pronged approach. This publication series reflects the commitment of the Consumer Focus Collaboration to provide strategic resources in a number of areas including education and training, building consumer capacity to participate, building provider capacity to respond to consumer need, and research into aspects of consumer involvement in health services.

Consumer Focus Collaboration
June 2000

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Executive summary

This literature review was funded by the Commonwealth Government through the Department of Health and Aged Care and overseen by the Consumer Focus Collaboration (CFC).

The CFC was established in 1997 to further the goal of enhancing quality and safety through increasing the consumer focus of the health system. The CFC has a membership representing consumer organisations, provider organisations, health insurers and health departments. It aims to develop strategic alliances and projects that will promote the development of a more consumer-focused health care system.

The literature review was undertaken by the National Resource Centre for Consumer Participation in Health (NRCCPH). The centre is funded by the Commonwealth. Its primary functions are to collect and disseminate information on consumer participation across the health system, and to become a centre of excellence which can assist people to develop strategies, analyse methods and models of participation and contribute to relevant research and development.

CONSUMER PARTICIPATION IN HEALTH

The principle of consumer participation in the planning and implementation of health care is increasingly being recognised as critical to the development of health systems which promote the health and wellbeing of communities.

In Australia, a great deal of innovative work is being done to increase consumer participation in the health system. However, policy makers, service providers and consumer organisations often find it difficult to ensure the diversity of consumers and community members is reflected in participation initiatives. A key finding of the literature review is that consumers from diverse groups can provide valuable feedback and insights about services.

DEFINITIONS

In this report *consumer participation* is used to describe the involvement of consumers in the development of health services. This can include involvement in policy development, strategic planning, service planning, service delivery and evaluation and monitoring. There are different degrees to which consumers are involved at each of these levels, ranging from information seeking and information sharing (low levels of participation) through to consultation, partnership and consumer control (higher levels of consumer participation).

Consumer feedback is one form of consumer participation. It is a process in which health services seek information from consumers. The service then analyses the information, decides what to do with the information and decides what action it will take based on the information. This form of participation is thus at the level of information seeking and requires a low level of consumer participation. There has been a large amount of activity in the Australian health system around the development of consumer feedback processes, such as patient satisfaction surveys.

While much work has been done to enhance the capacity of the health system to respond to the diversity of consumers, many groups are excluded from receiving appropriate services from mainstream health care organisations. They are also excluded from participating in commonly used strategies to seek feedback from or involve consumers in service development such as patient satisfaction surveys. There is little resourcing provided to consumers, especially marginalised consumer groups, to develop their capacity to participate.

In a Needs Assessment undertaken in 1999, the NRCCPH found that where mainstream organisations had developed mechanisms for involving consumers, these structures and processes were often not appropriate to involving consumers from diverse backgrounds. In general, many groups of consumers were only involved when they were the focus of a specific project or strategy. The development of effective structures and processes to ensure the participation of a diversity of consumers is a considerable and ongoing challenge for most organisations.

The groups identified by participants in the NRCCPH's Needs Assessment as being the most excluded from mainstream participation mechanisms were consumers who are:

- from a range of cultural and linguistic backgrounds;
- of Aboriginal and Torres Strait Islander descent;
- living with chronic 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 FEEDBACK, PARTICIPATION AND CULTURAL DIVERSITY PROJECT

The Feedback, Participation and Consumer Diversity project was undertaken as part of the establishment phase of the NRCCPH.

The CFC was concerned that while much work was being done on consumer participation and feedback, many consumer groups were excluded from participating in mainstream processes for seeking such input. This project was undertaken to draw together existing information about: participation of previously excluded groups of consumers and to highlight existing barriers to participation of these groups which had been marginalised.

The project methodology included establishment of a reference group and a panel of critical reviewers; a systematic search of the literature (including searching electronic data bases, hand searching and telephoning key organisations and individuals); development of an annotated bibliography and writing of this literature review.

Limitations of this review include that relevant literature is dispersed throughout a wide range of publication types; there is a large body of work that is not yet written up or evaluated; time restrictions meant that not all identified literature could be reviewed; and some highly relevant work was published just as the project was being concluded.

WHY WAS CONSUMER INPUT SOUGHT?

Much of the literature identified in the review documented work done to seek feedback from or involve a specific group of consumers. Only a small proportion of the literature looked across populations to identify ways a range of groups could be involved in the one strategy.

The key motivations identified by authors for undertaking work to involve or seek feedback from marginalised consumer groups included:

- known poor access to services;
- exclusion from previous feedback or participation processes;
- development and testing of feedback tools;
- that the needs of the group are unknown;
- evaluation of changes to service provision;
- evaluation of specific programs or resources or evaluation of consumer participation;
- commitment to involving consumers in developing services or new models of care; and
- consumer-led activities to address issues for specific groups.

BARRIERS: STRUCTURAL ISSUES

There are many ways different consumer groups are marginalised from participating in, or giving feedback to, health services. Often the mechanisms of marginalisation (otherwise known as barriers to participation) are closely linked to broader issues of access to services.

The literature review showed that, while individual reports documented the barriers to participation for a specific group of consumers, many of these barriers were common across groups, i.e., these barriers are systems issues, rather than issues about particular types of consumers.

These structural barriers to participation of consumers from marginalised groups appear to be linked to barriers to accessing services. They include that:

- many mainstream organisations have developed neither the capacity to provide appropriate and accessible health care services to the diverse groups within their communities, nor systematic and appropriate strategies for seeking input from consumers from diverse groups - unless inclusion of diverse groups is specifically addressed in the design of feedback and participation processes these consumers are generally under-represented in resultant activities;
- traditionally, services have located the reasons for marginalisation with consumers, especially those from marginalised groups, rather than focusing on organisational structures and cultures;
- many organisations have a limited capacity to acknowledge and consult with a range of people within different groups which can result in the development of stereotypes;
- inappropriate attitudes of service providers to consumers from marginalised groups works against their participation;
- the models of care utilised by services often do not support participation and can disempower consumers through treating them as dependant, focusing on their disabilities rather than their abilities, failing to respect their rights, and failing to communicate;
- in the absence of appropriate service delivery by mainstream organisations there is an increased reliance on group specific services which are often poorly funded and have little capacity to impact on mainstream services;
- the work done with consumers from marginalised groups is often undertaken as a once-off project, outside of any integrated approach to the development of appropriate services, which means this work is ad hoc and seen as something to be added on when funding is available, rather than being part of the core business of mainstream services; and
- while much work has been done to find out from consumers what the barriers and issues are, services often do not act on this information with the consequence that consumers can become sceptical about invitations to give feedback and may see it as a way of delaying action.

BARRIERS: ISSUES ABOUT THE QUALITY OF THE INFORMATION OBTAINED THROUGH FEEDBACK AND PARTICIPATION PROCESSES

A range of issues which impact on the quality of information and knowledge developed through consumer feedback and participation activities were raised in the research reviewed. The consequence of poor processes can be that the information gathered is not useful for informing or implementing change. These issues will impact on the quality of the information gained in feedback processes, especially if these issues are not addressed by mainstream service providers undertaking routine or mainstream feedback processes. These issues include that:

- many groups are routinely excluded from participating in mainstream feedback processes;
- the model of participation may not empower consumers to participate, and until consumers can experience being given more power in decision making they may be reluctant to participate;
- it can be critical to build relationships with consumers and consumer groups, and find out about their needs and preferences, to ensure feedback and participation strategies are successful but models of participation may not be appropriate to consumers from marginalised groups and may even reproduce patterns of inequality;
- low response rates can make it difficult to interpret the results of participation and feedback activities;

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- health professionals may believe that some consumers do not have the capacity to give feedback but, while it may be the case that some consumers cannot give feedback all of the time, authors investigating this issue found that most consumers could give valuable feedback about services;
 - consumers may be sceptical about the capacity of service providers to hear their feedback;
 - the types of scales used to measure consumer responses may not be meaningful to consumers;
 - there needs to be development of ways to improve the representativeness of samples and involve a diverse range of consumers in all activities: representativeness can be enhanced by developing a range of different strategies to enable consumers with different needs to participate;
 - there is a range of issues specific to patient satisfaction surveys: a key issue is that the questions that are asked are often those that are of interest to service providers; other issues include questions about whether they are an appropriate tool per se, whether the concept of satisfaction indicates consumers are happy with the quality of care, limitations on the usefulness of the information obtained when high levels of satisfaction are expressed, issues about validity and reliability; and low response rates.

BARRIERS: CONSUMER ISSUES

Consumer reports identify a range of barriers and issues for them in participating. Many of these issues are not well documented as consumer groups tend not to have access to the resources or infrastructure to either research and/or publish their experiences.

There are many barriers to the participation of consumers, especially consumers from marginalised groups, in service development. The capacity of consumers, as well as of service providers, needs to be developed to ensure participation is an effective means of quality improvement.

These barriers include:

- consumers may not want to give negative feedback or complain;
- consumers may experience, or fear, discrimination as a consequence of providing feedback;
- consumers may not have access to the structures or resources to participate – in addition, structural inequalities may mean that those who receive the poorest services are given the least opportunity to participate;
- unequal power relationships between consumers and providers can make it difficult for consumers to provide feedback or complain;
- the questions asked are not relevant to consumers; and
- developing an infrastructure that supports the participation of consumers from diverse backgrounds in service development requires enhancing the capacity of consumers to be active in these processes.

SUMMARY OF THE GROUPS IDENTIFIED AND PARTICIPATION AND FEEDBACK METHODS

There was a considerable amount of information in the literature about the ways services have involved consumers from marginalised groups. A table is provided in the report following which summarises methods used to work with specific groups of consumers previously marginalised in service development. The groups of consumers are:

- people with mental health issues;
- people from non-English-speaking backgrounds;
- those with disabilities;
- young people;
- older people;
- people experiencing homelessness;
- those living on low incomes;
- those with low literacy skills;
- people with chronic health conditions;
- indigenous peoples;

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- parents;
 - carers;
 - women;
 - people living in rural and remote areas;
 - frail people;
 - survivors of violence.

LINKING WITH COMMUNITIES

Developing the kinds of organisations that respond to, and seek input from, a diverse range of consumer groups, in particular those who have previously been marginalised requires that organisations:

- ask questions about their commitment to utilise information provided by consumers to inform service development;
- develop partnerships with consumers and communities to facilitate the conduct of mutually beneficial work; and
- develop a range of strategies to link with consumers and community groups.

Issues that need to be considered prior to engaging with consumers include:

- organisational commitment to utilising consumer information to improve services
- development of strategies for working collaboratively and sensitively with communities;
- understanding how consumers want to work with services;
- development of ways of linking with communities; and
- development of strategies for accountability to consumers and for demonstrating how consumer input has been utilised to improve services.

Some of the ways organisations and researchers linked with consumers were:

- snowball sampling;
- geographic based sampling;
- asking consumers to participate while they are utilising a service;
- utilising health service client lists or contacting clinicians working with the target group;
- identification of people with common family surnames from the phone book;
- making links through a group specific service coordinator or worker;
- linking with consumers through existing support and self help groups;
- outreach: going to where members of specific groups meet;
- asking schools to participate in projects;
- seeking feedback as part of other activities;
- advertising the study;
- public meetings;
- involving consumer groups, consumer organisations and community based group specific agencies in the study.

The most appropriate method utilised to link with consumers may depend on the purpose of the work.

In order to develop accountability to consumers and to funders it is important that services develop systems for documenting and evaluating the changes made as a result of consumer participation. In addition, changes that have been recommended and not made could also be highlighted for future action. It is critical that funders require organisations to monitor and document achievements in this area.

ISSUES TO CONSIDER IN DEVELOPING A PARTICIPATION STRATEGY

Developing feedback and participation processes that enable specific consumer groups to participate includes thinking through a number of issues about how to make those processes most appropriate to consumers who have been marginalised. Some of the issues discussed in the literature include:

- employment of community members;
- consultation with consumers about appropriate strategies;
- consideration of payment for consumers in recognition of their expertise and participation;
- whether surrogate consumers should be employed;
- development of appropriate translations;
- confidentiality and anonymity;
- involving both consumers and staff; and
- building feedback into other activities.

A second set of issues exists around the most appropriate methodological approaches to seeking feedback and consumer participation. Some of the literature suggests that:

- the methodology chosen to seek feedback should reflect the reasons for seeking that feedback;
- the methodology should enable the collection of information that reflects what consumers think;
- it is equally important to collect information that is complex and difficult to measure as well as information that is more easily quantified.

Building on this, it may also be important to ask what sort of feedback strategy or participation process will most likely produce the type of information or knowledge required to create organisational change and improvements to service quality.

A number of points were made about the relative usefulness of qualitative and quantitative methodologies. These include that:

- qualitative methodologies may be more useful when little is known about the area, when quantitative data is ambiguous or when measures utilised to seek quantitative information are inappropriate to specific consumer groups; and
- combinations of quantitative and qualitative methods may be useful, especially when qualitative methods are used to inform questionnaire development and the use of both types of methods assists in the development of more in-depth understanding of complex issues.

HOW FEEDBACK METHODS HAVE BEEN USED TO INCLUDE MARGINALISED GROUPS

Engaging with consumers who have previously been marginalised from participation in feedback and service development activities requires developing and adapting strategies so that participation is achieved. Some of the means of informing the adaptation of existing methods included:

- consulting with and involving consumers, relevant workers and community organisations about the types of questions that should be asked, how those questions should be asked and what types of methods would be the most appropriate for seeking information;
- thinking about the types of questions that need to be asked to gather information that is useful for informing service development;
- thinking about what types of approaches and strategies are appropriate to different consumer groups, and how can these strategies be adapted to improve participation and ensure people are able to be involved; and
- thinking about how consumers can be involved in long term change at all levels.

There are many ways in which feedback from, and involvement of, consumers from marginalised groups has been sought. Adaptation of the following methods were commonly utilised:

- questionnaires
- focus groups
- interviews
- forums summits and meetings
- observation by researchers
- project advisory, steering or reference groups
- outreach
- community development and action research processes.

LINKING FEEDBACK TO QUALITY IMPROVEMENT

Appropriate types of information and feedback appropriately collected can result in enhanced outcomes (in terms of quality and consumer focus) through:

1. providing the type of information that enables people to make changes to the way things are done;
2. motivating people to achieve better outcomes;
3. creating better relationships between service users and service providers resulting in 'power-sharing';
4. measuring quality and consumer focus outcomes, as in any system, one tends to get what one measures!

Going one step further than this, Draper suggests that in order to create effective change, service providers need to move beyond seeking feedback to engaging with consumers through inquiring with consumers, planning with consumers, acting with consumers and evaluating with consumers (Draper M 1997, *Involving consumers in improving hospital care: lessons from Australian hospitals*, Australian Government Publishing Service, Canberra).

This literature review identified that there was an overwhelming amount of work done to seek feedback and involvement of consumers who had previously been marginalised from participation in health service development. Given that this work is being done, the critical question becomes: has this information created the kinds of mainstream services that are accessible and appropriate to all members of communities, and if not, why not.

It would seem that many of the very important lessons learnt from this type of work at local levels are not incorporated into strategies for system wide change. This means that there will be some services and some parts of services that are responsive and do listen to their communities, but that this will be localised and not impact on broader service delivery, or on the strategies utilised by mainstream services to routinely collect information from consumers.

The difficulty in changing service systems and cultures was a topic reflected on in a number of reports. Changing service systems requires a commitment to sharing information, changing power relationships and to developing feedback and participation methods that create the kinds of information and activities that make organisational change imperative. The capacity of organisations to respond effectively to different types of feedback also needs to be strengthened.

Some reports which set out to look at how systems could be changed identified a range of strategies and organisational tools that need to be considered if feedback from consumers from diverse groups is to be incorporated into mainstream systems development. These include:

- development of a commitment to consumer participation in service development and leadership within the organisation to support this commitment;
- commitment to developing organisations that systematically provide accessible and appropriate services to all community members;
- establishment of a quality improvement framework which incorporates a cycle of planning, acting, observing and reflecting;
- development of systematic ways to involve and seek feedback from consumers from diverse consumer groups so that these processes become routine and 'do-able';

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- establishment of multiple ways of seeking and hearing consumer feedback and for involving consumers – methods which may be very different in different organisational settings and contexts and should be developed so that they ensure feedback is sought from diverse groups of consumers;
 - supporting changes to service culture so that the organisation becomes one that does listen and respond to consumers from many different groups;
 - supporting staff-consumer communication, including the development of dialogues to enable consumers and staff to understand each other's perspectives and to work together to solve problems, including establishing consumer-only, staff-only and consumer-staff sites for dialogue, discussion and decision making;
 - incorporation of consumer participation into all levels of the organisation
 - payment of consumers and consumer advocates for their expertise and participation;
 - supports for consumers working as systems advocates;
 - supports for staff who may experience anxiety and stress around this type of interaction and around cultural shifts within the organisation; and
 - monitoring of participation activities including annual audits, reporting, meeting identified targets and documentation of evidence that services are complying with relevant policy and legislative guidelines.

Overall, from reviewing the literature, it appears that a lot of work has been done in seeking feedback from a great diversity of consumers and consumer groups. This work has been critically important for developing appropriate and accessible services to consumers from diverse backgrounds. However, this work is often undertaken as an individual project, or by a part of a bigger health service. A consequence of this is that many of the valuable lessons learned either about making services more accessible and appropriate to particular groups of consumers, or about involving consumers from previously excluded groups, are not translated across organisations and systems. **Therefore the critical question is not about how to seek feedback from specific consumer groups per se, but how to ensure that this feedback is utilised to create the kinds of health care systems that provide services that are appropriate and sensitive to the diversity of the communities in which they are established to provide care.**

SUMMARY

The primary goal of all health services is to provide effective care to all members of the community in which they exist. Consequently consumers have an important role in determining, and commenting on, the quality of those services.

The literature review identified that there was an enormous amount of work done to seek feedback from and involvement of consumers who had previously been marginalised from participation in health service development. While these initiatives have been critical in the establishment of appropriate and accessible localised services, it would seem that many of the lessons learnt from this type of work are not incorporated into mainstream strategies for service improvement. Thus, a critical question is not necessarily about how to seek feedback from specific consumer groups per se, but how to ensure that this feedback is utilised to create the kinds of health care systems that provide appropriate and accessible care to the diversity of consumers in communities. Linked to this is the importance of ensuring organisations monitor their consumer participation activities, ensure they meet identified targets, and document evidence that they are complying with relevant policy and legislative guidelines.

Chapter 1: Introduction

1.1 CONSUMER PARTICIPATION IN HEALTH

There is an increasing recognition of the potential role of consumers in developing appropriate and effective health care systems. World Health Organization conventions such as the Alma-Ata Declaration (1978), the Ottawa Charter (1986) and the Jakarta Declaration (1997) identify the principle of consumer participation in the planning and implementation of health care as critical to the development of systems which promote the health and wellbeing of communities.

Evidence of the wisdom of involving consumers at all levels in health system development is beginning to emerge. For example, an evaluation of Australia's response to HIV and AIDS, which is internationally recognised for its success in controlling the spread of HIV and minimising the impacts of the disease, identified that partnerships between governments, community-based organisations, affected communities, health professionals and researchers were critical to the success of the strategy. These partnerships occurred at all levels, including policy development, research, planning, and development of models of service delivery (Commonwealth of Australia 1995 and 1996).

In Australia an enormous amount of innovative work is taking place to increase consumer participation in the health system (NRCCPH 1999). This work is being done at local, state and territory and Commonwealth government levels. It is being driven by different stakeholders (consumers, policy makers, funders, service providers) with different perspectives, all of whom are committed to a health system which focuses on those whose needs it was established to meet (for a summary of some of these activities see NRCCPH 1999).

This work is also taking place across different levels of decision-making within the health system, including policy development, strategic planning, service planning, service delivery and evaluation and monitoring. There are also different degrees to which consumers are involved at each of these levels, ranging from information seeking and information sharing through to consultation, partnership and consumer control (NRCCPH 1999).

Some of the guides, kits and resources developed in Australia to assist organisations and consumers in the development of participatory processes are listed in appendix 1.

Some definitions

In this report *consumer participation* is used to describe the involvement of consumers in the development of health services. This can include involvement in policy development, strategic planning, service planning, service delivery and evaluation and monitoring. There are different degrees to which consumers are involved at each of these levels, ranging from information seeking and information sharing (low levels of participation) through to consultation, partnership and consumer control (higher levels of consumer participation).

Consumer feedback is one form of consumer participation. It is a process in which health services seek information from consumers. The service then analyses the information, decides what to do with the information and decides what action it will take based on the information. This form of participation is thus at the level of information seeking and requires a low level of consumer participation. There has been a large amount of activity in the Australian health system around the development of consumer feedback processes, such as patient satisfaction surveys.

1.1.1 Commonwealth Government initiatives to enhance consumer participation

Commonwealth governments have supported a range of initiatives which have strengthened the focus on consumer participation in the health system over a number of years. Key policy initiatives include:

- provision of funding for the Consumers' Health Forum, a national peak consumer organisation;
- National Health Strategy reports, including *Healthy participation* (1993) and *Removing cultural and language barriers to health* (1993);

-
- funding research on the role of consumer feedback in improving quality of health care (Draper and Hill 1995) and on the role of consumer participation in improving hospital care (Draper 1998; Draper and Silburn 1999);
 - establishing a national health complaints project to develop a framework for national collation and comparison of hospital complaints data;
 - funding the development of accreditation programs;
 - incorporating requirements for the development of patient charters into the 1993 Medicare, and requirements for quality improvement into the 1998 Australian Health Care Agreements;
 - establishing the Taskforce on Quality in Australian Health Care in response to studies indicating a high level of adverse events in hospitals. This taskforce recommended that there should be a systematic approach to developing a health system more focused on consumer needs (Australian Health Ministers Advisory Council 1996);
 - consequently establishing the National Expert Advisory Group on Safety and Quality in Australian Health Care to take the recommendations of the taskforce forward, especially in six areas, one of which was consumer focus (Commonwealth of Australia 1999);
 - funding the National Demonstration Hospitals Program;
 - establishment of the CFC and funding a consumer focus strategy; and
 - Funding the National Resource Centre for Consumer Participation in Health (NRCCPH).

1.1.2 State and territory government initiatives to enhance consumer participation

At the state and territory level there has been support for a range of activities to advance consumer participation. There has been support for:

- a program of initiatives around state-wide patient satisfaction surveys;
- the development of plans and agreements supporting consumer and community participation; for example, each state/territory has signed a framework agreement for Aboriginal health which includes agreements about partnerships between governments and Aboriginal-controlled organisations;
- legislative or policy directives requiring regions or individual health services to establish consumer participation structures. Examples include state/territory consumer advisory committees on specific issues such as mental health; regional consumer councils, such as the Rural Health Councils in New South Wales, District Health Councils in Queensland and regional health promotion units in Western Australia; in New South Wales a particular emphasis in some regions has been on increasing participation of people who are often excluded from such activities;
- monitoring, or requiring reporting on, consumer participation stipulated in legislative or policy initiatives or in funded projects and programs; and
- public consultations, improving information for the public about health services, funding consumer organisations and groups, requiring consumer participation as a condition of project and service funding and in some cases monitoring of consumer participation.

1.1.3 Local level initiatives to enhance consumer participation

At the local level there is a plethora of projects, partnerships and activities. Consumers and service providers are working together in a range of ways to develop more appropriate, on-the-ground, consumer-focused services. At one end of this spectrum of work is patient satisfaction surveys, in which consumers are often passive givers of information to service providers who make decisions about how the information will be used. At the other end of the spectrum consumers are driving the development of services and/or agencies are engaging with consumers on strategies to move their services towards being consumer or community controlled. In between, a range of participatory projects in which consumers and providers are collaborators is being undertaken. Many of these projects are based on principles of community development. This may mean that consumers and community members participate in identifying and defining issues, making decisions about what to do and taking action to produce change. In the process, consumers and providers often learn new skills and acquire new knowledge. Commitment to community development processes can result in changing 'the social landscape so that new and more equitable power relations are formed' (Centre for Development and Innovation in Health 1993).

