Improving health services through consumer participation

A RESOURCE GUIDE FOR ORGANISATIONS
IMPROVING HEALTH SERVICES THROUGH CONSUMER PARTICIPATION

A RESOURCE GUIDE FOR ORGANISATIONS

Produced by the Department of Public Health, Flinders University, and the South Australian Community Health Research Unit

A Consumer Focus Collaboration publication
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.

This resource guide was prepared as a tripartite project involving the Consumer Focus Collaboration, the Consumers’ Health Forum, and the Health Advisory Committee of the National Health and Medical Research Council. The Collaboration acknowledges the valuable input to the document of many stakeholders including search conference and focus group participants.

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).
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 consumers 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
What the resource guide is and how to use it

THE BACKGROUND

This guide is for people working in health care organisations who want to increase consumer participation in the planning, management and evaluation of those organisations. It includes an introduction explaining the potential benefits of consumer participation, an assessment and planning section, a tools catalogue and additional sections on dealing with common challenges, answering frequently asked questions and listing additional resources and where to find them. The resource guide has been designed to be used by people working at all levels in health care organisations and especially those with management responsibilities, be they project officers, nurse managers or chief executives.

The guide was prepared by a consultancy team of experienced health workers and researchers. The project received guidance from a steering committee with strong grounding in consumer participation policy. An initial draft was distributed to a range of health organisations, consumer groups and other interested individuals and agencies and many of these attended a search conference to provide feedback. A revised document was then sent out to a number of partnership sites where organisations and their consumers considered the usefulness of the prototype to consumer participation in their particular settings. This feedback was used by the team to produce a final document in consultation with the steering committee and the DHAC project manager.

SUMMARY GUIDELINES

When using the resource guide, remember that there are some basic features of effective consumer participation that have been shown to produce good results:

- Effective consumer participation means that your organisation must be prepared to change as a consequence.
- The capacity of your organisation to increase consumer participation may need developing. This can include training and structural change.
- Consumer participation is only really effective across an organisation if it is supported by management at all levels.
- Information sharing is critical to effective consumer participation. Consumers need clear, accessible information at all levels of contact, from patient to boardroom, and health care organisations need to listen actively, using many tools to do so.
- Enhanced consumer participation may mean that conflicts emerge and need to be managed. This is okay and is likely to lead to better quality service and improved health outcomes in the medium- to long-term.
- Building better consumer participation is all about relationships—people skills are a valuable asset.
- Partnerships with consumers are based on dialogue and trust. Trust is built by openness and consistency.
- Multiple strategies are essential. They reflect the complex variation among your consumers and the issues your organisation deals with.
- Engage consumers early in the process—even the process of deciding how you will engage consumers better.
- Be careful not to promise what you can’t deliver. Be clear about your organisation’s capacity to inform consumer involvement and to respond to consumer concerns.
HOW TO USE THE GUIDE

This guide can be read straight through if you have the time and want to gain a comprehensive overview before taking action. If you prefer, you may skip the first section and move straight to the sections on Assessment and Planning (section 2) and the Tools Catalogue (section 3). In sections 1 and 2 you will find a number of tools to help you with assessment and planning. They are marked with this symbol:

STEPS IN DEVELOPING YOUR OWN SET OF CONSUMER PARTICIPATION TOOLS

The strategies set out in the Tools Catalogue (section 3) should be seen in the context of an important cyclical process of assessing, planning, implementing and evaluation. These can be seen as a series of key steps. Strategy selection and implementation should always be done as part of a progression through these steps. In section 2 there is a five-step planning checklist to help you to:

1. Clarify what you are trying to achieve and why.
2. Identify the consumer groups you want to involve and assess current and historical involvement.
3. Assess the capacity of your organisation for greater consumer participation and estimate what might be needed to enhance it.
4. Identify the organisational focus for consumer participation. At what level and what section of your organisation are you aiming? What strength of consumer participation do you hope to achieve?
5. Check time and money parameters. How much time do you have and what resources are available?

Answering these questions means you have the information you need to select the consumer participation strategies from the Tools Catalogue (section 3) to best suit your circumstances.