1.1.4 Key barriers and issues to consumer participation

There are many barriers to consumer participation in the health system. The NRCCPH, through undertaking a needs assessment to direct its planning, found that people in the field identified a range of cultural, organisation and structural barriers to greater consumer participation in health service development (NRCCPH 1999). These included:

- some policy directives work against participation and collaboration;
- lack of commitment to and leadership for consumer participation;
- lack of management support and management for consumer participation;
- limited evaluation and evidence of the benefits of consumer participation;
- lack of education and training that promotes and supports participation;
- lack of capacity of organisations to involve consumers;
- lack of infrastructure for consumers to support and facilitate their participation; and
- difficulties for policy makers, service providers and consumer organisations in ensuring the diversity of consumers and community members are included in participation initiatives.

In a *Needs Assessment undertaken in 1999*, the NRCCPH found that where mainstream organisations had developed mechanisms for involving consumers, these structures and processes were often not appropriate to involving consumers from diverse backgrounds. In general, many groups of consumers were only involved when they were the focus of a specific project or strategy. The development of effective structures and processes to ensure the participation of a diversity of consumers is a considerable and ongoing challenge for most organisations.

The groups identified by participants in the Needs Assessment as being the most excluded from mainstream participation mechanisms were:

- from a range of cultural and linguistic backgrounds;
- of Aboriginal and Torres Strait Islander descent;
- living with chronic 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.

1.2 CONSUMER DIVERSITY AND HEALTH SERVICES

Much has been written about the diversity of the Australian population and the importance of developing service systems that respond appropriately to this diversity. Consumer diversity is influenced by a range of factors such as ethnicity, race, ability, class, socio-economic background, education, gender, sexuality, religion and health status or health condition. It is often the intersections of a range of factors that contribute to each person's sense of their identity or culture. Understanding diversity in this way highlights the danger of developing stereotypes about any particular group. Therefore, services which are appropriate to the diversity of populations must be able to respond to each individual in their diversity. The concept of culturally safe services is useful in thinking about what this might mean.

Cultural safety can be defined as the creation of:

an environment which is safe for people; where there is no assault, challenge or denial of their identity, of who they are and what they need. It is about shared respect, shared meaning, shared knowledge and experience, of learning together with dignity and truly listening (Williams 1999).

- research into the development of tools for seeking feedback from clients of home and community care services (Australian Institute of Health and Welfare 1998);
- work in the Mental Health Branch, Department of Health and Aged Care, which includes establishment of a national community advisory committee which is represented on the Ministerial Advisory Group; development of mental health standards in which consumer participation is a benchmark; requirement for the training of mental health consumers to participate as surveyors in teams evaluating organisations against the standards; yearly reporting by each state and territory on their consumer participation activities; and funding of training and research (see Commonwealth of Australia 1997, 1998 and 1999);
- strategies in the HIV/AIDS area which have partnership as a key element; and
- joint funding with the states/territories for programs and services such as the National Women's Health Program and migrant resource centres.

1.2.3 State/territory level initiatives enhance service responsiveness

At state/territory government levels there are many initiatives in similar areas. A few examples include that most states/territories have developed framework agreements for working with Aboriginal-controlled health organisations, resources for working in culturally diverse communities; and frameworks for consumer participation in mental health services. States/territories have also provided funding for group-specific services such as migrant resource centres, women's health centres and homeless persons' programs. In addition to supporting specific projects, programs or services, some state/territory funding arrangements include increased weightings for provision of services to people from non-English-speaking backgrounds, Indigenous peoples and people living in rural and remote areas.

1.2.4 Local level initiatives to enhance service responsiveness

At the local level many services have worked with consumers and communities from specific groups to develop services and programs responsive to their needs. In fact, research by the NRCCPH (1999) demonstrated that many of the consumer participation initiatives undertaken by local services were focused around increasing the appropriateness of services for specific consumer groups.

1.3 CONSUMER DIVERSITY AND CONSUMER PARTICIPATION

Despite the work that has been done on developing services that are more responsive to the diversity of consumer groups, it has been noted that:

- Those who have the poorest health status and potentially the greatest need for services, also often have the poorest access to services, the poorest access to participating in service development (Bartram *et al* 1999) and access to the least favoured models of care (Small *et al* 1997). These groups include, for example, Indigenous peoples, people on low incomes, people from culturally and linguistically diverse backgrounds, and homeless people.
- Many groups of consumers, including those with the poorest health, are often excluded from mainstream feedback and participation mechanisms such as patient satisfaction surveys and complaints processes. They are often included only if they are the focus of a particular strategy or program (NRCCPH 1999).

Poor access to appropriate services has been linked to barriers to participation. For example, in the Victorian *Report of the Ministerial Taskforce on Ethnic Health* (Health Department Victoria 1991) it was identified that despite the existence of broad policies relating to access and equity, mainstream health care services often did not provide access to culturally appropriate care and information and that this was a *consequence of service structures not reflecting or involving the diversity of community members*. While this report focused on ethnic health, the same principle could be applied across a diversity of consumer groups.

This highlights the need to challenge the way mainstream health services engage with the diversity of consumers who make up Australian communities. Until these services recognise that 'the mainstream' is diverse, and does not only consist of individuals who are all from similar (often white, educated, English-speaking backgrounds), it is unlikely that mainstream services that are appropriate to all members of the community will be developed.

1.4 BACKGROUND TO THE FEEDBACK, PARTICIPATION AND CONSUMER DIVERSITY PROJECT

1.4.1 The Consumer Focus Collaboration

The CFC was established in 1997 to further the goal of enhancing quality and safety through increasing the consumer focus of the health system. The CFC is chaired by the Commonwealth and has a membership that represents many key stakeholders in the health system, including consumer organisations, provider organisations, health insurers and state and territory governments. The CFC does not represent the views of consumers, but aims at developing strategic alliances and projects that will promote the development of a more consumer-focused health care system.

The CFC has four major goals, which are:

1. To improve accountability and responsiveness of the health care system to consumers.
2. To facilitate the provision of health information to consumers in appropriate formats.
3. To facilitate active consumer involvement in health system planning, delivery, monitoring and evaluation.
4. To promote education and training that supports active consumer involvement in health service planning, delivery, monitoring and evaluation.

1.4.2 The National Resource Centre for Consumer Participation in Health

The NRCCPH is funded by the Commonwealth. The NRCCPH's primary functions are to collect and disseminate information on consumer participation across the health system, and to become a centre of excellence which can assist people to develop strategies, analyse methods and models of participation and contribute to relevant research and development.

1.4.3 Rationale for undertaking the project

The CFC was concerned from the outset that while much work was being done on consumer participation and feedback, many consumer groups were excluded from participating in mainstream processes for seeking such input. The CFC's Strategic Plan (1997–98; 2000–01) identified:

There is a growing body of evidence which indicates that there are groups of consumers who experience particular barriers to access health services and who have difficulty in providing effective feedback to health services about their experience. The collaboration recognises that if health services are to produce equal outcomes across the community, each strategy in the plan needs to specifically address the capacity for consumers who are disadvantaged by current health service arrangements to participate in health services.

Consequently, it was specified by the CFC that as part of establishing the NRCCPH, a project be undertaken to review existing literature about feedback and participation of consumers from marginalised groups in health service development. This project was subsequently developed for funding by the Commonwealth.

1.5 ABOUT THIS REPORT

Through reviewing literature which focuses on the participation of consumers from marginalised groups, this report aims to consolidate knowledge in this area. In addition, this report aims to highlight some of the continuing structural and cultural barriers to the involvement of the diversity of consumers in health service development.

Aside from chapter 7, which outlines some of the specific groups and methods used to work with some marginalised groups, this report does not focus on any specific group, or attempt to determine who is the most marginalised, as there are many groups who could rightly claim exclusion. Instead, by reviewing work which has set out to involve specific consumer groups because they have been marginalised in some way, this report draws together themes that shed light on processes of marginalisation and re-focuses the debate on the systematic and cultural issues that create exclusions and marginalisation.

Chapters 1 and 2 outline the background to the project the methodology used.

Chapter 3 outlines why input has been sought from consumers who have previously been marginalised from participation.

Chapters 4, 5 and 6 provide an overview of the barriers to participation of consumers from marginalised groups. Chapter 4 focuses on structural issues, chapter 5 focuses on issues of quality and chapter 6 focuses on consumer issues.

Chapter 7 provides a summary of the literature with a focus on the groups that have been targeted and the groups and the methods utilised to seek feedback from members of those groups.

Chapters 8, 9 and 10 highlight some of the different strategies and methods that have been utilised to engage consumers who have been marginalised.

Chapter 11 highlights the importance of utilising information provided by consumers to inform quality improvement.

Chapter 12 outlines recommendations arising from this literature review.

1.6 SUMMARY

- There is an increasing recognition of the potential role of consumers in developing effective and appropriate health care services. There is also emerging evidence which supports the wisdom of this participation.
- There has been a lot of work done at Commonwealth, state and territory, and local levels towards developing a more consumer focused health system. This work includes developing structures and mechanisms for increasing consumer participation.
- There has also been much work done on enhancing the capacity of the health system to respond to the diversity of consumers living in Australian communities.
- Despite the work done in both of these areas, many consumer groups continue to be excluded from receiving appropriate services from mainstream health care organisations.
- Many consumer groups are also excluded from participating in commonly used mainstream strategies to seek feedback from, or involve consumers in, service development, unless they are the focus of a particular strategy or project. Concurrently, there is little resourcing provided to consumers, especially marginalised consumer groups, to develop their capacity to participate.
- There appears to be a link between the participation of consumers from diverse backgrounds and the development of appropriate health care services. The development of appropriate services may entail the empowerment of consumers to teach the system or service about themselves and their needs. It may also involve the development of organisational capacity to listen to, and act on, the voices of the full diversity of consumers and communities.

The background to this report includes that:

- The CFC was established to develop strategies and projects to promote the development of a more consumer focused health care system.
- The NRCCPH was funded by the Commonwealth.
- In order to ensure that issues relevant to groups of consumers who experience barriers to accessing services and to providing feedback to services were addressed, the CFC specified that the NRCCPH undertake a project in this area during its establishment phase.

Chapter 2: The Feedback, Participation and Consumer Diversity Project

The Feedback, Participation and Consumer Diversity Project was undertaken as part of establishing the NRCCPH and was an initiative of the CFC. Both the NRCCPH and this project are funded by the Commonwealth Department of Health and Aged Care. This chapter provides an outline of the project aims and methodology.

2.1 PROJECT AIMS

The key aim of the project was to review project reports and published literature to draw together existing knowledge about processes which have been developed to seek feedback about health services from groups of people who have been marginalised from giving this feedback.

Through reviewing published documents, the project set out to:

1. Identify structural and cultural barriers to consumers providing feedback to health services.
2. Identify some of the groups who are currently marginalised from providing feedback to health services.
3. Identify widely used approaches to overcoming these barriers.
4. Recommend priority tasks in underdeveloped areas.

2.2 PROJECT METHOD

2.2.1 Reference group and critical commentators

The project was greatly assisted by a reference group representing a diverse range of consumers and service providers. Members of the reference group are listed in appendix 2. Critical comment on the final draft of the report was also received from a range of people across Australia and from members of the CFC.

2.2.2 Literature search

A systematic and extensive search of the literature was undertaken. Three main strategies were used to locate relevant literature.

Published and indexed material

Searching for published and indexed material involved a process of defining terms and concepts, searching electronic databases and the World Wide Web.

Defining scope, terms and concepts

Database searches were restricted to literature published between 1990 and 2000. Some earlier literature, identified through hand searching, was included.

Keyword lists and thesauruses were consulted where available and the following terms were used to construct varieties of search strings to cover individual and grouped concepts:

- consumer participation and/or consumers/empowerment/advocacy/patient/client feedback or complaints
- barriers and/or structural/cultural/minority groups/language/socio-economic/young people
- homeless people/people with disabilities/Aboriginal people/Torres Strait Islander people/chronic illness/addiction/rural/isolation
- low literacy/poverty
- barriers and/survey methods/communication/staff attitudes/management attitudes
- resource allocation
- health services and/or hospitals/community health services/primary health care/acute
- health care/carers/service development/organisational change/peak bodies
- research and/or research and development/community development/projects

- literature reviews/reports/health policy/methods/models
- social capital/social exclusion/health outcomes/human rights

Below is an example of a typical search strategy used to search AustHealth databases, working on the results to achieve maximum relevance and a manageable number of records needing to be scanned. In the following example, an asterisk after a term means the term has been truncated. This simplifies searching, as, for example, community* will find community or communities.

Search No	Combinations of terms	Results
3	consumer* or community* or patient* or client*	33 243
4	health service* or hospital* or community service*	36 838
5	research or community development	23 493
6	planning or evaluation or review or feedback or complaints	16 464
7	process* or method* or model*	18 862
8	participation	1943
9	N/A	
10	3, 4, 6	2871
11	3, 4, 6, 8	179
12	7, 11	90
13	5, 12	44
14	service development or organisational change	177
15	N/A	
16	13, 14	2
17	(structural or cultural) near barriers	56
18	3, 4, 6, 17	0
19	3, 8, 17	5
20	14, 17	1

The above example demonstrates that when the concept of barriers (search 17) is coupled with broad terms the number of articles retrieved is significantly reduced. For this reason the 56 references retrieved in search 17 were scanned. Search results for the combination of concepts 'service type, individual type, type of activity and participation' (search 11) were also scanned. Relevance rate in all searches was monitored.

Searching specialised indexing systems

The following databases were searched for research material:

- Austhealth databases:
 - APAIS Australian Public Affairs Information Service
 - ATSIHealth Aboriginal Health
 - RURAL Rural and Remote Health
 - AMI Australian Medical Index
 - H & S Health & Society
- ERIC Educational Resources Information Centre
- MEDLINE Provided by the US National Library of Medicine, this database contains 8.8 million bibliographic citations from over 3800 medical and allied health journals published in 70 countries
- UNCOVER An American database of contents pages of approximately 20 000 journals
- ABN Australian Bibliographic Network, provided by the National Library of Australia

Library online gateways

Located at La Trobe University, Bundoora, the project had access to resources of the Borchardt Library. This included electronic indexes, abstracts and full text databases plus the catalogues of other academic libraries throughout Australia. Databases searched included Elsevier gateway to Blackwell's biomedical journal navigator; OVID, a gateway to nursing literature; and MAIS, a gateway to literature relevant to multiculturalism. As these searches yielded disappointing results some of Elsevier's Business and

Management databases were also scanned, with interesting results. For example, an article 'Health care power shifts to the people' in the journal *Business and Health* was available in full text.

Key policy documents were identified on the Australian Council of Social Services (ACOSS) Online Library <http://coss.net.au> using keywords 'Consumer participation'. Retrieval rate dropped to four with the terms 'minority groups' and zero when coupled with 'health services'. Similarly, the web sites of the Commonwealth Department of Health and Aged Care and Department of Human Services Victoria were good sources of policy resources and links to government projects and initiatives.

Litserve

A litserve is a mailing list of people with similar interests which functions to keep subscribers up to date on specific topics. A search of the LISZT mailing list directory retrieved no matches. Other litserve known to the NRCCPH were searched.

For example, <http://www.GLOBALHEALTH2000.com> was searched using the terms 'Health services & minority groups & planning'. This search retrieved many records but with little relevance to the project. For example, minority groups were frequently coupled with the assessment of their needs but not with participation in service planning.

World Wide Web subject searches

Simple searches using keywords 'consumer participation' performed using search engines AltaVista, Yahoo, Excite, Hotbot, Lycos and Infoseek, with surprisingly good results. Example sites retrieved included—Removing Barriers—a web site of health issues, racial, cultural, vulnerable and marginalised communities, and Australian Transcultural Mental Health Network—a rich source of research publications, policy, web sites and organisations. Unlike information contained in research oriented databases such as Medline and Psychlit, World Wide Web sites link the researcher into diverse networks of people, personal experiences, innovative organisations and projects, key policies and strategies, plus catalogues of resources and services.

Catalogues of special libraries were searched where they were available via the Internet. For example, Women's Health Victoria provides WWW access to its library catalogue.

Published material which was not indexed on electronic databases

Harder-to-locate material, including articles not found through database searching, project reports written by local services or consumer groups, annual reports and information sheets were located in a number of ways.

Hand searching specialist collections

Hand searching was undertaken in a number of specialist collections in Victoria, including the libraries of the Centre for Culture, Ethnicity and Health, the Department of Human Services, and the Health Issues Centre.

Contacting peak organisations and others who were known to have done relevant work

Approximately 70 organisations and individuals, including members of the CFC, policy makers, health service providers and consumers across Australia who were likely to have done work, or to know about work done in the area, were contacted by telephone. People contacted in this way were asked if they would like to provide any documentation about their work for inclusion in the literature review.

Advertising the project

The project was advertised through the mailing list of the NRCCPH (approximately 160 organisations, government departments, non-government bodies, university departments and individuals), on the electronic discussion groups of the Australian Resource Centre for Hospital Innovations, the Chronic Illness Alliance (Victoria) and Health Issues Centre. It was also promoted at presentations given by staff of the NRCCPH and on the web site of the NRCCPH. Anybody interested in providing information to the project was invited to contact the project officer.

2.2.3 Annotations

Annotations highlighting the reasons for undertaking the work, the groups targeted, the methods utilised to involve consumers and the key findings were written. These are included in this review's companion volume, *Feedback, Participation and Consumer Diversity, an annotated bibliography*. They are also available on the online catalogue accessible through the NRCCPH's web site at <http://nrccph.latrobe.edu.au> by firstly going to the

catalogue, then clicking on the 'searches prepared by us on specific topics' and then clicking on the topic heading 'Groups marginalised by the system'. This database of resources will continue to be updated by the NRCCPH.

2.3 PROJECT LIMITATIONS

There are four key limitations to this work.

1. There is an extensive literature on consumer participation and feedback. However, it is widely dispersed and different terminology is utilised in different countries to describe these activities. Different terms are also used to describe consumers who have been marginalised. This means that literature was easily missed, even when systematic searches were undertaken. In addition, literature pertaining to marginalised groups was often found only when a term describing a specific group was added to the list of terms for searching electronic databases. In general, when a group was specified, at least one article was found about seeking feedback from that group. Much may also have been learned from searching outside the health and welfare literature, but due to time and resource constraints this was not possible.
2. There is a large body of work being done that has not been written up or evaluated. This reflects the time and resource constraints of people working on developing innovations in health care services.
3. Due to the large number of articles and reports retrieved and the short time frame for the project, not all literature was annotated for the review. Resources collected but not yet annotated are listed in appendix 3.
4. A number of highly relevant documents were published just as this project was being concluded. For example, the Australian Transcultural Mental Health Network released a report called *Mental health consumer participation in a culturally diverse society* (Sozomenou et al 2000). These documents have not been included in this review.

2.4 SUMMARY

- The feedback, participation and consumer diversity project was undertaken as part of establishing the NRCCPH and was an initiative of the CFC.
- The project methodology included establishment of a reference group and a panel of critical reviewers; a systematic search of the literature (including searching electronic databases, hand searching and telephoning key organisations and individuals); development of an annotated bibliography and writing of this literature review.
- Limitations of this review include that relevant literature is dispersed throughout a wide range of publication types; there is a large body of work that is not yet written up or evaluated; time restrictions meant that not all identified literature could be reviewed; and some highly relevant work was published just as the project was being concluded.

Chapter 3: Why was consumer input sought?

Much of the literature identified in the review documented work done to seek feedback from or involve a specific group of consumers. Only a small proportion of the literature looked across populations to identify ways a range of groups could be involved in the one strategy.

This chapter highlights the reasons that projects were undertaken. Examining the reasons for undertaking work with specific consumer groups is illustrative, in that it serves as a way of identifying current barriers to participation of those groups. In a sense, the reasons for undertaking this work constitute a 'grass-roots' statement of the problem.

3.1 KNOWN POOR ACCESS TO SERVICES

Knowledge that specific groups of consumers had poor access to services was a major reason feedback was sought from those consumers. This type of work sought to find out about the barriers and issues which limited access for consumers from a particular group and, sometimes, to ask consumers how services could be developed so that they were more appropriate to their needs.

There were different ways of conceptualising access issues. For example:

1. It had been identified that there was a high number of people from a particular group living within a region, but these people were not accessing services. For example, women from non-English-speaking backgrounds living in the North Eastern Region of Melbourne were not accessing post-acute psychiatric services (Centre for Development and Innovation in Health 1994).
2. People from particular groups had lower access to specific types of services. For example, rural women were more likely than urban-dwelling women to have a mastectomy instead of breast conserving surgery as treatment for breast cancer (Davis *et al* 1998).
3. People from particular groups are routinely excluded from receiving appropriate services. In particular, this seems to occur when people do not fall into categories defined by one characteristic. For example, women from non-English-speaking backgrounds with disabilities (Meehan and Hanson 1999) and homeless people with mental health issues and drug dependency issues (Gauntlett *et al* 1995, Success Works 1999) often received inappropriate services because they 'fell between the cracks' of the missions of different services.

3.2 EXCLUSION FROM PREVIOUS FEEDBACK OR PARTICIPATION PROCESSES

One reason for targeting specific groups was a recognition that they had been under-represented and thus excluded from previous feedback or participation processes. For example, in a survey of maternity care in Victoria seeking the views and experiences of recent mothers it was identified that although questionnaires were posted to most women who gave birth in a defined period of time, women of non-English-speaking backgrounds, younger women and single women were under-represented in the final sample (Brown and Lumley 1997). In order to address some of these exclusions, a second study was undertaken by the same research centre to seek the views of Vietnamese, Turkish and Filipino women (Small *et al* 1997).

3.3 TO DEVELOP AND TEST FEEDBACK TOOLS

A number of studies were aimed at seeking feedback from a specific group of consumers and/or testing methods and tools for seeking feedback from specific groups. For example, both Dagnan *et al* (1994) and Cardone (1999) examined whether or not useful feedback could be obtained from people with varying degrees of intellectual disability; whether this feedback was valid and reliable; what types of measures and scales could be developed to facilitate getting this feedback; and how to test for validity and reliability among these consumer groups.

3.4 THE NEEDS OF THE GROUP ARE UNKNOWN

Some workers sought consumer feedback because they recognised that little was known about the information or care needs of a specific group of consumers. For example, both Huabg *et al* (1999), who examined the information needs of Chinese cancer patients, and Fyffe *et al* (1996), who looked at the needs of carers of people with acquired brain injury living in rural areas, did so because little was known about the specific needs of these groups.

Sometimes this type of work was prompted by a knowledge that there was a high incidence of a particular condition amongst a group of consumers, but little was known about the access of that group of consumers to services. For example, there are high rates of cervical cancer among Vietnamese women (Cheek 1999) and women from Pacific Islands (Jameson *et al* 1999), yet little was known about their participation in screening programs. The authors of these studies emphasised that developing appropriate programs required learning about how consumers understand the condition and related health issues.

3.5 EVALUATION OF CHANGES TO SERVICE PROVISION

There have been many changes to the way health services are delivered in Australia over the last decade. In some instances feedback from consumers and/or their carers was sought to identify the impact of such changes on specific groups. A number of studies examining the impact of shorter lengths of stay in hospital are illustrative (Health Issues Centre 1997, Jackson *et al* 1999, Triado 1999). Authors of these studies identified that in the absence of evaluation, problems which arose as a consequence of a new service delivery model were not acknowledged. As a result, neither relevant policy development nor appropriate funds were directed towards addressing the problem.

3.6 EVALUATION OF SPECIFIC PROGRAMS, RESOURCES OR PARTICIPATION PROCESSES

The input of consumers from specific groups was often sought as part of the evaluation of services and programs. This included an evaluation of:

1. *Consumer participation in health services and systems.* For example, the Mental Health Division of the Department of Human Services Victoria funded an evaluation of participation in the public mental health system (Department of Human Services Victoria 1999).
2. *Health service facilities.* For example, an innovative evaluation of an acute-psychiatric facility is described by McGuinness and Wadsworth (1992). This report describes how an evaluation that was originally planned to be a one-off self administered questionnaire with closed-ended questions was developed into a series of individual and group interviews with consumers and staff. Information from these interviews was then swapped so that consumers could see what staff were saying and vice versa. This process was built upon so that further comments were exchanged. This process evolved into a 'constructed conversation' through which consumers participated in developing recommendations for change (1992).
3. *Models of service delivery.* For example, young people from Cambodian, Lao and Vietnamese backgrounds requiring drug and alcohol services, their parents and community leaders were involved in evaluation of current service provision and in making recommendations about enhancing access to these services (Department of Human Services Victoria 1998).
4. *Effectiveness of health promotion strategies.* For example, young people from ethnic minority groups living in areas where many people were poor were involved in evaluating different health promotion strategies about drug use (Lisnov *et al* 1998).
5. *Usefulness of information resources* for the needs of specific groups with the aim of adapting resources to better meet consumer needs. For example, young mothers were asked to provide feedback about a parenting manual (Lambert 1998).

3.7 COMMITMENT TO INVOLVING CONSUMERS IN DEVELOPING SERVICES OR NEW MODELS OF CARE

There are many projects which document the involvement of consumers in developing new and innovative models for service provision. These projects were generally either consultations which specifically set out to involve a number of different groups (Faulkner 1996, Success Works 1999) or based on principles of community development and or participatory action research and focused on the needs of a group of consumers with something in common (Radoslovich 1998, Healy and Walsh 1997, Minicucci 1997). Some of these authors indicated that the consultation or the project was undertaken in the context of the organisation wanting to develop ongoing links with particular consumer groups.

Key elements of the more participatory of these projects included that they sought to develop processes in which consumers defined the problem, further developed their knowledge and expertise about the problem through sharing their experiences and working with service providers, and collaborated in developing solutions to problems or in developing new models of care. Thus, the needs and knowledge of consumers were taken as the starting points for the development of new initiatives. Many of the authors documenting

these projects discussed a range of issues that staff participating in the project had to deal with. These include that: power relationships and roles of consumers and staff change over the course of the project, and staff may need to learn new ways of working to enable this to occur; new ways of thinking about coordinating programs and allocating resources may have to be developed; and staff need to develop processes to ensure they are accountable to consumers (Radoslovich 1998, Healy and Walsh 1997, Minicucci 1997). In addition, in areas such as disability services and mental health services where there are standards and guidelines for consumer participation and consumer rights, staff need to know what the standards are and how they should be working to meet them (Buller 2000, personal communication).

3.8 CONSUMER-LED ACTIVITIES TO ADDRESS ISSUES FOR SPECIFIC GROUPS

Consumers, consumer groups and consumer organisations have done a lot of work which provides insight into improvements that need to be made in order to develop a consumer-focused health system. This work often includes research, peer support, peer education combined with systems advocacy and lobbying. There are many examples of this work, some of which are summarised by Draper and Hill in their 1995 report on the role of patient satisfaction in quality improvement. Other examples include the Understanding and Involvement Project undertaken to improve consumer participation in mental health services (Wadsworth and Epstein 1996) and the Medicine Information Person's program, which aims to enhance participation of older people and provide peer education on the use of medicines (Velasco 1999).

3.9 SUMMARY

The key motivations identified by authors for undertaking work to involve or seek feedback from marginalised consumer groups included:

- known poor access to services;
- exclusion from previous feedback or participation processes;
- to develop and test feedback tools;
- that the needs of the group are unknown;
- evaluation of changes to service provision;
- evaluation of specific programs or resources or evaluation of consumer participation;
- commitment to involving consumers in developing services or new models of care; and
- consumer-led activities to address issues for specific groups.

The reasons authors identified for undertaking work to seek feedback and involvement of consumers from specific groups highlight that the participation of these consumers is important in developing services that are accessible and appropriate to them. Often work was done because researchers, organisations or consumers had identified that specific groups experienced disadvantage in relation to access to appropriate health services.

These issues indicate a relationship between the development of appropriate and accessible services and consumer participation.

Chapter 4: Barriers 1: Structural issues

There are many ways different consumer groups are marginalised from participating in, or giving feedback to, health services. Often the mechanisms of marginalisation (otherwise known as barriers to participation) are closely linked to broader issues of access to services.

This section focuses on the barriers to participation of consumers from marginalised groups identified in the literature. From the literature it became clear that while individual reports documented the barriers to participation for a specific group of consumers, many of these barriers were common across groups. This highlights the point that these barriers are systems issues, rather than issues about particular types of consumers.

4.1 LIMITED CAPACITY OF HEALTH SERVICES TO PROVIDE APPROPRIATE AND ACCESSIBLE SERVICES AND TO INCORPORATE FEEDBACK FROM DIVERSE GROUPS INTO MAINSTREAM STRATEGIES

Many health services are limited in their capacity to provide appropriate and accessible services to the diverse community in which they exist. Without mechanisms to provide appropriate services, it is unlikely that mainstream mechanisms for seeking feedback in appropriate ways will exist. For example, in providing services for people of non-English-speaking backgrounds, appropriateness of services can be enhanced by employing bilingual health workers (Kline *et al* 1980, Guendelman and Witt 1991-2), providing cross cultural training for staff (Langer *et al* 1997, Kline *et al* 1980) and developing good interpreter services (Kline *et al* 1980). These are also issues which need to be addressed if feedback is to be sought from consumers who speak languages other than English. Similarly, if services and feedback are to be relevant to those who are not literate in English, appropriate mechanisms to ensure this must be developed.

There is no systematic framework for participation or for providing feedback for many groups of consumers (Otto 1990), and unless inclusion of diverse groups is specifically addressed in the design of feedback and participation processes, these consumers are generally under-represented in the resultant activities (Cockburn *et al* 1999). In addition, the issues important in assessing the quality of health services are often defined by service providers and policy makers and not by consumers from diverse cultural groups (Abbott-Chapman and Easthope 1998). Without this type of participation, it is unlikely that more appropriate and accessible services will be developed.

Thus, there is a circular relationship between the capacity of organisations to routinely collect information from marginalised groups, their capacity to develop appropriate services and their consequent capacity to seek further feedback from those groups.

4.2 FOCUS ON MINORITY AND MARGINALISED GROUPS AS THE PROBLEM

Traditionally, health care institutions have tended to locate the reasons for marginalisation with groups of consumers rather than seeing the organisational barriers that prevent access to the diversity of the community in which they operate (Doyal and Visano 1980). This was illustrated in one study which sought feedback from Latina women and service providers in San Francisco about access to prenatal services:

There was a high degree of agreement between provider and consumer views about barriers to prenatal care; however, providers were more likely to identify individual characteristics and cultural beliefs as reasons for women not using care (Guendelman and Witt 1991-2).

As well as preventing services from focusing on what they need to change, this focus on the features of the consumer as the problem can result in consumers refusing to participate as they do not want to be viewed in this way. It may also be why consumers often report that they are not treated with respect. In work looking at participation of students with disabilities in education, Abbott-Chapman and Easthope (1998) note that some of the students identified by teachers as having disabilities refused to participate because they did not see themselves as belonging to the group defined as 'disabled'. These authors argue that the reason for this is that once a label of disadvantage or disability is imposed on people by the system, these people become viewed as problems to the system, rather than as individuals with needs (1998). Imposing such labels also denies that these consumers are people with insights and experiences of value.

The power of the way consumers can be made into problems was illustrated in one report in which a group of consumers identified that they did not want a media campaign directed specifically at them because they were frustrated that people from their group were often seen as social problems (Jameson et al 1999).

Abbott-Chapman and Easthope (1998) propose that part of developing appropriate responses is constructing service systems which enable consumers to become full members of communities and organisations. In relation to education this requires:

the interrogation and debunking of traditional attitudes, ideologies and expertise which label students with disabilities as 'defective'. Integration is a political concern which addresses the issue of who belongs, and who does not belong, and how we might reframe our curriculum, our ways of teaching and our school organisation in order to enable all students to learn together ...The arguments about inclusion and treatment of students with disabilities may be equally applied to those who are perceived as different and a 'problem' because they are poor or Aboriginal or of non-English-speaking background. The deficit model has the same sorts of consequences as stigmatising, limiting choices, and denying self respect (1998).

Similarly, Pinches and Dunstone (1998) argue for the development of the types of services that support consumers to participate and the development of a 'therapeutic community' in which consumers are full members.

4.3 LIMITED CAPACITY OF ORGANISATIONS TO ACKNOWLEDGE AND CONSULT WITH A RANGE OF PEOPLE WITHIN GROUPS

Systems which treat all people as if they are the same, rather than a diverse range of individuals, construct barriers to participation and change by creating stereotypes against which all people superficially belonging to particular groups are treated and judged. Older people identified that it was important that services focus on individuals and their needs and not on the category of old people (Department of Human Services Victoria 1999). Other groups for which this was identified as an issue include students with disabilities (Abbott-Chapman and Easthope 1998), people of non-English-speaking backgrounds (Lillie-Blanton and Hoffman 1995) and women living with HIV and AIDS (Radoslovich 1998).

In order to seek feedback which is useful for service development, acknowledgment of diversity within groups is important, as this can be politically critical and can result in the need to change how methodologies are developed (Lillie-Blanton and Hoffman 1995). For example, it may mean that it is important to hold men- or women-only meetings, hold small group meetings rather than large group meetings, and build relationships with people and leaders from different parts of the community (Bartram et al 1999).

4.4 SERVICE PROVIDER ATTITUDES

A number of groups have identified service provider attitudes as a key barrier to consumer participation and feedback. For example, older people identified that the traditional assumptions, stereotypes and images associated with older people were key barriers to their participation. Changing this would require a shift away from seeing older people as dependent and from devaluing of their contributions (Department of Human Services Victoria 1999). A list of hints in this document included:

don't treat people as objects; don't leave old people out; don't deny rights; don't stereotype; don't regard old age as an illness; don't create dependency; don't ignore social divisions; don't treat older people as children; don't take carers for granted; don't ignore death and dying; don't get stuck in routines; don't collude with ageism (1999).

Similarly, students with a disability identified that some of the biggest barriers to their participation in education were the attitudes of some teachers (Abbott-Chapman and Easthope 1998). Women from non-English-speaking backgrounds with a disability noted that there are many negative and 'handicapping' attitudes to women with disabilities resulting in discrimination, exclusion and diminished dignity (Meehan and Hanson 1999). These authors reported that women with physical disabilities are not listened to, are often talked over, may not be communicated with at all, treated as if they have both physical and intellectual disabilities, treated with fear and ignorance and infantilised (1999). Consequently, staff may consider that people from these groups have a limited capacity to give feedback (see section 5.5)

In a British study of the potential of audit as a method for improving services for people of black and ethnic minority backgrounds, Bhatti-Sinclair (1999) identified that racism and attitudes towards people based on

their race and ethnicity are powerful barriers to service change and to participation of people from these groups. She argues that because racism within health services is a reflection of wider socially held views and has been incorporated into professional ideology, change in this area requires long-term commitment, highly skilled facilitators and continual evaluation (1999). Key issues which prevent this change include:

- individual staff often do not know how to address or challenge the (racist)
- views of other team members;
- anti-racist organisational values and principles are not established;
- attitudes are not addressed within teams and across organisations;
- the nature of the topic creates a high level of anxiety and defensiveness within
- services and individuals; and
- there is no long term commitment to change.

A further issue, identified by Bartram *et al* (1999) in developing a strategy to involve consumers from black and ethnic minority backgrounds in the development of better quality services, was that staff fear the unknown and see consulting with diverse groups as too difficult. These authors recommended that 'the best way of overcoming this fear of the unknown is to do some research about the communities and evaluate it' (1999).

4.5 MODELS OF CARE ARE DISEMPOWERING

The models of care utilised by services often do not encourage consumer involvement; they may or even work against it. Consumers identified that the approach to care, could disempower people through treating them as if they were highly dependent, focusing on their disabilities rather than their capacities and abilities, failing to respect their rights, discriminating against people based on aspects of their culture or their ability, failing to communicate well, and focusing on a charity model rather than a holistic model of care (Abbott-Chapman and Easthope 1998, Meehan and Hanson 1999, Department of Human Services Victoria 1999, Hanson 1999). Some consumers reported this had resulted in a situation where they had lost faith in doctors and medical practice more generally (Zarcadoolas *et al* 1997) and other authors argued that these kinds of interactions tended to reproduce existing social inequalities (Abbott-Chapman and Easthope 1998).

4.6 RELIANCE ON GROUP-SPECIFIC SERVICES

Despite the fact that many mainstream services are unable to meet the needs of the diversity of their populations, they are often unlikely to consult these communities about enhancing service provision (Doyal and Visano 1980, Abbott-Chapman and Easthope 1998). As a result of mainstream services being unable to provide appropriate services, there is an increased reliance on often poorly funded group-specific services, which themselves have little capacity to impact on the mainstream. Together, these two factors result in issues of access and development of appropriate services not being debated within mainstream services.

The 'Catch-22' of this situation was illustrated in an evaluation of a project in which 'Positive Women' were involved in the development of a clinic to meet their needs as well as to raise issues about appropriate service provision to other agencies. While the project was successful, it appeared that some mainstream services tended to use the existence of the project as a reason for not addressing the needs of this group (Radoslovich 1998).

A corollary to this type of situation is where group-specific services which have been good at involving consumers become 'mainstreamed' and in this process the structures and processes they have developed for consumer participation may be lost (NRCCPH 1999).

4.7 THE NATURE OF PROJECT WORK AND FEEDBACK EXERCISES

Often work done with specific groups of consumers is undertaken as a one-off project within a specific part of a service for which it is difficult to get sustained funding. This work often takes place 'outside any general or integrated approach to the provision of quality services to a culturally diverse constituency' (Pardy 1994). This illustrates that the provision of appropriate services to people from diverse backgrounds and marginalised groups is sometimes seen as something to be added on when funding is available, rather than being seen as part of the core business of the service. In addition, these projects can often be constrained by short time frames which can put constraints on the capacity of workers to develop relationships of trust with consumers and other service providers, thus limiting the number of participants and the type of information provided by them (Centre for Development and Innovation in Health 1994).

Similarly, feedback activities such as patient surveys and focus groups can be done as one-off activities, rather than as part of an ongoing organisational strategy.

An additional problem with this approach is that consumers often end up feeling as if they have 'been researched' and have seen little change or heard little back about the research (Lillie-Blanton and Hoffman 1995). This can create cynicism about participation in the future.

4.8 FAILURE OF THE SERVICES TO ACT IN RESPONSE TO FEEDBACK

There is now a range of reports that note that while much is known about the barriers to the development of services which reflect the diversity of populations, little change occurs as a result of this knowledge. For example, a report published by the Ministry of Health in Ontario identified that:

Although providers express a sensitive appreciation of the problems inherent in securing access, the results are disturbing in terms of actual accomplishment or adoption of measures to reduce barriers (Doyal and Visano 1980).

In addition, when funding to health services is being cut, service development tends to focus on the concerns of 'majority' rather than 'minority' groups and the types of models which may work best for people from diverse groups are often phased out (Bhatti-Sinclair 1999).

Consequently, specific consumer groups can become sceptical about health service research or invitations to give feedback or participate because they see that firstly, seeking feedback can be a way of delaying action, and secondly that services and researchers gain knowledge at their expense without any changes being made (Lillie-Blanton and Hoffman 1995). In this instance it may be more useful to engage consumers in working out how to overcome the already identified barriers and issues rather than continuing to seek feedback about what the barriers are.

4.9 SUMMARY

It became clear from the literature that there are many common barriers to the participation of consumers from different marginalised groups. This highlights that these barriers are systems issues, rather than issues about particular types of consumers.

These structural barriers to participation of consumers from marginalised groups appear to be linked to barriers to accessing services. They include that:

- many mainstream organisations have not developed the capacity to provide appropriate and accessible health care services to the diverse groups within their communities. Similarly, they have not developed systematic and appropriate strategies for seeking input from consumers from diverse groups. Unless inclusion of diverse groups is specifically addressed in the design of feedback and participation processes, these consumers are generally under represented in resultant activities;
- traditionally, services have located the reasons for marginalisation with consumers, especially those from marginalised groups, rather than focusing on organisational structures and cultures;
- many organisations have a limited capacity to acknowledge, and consult with, a range of people within different groups. This can result in the development of stereotypes;
- the discriminatory attitudes of service providers to consumers from marginalised groups work against their participation;
- the models of care utilised by services often do not support participation and can disempower consumers through treating them as dependent, focusing on their disabilities rather than their abilities, failing to respect their rights, and failing to communicate;
- in the absence of appropriate service delivery by mainstream organisations there is an increased reliance on group-specific services, which are often poorly funded and have little capacity to impact on mainstream services;
- the work done with consumers from marginalised groups is often undertaken as a one-off project, outside of any integrated approach to the development of appropriate services. This work is thus *ad hoc* and seen as something to be added on when funding is available, rather than being part of the core business of mainstream services; and

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- while much work has been done to find out from consumers what the barriers and issues are, services often do not act on this information. Consequently consumers can become sceptical about invitations to give feedback and may see it as a way of delaying action.

These barriers can result in a circular process in which services which can identify that they do not have appropriate and accessible services seek feedback from marginalised groups as part of a one-off project and are then unable to implement change based on the information they have gathered.

Chapter 5: Barriers 2: Issues about the quality of the information obtained through feedback and participation processes

A range of issues which impact on the quality of information and knowledge developed through consumer feedback and participation activities was raised in the research reviewed. The consequence of poor processes can be that the information gathered is not useful for informing or implementing change.

This chapter focuses on some of the issues which can impact on the quality of consumer participation and consumer feedback activities.

5.1 EXCLUSION FROM PARTICIPATION IN MAINSTREAM FEEDBACK PROCESSES

Many groups of consumers are actively excluded from participating in mainstream feedback processes. For example, surveys conducted only in English exclude those who speak and write languages other than English, and surveys requiring written responses exclude those who have low literacy. While many authors do not specify those they excluded from the study, some did. These groups included:

- people who spoke languages other than English (Curtis *et al* 1999, Davis *et al* 1998, Brown and Lumley 1997);
- people who had dementia (Curtis *et al* 1999);
- people living in rural areas who could not or chose not to travel for treatment (Davis and Duffy 1999);
- young people (Davis and Duffy 1999, Brown and Lumley 1997);
- those with a psychiatric illness (Davis and Duffy 1999);
- people in custody (Davis and Duffy 1999);
- emergency department category 1 patients (Davis and Duffy 1999);
- people who were too ill to provide feedback (Centre for Development and innovation in Health 1994); and
- people who were not accessing services (Centre for Development and Innovation in Health 1994).

'Positive Women' identified that because they were a minority within a minority group they were generally excluded from the development of services for people with HIV and AIDS (Radoslovich 1998).

In addition, there was anecdotal evidence that hospitals were often reticent to ask consumers who had poor outcomes to participate in surveys (personal communication).

5.2 MODEL OF PARTICIPATION IS DISEMPOWERING

Consumers often note that they are asked for feedback but not given the opportunity to participate in developing solutions to issues. Many consumer reports identify that participating in processes in which consumer involvement is tokenistic creates a barrier to participation in the future (Department of Human Services Victoria 1999). In addition, consumers who have been marginalised are often cynical about the intent of service providers who ask them to participate, as they have experienced exclusion from participating in developing solutions relevant to their lives over long periods of time.

In a project to develop a neighbourhood based model for service delivery in an area where many people were unemployed and from ethnic minority groups, Minicucci (1997) found that while community leaders and individuals were initially reticent about participating, it was only as they experienced being given increased control over decision-making that they became active participants. As previously disenfranchised groups experienced increased input into decision-making processes, a range of mechanisms evolved which enabled many community members to participate in service development, service delivery (through employment of community members) and peer support. As a consequence, policy makers and service providers gained an understanding that community based information was essential for setting priorities, measuring progress and mobilising support for action (1997).

In NSW, social workers facilitated the development of an action research project with young mothers to address violence against them. They identified that the process of enabling these young women to participate required providing a lot of input and support in the initial phases of the work and then being able give up

the role of 'expert' to promote the skills and knowledge of the young women. They also identified that this work required the development of joint training for consumers and professionals, ongoing reflection on the process, review and negotiation about roles, and the development of processes (such as external facilitation for process review) to ensure professionals are accountable to consumers (Healy and Walsh 1997).

5.3 MODEL OF PARTICIPATION IS NOT APPROPRIATE TO A PARTICULAR GROUP

Often health service providers will complain that they tried to consult with consumers, but nobody came to their meeting, forum or other activity. This is often because the model chosen for seeking consumer input is not appropriate to the consumer group (Cooper and Jenkins 1998) and may even reproduce patterns of inequality (Abbott-Chapman and Easthope 1998).

While some authors reflected in detail on the methodological issues in seeking feedback and involvement from specific groups of consumers, many simply stated their methodology and focused on the findings of the work without reflecting very much on the methodological problems or successes they encountered. Some authors who did reflect on methodological issues did so from their perspective as researchers and service providers (for example, they may have focused on validity and reliability of information). While this viewpoint is important, it is also important that there is reflection on the appropriateness of the methodology to consumers.

Bartram *et al* (1999) noted that in order to find out how to consult with a range of different ethno-specific groups it was important to first talk with ethno-specific organisations and community leaders to develop an understanding of how best to approach, consult with and frame questions for each group. Sometimes this included consulting with men and women separately, or with older and younger people separately. They also highlighted that for many people, especially those with low literacy skills, written consultations provided limited capacity for participation.

Other researchers identified the importance of asking people from the specific consumer group about how they would like to be consulted about a sensitive issue (Jameson *et al* 1999). These authors concluded that if they had not done this they would not have been able to collect information that was useful to developing appropriate services. Jenkins and Cooper (1998) noted that focus groups and personal interviews conducted by people from similar backgrounds to consumers might be the most appropriate way of seeking feedback from people of non-English-speaking backgrounds, while mail surveys and telephone interviews might not be useful as they did not overcome cultural and language barriers.

A related issue was the importance of providing consumers with support to enable them to participate. For example, Yates *et al* (1997) noted that meeting the needs of carers was critical to the success of their project. This included identifying appropriate venues, times, method of consultation (focus groups or interviews) and provision of respite. In addition, they noted that it was important to greet participants in focus groups on arrival, and ensure professional support would be available if participants required it (1997).

A range of other issues will affect the appropriateness of consultation strategies to particular groups. These include:

- consultation processes may not respect community processes and ways of doing things;
- consumers may not be consulted in culturally appropriate ways;
- the time frame for the consultation may not be long enough;
- the timing and place of meetings may not be appropriate;
- consumers may not have any control over or input into the consultation process; and
- consumers may not be invited to participate in analysis of data and development of strategies and recommendations.

Thus, to ensure that feedback and participation strategies are successful, it is important to build up relationships with consumers and consumer groups, and find out about their preferences and needs in relation to participation.