The resource guide also includes three other sections, which support the planning steps and strategy implementation:

• Introduction to consumer participation (section 1)
• Frequently asked questions (section 6)
• Links to resources (section 7)

You can use the frequently asked questions (FAQ) section (6) if you have a specific question or issue you need help with. For each FAQ there are brief answers and pointers about where to find more detailed information. The links section (7) provides information on where to find other resources and networks on participation. By referring to the links section you can find out where to get greater detail on specific strategies and how to get in touch with others who may be able to share their experiences with you and offer advice and support.
CONTENTS

SECTION 1
Introduction
- Reasons for participation Page 1
- Levels of participation Page 3
- Key terms Page 4

SECTION 2
Assessment and planning
- How to use this section Page 5
- Eight key principles for participation Page 6
- Assessing organisational culture and capacity for change Page 7
- Key organisational assessment questions Page 7
- Setting a direction for consumer participation Page 8
  Tool—planning checklist Page 10
  Strategy Selection Page 12
  Tool—resources and results checklist Page 13
  Supporting consumer participants through the process Page 14
  Some examples of strategy selection Page 15

SECTION 3
The tools catalogue
- How to use this section Page 17
- Strategy selector table Page 18

SECTION 4
Managing the challenges
- How to use this section Page 101
- Maximising the ability of consumers to participate Page 101
- Resources Page 101
  Tool—putting supports for consumer participation in place Page 103
  Tool—overcoming barriers to meetings checklist Page 107
  Tool—power, culture and attitude barriers checklist Page 109
SECTION 1: INTRODUCTION

Interested in consumer participation? You are in step with health care workers all over the country who are keen to see consumers actively involved in the planning, policy development and evaluation of health care services.

Not quite sure how to go about it? This resource guide provides over 50 tools or techniques to assist you to do it in ways that are right for your organisation and consumers you work with.

Some heartening stories

- The Emergency Department (ED) of the Lyell McEwin Hospital in Adelaide’s northern suburbs initiated a project that aimed to give ‘a voice to the community’. Using many consumer participation tools, people of all ages and walks of life had a say about what the ED could do better. The results have been outstanding (Stuart and Parker 1999). The ED staff have shifted in their approach to care, improved the waiting room facilities, established a consumer advocacy group, undergone cultural awareness training and worked more closely with outside community groups. One of the key outcomes has been that complaints have dropped by 80 per cent, compared with the previous 12-month period. Visit them on their web site for more details of the project (http://www.saftcon.com.au/edcon).

- Involvement of large numbers of women in the Brisbane Women’s Cancer Screening Program was a huge success that resulted in an increase in funding and an expansion of the project. Pivotal to the project were a commitment to consumer participation and the use of bilingual educators who were community members (CDIH 1996, p 112).

- Port Augusta Hospital and Regional Health Service in country South Australia has developed a model for consultation with remote communities, Aboriginal communities and children’s service providers. This has become an effective way of gaining a picture of the needs in the region and the best ways to meet them. Without community participation it would not have worked so well. It has resulted in new culturally appropriate initiatives and the creation of a Division of Child Health in the Port Augusta Hospital (Bradley and Coulthard 1996).

- Midwives at the Nepean Hospital in Penrith, NSW (part of the Wentworth Area Health Service) have been acknowledged for developing best practice intervention in postnatal depression. The key to their success has been in adopting a customer focus. Staff have listened to and acted upon the experiences of new mothers. The result has been a better understanding of how to assist new mothers to deal with the management of postnatal depression (Price 1996).

In policy and planning terms, there has been a steady transition of users of health care services from passive ‘patients’ to becoming partners with care providers in restoring and maintaining their health.

Reasons for participation

There are four reasons why health care organisations should have a strong consumer focus and be involved in enhancing and responding to consumer participation.

- Participation is an ethical and democratic right.
- Participation improves service quality and safety and helps gain health service accreditation.
- Participation improves health outcomes.
- Participation makes services more responsive to the needs of consumers.
Each has in common the idea that involving consumers in health care decision-making, planning, evaluation and review will lead to changes that will improve health. The main arguments for each are now outlined and linked to recommended readings.

### Ethical and democratic right
Participation in decisions that affect citizens is intrinsically worthwhile and is viewed by many as a democratic right. Participation as a democratic right in a liberal democracy is reinforced by government legislation (for example, consumer’s rights, requirements for public participation in environmental health planning, local government legislation etc).

The National Health Strategy (Macklin 1992) outlined a democratic approach to participation, centring on three factors:
- public participation at a range of levels;
- focus on consumers and communities, rather than providers and funder interests; and
- an open system (information, public accountability, transparent and conspicuous decision-making).