5.4 LOW RESPONSE RATES

Low response rates can make it difficult to interpret the results of questionnaires and surveys, especially as those who do not respond may be those who are least satisfied (O'Neal 1999, Cooper and Jenkins 1998). Response rates to generic questionnaires are likely to be lower for consumers from minority groups as the questionnaire itself may not enable their participation. For example, written postal surveys provided only in English will automatically exclude those who are not literate in the English language. They may also preclude people with physical and intellectual disabilities and people who are homeless.

Response rates may be improved if health professionals personally deliver questionnaires; however, consumers are more likely to respond positively if the 'researcher' is seen to be a member of the service delivery organisation (Cooper and Jenkins 1998). Rates may also be improved if consumers have some ownership over the services being provided or the information being collected (Woodruff 1993), and if they are assured that the information is confidential, anonymous and will not impact on the care they receive (Woodruff 1993, Davis *et al* 1998).

Few authors speculated on the reasons for non-response to their surveys. However, Woodruff (1993) postulated that possible reasons for non-response to a postal survey targeting people utilising HIV/AIDS services included illness, fear that dissatisfaction would result in reprisal, language barriers, HIV-related disability such as dementia, and that the participant might have died. Similarly, Rose *et al* (1998) suggested that consumers with mental health issues who refused to be interviewed for an evaluation of a mental health service might not have wanted to participate because they were very ill, they were 'over-researched', or they might not have been clear about what they were being asked to do.

In addition, when consumers are contacted through key workers, the attitudes of these key workers towards evaluation may influence the preparedness of consumers to be involved (Rose *et al* 1998).

5.5 PERCEPTIONS ABOUT CONSUMER CAPACITY TO GIVE FEEDBACK

Health professionals may perceive that some groups of consumers, in particular those with mental health issues or with physical or intellectual disabilities, are not capable of giving feedback. Equally, consumers may be sceptical about the capacity of service providers to hear their feedback.

While it may be the case that at some time consumers cannot or do not want to give feedback (for example, when people are extremely ill), a number of authors identified that most consumers, including consumers with mental health issues (O'Neal 1999), consumers with intellectual disabilities (Dagnan *et al* 1994), and consumers with acquired brain injury (O'Brien and Mahony 1999) were able to give informative, valid and reliable feedback about the quality of services. One author, having investigated the reliability of answers given by people with intellectual disabilities by asking the same question in different ways, noted that consumers got frustrated with being asked the same question more than once (Cardone 1999).

However, while most consumers may be capable of participating, some may not have the economic or physical resources to enable their participation. For example, people who are living in chronic poverty may require all the resources they do have for survival.

5.6 RATING SCALES MAY NOT BE VERY MEANINGFUL

A range of ways was developed to try to increase the meaning of rating scales to specific groups of consumers. For example, in asking students to evaluate drug education strategies, Lisnov *et al* (1998) asked them to give each question a grading (A to F), similar to the gradings they would receive for schoolwork.

In the literature on seeking feedback from people with learning disabilities there is some debate about whether using pictures to represent the extremes of a scale is more useful for seeking feedback from consumers with poor language skills than are questions which require choosing between a number of possible answers. One author suggested that it was not the type of scale that determined whether people responded to the questions, or gave reliable answers, but rather, it was the way the questions were asked and the number of possible answers the consumers were given to choose from that determined the quality of the information obtained (Cardone 1999).

5.7 REPRESENTATIVENESS OF THE SAMPLE OF CONSUMERS

Concern about the representativeness of samples was a common issue identified by those doing both quantitative and qualitative work. Representativeness was particularly an issue in quantitative methodologies where authors wanted to make generalisations about the needs of specific groups based on their samples.

To address this issue, some workers purposefully oversampled sub-groups they knew to have been excluded from previous studies. For example, in a study of young homeless people Kipke *et al* (1997) oversampled young people they met in the street and in locations where young people 'hang out' over individuals recruited through drop-in centres or shelters.

Other authors compared the sample of people they interviewed with population data such as census or service utilisation data. For example, Small *et al* (1999), in checking the representativeness of a sample of Vietnamese, Turkish and Filipino women utilising birthing services, compared the demographic information about participants in their study with data from the Victorian Perinatal Data Collection Unit, which includes information on all women giving birth in Victoria.

To increase the representativeness of participation in qualitative research, authors highlighted the importance of developing links with different groups within communities, and of using a range of different strategies for consulting with consumers, to enable consumers with different needs and abilities to participate.

5.8 SPECIFIC ISSUES WITH PATIENT SATISFACTION SURVEYS

A range of difficulties was associated with patient satisfaction surveys as a way of seeking feedback from diverse groups. Some of these difficulties are highlighted below.

1. Questions about the appropriateness of patient satisfaction surveys as a method of seeking feedback

The South Australian Community Health Research Unit (1996) argued that patient satisfaction surveys were not appropriate methodologies for seeking feedback in situations where consumers were expected to be active participants in their care. They also suggested that, because surveys do not facilitate the development of a dialogue between consumers and providers, they were limited in their capacity as a tool for effective health service development. This may be particularly the case when consumers and providers come from very different cultural and social backgrounds and their attitudes and understandings about what constitutes health, illness and high service quality may be quite different. Indeed, older consumers, in a consultation about how they would like to participate, identified that surveys did not allow them to have adequate input into service planning as the questions were too broad and did not allow for the identification of the 'diversity of needs' (Department of Human Services Victoria 1999).

Draper and Hill (1995) noted that the questions in satisfaction surveys are often those of interest to health service providers. Given the limited representation of minority population groups in the service provider workforce, surveys developed by staff alone are unlikely to be relevant to the diversity of the community. In addition they suggested that:

Certain groups of people, whose social position or state of health may make them vulnerable to poorer quality care, are extremely difficult to reach via the conventional questionnaire (1995).

2. Questions about the concept of satisfaction

Some authors criticise the measurement of patient satisfaction *per se* on the grounds that people use different reasons and value systems for determining satisfaction with a service. Consequently, they argue, measuring satisfaction is very unlikely to provide the type of information useful for informing organisational change (Janssen and Kars 1994, Woodruff 1993). One author suggested that as a consequence of this, levels of dissatisfaction might be a better indicator for problem solving (Woodruff 1993).

Other authors have attempted to determine whether or not there are specific individual characteristics or aspects of service provision that correlate with high levels of satisfaction. Aharony and Strasser (quoted in Dent *et al* 1999), after reviewing 86 patient satisfaction surveys, suggested levels of satisfaction were more likely to depend on the context in which satisfaction was studied and the type of care received than any other variables. Along similar lines, Morse *et al* (cited in O'Neal 1999) identified that homeless people with psychiatric disabilities expressed higher levels of satisfaction with an outreach treatment team if they also received disability support services to complement clinical treatment.

In addition, there is a range of assumptions about patient satisfaction which may not be true. These include that an expression of satisfaction means that consumers are happy with that aspect of care; that satisfaction means that the expectations of clients have been met; and the values that consumers hold about their health and health care enable the evaluation of satisfaction (Williams cited in Cooper and Jenkins 1998).

3. High levels of satisfaction expressed

A number of authors have commented on the high satisfaction rates identified in many satisfaction surveys and have raised questions about the usefulness such information has in informing service development (Draper and Hill 1995, Cooper and Jenkins 1998, Janssen and Kars 1994).

As marginalised groups may only have access to models of care that are less sensitive to their needs, rates of satisfaction with some types of services may be lower for people from these groups (Small *et al* 1997, Curtis *et al* 1999), but this will not be identified if these groups are under-represented in survey samples and are not specifically targeted (Small *et al* 1997).

Consumers from specific groups may also be more reluctant to provide negative feedback about services for fear of losing access to the service or of being discriminated against when using the service again (also see section 6.1).

4. Issues with validity and reliability

In their review of the international literature, Cooper and Jenkins (1998) identified that survey instruments which produce high satisfaction levels may lack 'discriminant validity', or that the data collection may be biased or confounded. This means that such data is of little use in identifying how services can be improved, measurement of improvement over time, and comparison of different models of service provision. In this review the authors discussed the way that factors such as social desirability, acquiescent responses, fear of reprisal, gratitude, low expectations and loyalty to paid carers, might all result in a biasing of results (Cooper and Jenkins 1998).

5. Low response rates

Satisfaction surveys may achieve low response rates, thus limiting the usefulness of the information obtained. See section 5.4 for a discussion about low response rates.

5.9 SUMMARY

A range of issues which impact on the quality of information and knowledge developed through consumer feedback and participation activities was raised in the research reviewed. The consequence of poor processes can be that the information gathered is not useful for informing or implementing change.

It is critical that methods are developed to ensure the production of knowledge that is useful for improving health services. It is also important that methods are developed to maximise the use of this information and knowledge to inform service development.

There is a range of issues about capacity of feedback and participation processes to involve consumers from marginalised groups. These issues will impact on the quality of the information gained in feedback processes, especially if these issues are not addressed by mainstream service providers undertaking routine or mainstream feedback processes. These issues include that:

- many marginalised groups are routinely excluded from participating in mainstream feedback processes;
- the model of participation may not empower consumers to participate, and until consumers can experience being given more power in decision-making they may be reluctant to participate;
- models of participation may not be appropriate to consumers from marginalised groups and may even re-produce patterns of inequality. It can be critical to build relationships with consumers and consumer groups and find out about their needs and preferences to ensure feedback and participation strategies are successful;
- low response rates can make it difficult to interpret the results of participation and feedback activities;
- health professionals may believe that some consumers do not have the capacity to give feedback. However, while it may be the case that some consumers cannot give feedback all of the time, authors investigating this issue found that most consumers could give valuable feedback about services;
- consumers may be sceptical about the capacity of service providers to hear their feedback;

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- the types of scales used to measure consumer responses may not be meaningful to consumers;
 - there needs to be development of ways to improve the representativeness of samples and involve a diverse range of consumers in all activities. Representativeness can be enhanced by developing a range of different strategies to enable consumers with different needs to participate; and
 - there is a range of issues specific to patient satisfaction surveys. A key issue is that the questions that are asked are often those that are of interest to service providers. Other issues include questions about whether they are an appropriate tool *per se*, whether the concept of satisfaction indicates consumers are happy with the quality of care; limitations on the usefulness of the information obtained when high levels of satisfaction are expressed; issues about validity and reliability; and low response rates.

Chapter 6: Barriers 3: Consumer Issues

Consumer reports identify a range of barriers and issues for them in participating. Many of these issues are not well documented, as consumer groups tend not to have access to the resources or infrastructure to either research and/or publish their experiences.

In addition, consumer participation that is driven by service providers means that consumers may just be responding to service provider needs, rather than setting their own agendas for health care and the way health services should be developed (NRCCPH 1999).

6.1 CONSUMERS MAY NOT WANT TO GIVE NEGATIVE FEEDBACK OR COMPLAIN

There is a range of reasons for consumers not wanting to give feedback, in particular negative feedback, to health services. Consequently consumers may express positive views even when they have received poor service (O'Neal 1999).

Some of the reasons consumers may not want to give negative feedback or complain are:

- they fear that they will be discriminated against in terms of accessing or utilising a service, even when they are assured their responses will be confidential and/or anonymous (O'Neal 1999);
- they fear that the service will be withdrawn or funding reduced if negative feedback is given (O'Neal 1999, South Australian Community Health Research Unit 1996). This may be particularly the case in rural areas where there are limited services (Draper 1998, South Australian Community Health Research Unit 1996). In rural areas the existence of a service might be more important than the 'finer points of quality' (Cooper and Jenkins 1998).
- consumers may always respond positively to questions asked by or about an authority figure (an acquiescent response), particularly if they are dependent on the service, for example in disability or aged care services (O'Neal 1999, Cooper and Jenkins 1998);
- people may not have an appropriate standard of comparison. An expression of satisfaction may mean that the service is better than nothing (O'Neal 1999);
- consumers may not want or be able to apply a 'consumerist' approach to health services and may therefore not make negative judgements about health care (Cooper and Jenkins 1998); and
- giving feedback or complaining to health services may not be a culturally relevant practice for some consumers.

6.2 CONSUMERS MAY NOT HAVE ACCESS TO THE STRUCTURES OR RESOURCES TO PARTICIPATE

A critical issue for consumers is that there is very little infrastructure and resources to support them in developing their capacity to participate (NRCCPH 1999, South Australian Community Health Research Unit 1996). Many consumers have little access to ways of learning about participation or access to the information to develop an understanding about health services and their decision-making structures (Otto 1990). This makes it very difficult for them to develop strategies for working with services. In addition, consumers are often expected to bear the material costs of their participation.

Structural inequalities may also mean that those who receive the poorest services are often given the least opportunity to participate (Otto 1990). Unless outreach activities are engaged to seek feedback, consumers from groups who cannot access services will not have a voice.

6.3 UNEQUAL POWER RELATIONSHIPS BETWEEN CONSUMERS AND PROVIDERS

Many consumers report that the way power operates does not favour participation, particularly to the level of partnership. Power inequalities can make participation difficult, or can lead to consumers telling providers what they think providers want to hear, particularly if consumers have little choice in the service they use, have to use the service over a period of time or are dependent on services (O'Neal 1999). For example, Cooper and Jenkins (1998) noted that as people became older and/or experienced increased vulnerability and dependence they might need to be more trusting of their health care provider and this might affect their willingness to comment negatively on them.

A further consequence of these differentials is that service providers may not be able to hear what consumers are saying and consumer views may not be taken seriously. These types of experiences further disempower consumers (South Australian Community Health Research Unit 1996).

6.4 THE QUESTIONS ASKED MAY NOT BE RELEVANT TO CONSUMERS

Draper and Hill (1995) argue that one of the problems with patient satisfaction surveys is that they often ask the questions that service providers perceive to be important. These may not be the same issues consumers perceive to be important (1995). Reports which identified that when consumers were interviewed they raised issues that service providers did not identify illustrate this point (for example, see Bartram *et al* 1999). For some groups of consumers the issues about which questions were asked are so irrelevant to the issues that concern them that there is no motivation to participate. These consumers may experience a hopelessness about being able to 'shape the system we want rather than to have the system shaped for us' (Sen 1994).

6.5 SUMMARY

There are many barriers to the participation of consumers, especially consumers from marginalised groups, in service development. The capacity of consumers as well as of service providers needs to be developed to ensure participation is an effective means of quality improvement.

These barriers include:

- consumers may not want to give negative feedback or complain;
- consumers may experience, or fear, discrimination as a consequence of providing feedback;
- they may not have access to the structures or resources to participate. In addition, structural inequalities may mean that those who receive the poorest services are given the least opportunity to participate;
- unequal power relationships between consumers and providers can make it difficult for consumers to provide feedback or complain; and
- the questions asked are not relevant to consumers.

Developing an infrastructure that supports the participation of consumers from diverse backgrounds in service development requires enhancing the capacity of consumers to be active in these processes.

Chapter 7: Summary of the groups identified and participation and feedback methods

This chapter provides a snapshot of some of the literature collected during this review to provide a quick reference for those wanting to get an overview of the different methods that have been used to work with specific groups of consumers. It is important to note at the outset that there was a considerable body of literature which identified strategies for engaging with consumers from marginalised groups. Due to time and resource limitations, not all of this literature could be included in this review. Literature that was collected but not utilised is listed in appendix 3.

The Consumer Focus Collaboration publication series includes an annotated bibliography containing further information about each of the reports summarised in the following tables.

Interviews with researchers, service providers and members of community organisations identified that while there was a lot of work being undertaken, much of it was not documented. Resource issues and service demands played a part in this.

A limitation was the way specific groups were identified in this review process. It became clear as the project unfolded that literature was easiest to find when a specific consumer group was put into database searches. Our observation from doing this was that whatever group we chose, there had been some work done in involving consumers from that group. Consequently this review cannot claim to make a definitive statement about which groups are marginalised and which are not. In many ways this is not the critical issue. Rather, the key point is that health systems and organisations have systematically marginalised many groups. Some of the reasons for consumers being marginalised from participation in service development are summarised in chapters 4, 5 and 6.

A further observation was that it is difficult to break marginalisation up into specific categories. For example, a project might seek to involve those who have previously been excluded from participation in mental health services and focus on women from non-English-speaking backgrounds. This illustrates that marginalisation occurs through intersections of factors, in this case health issue, ethnicity and gender. For this reason, all of the reports are in one table, roughly grouped under themes, rather than being segmented into separate tables.

People from the following groups (and combinations of groups) are included in the work summarised in the following table:

- people with mental health issues (pages 30 to 32)
- people from non-English-speaking backgrounds (pages 36 to 40)
- those with disabilities (pages 33 and 34)
- young people (pages 34 and 35)
- older people (pages 42 to 45)
- people experiencing homelessness (pages 35 and 49)
- those living on low incomes (page 49)
- those with low literacy skills (page 49)
- people with chronic health conditions (pages 41, 42 and 47)
- indigenous peoples (pages 47 to 50)
- parents (page 41)
- carers (page 33 and 41 to 42)
- women (pages 45 to 47)
- people living in rural and remote areas (pages 50 and 51)
- frail people (page 42)
- survivors of violence (page 45).

The page numbers in brackets give a rough indication as to where reports addressing the relevant groups can be found; however, the reports on the pages listed may address more than one target group. An analysis of the methods used to involve these groups of consumers is provided in chapters 8, 9 and 10.

In this review there is very little information about involvement of Aboriginal communities, except when mainstream services have commented on the success or otherwise of their strategies for working with Aboriginal peoples. This is because, as a non-Indigenous person undertaking a literature review, it would not have been appropriate for me to comment on this work. If further work on feedback and participation is to be funded through the CFC, this is an area that should be further investigated. Any work to review or develop reference guides on the participation of Aboriginal peoples should be developed and undertaken by or in collaboration with Aboriginal community controlled health organisations.

7.1 SUMMARY

- There was a considerable amount of information in the literature about the ways in which services have involved consumers from marginalised groups. Time and resource restraints meant that not all of this information could be covered in this review.
- Interviews with researchers, service providers and members of community organisations identified that a lot of work was being undertaken and not documented due to resource and service constraints.
- It was observed that whenever a specific consumer group was put into a database search, some work had been done on seeking input from that group. Consequently, this review cannot make a definitive statement about which groups are the most marginalised; however, this is not the critical issue. Rather, the critical issue is that health systems and organisations have marginalised many groups.
- Marginalised groups cannot be identified by single categories as often it is the intersections of different factors (for example, ethnicity, health condition and gender) that will determine consumer experiences of marginalisation.
- It was not appropriate for me as a non-Indigenous person to comment on the success or otherwise of strategies for involvement of Aboriginal peoples. Consequently this review only covers articles in which mainstream health services have commented on their strategies for working with Aboriginal peoples.

Table 1: Summary of the methods used to work with specific groups of consumers previously marginalised from participation in service development (cont.)

Authors	Target group(s)	Reason for undertaking the work	Methods	Findings about methods
Department of Human Services Victoria 1999	Mental health: Consumers Consumer consultants Service providers Policy makers Carers Peak bodies	To evaluate consumer participation in Victoria's public mental health system	<ul style="list-style-type: none"> • Discussion paper circulated • Evaluation advertised to key stakeholder groups • Questionnaires • Focus groups • Interviews • Free phone line • Written submissions • Literature review 	
Otto Di 1990	Consumers of mental health services Women and people of non-English-speaking-background identified as particularly marginalised	To develop strategies for involving consumers in the mental health system	Community development approach including discussions with consumers and staff and development of pilot projects	Enabled the development of a number of strategies for action.
McGuiness Maggie & Wadsworth Yolanda 1992	Consumers and staff of acute psychiatric services	To evaluate an acute psychiatric hospital	<ul style="list-style-type: none"> • Individual and group interviews with consumers and staff separately • Information from interviews swapped • Consumers participated in development of recommendations 	Establishment of a 'constructed conversation' enabled consumers and staff to gain an understanding of each other's positions and develop useful recommendations.
Wadsworth Yolanda & Epstein Merinda 1996	Consumers of acute mental health services	To build consumer participation into evaluation and service development	Participatory action research including facilitated exchange of views between consumers and staff	<p>Key elements required:</p> <ul style="list-style-type: none"> • quality improvement framework • commitment to consumer feedback and staff-consumer communication • development of systematic processes for consumer input which are routine and 'do-able' and built in at all levels • multiple feedback mechanisms • consumer-only, staff-only and consumer-staff sites for dialogue, discussion and decision-making • payment of and support for consumers • supports for staff

Authors	Target group(s)	Reason for undertaking the work	Methods	Findings about methods
Kline Frank, Acosta Frank, Austin William & Johnson Richard G 1980	Spanish-speaking people utilising psychiatrists	To explore consumers' experiences as service is not used much by this group	Questionnaires for consumers and psychiatrists	
Gauntlett Nick et al 1995	People with mental health issues not accessing mainstream services, especially people from ethnic minority groups and/or homeless people	To describe a service approach	Outreach	Outreach is a successful strategy for working with and involving people from the target group, as shown by a reduction in hospitalisation and potential homelessness.
O'Neal Paul D 1999	Consumers with mental health issues	To review literature on consumer satisfaction	Literature review	<p>Raises a range of methodological questions including those about:</p> <ul style="list-style-type: none"> • high satisfaction expressed • use of vicarious measures • factors which may predict satisfaction, payment for participants.
Centre for Development and Innovation in Health, North East Women's Health Service and Women and Mental Health Advisory Group 1995	Women of non-English-speaking background with psychiatric disabilities	To find out why women from this group were not accessing services and to develop recommendations to address this	<ul style="list-style-type: none"> • Literature reviews • face-to-face or telephone interviews with consumers and service providers • Focus groups • Workshop with service providers • Information sought from workers 	<p>Limitations include that the short time frame did not allow relationships of trust to be built between the project workers, women and service providers, limiting the number of participants and the type of information provided; some women were not able to participate because of illness and women not utilising services were not able to be contacted.</p>
Rogers Anne & Pilgrim David 1993	People with mental health issues	Little known about the views of people using psychiatric services	<ul style="list-style-type: none"> • Consumers contacted through an NGO, consumer groups and social services • Semi structured questionnaire developed • Questionnaire piloted and amended • face-to-face interviews 	The use of quantitative and qualitative questions enabled the researchers to explore complex issues.

Table 1: Summary of the methods used to work with specific groups of consumers previously marginalised from participation in service development (cont.)

Authors	Target group(s)	Reason for undertaking the work	Methods	Findings about methods
Taylor Brent & Clarke Richard 1993	Consumers with mental health issues	To seek feedback to inform service development	<ul style="list-style-type: none"> Questionnaire developed in consultation with staff and community members and informed by interviews with policy makers, service providers and carers. Draft questionnaire reviewed by former patients People using a facility were given the questionnaire and asked to post it back 	Former patients were asked whether they would have been prepared to answer each question.
Epstein Merinda & Shaw Jullie 1997	People with mental health issues	To develop a model for education and training for consumer participation	<ul style="list-style-type: none"> Consumer led and controlled Model developed in long process of discussion and exploration 	Factors required for successful consumer participation include: <ul style="list-style-type: none"> reflective practice appropriate service structures commitment to consumer-staff dialogue
Sozomenou Andrew, Mitchell Penny, Fitzgerald, Maureen & Malak Abd (no date)	People of non-English-speaking background with mental health issues, carers and community members	To identify innovative strategies for participation	<ul style="list-style-type: none"> Advisory committee Literature and policy review National survey with open and closed ended questions to identify strategies Case studies State-wide forum 	
Centre for Mental Health Services 1998	People of color with mental health issues	To seek input of consumers	<ul style="list-style-type: none"> Teleconferencing used to develop networks Regional meetings National people of color consumer/survivor summit of consumers and key decision-makers Summit facilitated by a health professional who was a person of color 	
Rose Diana et al 1998	People with mental health issues	To involve consumers in 'evaluation of mental health services	<ul style="list-style-type: none"> Coordinating group of 12 consumers Project coordinator a consumer Consumers were trained as evaluators Questionnaires were developed and piloted Consumers to be interviewed were contacted through key workers Consumers conducted interviews and site visits Interviewers were de-briefed 	The attitudes and concerns of key workers had a big influence on their preparedness to ask consumers to participate.

Authors	Target group(s)	Reason for undertaking the work	Methods	Findings about methods
Rees Roger J & Hannaford Meredith 1996	Carers of people with acquired brain injury	To explore the experiences of carers	<ul style="list-style-type: none"> Participants randomly selected from those utilising a rehabilitation service face-to-face interviews Participant observation Diary review Clinical record review 	
Abbott-Chapman Joan & Easthope, Gary 1998	Students with physical and sensory disabilities	To explore issues of inequality, disadvantage, participation and inclusion	<ul style="list-style-type: none"> Face-to-face interviews 	Some students identified by teachers as disabled did not identify as such and would not participate.
Daghan D et al 1994	People with learning disabilities	To develop and test tools for collecting information about service quality and to examine patient satisfaction with a psychology service	<ul style="list-style-type: none"> face-to-face interviews in people's work places Three question formats tested 	More sophisticated information was obtained when people were given a bigger range of options. Open ended questions resulted in collection of valuable information.
O'Brien, Anne & Mahony, Kate 1999	People with acquired brain injury	To research difficulties experienced by people with acquired brain injury when utilising automated services	<ul style="list-style-type: none"> Literature review Open ended questionnaire based on a survey of agencies face-to-face interviews by case worker Consumers given tasks and accompanied by a researcher who observed their difficulties People's perceptions of their difficulties were checked against researcher observations Training for people experiencing difficulties was implemented and evaluated 	Comparison of researcher observations with what people reported indicated that they could accurately report their difficulties.
Meehan Effie & Hanson Kate 1999	Women of non-English-speaking background with disabilities	To identify health issues and barriers to accessing services and to make recommendations for change	<ul style="list-style-type: none"> Researcher from the target group Working party Questionnaires developed and tested with working party Interviews with consumers 	
E-Qual 1998	People with disabilities	Review of survey methods for seeking feedback	<ul style="list-style-type: none"> Review of literature, large scale surveys Interviews and meetings with people working on surveys 	

Table 1: Summary of the methods used to work with specific groups of consumers previously marginalised from participation in service development (cont.)

Authors	Target group(s)	Reason for undertaking the work	Methods	Findings about methods
Fyffe Chris & McCubbery Jeffrey 1996	People with acquired brain injury living in rural areas and their carers	To identify needs	<ul style="list-style-type: none"> Consumers and carers identified through public meetings, referral from other carers and consumers Questionnaire published in local newspapers Individual interviews Group interviews Self completed questionnaires Some carers acted as surrogate consumers 	
Cardone Denise 1999	People with learning disabilities	To identify a reliable, easy to score method for seeking information from people with learning disabilities	<p>* Consumers were asked to respond to two different questionnaires; one provided three answers to a question and the other utilised a pictorial scale</p>	<p>People with better language ability gave more reliable answers to both types of questionnaires. It could be the way questions are asked, and the number of possible responses, that determines whether people respond and how reliable their answers are, rather than the nature of the method itself. People got frustrated with answering the same question in different ways. Qualitative methods may be more appropriate.</p>
Pritchard, Colin et al 1998	Young people	To seek young people's views on their educational social worker	<ul style="list-style-type: none"> Questionnaire developed and piloted Quotes from young people incorporated into the questionnaire Questionnaire distributed by social workers Questionnaires returned in prepaid envelope Pizza parties Graffiti sheets 	
Shoalhaven Youth Health Service 1996 development	Young people	To increase awareness about binge drinking and seek feedback to inform service		Young people enjoyed parties and gathered information

Authors	Target group(s)	Reason for undertaking the work	Methods	Findings about methods
Department of Human Services, Victoria 1998	Young people from Cambodian, Lao and Vietnamese backgrounds requiring drug and alcohol services	To evaluate current service provision and make recommendations for enhancing access	<ul style="list-style-type: none"> • Reference group • Literature review • Review of statistics and data • Young people were contacted through service providers • face-to-face interviews with young people by a person who had worked with them • Interviews, focus groups and group discussions with service providers, ethnospecific agencies and juvenile justice centres • Group discussions with young people • Consultation with parents 	Utilising links with local agencies and local outreach and support workers and using a snowballing approach were useful strategies in identifying key informants.
Kipke Michele D, Unger Jennifer B, O'Connor Susan, Palmer Raymond F & LaFrance Steve R 1997	Young people living on the streets	To develop ways of getting feedback	<ul style="list-style-type: none"> • Young people recruited from shelters, drop-in settings, the street and places where they 'hang out'. • Young people were asked to respond to a questionnaire to determine eligibility • Interviews were undertaken with those who wanted to participate • Participants were given food vouchers 	Going to where young people are is important; otherwise only those who utilise services are included in feedback strategies.
Lambert Connie 1998	Adolescent parents	To evaluate the usefulness of a parenting manual for young mothers.	<ul style="list-style-type: none"> • Participants contacted through a high school program • The director of the program conducted the evaluation • Participants were told how their input would be utilised • Semi structured questionnaires • Highlighted parts of the text that were not accessible or not relevant 	
Healy Karen and Walsh Karyn 1997	Young women	To address issues of violence against young women.	<ul style="list-style-type: none"> • Participatory action research • Analysis of issues • Development of responses and strategies • Development of group roles and responsibilities • Reflection on process and change 	This was a successful strategy in developing responses and action. Initial facilitation by health workers important in establishing group. Later workers played a more peripheral role. Reflection on changing roles and role development important. Training for consumers and staff important. Valuing knowledge of consumers and staff important.

Table 1: Summary of the methods used to work with specific groups of consumers previously marginalised from participation in service development (cont.)

Authors	Target group(s)	Reason for undertaking the work	Methods	Findings about methods
Bhatti-Sinclair Kish 1999	People from black and ethnic minority groups	Evaluation of social work and medical practice with a focus on developing anti-racist and anti-oppressive practices.	<p>Audit process including:</p> <ul style="list-style-type: none"> standards development practice observation comparison to standards interviews development of recommendations and action plans implementation of change re-audit 	<p>External review can create anxiety amongst professionals.</p> <p>Independent researchers undertaking face to face interviews with clients in their homes may overcome biases of satisfaction surveys.</p> <p>Employment of skilled interviews of similar backgrounds to clients may improve quality of information obtained.</p>
Lopez Rafaela & Fazalori Lella 1999	Women from Vietnamese, Chinese Salvadoran, Chilean, Russian, Ukrainian and Lebanese backgrounds	To examine services, policies, structures and attitudes which affected service delivery	<ul style="list-style-type: none"> Steering group Literature review Survey Review of hospital policies and protocols Examination of hospital structures Consultations with staff and workers at community based organisations 	
Boston Vera 1999	People from diverse backgrounds	To address issues created by amalgamation of community health centres	<ul style="list-style-type: none"> Community Liaison Committee established Staff member given responsibility for developing links with communities Community Liaison meetings held in a public venue and translated into eight languages 	<p>Elements of success of the model include:</p> <ul style="list-style-type: none"> all staff are committed to participation community liaison skills are valued within the organisation time is committed interpreters at meetings allow people to participate in complex discussions transport is provided.
Zarcadoolas Christina, Ahern David K, Follick Michael J, Blanco Mercedes S, Evans Joann M and Getting James P 1997	People living on low incomes, people with low literacy levels and people from ethnic minority groups	<p>To identify consumer information needs and develop educational materials</p> <p>To increase the quality of care</p> <p>To improve appropriate use of health services</p> <p>To improve patient satisfaction</p>	<ul style="list-style-type: none"> Establishment of information panels of health professionals Focus groups with consumers held in community locations Focus groups with service providers Review of literature, web sites and consumer materials Monitoring calls to a multilingual health line Consumers participated in developing and revising tools 	<p>This method enabled the development of tools to assist people in asking questions of their doctors.</p>

Authors	Target group(s)	Reason for undertaking the work	Methods	Findings about methods
Pardy Maree 1994	Women utilising interpreting services	To explore experiences of women utilising interpreting services	<ul style="list-style-type: none"> • Women asked to talk about their experiences 	
Bartram Mike, Abell Anita & Murphy Rue 1999	People from black and ethnic minority groups	To involve consumers who have the poorest access to services in service development	<ul style="list-style-type: none"> • Working group • Census data utilised to identify groups * Letters sent to local black and ethnic minority groups and to national organisations • Telephone contact was made with groups • Hospital staff went out to speak to groups • Open ended questions about service quality were asked at meetings • Notes from meetings sent back for verification • Action areas were identified and specific projects developed 	<p>Contacting groups by phone was more successful than contacting groups by letter. Phone contact allowed staff to find out more about each community, how best to talk with community members and to explain and build support for the project. Communities were willing to participate and involving them produced some creative solutions.</p> <p>Tips for consultation include:</p> <ul style="list-style-type: none"> • involve community leaders • hold meetings in community settings at times appropriate to the community • give everyone a chance to contribute • have some small group meetings to allow in-depth discussion • build relationships with people from different parts of each community • go back to groups to further discussions and build relationships of trust • use interpreters • have a long term plan which is communicated to communities.
Hart Vicki R et al 1996	People from ethnic minority groups with Alzheimers disease	To develop culturally appropriate services	<ul style="list-style-type: none"> • Outreach programs • Development of working relationships with community and ethnospesific agencies • Employment of bicultural workers • Establishment of satellite centres in rural communities or in area with high populations of older people from specific ethnic backgrounds • Development of a culturally relevant diagnostic dementia program form Latin American peoples 	<p>Participation of older people from ethnic minority groups increased over a two year period. Leadership is important to ensure appropriate time is allocated to outreach activities and funds are made available for education, training and development of assessment tools. Employment of bicultural staff is critical to success of strategy.</p>

Table 1: Summary of the methods used to work with specific groups of consumers previously marginalised from participation in service development (cont.)

Authors	Target group(s)	Reason for undertaking the work	Methods	Findings about methods
Drug Treatment Services Unit, Aged Community & Mental Health Branch Division, Department of Human Services 1998	People from culturally and linguistically diverse backgrounds and Koori people	To develop a strategy to ensure drug and alcohol services are accessible and appropriate	<ul style="list-style-type: none"> Reference group Literature review Telephone and face-to-face interviews (with consumers and staff) Questionnaires Agency mapping Workshops Focus groups Site visits 	
Small Rhonda, Lumley Judith, Yelland Jane, & Rice Pranee Liamputtong 1999	Vietnamese, Filipino and Turkish women	Discussion of methodological issues	<ul style="list-style-type: none"> Written material and interview schedules translated by accredited translators Translations discussed by a group of people from each community to check clarity, accuracy, meaning, accessibility and appropriateness Questionnaires were modified and both versions piloted Original English version and translated version also completed by bilingual women Results translated and discussed Semi structured interviews undertaken by bilingual workers in women's homes Interviews were taped for quality checking A range of strategies was employed to ensure quality of information 	<p>Issues impacting on meaning and quality of translations include:</p> <ul style="list-style-type: none"> technical terminology translations did not give the same meaning as the original some response options were too similar meanings in different cultural contexts review processes allowed researchers to pick up problems and issues.
Small Rhonda, Yelland Jane, Lumley Judith & Rice Pranee Liamputtong 1999	Women from non-English-speaking backgrounds	Patient satisfaction	Issues paper	<p>Good discussion of:</p> <ul style="list-style-type: none"> sampling issues (including recruitment, sample size, representativeness), and training of bilingual workers
Cappetola Teresa 1990	Women of non-English-Speaking background	To find out about women's experiences of hysterectomy No existing literature	<ul style="list-style-type: none"> Literature search Ethnic health workers approached to seek permission to attend women's groups Four meetings with each group face-to-face and telephone interviews 	Method was developed so that it was about an active exchange of information.

Authors	Target group(s)	Reason for undertaking the work	Methods	Findings about methods
Callan V, & McElwain D 1980	People from ethnic minority groups	To suggest guidelines for undertaking research with people from ethnic minority groups	Reflection on field work experiences	Develop detailed proposals and discuss with the group. Ensure the timelines respect the needs and lifestyles of the community. Ensure issues are those that are important to the community. Develop an understanding of relevant political and cultural issues and the differences within communities. Identify other work done to reduce duplication and promote collaboration. Develop culturally relevant tools. Employ and train bilingual workers and interpreters. Develop and maintain ongoing links with communities. Provide feedback to communities.
Guendelman Sylvia & Witt Sandra 1991–92	Latina women living on low incomes in California	To explore ways if improving services to women who receive no prenatal care	<ul style="list-style-type: none"> Consumers were identified through community workers Consumers were paid Focus groups (with staff and consumers separately) run by bilingual health workers 	Method allowed the authors to recommend changes to the way services were provided and cultural and structural changes to improve service provision.
Fitzroy Community Health Centre 1992	Community members, especially people from non-English-speaking background	To seek consumer input into service development	Quarterly community forums translated into seven languages	Useful as one part of a service strategy to respond to diversity.
Doyle Robert & Visano Livy 1980	Consumers from diverse cultural and racial groups	To examine access to services and to participation in service planning and development in Toronto	<ul style="list-style-type: none"> face-to-face interviews Self administered questionnaires Policy review Case studies 	

Table 1: Summary of the methods used to work with specific groups of consumers previously marginalised from participation in service development (cont.)

Authors	Target group(s)	Reason for undertaking the work	Methods	Findings about methods
Madhok Rajan & Bhopal Rajinder S 1992	Consumers from 'Asian' and 'non-Asian' backgrounds	To compare satisfaction of non-clinical aspects of care between groups	<ul style="list-style-type: none"> Participants identified by ethnic health coordinator and the researcher and matched for gender and age Promotion in local media and through community leaders Questionnaire developed and piloted Interviews conducted by one person who spoke five languages 	
Henenberg Cathy & Pardy Maree 1995	Women of non-English-speaking background	To explore issues about interpreting services	<ul style="list-style-type: none"> Interviews and discussions 	
Huang X., Butow P., Meiser B, & Goldstein D 1999	Chinese-born people with cancer	To explore information needs to inform development of culturally appropriate practice	<ul style="list-style-type: none"> People were recruited from teaching hospitals and a support group Telephone interviews Focus groups run by a Chinese psychiatrist in Cantonese, Mandarin or English Acculturation questionnaire Information transcribed by the psychiatrist and checked by others Feedback was given to the group on preliminary findings 	<p>Qualitative methods were useful because there were no pre-existing quantitative measures and no previous research done in this area.</p> <p>A limitation of focus groups was that some people were less likely to participate and others conformed to the majority view.</p>
Cheek Julianne, Fuller Jeff, Gilchrist Sue, Maddock Agnes and Ballantyne Alison 1999	Vietnamese women	Vietnamese women have a higher incidence of cervical cancer and little is known about their use of services	<ul style="list-style-type: none"> Vietnamese names selected from electronic phone book Vietnamese women trained as interviewers Structured questionnaire translated by an accredited translator with assistance from a Vietnamese researcher Questions piloted with Vietnamese health workers Face-to-face interviews 	
Rice Pranee Liamputtong Naksook, Charin 1998	Thai women	To explore perceptions of Thai women about having a caesarean	<ul style="list-style-type: none"> Researchers were Thai women Women recruited through community venues, through the researchers networks and through snowball sampling. Face-to-face interviews were undertaken and transcribed in Thai 	

Authors	Target group(s)	Reason for undertaking the work	Methods	Findings about methods
Janssen CGC & Kars H 1994	Parents of people with mental handicaps	To explore whether differences in the roles and expectations of parents influenced the satisfaction expressed with services	<ul style="list-style-type: none"> Parents critical of the service were interviewed and asked about the aspects of care they considered important. This was used to develop a satisfaction survey, which was then evaluated, commented on and revised by professionals and parents. The PSS was piloted and adjusted prior to giving to parents 	
Santamaria Nick & McKenzie, Margaret 1999	Carers	To develop an understanding of impacts on carers of hospital in the home	<ul style="list-style-type: none"> Participants selected from databases Structured interview conducted in carers' homes 	
Grant Gordon et al 1994	Families and carers of people with intellectual disabilities in rural and urban areas		<ul style="list-style-type: none"> Participants identified through community support teams Self-report questionnaires posted Assistance with completing questionnaires offered 	
McGrath Morag 1989	Carers of people with intellectual disabilities	To explore why carers had not participated in service development despite the existence of strategies to promote participation	<ul style="list-style-type: none"> Observation at meetings Interviews with service providers and carers 	<p>Important to:</p> <ul style="list-style-type: none"> ensure participation is relevant to the expertise of participants develop guidelines for function and role of groups provide practical assistance to carers provide training to carers establish dialogue between different stakeholders
Yates BD, McEwan C & Eadie D 1997	Carers of people with AIDS	To find out about needs and to produce a video to address deficits in information	<ul style="list-style-type: none"> Steering group of health professionals Carers identified through clinicians A person from the consumers care team was nominated to liaise with the carer Focus groups Interviews (with carers and service providers) Making and piloting a video Adapting the video in response to feedback. 	<p>Development of relationships between the researchers and carers and between the liaison officers and carers was critical to the success of the project.</p> <p>Meeting the needs of carers in relation to venue, time, provision of respite and the types of activities (focus group or individual interview) was also critical.</p>

Table 1: Summary of the methods used to work with specific groups of consumers previously marginalised from participation in service development (cont.)

Authors	Target group(s)	Reason for undertaking the work	Methods	Findings about methods
McLean Cameron & Roberts Richard 1995	Partners of gay men with AIDS	To develop an understanding of issues and needs relevant to carers of gay identified men with AIDS	<ul style="list-style-type: none"> Unstructured interviews Social worker-researcher could refer to appropriate supports. 	A non-random sample was considered appropriate as interviews were used to generate hypotheses and concepts rather than to make valid and reliable conclusions.
Trollor, John 1997	Carers of people receiving palliative care in rural and remote NSW	To examine satisfaction and inform service planning	<ul style="list-style-type: none"> Questionnaires developed in consultation with researchers and health professionals Participants identified by community nurses Postal questionnaires 	
Health Issues Centre 1997	Women carers	To examine the impact of shifting care out of hospitals into the home.	<ul style="list-style-type: none"> Project reference group Literature review Policy review Interviews with key informants 	
Iutocovich Joyce Miller 1993	Rural older people	To inform service planning and development	<ul style="list-style-type: none"> Community advisory group Employment of project director and community organiser Identification and training of community volunteers Collection and analysis of information Town meeting 	<p>Importance of community organiser role.</p> <p>Recognition of the expertise of all people critical.</p> <p>The town meeting did not produce the expected outcomes.</p> <p>Role too time consuming for volunteers.</p>
Cooper David and Jenkins Anne 1998	People utilising home and community care services, primarily frail and disabled older people, younger people with disabilities and carers. Identified special needs groups included people with dementia, people from non-English-speaking background, indigenous people, people who are financially disadvantaged and people living in rural and remote areas.	To inform the development of a national tool for seeking feedback from people utilising HACC services	Literature review	<p>Self administered questionnaires were the most commonly utilised survey method.</p> <p>Personal interviews, focus groups and telephone interviews were also utilised.</p> <p>Satisfaction surveys often report high levels of satisfaction and have low response rates.</p> <p>Discusses a range of methodological issues.</p>

Authors	Target group(s)	Reason for undertaking the work	Methods	Findings about methods
Velasco Maria-Jesus 1999	Older people, including people of non-English-speaking background	To train and support older people to be peer educators and advocates	<ul style="list-style-type: none"> • Steering committee • Training, run in eight languages • Older people then work as educators and advocates 	Peer approach good because older people are more likely to respect, listen to and talk with other older people. Evaluation showed process is a good one and has been successful in creating collaborations and in enhancing participation of older people in a range of health system activities.
Triado Tony 1998	Older people discharged from hospital and their carers, including older people of non-English-speaking background	To explore experiences to identify good practices from a consumer perspective and develop recommendations for service development	<ul style="list-style-type: none"> • Questionnaires were developed and piloted • Semi structured interviews were conducted in people's homes four weeks after discharge • Quantitative information about health outcomes collected • Satisfaction surveys • Information was translated into Italian and Greek • Interpreters and ethnic health workers were available to consumers • Next of kin were asked to participate if people had dementia • Interviews and focus groups with service providers 	Interviews in people's homes important for involving frail older people
Hickson Louise, Worrall Linda, Yiu Edwin & Barnett Heather 1996	Older people	To plan an education program	<ul style="list-style-type: none"> • Advertisements placed in newspapers and at community locations • Nominal group process • Facilitators experienced in working with people with communication disabilities 	Nominal group technique was useful as all members of the group could participate. Identify communication difficulties prior to running groups so that facilitators are aware of and can plan for working appropriately. Employ skilled facilitators used to working with older people with communication difficulties. Hold meetings in appropriate settings in well lit rooms with little background noise. Method can be time consuming, but authors suggested that the information obtained was much better than that obtained from more time efficient methods such as questionnaires.

Table 1: Summary of the methods used to work with specific groups of consumers previously marginalised from participation in service development (cont.)

Authors	Target group(s)	Reason for undertaking the work	Methods	Findings about methods
Jylha Marja 1994	Older people	To develop an understanding of the meanings associated with self reported health status	Interviews	
Department of Human Services, Victoria 1999	Older people	To develop a resource about consumer participation by older people	<ul style="list-style-type: none"> • Working group made up of older people from diverse backgrounds • Project advertised in media • Consultations, including specific forums for people of non-English-speaking backgrounds and people with high needs. • Workshops with service providers where findings were reported and strategies developed. 	<p>Principles and preconditions for participation included:</p> <ul style="list-style-type: none"> • recognise each person as an individual • involve consumers in decision-making and in developing solutions • develop supportive environments • allow enough time • respect consumers • provide clear and concise information • preferably talk to people rather than use written methods. <p>Specific findings include:</p> <ul style="list-style-type: none"> • face-to-face discussions were preferred over invitations to make written responses • face-to-face interviews were preferred over self-completion questionnaires or telephone interviews • working groups are valuable at all stages of planning processes • multiple methods should be used to ensure participation of a range of people • consultation with existing groups is useful • consult with peak consumer groups • consult with people in their homes.
Quine Susan & Cameron Ian 1995	Women over 75 years old with physical disabilities	To examine whether focus groups are a useful way of seeking input from older women with disabilities	<ul style="list-style-type: none"> • Participants were currently utilising a rehabilitation service • Focus groups 	<p>Focus groups are effective.</p> <p>Keep groups to five or six participants.</p> <p>Limit time to half an hour as people get tired.</p> <p>Ensure the space is adequate to accommodate people with mobility aids.</p>

Authors	Target group(s)	Reason for undertaking the work	Methods	Findings about methods
Dent OF, Broe GA, Creasey H 1999	Older people	To examine satisfaction with a range of health services	<ul style="list-style-type: none"> Consumers selected randomly from households (to enable evaluation of a range of services) Interviews 	
Jenkinson Crispin, Jenkinson Damian, Sheppard Sasha, Layte Richard & Petersen Sophie 1997	Older people with congestive heart failure	To evaluate quality of life measures	Questionnaire	Standardised quality of life measures may not be sensitive enough to pick up significant changes in quality of life for this group.
Norton Ilena M & Schauer Joan 1997	Women survivors of domestic violence	To evaluate a hospital based support group	Women attending the group were asked to fill in a questionnaire	
Brown Stephanie & Lumley Judith 1997	Women utilising maternity services	To seek feedback from women about different models of care	Questionnaires posted to women who had given birth over a two week period in Victoria.	Women of non-English-speaking background, younger women and single women were under-represented.
Small Rhonda, Lumley Judith, Yelland Jane & Rice Pranee Liamputtong 1997	Vietnamese, Turkish and Filipino women utilising birthing services	To find out about women's experience of maternity care	<ul style="list-style-type: none"> Bicultural interviewers were trained Interviewers asked women to participate while they were in hospital Women were interviewed in their own homes, in their preferred language, 6–9 months after having their baby 	Importance of employing and training bilingual staff. Importance of addressing translation issues.
Sen Rinku 1994	People living on low incomes, people of color and immigrant peoples.	Development of a model for activism of disenfranchised communities to facilitate participation in health system development	<ul style="list-style-type: none"> Local residents approached to join a local NGO Discussions about health and health care held in local meeting places Key strategies for action were developed 	Enabled the development of activism around common themes Five phases in developing relationships: <ul style="list-style-type: none"> conflict confrontation negotiation and agreement monitoring partnership

Table 1: Summary of the methods used to work with specific groups of consumers previously marginalised from participation in service development (cont.)