### Improved quality of services and health service accreditation
Customer focus can be a very effective driver for improving the quality of services and is central to a process of continuous improvement. Factors common to a quality improvement approach are the commitment to consumers, workforce development, visionary leadership and a systemic understanding of organisations and organisational change.

Demonstrating an organisational commitment to consumer or community participation is a requirement of Australian health service accreditation programs.

- **Evaluation and Quality Improvement Program (EQuIP)**—Consumer participation is a requirement in standards relating to consumer participation in care delivery, planning and quality improvement (ACHS 1996).
- **Australian Health and Community Services Standards (AHCSS)**—Consumer participation is a requirement in standards on management and leadership, quality improvement, service planning and evaluation, consumer rights, and consumer and community participation (AHCSS 1998).
- **Community Health Standards and Accreditation Program (CHASP)**—Community participation is an integral part of the standards against which an organisation’s performance and functioning are assessed. There is also a separate standard that relates to participation (QMS 1999).
- **Practice Incentives Program (PIP)**—General practice is required to obtain patient feedback for entry under the Australian General Practice Accreditation Limited (AGPAL) (CHF 1999).

### Improved health outcomes
There is increasing evidence that the process of participation itself improves health outcomes for participants. Renhard (1998) notes that not only is participation likely to lead to more appropriate and better quality treatment with better outcomes, but that the very act of participating in health care decisions has been shown to improve outcomes, irrespective of the treatment chosen.

### Service responsiveness
Participation can have the very important outcome of increasing the responsiveness of the service to the community/consumers.
Levels of participation

Different modes of participation are sometimes represented as a continuum. Brager and Specht (1973) have developed a continuum that ranges from no participation through minimal levels where consumers receive information, but little say, through to joint planning and ultimately to consumer or community control.

The ladder of participation

<table>
<thead>
<tr>
<th>Degree</th>
<th>Participants’ action</th>
<th>Illustrative mode</th>
</tr>
</thead>
<tbody>
<tr>
<td>High</td>
<td>Have control</td>
<td>Organisation asks community to identify the problem and to make all the key decisions on goals and means. Willing to help community at each step to accomplish goals.</td>
</tr>
<tr>
<td>High</td>
<td>Have delegated</td>
<td>Organisation identifies and presents a problem to the community, defines the limits and asks community to make a series of decisions, which can be embodied in a plan it can accept.</td>
</tr>
<tr>
<td>High</td>
<td>Plan jointly</td>
<td>Organisation presents tentative plan subject to change and open to change from those affected. Expects to change plan at least slightly and perhaps more subsequently.</td>
</tr>
<tr>
<td>High</td>
<td>Advise</td>
<td>Organisation presents a plan and invites questions. Prepared to modify plan only if absolutely necessary.</td>
</tr>
<tr>
<td>Low</td>
<td>Are consulted</td>
<td>Organisation tries to promote a plan. Seeks to develop support to facilitate acceptance or give sufficient sanction to plan so administrative compliance can be expected.</td>
</tr>
<tr>
<td>Low</td>
<td>Receive information</td>
<td>Organisation makes a plan and announces it. Community is convened for informational purposes. Compliance is expected.</td>
</tr>
<tr>
<td>Low</td>
<td>None</td>
<td>Community not involved.</td>
</tr>
</tbody>
</table>

Clarifying the ideas and assumptions that are guiding your practice of participation is an essential undertaking because participation can operate at different levels and be motivated by contradictory intentions. Agendas are varied. Consumers can demand participation for a range of reasons that may or may not be similar to what an organisation has in mind.
### KEY TERMS

**Consumer**

‘Consumer’ refers to people who either directly or indirectly make use of health services. Consumers are as diverse as the full range of people living in contemporary Australian society. Any definition of ‘consumer’ must incorporate women and men, people from diverse cultural experiences, class positions and social circumstances, sexual orientations, health and illness conditions. Draper (1997) identifies a range of consumer voices:

- **Individual**
  - Individuals who are receiving or have received health care services
  - Carers and/or family members who support individuals who receive health care
  - Groups of consumers (who may share a common experience or chronic illness)
  - Consumer organisations including advocacy, self-help and consumer network organisations
  - Potential consumers such as those with unmet needs or from population groups with particular needs or access issues
  - Members of the community including future users and the wider community that benefits from health care services

- **Community**
  - Taxpayers and citizens who ultimately pay for services

As you move down the list, the focus spreads outward from the individual and comes to effectively embrace the whole community. For this reason consumer participation at these broader levels is also referred to as community participation. All these voices have a potential contribution to make through involvement in your health care organisation. Consumers are diverse, but be aware that participation approaches can sometimes be limited to ways that appeal to certain ethnic and socio-economic groups only.