Authors	Target group(s)	Reason for undertaking the work	Methods	Findings about methods
Lillie-Blanton Marsha & Hoffman Sandra C 1995	Ethnic minority groups	Needs assessment	Reflection	<p>Researchers should:</p> <ul style="list-style-type: none"> • be sensitive to how they are perceived within the community • develop knowledge and understandings about communities • develop mutually beneficial partnerships • communicate throughout the project • establish ways the research can benefit the community.
Faulkner, Kathryn 1996	Women, including women who live in a caravan park, working women, Aboriginal and Torres Strait Islander women, young parenting women and women of non-English-speaking background	To increase community participation in a tertiary hospital	<ul style="list-style-type: none"> • Steering committee with equal numbers of consumers and providers • Literature review * Consultation with consumer and community groups and community based workers • Interviews • Focus groups held in community settings. • Consumers participated in development of a training program for staff and in facilities planning 	In order to ensure specific and often unrepresented women were involved in the process, the organisation had to go out to meet with these groups.
South Australian Community Health Research Unit 1994	Women's health, community health consumers and staff	To explore ways consumer feedback was collected	<ul style="list-style-type: none"> • Project advisory group • Telephone interviews 	<p>Both informal and formal feedback mechanisms existed.</p> <p>A range of organisational issues needs to be addressed to ensure feedback (especially informal feedback) is utilised for improving services.</p>
Cockburn, Jill, Pit, Sabrina & Redman, Sally 1999	Women aged between 40–49	To explore views on mammography to inform policy development as little was known about the views of this group of women	<ul style="list-style-type: none"> • Randomly selected from phone book • Telephone interviews (evenings and weekends) 	Method resulted in sample consisting of women who were better educated, more likely to be working and to be married than other women in this age group.
Fraser, Diane M 1999	Pregnant women	To inform curriculum development	<ul style="list-style-type: none"> • Longitudinal study • Semi structured and unstructured interviews (at three times) • Interpreters employed where appropriate 	

Authors	Target group(s)	Reason for undertaking the work	Methods	Findings about methods
Radoslovich Helen 1998	'Positive Women'	To evaluate an HIV/AIDS women's project	<ul style="list-style-type: none"> Reference group Positive women participated throughout the project 	The key elements in the success of the project include: involvement of positive and affected women throughout the project.
Woodruff Ian W 1993	People living with HIV and AIDS	To investigate consumer satisfaction	<ul style="list-style-type: none"> Project auspiced by People Living with HIV and AIDS Questionnaire developed and piloted with health professionals and service users. Survey mailed to participants 	Auspicing facilitated recognition of the project amongst the target group and potentially enhanced the response rate. Important that a process to ensure confidentiality and anonymity was implemented.
Curtis J Randall, Patrick Donald L, Caldwell Ellen, Greenlee Heather & Collier, Ann C 1999	People with HIV and AIDS	To examine the quality of communication about end of life decisions	<ul style="list-style-type: none"> Focus groups conducted to identify four key items which determine quality of communication to inform questionnaire development Consumers recruited through advertisements in community settings and clinics face-to-face interviews with consumers Telephone interviews with doctors Interviews compared to identify if the same perceptions about communication were held 	This methodology allowed for the development of an effective and valid tool for measuring quality of communication.
Jenkinson Crispin, Fitzpatrick Ray, Oeto Viv, Greenhall Richard & Hyman Nigel 1997	People with Parkinson's disease	To develop and pilot a quality of life measure specifically for people with Parkinson's disease	<ul style="list-style-type: none"> Survey based on interviews with people with Parkinson's disease posted to consumers Final survey based on response to posted questionnaires Final survey posted to consumers or administered in a neurology clinic 	Response rate was higher when surveys given out in the clinic. Self reported survey results corresponded with the clinical assessments, indicating that the questionnaire was a reliable and valid means of assessing the impact of Parkinson's disease.
Salisbury Christine 1998	Aboriginal and Torres Strait Islander peoples	To develop appropriate models of care to address high morbidity and mortality and increasing mental health issues	<ul style="list-style-type: none"> Participatory action research process including: <ul style="list-style-type: none"> transfer of power and authority to aboriginal organisations reference group discussion about the project in many settings consensus decision-making (open to review) evaluation of strategy 	A range of solutions was developed. There was a large increase in service utilisation.

Table 1: Summary of the methods used to work with specific groups of consumers previously marginalised from participation in service development (cont.)

Authors	Target group(s)	Reason for undertaking the work	Methods	Findings about methods
Ratima MM et al 1999	Maori people living in rural areas	Maori people suffer higher rates of asthma than non-Maori people and have poor access to culturally appropriate services To evaluate a self-management strategy developed as a partnership between Maori communities and a university	<ul style="list-style-type: none"> • A Maori tribal representative and Maori community workers coordinated the project • Community meetings • Participants identified through community networks • Plans were developed * Maori workers supported people participating in the plan • Participants were interviewed throughout the program • Participants kept a diary 	This was a successful approach. Employment of Maori workers and development of culturally appropriate programs and information was critical.
Tidemann Sonia C, Bohme J, Burnett R, Camphoo J, Cook H, Daniels L, Dixon B, Dixon F, Fernando D, Heffernan K, Huddleston B, Huddleston V, Law M, Lee M, Marika K, Mayanini G, Maxted M, Mununggurr L, Muthamuluwuy K & Yikaniwuy S 1996	Aboriginal peoples living in the Northern Territory	To develop ways that Aboriginal people could provide feedback to acute health services	<ul style="list-style-type: none"> • Aboriginal health workers involved from the beginning with joint ownership of the project • Aboriginal Health workers employed in communities interviewed people in their preferred language and then translated the information into English <p>A non-Aboriginal person acted as a scribe</p>	Most effective method was for an Aboriginal health worker to organise and undertake interviews with a person in their preferred language. Open ended questions resulted in more useful information than closed ended questions. It was important for interviewers to behave in culturally appropriate ways.
Jameson Anna, Sligo Frank & Comrie Margie 1999	Pacific Islander women	Pacific Islander women have higher rates of cervical cancer than European women and little known about their understanding of cervical cancer or their use of services	<ul style="list-style-type: none"> • Methodology was discussed with Pacific Islander women • Snowball sampling • Semi-structured face-to-face interviews 	Discussion of methodology with women from the target group enabled an appropriate methodology with would enable collection of useful information to be chosen.

Authors	Target group(s)	Reason for undertaking the work	Methods	Findings about methods
Jackson Debra, Teale Gloria, Bye Rosalind, McCallum John & Stein Irene 1999	Older Aboriginal people discharged from hospital	To explore the impact on reduced length of stay	<ul style="list-style-type: none"> • Aboriginal researchers employed • Aboriginal people including health workers were asked to participate • Interviews were held by phone or face-to-face • Transcripts of interviews were sent to those interviewed for checking 	Methodology ensured that a range of perspectives on the health needs of homeless people were included.
Success Works Pty Ltd 1999	People experiencing homelessness. Specific groups included young people, women, men, older people, Koori people, people from non-English-speaking background	To develop a framework for service provision	<ul style="list-style-type: none"> • Advisory committee • Literature review • Analysis of health and demographic data • Consultation with service users, service providers • Review of good practice models • Participant observation at services Consultation methods included: <ul style="list-style-type: none"> • questionnaires • phone calls • focus groups • interviews 	Methodology ensured that a range of perspectives on the health needs of homeless people were included.
Zarcadoolas Christina, Ahern David K, Blanco Mercedes S, & Christner Anne Marshall 1999	People living on low incomes, with low literacy and/or from ethnic minority groups	To coach people to assist improving communication with doctors	<ul style="list-style-type: none"> • Tool kit, interactive phone system and ESL curriculum were developed in consultation with consumers and field tested • Focus groups • Observation of ESL classes • Monitoring calls to phone line 	
Langer Ana et al 1997	Consumers living in a poor rural area in Mexico. Most were Indigenous and spoke languages other than Spanish	To find out about women's experiences	<ul style="list-style-type: none"> • Questionnaires • Clinical record review • Interviews with consumers and staff • Researcher observation of clinical consultations 	Method enabled the development of strategies to improve care.
Washington Valora 1985	Pre-school children and their parents, from ethnic minority groups living in poverty in America	To develop an early education program to reduce transgenerational poverty	<ul style="list-style-type: none"> • Community control • Parent participation 	Community control and parent participation were critical to the success of the program over 30 years.

Table 1: Summary of the methods used to work with specific groups of consumers previously marginalised from participation in service development (cont.)

Authors	Target group(s)	Reason for undertaking the work	Methods	Findings about methods
Minicucci Catherine 1997	People from African American, Hispanic and Asian backgrounds living on low incomes in a Sacramento neighbourhood.	To establish and evaluate a neighbourhood based, community governed, multidisciplinary service.	<ul style="list-style-type: none"> Establishment of community governance structures Development of self help and support mechanisms Consultation Staff development Reorganisation of health and welfare services. 	<p>A range of issues had to be addressed in establishing this model. These included:</p> <ul style="list-style-type: none"> cynicism of consumers overcoming staff barriers developing new accountability structures developing new ways of allocating scarce resources.
Lisnov Lisa, Harding Carol, Gibb Safer, Arthur L & Kavanagh Jack 1998	Students from ethnic minority groups and/or low income families	To evaluate different types of drug education programs	<ul style="list-style-type: none"> Survey was developed and piloted with students Students were asked to rate or grade the questions on the same scale used to grade their school work 	
Gething Lindsay, Fethney Judith & Blazely Angela 1998	Older people The old identified as particularly marginalised	To use a range of quality of life measures to assess function, ability and confidence in undertaking daily tasks after discharge from hospital	<ul style="list-style-type: none"> Consumers interviewed by health professionals A range of quality of life measures were utilised 	
Davis Cindy, Girgis Afaf, Williams Phillipa and Beeney Linda 1998	Rural and remote women travelling to the city for treatment for breast cancer	To explore women's experiences and examine why women living in rural and remote areas are more likely to have mastectomy than breast conserving therapy	<ul style="list-style-type: none"> Women sent a letter explaining the study and inviting their participation from a member of the team treating them A short telephone interview 	
Davis Barbara A, & Duffy Elaine 1999	People utilising emergency departments in a rural and an urban setting	To evaluate satisfaction with nursing care	<ul style="list-style-type: none"> Anonymous questionnaires distributed while people were in the emergency department 	

Authors	Target group(s)	Reason for undertaking the work	Methods	Findings about methods
Stewart Fiona J, & Rosenthal Doreen A 1997	Rural and urban adolescents living in areas where many people were living on low incomes	Explore issues relating to sexual health and attitudes to services	<ul style="list-style-type: none"> • Focus groups conducted to inform the development of questionnaires • Questionnaire piloted amongst young women • Parents and young women were asked to fill in consent forms • Self-completed questionnaire 	
Oawar Manohar S & McClinton John 1999	People living in poverty in rural Victoria	To find out about experiences of poverty, views on services and suggestions for reducing poverty	<ul style="list-style-type: none"> • Used ABS data to choose a region with large numbers of people living in poverty • Participants identified through local workers, advertisements in newspapers and leafletting houses. • Interview questions developed and reviewed with community consultation • Interviews 	

Chapter 8: Linking with communities

This chapter will focus on discussions around developing the kinds of organisations that utilise consumer information for improving services and the ways organisations or individual researchers have linked with consumers or communities.

8.1 SETTING THE AGENDA AND DOING GROUNDWORK

A number of issues to be considered by an organisation before engaging with consumers from marginalised groups were identified in the literature. This type of discussion can be useful for pointing to the kinds of organisational principles and structures that may need to be developed. The discussion can be grouped around:

1. Organisational commitment to utilising consumer information to improve services.
2. Developing strategies for working collaboratively and sensitively with communities.
3. Understanding how consumers want to work with the service.
4. Developing ways of linking with communities.
5. Developing strategies for accountability to consumers and for demonstrating how consumer input has been utilised to improve services.

8.2 ORGANISATIONAL COMMITMENT

The kinds of issues organisations may need to address if they are serious about promoting involvement of consumers in service development, whether that be through seeking and utilising consumer feedback or through developing working collaborations with consumers, can include:

- management commitment to seeking feedback and integrating it into organisational change;
- consequent strategic planning, resource allocation and cultural change to support this commitment;
- consideration of how consumer information will be utilised and at what levels organisations want to involve consumers;
- organisational commitment to hearing the views of consumers from diverse backgrounds and from marginalised groups;
- developing a range of feedback and participation processes to ensure a diverse range of voices are heard;
- commitment to collaborating with consumers/patients and involving them as problem solvers;
- development of relationships of trust over a period of time;
- understanding that both consumers and services will benefit from collaboration; and
- support for consumers and staff to develop skills and ways of working together.

(Adapted from South Australian Community Health Research Unit 1996, Draper 1998, Hamilton 1996).

Without addressing these issues, consumer participation is likely to remain an *ad hoc* activity which does not influence the organisation as a whole, but only those parts of the organisation where there are individuals committed to consumer involvement in their ward/unit/clinic.

8.3 DEVELOPING STRATEGIES FOR WORKING WITH COMMUNITIES

Organisations may also have to think carefully about how they work with or undertake research with consumers from marginalised groups. This may be particularly important if the organisation has failed to take into account the needs of these groups previously, as consumers may be reticent or suspicious about why the organisation is doing the work (Lillie-Blanton and Hoffman 1995). Several authors pointed to the importance of developing research in collaboration with community members to facilitate the development of mutually beneficial partnerships. Creating these partnerships requires establishing common goals and understandings of the policy and program implications of the research; identifying how the research can be useful to the community and developing agreements around this; involving the community in decisions about methodology; and building the capacity of the community through the transfer of skills and knowledge (Lillie-Blanton and Hoffman 1995, Callan and McElwain 1980).

More specifically, some of the practical things which may need to be taken into account are:

- What are the issues that are important to the group or community?
- What are appropriate time lines to suit the needs and lifestyles of the relevant community?
- What are some of the political and cultural issues and differences within communities?
- What other work has been done in this area. What have other agencies done? Is there any way this work can be built upon or collaborations between projects developed to reduce duplication?
- What are the links the organisation already has with the community?
- Are there relevant skills and knowledge within the organisation or will those skills need to be developed?
- Are there workers from the relevant communities employed to work on the project?
- How can feedback be provided to communities?

(Adapted from Callan and McElwain 1980).

Thinking through the organisational commitment and structures for utilising feedback and the capacity of the organisation to develop relationships with communities will influence the strategies the organisation can utilise to engage with consumers. For example, if there is little organisational commitment to engaging with consumers to create organisational change and few resources allocated to working with communities in ways that are sensitive to those communities, then it may not be an appropriate time for the organisation to try to do this work.

8.4 HOW HAVE CONSUMERS/COMMUNITIES IDENTIFIED THEY WOULD LIKE TO GIVE FEEDBACK OR PARTICIPATE?

Seeking information from consumers about how they would like to give feedback or participate is a useful way of initiating work as it involves consumers from the beginning. It also allows service providers to gain an understanding of the issues that will impact on participation of people from different groups and ultimately result in better information collection. For example, discussions with Pacific Islander women enabled Jameson *et al* (1994) to develop the most appropriate method for finding out about women's use of cervical screening services and their knowledge of cervical cancer.

Framework agreements being established in Aboriginal health establish clear formalised arrangements for collaboration between Aboriginal community controlled organisations, policy makers and service providers. Similar agreements are being developed at local levels between mainstream health services and local Aboriginal community controlled organisations. These agreements recognise the principle that community control and community participation are critical in initiatives aimed at improving Aboriginal health. In reflecting on work in this area, several authors highlighted that without appropriate levels of community involvement, strategies generally fail (Salisbury 1998, Gray *et al* 1998).

Older people participating in the development of *A guide to participation by older Victorians* (Department of Human Services Victoria 1999) identified that they would like to participate in all levels of health system development including policy development, needs identification, service priority setting, service reviews and evaluation, and development of new services. They discussed the advantages and disadvantages of different methods for participation at these levels. They identified five conditions which could impact on their participation and which needed to be considered. These included the time required for participation, their availability given the busy lives many people lead, the relevance of the issue to their lives, the method being utilised for seeking their input; and that they are empowered to participate. Some of their preferences are reproduced below.

We prefer:

- to be involved in discussion at an individual level or in small groups;
- to have the opportunity to influence the quality of the service being provided;
- to ensure that policies and regional plans reflect consumer opinions;
- to be intimately involved in our care plans;
- to be represented on working groups, user panels, committees or some other forum to consider the wider issues;
- to be offered assistance to access and influence services; and
- to be asked our opinions if we have a very severe disability.

Those of us from culturally and linguistically diverse backgrounds may need advocates, support, multilingual information and a commitment to inclusion.

Reproduced from *A guide to participation by older Victorians: developed for people who work with and for older people*, Department of Human Services, Victoria 1999, p20.

8.5 MAKING LINKS WITH CONSUMERS/RECRUITING CONSUMERS/SAMPLING

Making links with consumers was a critical issue for services and researchers seeking feedback and participation from previously excluded consumer groups. A range of ways of linking with consumers was discussed in the literature.

Several authors noted that while some groups were thought of as 'difficult to reach', they had not had difficulty in identifying groups, although contacting them was not always easy (Bhatti-Sinclair 1999). Some groups were more than happy to participate because they had never been asked for their opinions before (1999), while others felt alienated or ignored and were less keen to participate (Minicucci 1997).

Random sampling methodologies employed by those doing quantitative work often excluded consumers who were not from dominant cultural groups (Cockburn *et al* 1999). Small *et al* (1999b) noted that because traditional randomisation was very expensive when targeting specific groups, and there was often not appropriate data sets to allow estimation of sample size and proper randomisation, many people doing quantitative work employed some form of non-randomised sampling. One problem they identified with non-random sampling was that it could create biases that were hard to identify (1999b) and consequently generalisations across a group could not be made (Rice and Naksook 1998).

A range of ways of linking with consumers from previously excluded groups is discussed in the following section.

Snowball sampling

In working with people from culturally and linguistically diverse groups, snowball sampling often occurs via the social networks of community leaders, bilingual health workers, bilingual interviewers (Small *et al* 1999b) and bilingual researchers (Rice and Naksook 1998). One advantage of this approach when seeking feedback about sensitive issues is that consumers are introduced to the researcher or interviewer through a person known to them and this may reduce people's anxiety about participation (Jameson *et al* 1999). One disadvantage of this method is that participants may consequently come from a small sub-group within a community and may therefore have similar experiences and views to each other (1999).

Geographic based sampling

A second form of non-random sampling is to sample from a geographic region known to have a high number of residents from the target group, for example people living in poverty (Oawar and McClinton 1999). This method has also been used in studies which aim to find out about a range of services provided within a region, for example, older people's use of and satisfaction with medical, allied health and general practice services (Dent *et al* 1999).

Asking consumers to participate while they are utilising a service

In some cases, consumers were approached about participating in a feedback process (to be conducted later) while they were visiting a service. For example, in one study bilingual workers talked with women from non-English-speaking backgrounds about the study while they were in hospital after having a baby. Women who were interested in participating were asked to sign translated consent forms and were interviewed in their homes, in their preferred language, six to nine months after giving birth (Small *et al* 1997).

In other studies, consumers were asked to give feedback while they were at the service. This may be particularly useful when consumers may only visit the service once, for example an emergency department (Davis and Duffy 1999) or if consumers have difficulty getting to a venue for a focus group or interview and are already attending the service, for example older women with physical disabilities (Quine and Cameron 1995). This can also be a useful strategy if confidentiality is an issue. For example, women living on low incomes attending a hospital-based domestic violence survivors group were asked to fill in surveys while they were at the group so that their attendance at the group would remain confidential (Norton and Schauer 1997).

In one study which compared response rates between surveys that were posted to consumers with Parkinson's disease and surveys which were handed out in a neurology clinic, the latter method was found to achieve a higher response rate (Jenkinson *et al* 1997).

Health service client lists or contact with clinicians working with the target group

Sometimes consumers were contacted through health service client lists (Huabg *et al* 1999). A disadvantage of using this as the only method of contacting consumers is that those consumers who may need the service but be unable to access it will not be included in the survey (Centre for Development and Innovation in Health 1994).

An alternative to contacting people from client lists is to contact clinicians known to be working with consumers from a specific group. For example, in one project which aimed to find out about the needs of carers of people with HIV disease, many of whom were difficult to reach because of isolation and issues of confidentiality, the project team approached clinicians working in infectious diseases clinics and asked them to provide information about the project to these carers. In addition, a liaison person from the care team was nominated to work with those carers who wanted to participate (Yates *et al* 1997).

Identification of people with common family surnames from the phone book

One way of identifying consumers was to randomly select names from the phone book. For example, in a study to find out about the use of screening services by Vietnamese women, Vietnamese names were selected from lists of the most common Vietnamese names obtained from the electronic phone book (Cheek *et al* 1999).

Making links through a group-specific service coordinator or worker

A number of studies made contact with consumers through health care providers who coordinated or worked with a large number of consumers from specific groups—for example, ethnic health coordinators in hospitals (Madhok *et al* 1992), community based health workers (Centre for Development and Innovation in Health 1994, Troller 1997) or clinicians working with large numbers of people from the target group, for example people with AIDS (Curtis *et al* 1999, Yates *et al* 1997) and rural women receiving treatment for breast cancer (Davis *et al* 1998). In one report, hospital based clinicians working with people with HIV/AIDS were asked to identify a member of their staff team to be the ongoing liaison person between the researchers and carers of people with HIV so that carers would be supported throughout the process and if they did not want to be identified their anonymity could be assured. In this study, carers who wanted to participate in focus groups were met at the venue by a member of the steering group and were welcomed, offered tea or coffee and assured that professional support would be available if the interview became too stressful (Yates *et al* 1997).

Linking with consumers through existing support and self-help groups

Older people developing a participation manual identified that linking up with existing support groups was an effective way of working with them (Department of Human Services Victoria 1999) and in some work existing groups became a focus group (Centre for Development and Innovation in Health 1994). This was also an effective strategy for linking with Chinese-born people with cancer (Huabg *et al* 1999). In the HIV/AIDS area, the consumer group People Living with HIV and AIDS (PLWHA) has acted as an auspicing group for projects and has participated in sending surveys to members of the group (Woodruff 1993).

This latter process resulted in a high response rate to the survey which the author attributed to the ownership of the issues among gay men. This may also have been due to the role PLWHA played as active partners in the work.

Outreach: Going to where members of specific groups meet

Outreach strategies are particularly useful when feedback is being sought from groups that do not utilise services. This method was used to recruit young homeless people from shelters, drop-in settings, the street and other places where they 'hang out' (Kipke *et al* 1997). By visiting these sites Kipke *et al* were able to estimate the numbers of people frequenting each site and develop a sampling strategy based on this estimation. Going to places where consumers meet was also used as a way of recruiting Thai women from community centres and other settings (Rice and Naksook 1998) and older people from senior citizens centres, shopping centres (Hickson *et al* 1996), community organisations and ethnic groups (Velasco 1999).

Asking schools to participate in projects and recruiting young people through their schools.

Young people were sometimes asked to participate as part of a school program, or were approached to participate through their schools. For example, the director of a school program for mothers living on low incomes was engaged to involve these mothers in an evaluation of a parenting manual. This evaluation was integrated into the school program (Lambert 1998). In another study, rural and urban dwelling young women were recruited through metropolitan and rural schools for a study on their sexual health issues and use of health services. Consent of the young women and their parents was obtained before participation (Stewart and Rosenthal 1997).

Seeking feedback as part of other activities

The South Australian Community Health Research Unit (1996) identified that seeking feedback from consumers should ideally be incorporated into other work of the service. A good example of this are the pizza parties run by Shoalhaven Youth Health Service (1996). The aim of these is to increase awareness among young people about drinking, assist young people to develop strategies to avoid binge drinking and seek feedback and input from young people to assist the development of directions and planning for the service.

Advertising the study

When seeking participants workers sometimes advertised in local media (Curtis *et al* 1999, Oawar and McClinton 1999, Hickson *et al* 1996), at community-based organisations (Hickson *et al* 1996), at universities and health clinics (Curtis *et al* 1999), and through dropping leaflets in people's mailboxes (Oawar and McClinton 1999). One group focusing on the needs and experiences of service use by people living on low incomes published questionnaires in the local newspapers (Stewart and Rosenthal 1997).

Public meetings

Public meetings and forums were held to seek input into service development. For example, North Yarra Community Health Centre in Melbourne holds community liaison meetings which are attended by between 100 and 150 people. These meetings are held in a public venue and are concurrently translated into eight languages. The service pays local communities to provide refreshments and time is made for socialising and informal discussions. Transport is provided to all who need it (Boston 1999).

Involving consumer groups, consumer organisations and community-based group specific agencies in the study

Involving groups and organisations with existing links to specific groups as partners in projects or as auspicing agencies (Woodruff 1993) can facilitate recognition of the project among the target group. Linking with these organisations can also assist mainstream service providers find out more about each community or group, and how best to talk with community members (Bhatti-Sinclair 1999).

Thus, there are many different strategies that can be utilised to link with or contact consumers from a range of different groups. The way organisations and researchers chose to link with consumers may reflect the type of work they are undertaking, or the level of participation they are aiming to achieve. For example, if organisations are attempting to develop partnerships, linking with consumers through existing consumer groups and organisations or going out to where consumers meet may be the most appropriate. However, if organisations are seeking feedback about a service from someone who has utilised that service, identifying those who have used the service through client lists may be the most effective means of identifying the relevant consumers.

8.6 DEVELOPING STRATEGIES FOR ACCOUNTABILITY TO CONSUMERS AND FOR DEMONSTRATING HOW CONSUMER INPUT HAS BEEN UTILISED TO IMPROVE SERVICES

In order to develop accountability to consumers and to funders it is important that services develop systems for documenting and evaluating the changes made as a result of consumer participation. In addition, changes that have been recommended and not made could also be highlighted for future action.

In several areas, such as in mental health and in disability services, standards which specify consumer participation have been developed. It is critical that service providers are familiar with these standards and that systems are in place to ensure services are meeting them. It is also important for funders to require that organisations monitor their achievements and meet these standards.

8.7 SUMMARY

Developing the kinds of organisations that respond to, and seek input from, a diverse range of consumer groups, in particular those who have previously been marginalised, requires that organisations:

- ask questions about their commitment to utilising information provided by consumers to inform service development;
- develop partnerships with consumers and communities to facilitate the conduct of mutually beneficial work; and
- develop a range of strategies to link with consumers and community groups.

Issues that need to be considered before engaging with consumers include:

- organisational commitment to utilising consumer information to improve services;
- development of strategies for working collaboratively and sensitively with communities;
- understanding how consumers want to work with services;
- developing ways of linking with communities; and
- developing strategies for accountability to consumers and for demonstrating how consumer input has been utilised to improve services.

Some of the ways organisations and researchers linked with consumers were:

- snowball sampling
- geographic based sampling
- asking consumers to participate while they are utilising a service
- utilising health service client lists or contacting clinicians working with the target group
- identification of people with common family surnames from the phonebook
- making links through a group-specific service coordinator or worker
- linking with consumers through existing support and self-help groups
- outreach: going to where members of specific groups meet
- asking schools to participate in projects
- seeking feedback as part of other activities
- advertising the study
- public meetings
- involving consumer groups, consumer organisations and community-based group-specific agencies in the study.

The most appropriate method utilised to link with consumers may depend on the purpose of the work.

In order to develop accountability to consumers and to funders it is important that services develop systems for documenting and evaluating the changes made as a result of consumer participation. In addition, changes that have been recommended and not made could also be highlighted for future action. It is critical that funders require organisations to monitor and document achievements in this area.

Chapter 9: Issues to consider in developing a research strategy

A range of strategies was employed by organisations and researchers to enhance either the information collected from consumers from marginalised groups in feedback exercises or the processes for involving consumers in more participatory ways. The first part of this chapter explores some of the broader issues that have been considered when developing research strategies, and the second part explores some questions about different methodological approaches.

9.1 EMPLOYMENT AND TRAINING OF COMMUNITY MEMBERS

Employment and training of people from target groups was a key strategy used in both quantitative and qualitative approaches to feedback and participation (Small *et al* 1999b, Cheek 1999, Meehan and Hanson 1999). Older people who become Medicine Information Persons were found to be successful partly because older people were more likely to listen to, talk with, and respect other older people (Velasco 1999). In some work, such as that done by the Mercy Hospital for Women in aiming to make their whole service more accessible and appropriate to consumers from diverse backgrounds, employment of bilingual staff and project workers is part of an ongoing organisational approach to change (Mercy Hospital 2000). The employment of consumers and consumer consultants to facilitate exchange of information between consumers and service providers, organisational change and education and training of providers is another example.

In some studies the researchers were from the target group. One advantage of this, as articulated by Rice (1998) was that very little translation was required throughout the research process. This meant that the 'subtlety and meaning' of what consumers said could be maintained and accurately represented. A possible disadvantage of this is the risk that researchers may generalise from their own experiences rather than represent the views of a range of people.

The importance of the role of bilingual workers in cultural work was highlighted by Small *et al* (1999b):

While many of the issues have elements in common with any research project employing interviewers, they assume greater significance in a cross-cultural study where language and culture can form very real barriers between the research participants and the researchers. In this situation, the study interviewer takes on a specialised 'bridging' role between the two groups. To perform this task well, interviewers need to be proficient in both English and their community language, to have a good understanding of both cultures ...and they need to be able to make the links between the two so that the interview process is meaningful to participants and the researchers are able to make sense of the data collected (1999b).

These authors documented what they saw as an appropriate training program for bilingual interviewers undertaking a survey of women from non-English-speaking backgrounds of their experiences of birthing services.

Components of the bicultural interviewers' training program

- Introduction to and rationale for the proposed study
- Background about the health issues at the heart of the research
- Time to read and then discuss relevant papers
- Skills development in recruiting and interviewing study participants, including participating in mock interviews
- Participation in discussion sessions focused on the relevance of cultural issues to the study research questions (childbirth, motherhood, mental health)
- Involvement in the development of the interview schedules and the framing of questions
- Detailed discussion of the interview schedules, including making explicit the rationale behind each question, the prompts and probes to be used when following up incomplete answers, and the appropriate recording of responses
- Discussion and agreement on protocols for handling a range of situations that might arise during interviews
- Participation in the piloting of interviews and the translated standardised instruments used in the study, followed by a review of issues and problems encountered
- Time made available to develop resource lists of relevant community information likely to be helpful when interviewing mothers of young babies who were likely to have information needs and questions to put to the interviewer
- Participation in briefing meetings for hospital staff at the three recruitment hospitals.

Reproduced with permission from Small Rhonda, Yelland Jane, Lumley Judith and Rice Pranee Liamputtong 1999, Cross-cultural research: trying to do it better no 1. Issues in study design, *Australian and New Zealand Journal of Public Health*, vol 23, no 4, pp385–389.

For working with Indigenous peoples the importance of community control and employment of Indigenous workers was emphasised (Tidemann *et al* 1996, Salisbury 1998), with some papers reporting that their strategy had failed because it had not involved Indigenous communities adequately (Gray *et al* 1998). Many examples of the innovative work undertaken by Aboriginal health workers in developing appropriate services are documented in the *Aboriginal and Islander Health Worker Journal*.

9.2 CONSULTING WITH CONSUMERS ABOUT THE BEST STRATEGIES

A number of authors identified that the success of their strategy was due to consulting with consumers about how they would like to give feedback and/or appropriate ways of seeking information. This was sometimes done through building relationships with consumer organisations, or through consultation with individual consumers. Building relationships with groups of consumers of non-English-speaking background and developing cultural understandings of communities was seen as a way to improve information collection from some groups of consumers from non-English-speaking background (Cooper and Jenkins 1998).

In some cases, different strategies were employed to meet the needs of different individuals. For example, Yates *et al* (1997) ensured carers participating in their study were able to choose between attending a focus group or being interviewed individually. They also gave carers a choice of venue and time and offered respite care (1997).

9.3 PAYMENT FOR CONSUMERS

The payment of consumers for their participation was noted in a number of studies. This was done as an acknowledgment of their expertise and the value of their input and to potentially increase response rates (O'Neal 1999). Payments included money (Guendelman and Witt 1991-2) and food vouchers (Kipke *et al* 1997). Bartram *et al* (1999) noted that as consumers are rarely paid to be involved it is not reasonable for service providers to expect them to behave like paid staff.

9.4 SURROGATE CONSUMERS

There is a discussion in the literature of whether it is appropriate to include people who speak on behalf of consumers ('surrogate consumers') in studies. The most common 'surrogate consumers' are carers and service provider staff. This most often happens when the consumer has an intellectual disability, has a mental health issue, has dementia and/or is a child or adolescent. Sometimes consumers are asked to consent to people speaking on their behalf (Fyffe and McCubbery 1996). Investigations in this area suggest that the use of surrogate consumers can cause bias because the way need is perceived varies greatly depending on who is making the assessment (Llewellyn, McConnell and Bye, cited in Cooper and Jenkins 1998). In addition, those who utilise services a lot, such as people with mental health issues and people with disabilities, have particular experiences of services not experienced by those (such as carers) who have more transient or cursory contact with services (Rose *et al* 1998) and will be in the best position to comment on services from a consumer perspective.

However, it may be the case that surrogate consumers are appropriate in some circumstances. In this instance it may be important to establish that consumers do, in fact, need people to speak for them and to ensure that the person who speaks on their behalf is approved by the consumer (personal communication).

9.5 TRANSLATIONS

Translation was an issue that created many difficulties for researchers and service providers seeking feedback from people who spoke languages other than English. Translation is discussed in detail in Small *et al* (1999), who identified that even when qualified interpreters were used to translate questionnaires there was a range of issues that impacted on the meaning and quality of the translations. For example, some of the terminology was not appropriate for interviewing women, and some of the translations did not give the same meaning as the English version (for example, in one questionnaire, self-harm had been translated as suicide). Some of the response options were too similar to each other and some of these options had different meanings in different cultural contexts. These authors identified a range of strategies to ensure that questionnaires were translated as accurately as possible. These are summarised in the following table.

Key translation issues

Forward and back translations should be undertaken by qualified/accredited translators (ideally more than one independent forward and back translation should be undertaken for comparison purposes—acknowledging the fact that no one translation can be perfect).

A review process should be established involving bilingual professional and lay participants to address questions of comprehensibility, appropriateness to the target group of the language and especially of any colloquial phrases used; and of the appropriateness of the introduction and instructions for completion.

Consultation with bilingual experts in any content areas relevant to the translation is advisable, where available (eg bicultural psychiatrists for mental health questionnaires).

Piloting of translations should always be undertaken, preferably with both monolingual and bilingual community members of the relevant language group—bilingual people being able to complete (and compare) the original English and the translation.

A process for exploring unresolved difficulties with translation should be instituted (eg piloting different ways of translating particularly problematic questions; adding in probes after such items to determine how participants have understood them).

Caution should be exercised in the interpretation of unusual findings. The first question that should always be asked is: could translation error be the reason for the result obtained?

Documentation of translation processes (and problems encountered) should appear in published reports of the research—only in this way can studies be evaluated appropriately.

Reproduced with permission from Small Rhonda, Yelland Jane, Lumley Judith, Rice Pranee Liamputtong, Cotronei Valerie and Warren Rosemary 1999, Cross-cultural research: trying to do it better no 2. Enhancing data quality, *Australian and New Zealand Journal of Public Health*, 23(4) pp390–395.

Many people noted that they did not have the resources for this type of translation strategy and utilised a range of other methods including:

1. Having a researcher from the target group work closely with an accredited translator to translate a questionnaire which was then piloted with consumers and health workers from the target group (Cheek 1999).
2. Employing one interviewer who spoke a number of languages so that all interviews were conducted in the preferred language of the consumers by the same person (Madhok *et al* 1992).
3. Employing interpreters and/or ethnic health workers to assist during interviews (Triado 1999).

It was also noted by those providing feedback on the draft of this document that bicultural experts could include consumers as well as service providers.

9.6 CONFIDENTIALITY AND ANONYMITY

Confidentiality and anonymity of feedback is a critical issue for many consumers. This may be particularly important when service users have little choice of service (rural consumers, specialist services), when they are repeat users of a service, or when the topic about which information is being collected is sensitive, for example mental health or infectious diseases (Yates *et al* 1997).

Some ways of overcoming this were to employ researchers who were independent of the service to undertake surveys, interviews or focus groups (Woodruff 1993). For example, in one study which was auspiced by a consumer group whose members were likely to use infectious disease services, people were randomly selected from the consumer groups mailing list and sent a survey which was coded by number. The code was held by the consumer group and all responses were returned directly to the researcher located in a university without access to the codes (Woodruff 1993).

Another way employed by a group wanting to work with carers of people with HIV to develop a video was to nominate a member of the consumer's care team to act as a liaison person between the carer and the researchers (Yates *et al* 1997).

9.7 BUILDING FEEDBACK INTO OTHER ACTIVITIES

The South Australian Community Health Research Unit (1996), in its review of feedback mechanisms used by women's and community health centres in South Australia, suggested that one strategy for collecting feedback was to incorporate it into other service activities. One example of this was a service which held pizza parties for young people. The aims of these parties were to both ask young people about the service and how it could be improved and to inform them about binge drinking (Shoalhaven Youth Health Service 1996). A second example is a strategy developed by the Mercy Hospital for women who developed an outreach strategy to provide women from non-English-speaking background with information and services related to cervical health, while at the same time asking women about other health issues and services they require (Linardi *et al* 1997).

9.8 INTERVIEWING CONSUMERS AND SERVICE PROVIDERS

Interviewing consumers and service providers about access and care for specific groups was undertaken in some studies to identify issues from both perspectives (Triado 1999, Guendelman and Witt 1991-2); identify issues about which service providers wanted feedback from consumers (Triado 1999) or to compare the perceptions of consumers and providers about an aspect of care (Curtis *et al* 1999, Hickson *et al* 1996). This was a useful strategy as it allowed those seeking the feedback to identify some of the key barriers to change, such as different perceptions and understandings about issues or the causes of issues.

9.9 MATCHING THE METHODOLOGY TO THE PURPOSE FOR UNDERTAKING THE WORK

There was much discussion in the literature about the pros and cons of utilising different types of methodologies to seek feedback from and involve consumers. The South Australian Community Health Research Unit (1996) argues that the methodology chosen for seeking feedback should reflect the reasons for seeking that feedback. They suggest, for example, that quantitative methodologies which do not facilitate consumers taking an active role in either planning their own care or in service development are limited in their usefulness if the service wants to promote active consumer participation and partnerships (1996).

Other authors suggest that choosing the type of methodology requires making choices between scientific rigor and practical relevance:

The first revolves around the choice between scientific rigor (at the expense of practical relevance) versus practical problem-solving relevance (at the cost of scientific validity). The second deals with the problem of who takes the initiative to bring forth the problem. It is either a researcher operating out of a disciplinary/theoretical framework or a person with a real-world problem stated in everyday language (Elden and Levin).

A third way of looking at the issue is that formulated by Draper and Hill (1995) who suggest that the important question is:

Does the method of gaining users' experiences and views lead to an accurate reflection of what they (consumers) think, and do structured questionnaires capture the meaning of people's experiences as well as less structured interview methods? (1995).

They argue that the methodology chosen determines the data collected and that quantitative methods reduce the complexity of people's experiences (Draper and Hill 1995). These issues can be even more critical when feedback is being sought from consumers whose cultural backgrounds may be quite different from those of the majority of service providers and researchers. The danger is that quantitative methodology may reduce the experience of all people to the same dimensions, those dimensions largely being the dimensions recognised as important by those developing questionnaires. Along these lines, Cooper and Jenkins (1998) suggest that poor questionnaire development can 'act as a form of censorship imposed on clients'.

Other authors suggest that it is useful to remember that 'all measures are value laden, sometimes poorly defined or conceptualised, and open to various interpretations' (Abbott-Chapman and Easthope 1998). They also suggest that while it may be easier to measure services in terms of quantifiable things such as efficiency and outcomes it is equally important to also understand those qualitative aspects of services (such as participation) which may otherwise be ignored and consequently downgraded (Abbott-Chapman and Easthope 1998, Cooper and Jenkins 1998).

Each of these perspectives makes a point about the importance of the link between the methodology chosen for involving consumers and the purpose of that involvement. The next step is to ask what sort of feedback strategy or participation process will most likely produce the type of information or knowledge required to create organisational change and improvements to service quality.

When authors reported on the work they had done to seek input from specific groups of consumers they often discussed why they had chosen a methodology, especially if it was a qualitative methodology. Those undertaking quantitative work were generally concerned with collecting information about consumer satisfaction, while those utilising qualitative methods were more likely to be interested in feedback more broadly or the development of an active consumer-provider problem-solving partnership.

The debates in the quantitative literature tend to focus around whether or not the feedback elicited by 'the tool' is scientifically valid and reliable and is capable of capturing the real (authentic) meanings/experiences/understandings of people from specific groups. While qualitative researchers share the concerns of quantitative researchers about the representativeness of participants they are less concerned with validity. This may be because in methods which include dialogue, information can be clarified and checked, or in the more participatory instances acted upon and evaluated, thus incorporating validity checks into the research process. As this is not an option for those doing purely quantitative work, validity and reliability checks have to be built into research tools such as questionnaires.

9.10 USEFULNESS OF DIFFERENT METHODOLOGICAL APPROACHES

A number of observations and arguments were made by authors about the relative usefulness of qualitative and quantitative methodological approaches. Some of these are highlighted in the following section.

When little is known about the area

Qualitative methods were seen to be useful for exploring issues about the experience, access, responses to, or understanding of services when little was known about the perspective of the target group (Jameson *et al* 1999), or if there were no existing validated tools for exploring satisfaction with a particular group (Huabg *et al* 1999).

Jameson *et al* (1999) argued that:

only when policy makers and service providers have sufficient insights into the thinking and reactions of the target groups can the information and the services be well matched to client needs.

Similarly, McLean *et al* (1995) in their work with partners of gay men with AIDS argued that when the purpose of the study was to develop some preliminary understandings of issues and generate hypotheses and concepts rather than valid and reliable conclusions, qualitative methods and non-random sampling were legitimate methods. Similarly, in seeking the input of older people into the development of an education program for people with communication difficulties, Hickson *et al* (1996) argued that surveying older people with questions requiring categorical answers was too limiting and the most valuable information could be obtained through enabling older people to 'state their difficulties and describe their needs in their own words'.

A number of authors noted that while quantitative methods of collecting information was less time- and resource-intensive, the wealth of information gathered through focus groups and interviews often produced information that was more useful to informing change or development of services or resources (Hickson *et al* 1996). Consequently, while these methods may be more time-consuming and expensive they may be more effective.

When quantitative data is ambiguous

Cockburn *et al* (1999) identified that quantitative data had produced ambiguous results about whether screening mammography was acceptable to women between the ages of 40 to 49. As a consequence they collected qualitative data to assist them to develop a better understanding of women's perceptions and needs. They argued that the information collected in this way was useful for informing policy development in the absence of clear-cut quantitative information.

When measures utilised to seek quantitative information are inappropriate

Several authors identified that the measures utilised in existing quantitative tools, or the measures necessary to check validity and reliability of answers, might not be appropriate for working with specific consumer groups. In a study to compare the usefulness of different quantitative methods for seeking feedback from people with intellectual disabilities, Cardone (1999) noted that it might not be the nature of the method (for example, whether people are asked to respond to scales with pictures representing the extremes, or to a choice of words) that determined whether consumers responded or gave reliable answers, but rather the way questions were asked and the number of options people were given as responses. In addition, she noted that while checking the validity of responses by asking the same question in a different way might be important to the researcher, participants got frustrated by having to answer the same question twice. She concluded that while reliability checks for quantitative questionnaires were important, qualitative research might be a more appropriate way of seeking feedback from this group (Cardone 1999). Similarly, Dagnan *et al* (1994), after asking consumers with learning disabilities open and closed ended questions, identified that open ended questions yielded valuable information for informing service development.

The usefulness of combinations of methods

A combination of qualitative and quantitative methods was commonly used. This included:

- the use of qualitative methods to inform the development of quantitative questionnaires (see above for a discussion of this); and
- the use of both types of methods to develop a more in-depth understanding of the complexities of issues. An example of this combination was some work done by MIND, a British organisation working with people with mental health issues. Through seeking both quantitative and qualitative information, MIND was able to explore the apparent contradictions expressed by people receiving acute psychiatric treatments (Rose *et al* 1998). For example, they found that while consumers had negative experiences of electroconvulsive therapy and would recommend against its use, some of those consumers also said that they had experienced some positive outcomes from the treatment. Through a combination of methods they were able to link experiences of treatment with the side effects incurred, whether consumers were forced to have treatment and the attitudes of psychiatrists (1998); and
- the use of qualitative and quantitative questions to allow the collection of valid and reliable data for service development and the collection of valuable in-depth information about the service (Dagnan *et al* 1994).

9.11 SUMMARY

Developing feedback and participation processes that enable specific consumer groups to participate includes thinking through a number of issues about how to make those processes most appropriate to consumers who have been marginalised.

Some of the issues discussed in the literature include:

- employment of community members;
- consulting with consumers about appropriate strategies;
- considering payment for consumers to recognise their expertise and participation;
- whether surrogate consumers should be employed;
- developing appropriate translations;
- confidentiality and anonymity;
- involving both consumers and staff; and
- building feedback into other activities.

A second set of issues exists around the most appropriate methodological approaches to seeking feedback and consumer participation. Some of the literature suggests that:

- the methodology chosen to seek feedback should reflect the reasons for seeking that feedback;
- the methodology should enable the collection of information that reflects what consumers think; and
- it is equally important to collect information that is complex and difficult to measure as well as information that is more easily quantified.

Building on this, it may also be important to ask what sort of feedback strategy or participation process will most likely produce the type of information or knowledge required to create organisational change and improvements to service quality.

A number of points were made about the relative usefulness of qualitative and quantitative methodologies. These include that:

- qualitative methodologies may be more useful when little is known about the area, when quantitative data is ambiguous or when measures utilised to seek quantitative information are inappropriate to specific consumer groups; and
- combinations of quantitative and qualitative methods may be useful, especially when qualitative methods are used to inform questionnaire development and the use of both types of methods assists in the development of more in-depth understanding of complex issues.

Chapter 10: How feedback methods have been used to include marginalised groups

Many health services and organisations had worked hard at seeking feedback or involving consumers from specific groups. Generally this was done through adapting existing methods for seeking consumer feedback and participation. Some of the most widely used methods are discussed in the following section.

10.1 SELF-REPORTING QUESTIONNAIRES, INCLUDING PATIENT SATISFACTION SURVEYS

1. Questionnaire development (this is relevant to all forms of questionnaire)

The types of questions asked, how they are asked and who asks them

In many of the papers, the reason for doing the study was that little was known about the needs of, or access to services of, groups of consumers. In some of this work, consultation with consumers was undertaken to inform the development of questionnaires so that useful information was collected (Oawar and McClinton 1999). This consultation was generally about the types of questions that should be asked and the ways the questions should be phrased. In one case, quotes from young people were included in the questionnaire to make it more friendly (Pritchard *et al* 1998). In another example, 10 parents who were very critical of a service for their intellectually disabled children were interviewed about the aspects of care they considered important. This information was used to develop a satisfaction survey which was then evaluated and revised by parents and professionals (Janssen and Kars 1994). In a survey aimed at examining the satisfaction with services of people with HIV/AIDS, a previously developed questionnaire was further developed by undertaking interviews with consumers and service providers to find out what people understood each question to mean (Woodruff 1993).

Involving consumers in questionnaire design also took place through community consultation (Oawar and McClinton 1999), focus groups (Steward and Rosenthal 1997), interviews (Dagnan *et al* 1994) and involvement of bilingual health workers (Small *et al* 1997).

Another approach was to pilot questionnaires with consumers (Triado 1999, Woodruff 1993) and service providers (Woodruff 1993) and amend them in response to feedback from the pilot. In one study, one of the questions asked of a group of former patients reviewing the draft questionnaire was whether they would have been willing to answer the questions (Taylor and Clarke 1993).

An additional issue identified by Cooper and Jenkins (1998) was that questions asking specifically about particular aspects of service provision often resulted in more useful information than questions which asked general questions about services. They also suggest that many consumers will express satisfaction about those who care for them directly (sometimes, even when they have not behaved appropriately), but can be more critical of system issues (1998). Rose *et al* (1998) also found that consumers of mental health services expressed 'neutral satisfaction' when asked about services generally; however, unlike Cooper and Jenkins they identified that consumers expressed different levels of satisfaction with different types of service providers. Secondly, some authors increased the relevance of the information sought from consumers by asking them questions about service quality combined with questions about how they thought services could be improved (Doyal and Visano 1980, Davis and Duffy 1999) or how consumers might participate in service planning and development (Doyal and Visano 1980, Faulkner 1996).

Who asks the questions in interviews may also impact on the quality of the information collected. Bhatti-Sinclair (1999) noted in her work interviewing people from black and ethnic minority groups about social work and medical services that having skilled interviewers from similar backgrounds to clients and undertaking interviews in people's own environments could improve the quality of the information collected. Similarly, Small *et al* (1999) utilised bilingual interviewers to assist in improving the quality and meaning of the information collected by them about maternity services.

Some authors identified that one of the advantages of self-reporting questionnaires was that it allowed people time to reflect and fill in the answers (Jenkins and Cooper 1998 and Department of Human Services Victoria 1999). However, consumers may also not place a very high priority on filling in and returning the questionnaires (Department of Human Services Victoria 1999).

Ascertaining validity and reliability of questions

There is a discussion in the literature about how to design quantitative questionnaires which elicit meaningful information from people with learning and intellectual disabilities. One strategy often utilised to check the validity of responses of consumers from these groups is to ask the same question in different ways. This can be by positive and negative orientation of the same question (Cooper and Jenkins 1998) or by providing different ways of answering the question. For example Dagan and Wood (1994) asked the same questions in three formats: a simple either/or question, a scale with pictures representing either end of the scale (such as a happy or sad face), or questions with three possible responses. In addition, open-ended questions were included. These authors concluded that people with learning disabilities gave valid and reliable responses to close ended questions, that more useful data was obtained when a range of options were provided as answers to questions and that valuable information was gained in response to open ended questions (Dagnan *et al* 1994).

2. Improving response rates

Cooper and Jenkins (1998) in their review of international literature suggest that response rates can be improved if direct care service providers give the questionnaire to consumers. However, this is also likely to produce positive response biases, as consumers are less likely to criticise their direct care provider.

Personally contacting consumers by telephone or by letter before sending out surveys may be a way to improve responses to posted questionnaires. This may occur because consumers may be more likely to respond if they feel they have been consulted about the research (O'Neal 1999, Rice and Naksook 1998). Informing consumers about how their response would be utilised in planning and improving services (O'Neal 1999) and that it would not have any influence on the treatment they receive (Davis *et al* 1998) may also improve response rates. O'Neal (1999) also noted that market research companies have utilised payment for participation as an effective strategy for improving response rates.

10.2 FOCUS GROUPS

Focus groups were a widely used and apparently successful method of gathering information from specific and often excluded groups of consumers.

Focus groups allow participants to interact with each other, which can help people build confidence to express their views (Cooper and Jenkins 1998). On the other hand, some researchers noted that only the most confident in some groups expressed their views, and some people always agreed with majority views (Huabg *et al* 1999). One way of overcoming this, used by a group seeking input of older people into the development of a communication education program, was to use a nominal group technique where people were asked to consider questions in silence, then present their answers, discuss the answers and then individually rank the issues (Hickson *et al* 1996).

Focus groups are a good way of collecting in-depth information, but the range of issues covered in any one group can be limited (Cooper and Jenkins 1998). They can enable identification of issues which may have been outside those expected or anticipated by service providers (Guendelman and Witt 1991–2).

Older people identified 'working groups' which included focus groups as a meaningful way of consulting them about a range of issues including service planning. They suggested that 'working groups' should occur at every stage in service planning and should be utilised in combination with other methods of involving older people (Department of Human Services Victoria 1999).

A disadvantage of focus groups is that they are time consuming and it is difficult (and probably inappropriate) to include people from a range of backgrounds in any single focus group (Cooper and Jenkins 1998). However, when focus groups are designed to seek feedback from a specific group of consumers who have some characteristics in common (such as cultural background and age) they appear to be an extremely valuable method.

Focus groups may not be an appropriate method for seeking information that is seen as sensitive by some groups of consumers (Jameson *et al* 1999).

Some specific focus group strategies

Some points about running focus groups for specific groups of consumers include:

- when running focus groups for people with communication difficulties facilitators should be employed who are experienced in working with this group of consumers and who ensure that all participants know what is being said and written (Hickson *et al* 1996);
- provide transport to the venue for those participants who require it as lack of transport is a barrier to participation of people with limited mobility, people on low incomes, people living in rural areas and people who have little or no access to means of transport;
- employ bilingual or multilingual workers to run and transcribe focus groups, or alternatively employ qualified interpreters;
- meet participants when they arrive at a venue and provide them with refreshments;
- provide feedback on the findings of the focus groups to participants to check information is correct (Huabg *et al* 1999);
- hold focus groups in community settings (Hickson *et al* 1996), workplaces and educational venues such as adult literacy centres (Zarcadoolas *et al* 1997); and
- ask members of existing self-help and support groups to participate in focus groups.

10.3 INTERVIEWS

Interviews were also a widely used way of seeking feedback from consumers from specific consumer groups. Interviews were either face-to-face or over the telephone. Interview schedules and questionnaires were often developed in collaboration with consumers from the specific group either through focus groups and or piloting (see section 9.10). Interviews were particularly useful methods when the information being sought was sensitive or confidential (Jameson *et al* 1999, Kipke *et al* 1997), when it was difficult for people to get to venues for focus groups, or when individuals were difficult to reach and might not want to participate in a focus group.

Personal face-to-face interviews allow more in-depth exploration of issues and can overcome issues of reading and writing. Holding them in people's homes, or another venue identified by the consumer, can assist consumers to feel more comfortable. Disadvantages include cost often producing smaller sample sizes, questions about representativeness of the sample, and lack of anonymity. (Cooper and Jenkins 1998). Older people identified that face-to-face interviews were their preferred way of responding to surveys.

Telephone interviews can produce a high response rate in a short period of time, can allow people to provide detailed feedback and are more anonymous than face-to-face interviews. However, people who do not have a telephone or who are unable to get to or use one will be excluded, as will those with hearing, speech and cognitive disabilities. Many telephone interviews are conducted during business hours and this can exclude those who work outside the home (Cooper and Jenkins 1998). Telephone interviews were often the method used to seek feedback from people living in rural areas (Davis *et al* 1998, Cooper and Jenkins 1998). Older consumers identified that:

strong opposition exists to telephone surveys as they are impersonal, often occur at inconvenient times and do not provide the time to think about issues (Department of Human Services Victoria 1999).

Useful tips for interviewing identified in the literature

- Ascertain from the consumer group what type of interview is most appropriate to their needs;
- undertake preliminary interviews or discussions with people to find out if they meet the criteria for interview before arranging longer in-depth interviews (Kipke *et al* 1997);
- hold interviews in locations specified by consumers (eg) or in consumers' homes (Rice and Naksook 1998, Triado 1999);
- ensure interviewers are highly skilled, appropriately trained and sensitive to the issues and needs of the specific group of consumers (Oawar and McClinton 1999, Small *et al* 1997);
- employ consumers or health workers from the target group to undertake interviews; and
- ensure participants can have access to appropriate support services if needed as a consequence of the interview, especially if the issues are about a sensitive or distressing topic.

10.4 FORUMS, SUMMITS AND MEETINGS

Forums, summits and meetings were a good way of creating dialogues between consumers and service providers. Older people thought meetings were a good method of discussing plans for services as long as long notice of meetings was given, meetings were small and close to people's homes, several meetings were held on each topic to ensure a range of people could participate, held during the day, relevant to people's needs, represented a broad cross section of opinion, and had an agenda and the likelihood of an outcome. Meetings can have disadvantages for those who cannot attend during the day, those without transport and people who do not speak English (unless interpreters are provided).

North Yarra Community Health Service developed community forums as a way of seeking feedback from and involving people from diverse backgrounds in service decision-making. At these quarterly forums information is concurrently translated into six or seven languages. Community groups are paid to cater for each event and there are opportunities for dialogue and networking after the meetings. This service also involves consumers from diverse groups in their management committee (Boston 1999).

10.5 OBSERVATION BY THE RESEARCHER

In some studies researchers sat in clinics and observed the ways that people from specific groups were treated. Examples include observation at an outreach service for homeless people (Success Works 1999) and in an abortion clinic which provided services mostly to poor, Indigenous women in America (Langer *et al* 1997). Combined with surveys of women and a review of medical records this later study enabled researchers to identify that inappropriate clinical practices were being undertaken.

In one study undertaken to research difficulties experienced by people with acquired brain injury when trying to use automated technology such as automatic teller machines, the workers gave participants three tasks which required using automated services. The researcher accompanied the participants and observed the difficulties they had in undertaking these tasks. Each participant was then asked: 'Did you have any problems with this task?' This methodology allowed the researchers to identify how people's perceptions of their ability to use the technology compared to their observations of consumer use of technology (O'Brien and Mahony 1999).

10.6 PROJECT ADVISORY GROUPS/REFERENCE/STEERING GROUPS

Consumer participation in reference groups for developing feedback strategies was sometimes employed (Small *et al* 1997, Radoslovich 1998, Faulkner 1996). Project advisory, reference and steering group meetings are a good way of facilitating input from people with diverse perspectives throughout the project or process of seeking feedback. They can also improve accountability to a range of stakeholder groups.

Although it is hard to test from the literature, it appeared that the more consumers and community members were involved in the reference group, the more participatory the service was and the more consumer input and feedback was valued in service development. For example, in a project aimed at developing a service for 'Positive Women' in South Australia, 'Positive Women' were on the reference group and participated in planning and developing a clinic, employing the project worker and ongoing direction of the project. They also established support groups and peer support, provided information and lobbied other organisations and funders (Radoslovich 1998). The reference group in a project to look at ways of increasing consumer participation in a service in Queensland consisted of equal numbers of consumer and service-provider representatives (Faulkner 1996).

10.7 OUTREACH

Going out to consumers in community settings (outreach) was identified as a successful strategy, particularly for involving those who were marginalised and/or who did not access services. For example, Gauntlett *et al* (1995) described an outreach strategy to reach people with mental health issues not accessing mainstream services. Many of these people were from ethnic minority groups and/or were homeless. Through this outreach strategy, marginalised consumers were able to participate in developing their own care plans. This strategy resulted in a reduction in hospitalisation and potential homelessness.

Another successful outreach strategy included one that aimed to enhance the use of services for people with Alzheimers disease from culturally and linguistically diverse groups. This program aimed to work with nine centres across a region in America and enabled the identification of common problems and appropriate

solutions that were then used to inform policy development and the development of resources relevant to specific ethnic groups. Different methods of outreach were utilised by each of the nine participating centres. Some of the key strategies employed include: development of links with ethno-specific local agencies; employment and/or collaboration with bicultural workers; establishment of satellite centres in rural communities or in areas with high populations of older people from specific ethnic backgrounds; and conducting clinics and consultations in local settings. The participation of older people from ethnic minority groups increased over a two year period.

A Californian study which utilised outreach strategies to identify why Latina women did not access prenatal services not only identified issues relevant to those women, but also proposed the development of 'inreach' strategies to address the cultural inappropriateness of mainstream services (Guendelman and Witt 1991–2).

In some work aiming to seek feedback from Aboriginal communities about hospitals in the Northern Territory, Tidemann *et al* (1996) emphasised that the most effective way of seeking this information was to engage Aboriginal health workers to approach, organise and undertake interviews with people in their preferred language in their own communities.

Thus, outreach is a particularly effective strategy for engaging those who do not have access to appropriate services.

10.8 COMMUNITY DEVELOPMENT AND ACTION RESEARCH PROCESSES

Principles of community development provide a good framework for developing services which are well located in the communities they serve and are responsive to their needs.

A community development approach seeks to promote change in a situation of inequality or injustice by looking to the community affected to identify problems and issues, and to develop collective strategies to redress inequity. In other words, such an approach works from the grass roots rather than seeking to impose change through systems that have power over the grass roots (no matter how benevolent or sympathetic they may be) (Otto 1990).

There are many reports and papers about community development approaches to health service planning and care provision (for example, see *Best Practice in Primary Health Care*, Centre for Development and Innovation in Health 1996). The breadth of this work is outside the scope of this report; however, some examples of community development approaches to service provision are discussed below.

The advantages of community development and action research processes include that they often involve the gradual changing of power relationships between consumers and service providers and that through collaboration consumers and providers can create new knowledge and new solutions. This type of process is critically important when specific groups of consumers have been excluded, when services are not appropriate to their needs and when they experience little power in relation to their health and health care. In the long term these strategies aim to build up an ongoing participatory approach to health service development.

An example of this approach, initiated by social workers, was a project which aimed to address issues of violence experienced by young women (Healy and Walsh 1997). This required the development of a process whereby young women could reflect on their experiences of violence and develop a critique of structural and social issues that enhanced their vulnerability to violence (issues included poverty, isolation and stereotypes of young mothers). This critique meant that the young women in collaboration with the social workers could then be active in developing appropriate service, policy and education strategies to address these issues. As the young women developed their skills and knowledge the workers took a more peripheral role. This required ongoing reflection on changing roles and role development, training and skill development, support, outside mediation, seeking funding and valuing of the knowledge, skills and credibility that each participant brought to the project. This project resulted in young women lobbying for input into policy development, undertaking research, running an education campaign, having input into service development, providing peer support and outreach, staffing a telephone information line and becoming advocates.

A second example is a report which documents trialling a participatory action research approach to establishing partnerships with Indigenous people in the planning and development of a mental health service (Salisbury 1998). The authors state that:

To achieve this type of 'partnership' the health service had to be willing to enter the partnership and to give the authority to the Aboriginal and Torres Strait Islander Health Outcome Council to seek and trial solutions on Aboriginal and Torres Strait Islander mental health matters. This represented a structural change and a sharing of power.

The process evolved as an Aboriginal-owned action research process including cycles of planning, action, analysis and reflection. Discussions about the work were conducted among communities and occurred in many settings. Decisions were made by consensus and were always able to be reviewed. This enabled the development of a range of solutions to problems, indicated by the increase in utilisation of the service by Aboriginal people.

Much has been written about community development and action research as participatory processes for developing appropriate and accessible health services. These approaches require a commitment to ongoing collaboration with consumers in service development and to changing the way power operates so that consumers can become active agents in producing change.

10.9 SUMMARY

As discussed in previous chapters, engaging with consumers who have previously been marginalised from participation in feedback and service development activities requires developing and adapting strategies so that participation is achieved. Some of the means of informing the adaptation of existing methods are:

- consulting with and involving consumers, relevant workers and community organisations about the types of questions that should be asked, how those questions should be asked and what types of methods would be the most appropriate for seeking information;
- thinking about the types of questions that need to be asked to gather information that is useful for informing service development;
- thinking about what types of approaches and strategies are appropriate to different consumer groups, and how can these strategies be adapted to improve participation and ensure people are able to be involved; and
- thinking about how consumers can be involved in long-term change at all levels.

There are many ways in which feedback from, and involvement of, consumers from marginalised groups has been sought. Adaptations of the following methods were commonly utilised:

- questionnaires
- focus groups
- interviews
- forums, summits and meetings
- observation by researchers
- project advisory, steering or reference groups
- outreach
- community development and action research processes.

Chapter 11: Linking feedback to quality improvement

Since patient treatment and care is the major outcome of any health service, no definitive statements can be made about the quality of the service unless patients have been asked about that service (Taylor and Clarke 1993).

This position is one that makes common sense. It places the focus back on the reason services exist and highlights that consumers have a real role in determining what constitutes a quality health service. Taylor and Clarke (1993) argue that the types of information collected from consumers must be the type of information that can be used to monitor service delivery and service improvement. They suggest that appropriate types of information and feedback, appropriately, collected can result in enhanced outcomes (in terms of quality and consumer focus) through:

1. Providing the type of information that enables people to make changes to the way things are done.
2. Motivating people to achieve better outcomes.
3. Creating better relationships between service users and service providers resulting in 'power-sharing'.
4. Measuring quality and consumer focus outcomes, as 'in any system, one tends to get what one measures'.

Going one step further than this, Draper (1999) suggests that in order to create effective change, service providers need to move beyond seeking feedback to engaging with consumers through inquiring *with* consumers, planning *with* consumers, acting *with* consumers and evaluating *with* consumers.

This literature review identified that there was an overwhelming amount of work done to seek feedback and involvement of consumers who had previously been marginalised from participation in health service development. Given that this work is being done, the critical question becomes: Has this information created the kinds of mainstream services that are accessible and appropriate to all members of communities, and if not, why not?

It would seem that many of the very important lessons learnt from this type of work at local levels are not incorporated into strategies for system-wide change. This means that there will be some services and some parts of services that are responsive and do listen to their communities, but that this will be localised and not impact on broader service delivery or on the strategies utilised by mainstream services to routinely collect information from consumers.

The difficulty in changing service systems and cultures was a topic reflected on in a number of reports. For example, in a report evaluating a project set up to both establish a clinic for 'Positive Women' and to raise awareness of the issues of this group among other service providers and policy makers, it was found that:

Positive and affected women felt that there is still a lot more work needed on issues around discrimination while most other stakeholders reported a belief that significant change had occurred. This divergence in opinion may reflect a comment by some stakeholders that, while changes in attitudes had occurred, this change had not yet been translated into practice. It also reflects a difference in perspective between those who experience discrimination and those who observe its effects.

This report highlights that increasing understanding and knowledge is not always translated into changes in practice (Radoslovich 1998). At times it seems that the act of receiving the feedback may be seen as sufficient action.

Changing service systems requires a commitment to sharing information, changing power relationships and developing feedback and participation methods that create the kinds of information and activities that make organisational change imperative. The capacity of organisations to respond effectively to different types of feedback also needs to be strengthened.

Some reports which set out to look at how systems could be changed identified a range of strategies and organisational tools that needed to be considered if feedback from consumers from diverse groups was to be incorporated into mainstream systems development. These reports, such as those by Bhatti-Sinclair (1999), Wadsworth and Epstein (1996), Draper (1998), Lopez and Fazzalori (1995) and Silburn (1994), suggest some of the elements that may need to be considered if organisations are to really listen to the voices of consumers, particularly those most marginalised. These include:

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- development of a commitment to consumer participation in service development and leadership within the organisation to support this commitment;
 - commitment to developing organisations that systematically provide accessible and appropriate services to all community members;
 - establishment of a quality improvement framework which incorporates a cycle of planning, acting, observing and reflecting;
 - development of systematic ways to involve and seek feedback from consumers from diverse consumer groups so that these processes become routine and 'do-able';
 - establishment of multiple ways of seeking and hearing consumer feedback and for involving consumers. These methods may be very different in different organisational settings and contexts and should be developed so that they ensure feedback is sought from diverse groups of consumers;
 - supporting changes to service culture so that the organisation becomes one that does listen and respond to consumers from many different groups;
 - supporting staff-consumer communication, including the development of dialogues to enable consumers and staff to understand each other's perspectives and to work together to solve problems. This can include establishing consumer-only, staff-only and consumer-staff sites for dialogue, discussion and decision-making;
 - incorporation of consumer participation into all levels of the organisation;
 - payment of consumers and consumer advocates for their expertise and participation;
 - supports for consumers working as systems advocates;
 - supports for staff who may experience anxiety and stress around this type of interaction and around cultural shifts within the organisation; and
 - monitoring of participation activities. This may include annual audits, reporting, meeting identified targets and documentation of evidence that services are complying with relevant policy and legislative guidelines.

Overall, from reviewing the literature, it appears that a lot of work has been done in seeking feedback from a great diversity of consumers and consumer groups. This work has been critically important for developing appropriate and accessible services to consumers from diverse backgrounds. However, this work is often undertaken as an individual project, or by a part of a bigger health service. A consequence of this is that many of the valuable lessons learned either about making services more accessible and appropriate to particular groups of consumers, or about involving consumers from previously excluded groups, are not translated across organisations and systems. **Therefore the critical question is not about how to seek feedback from specific consumer groups per se, but how to ensure that this feedback is utilised to create the kinds of health care systems that provide services that are appropriate and sensitive to the diversity of the communities in which they are established to provide care.**

SUMMARY

The primary goal of all health services is to provide effective care to all members of the community in which they exist. Consequently consumers have an important role in determining, and commenting on, the quality of those services.

The literature review identified that an enormous amount of work had been done to seek feedback from and involvement of consumers who had previously been marginalised from participation in health service development. While these initiatives have been critical in the establishment of appropriate and accessible localised services, it would seem that many of the lessons learnt from this type of work are not incorporated into mainstream strategies for service improvement. Thus, a critical question is not necessarily about how to seek feedback from specific consumer groups *per se*, but how to ensure that this feedback is utilised to create the kinds of health care systems that provide appropriate and accessible care to the diversity of consumers in communities. Linked to this is the importance of ensuring organisations monitor their consumer participation activities, ensure they meet identified targets, and document evidence that they are complying with relevant policy and legislative guidelines.

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