**Consumer representative**

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

**Community**

Community is a problematic term as it is used in many different ways. It can be defined as relating to a geographic area, a community of interest and a cultural/racial group. Bjaras et al define community as ‘a group of people living in the same geographical area sharing defined basic values and organisations and/or a group of people sharing the same basic interests’ (1991 p200). A characteristic of the term ‘community’ is interactions between people.

**Consumer feedback**

The Consumer Focus Collaboration (1999) defines consumer feedback as: ‘processes whereby consumers can supply comments and make assessments on all aspects of their care. This can include: consumers providing direct feedback to individual care givers; involvement in surveys at the local, state/territory or national level; participation in focus groups at the local hospital or unit level; use of complaints processes—both internal and external to the hospital; and involvement in health care planning committees’. Feedback provided by consumers can cover a broad range of areas.
SECTION 2: ASSESSMENT AND PLANNING

How to use this section

In this section we cover two areas:

**Assessment** of the level and potential of consumer participation in your health care organisation helps you set the direction you wish your organisation to go in. A number of tools are provided for assessing the degree of consumer participation in your organisation. They include a checklist covering all the key organisational characteristics, such as culture, policy, structure and processes.

**Planning** for participation is no different from planning for other health care activities. A planning process is outlined that allows you to focus on where you want your organisation to head. At the end of this process you will be in a much clearer position to decide what consumer participation strategies are currently right for your organisation.

To help you begin

The assessment and direction-setting stages set the foundation for your consumer participation plans. You and your team will need to ensure you have the information you need, a process for sharing it and time to explore your options and reach a set of decisions. It is often helpful to have a planning process in mind that you all understand and are comfortable with.

Use a planning model

As with any other activity, planning for participation can help with the implementation of appropriate strategies for your circumstances and the consumers with whom you work. This resource guide is based on the simple but effective planning model that is set out below.
Involve consumers in the process as early as possible
Involving consumers early in the process helps services to develop appropriate policies, ensure that rights issues are addressed from the beginning and that strategies used are feasible. You also must be careful that planning and negotiating about different purposes and methods, investments and expectations happens at the beginning of the process, not when things go off the rails.

EIGHT KEY PRINCIPLES FOR CONSUMER PARTICIPATION

**PRINCIPLE 1:** Participation means partnership, means accepting uncertainty.

**PRINCIPLE 2:** Deciding for effective consumer participation means deciding for organisational change.

**PRINCIPLE 3:** Align your consumer involvement plans with organisational capacity. Involve staff in building that capacity.

**PRINCIPLE 4:** Consumer participation must be supported from the top.

**PRINCIPLE 5:** Consumer participation must be supported from the top down, but it is built from the bottom up.

**PRINCIPLE 6:** It’s all about relationships, so use and build people skills.

**PRINCIPLE 7:** Consumer participation needs partnerships, partnerships need dialogue, dialogue needs trust. So build trust.

**PRINCIPLE 8:** Multiple strategies work better.

(Adapted from Lapis and Verity 2000, Community participation: power, organisation and change.)
ASSESSING ORGANISATIONAL CULTURE AND CAPACITY FOR CHANGE

The key questions from the Audit Tool of the National Resource Centre for Consumer Participation in Health (below) highlight the crucial issues for ensuring your hospital has the capacity to enhance consumer participation.

- The full Audit Tool, which enables you to audit your hospital’s consumer participation focus, is included in appendix A and summarised on the following pages.
- A generic Organisational Capacity Assessment Tool which can be used in all health service settings is included as appendix B.
- See also appendix C for more detail on assessment of workforce capacity and organisational setting.

KEY ORGANISATIONAL ASSESSMENT QUESTIONS

From the Draft Community and Consumer Participation Audit Tool for Hospitals developed by the National Resource Centre for Consumer Participation in Health. See appendix A for full version.

1.1 Has community and/or consumer participation been incorporated into the hospital’s vision, values and other philosophical statements?

1.2 Has the hospital clearly identified who its community and consumers are?

1.3 Has the hospital clearly identified the purpose and mechanisms for involving community members and consumers at different levels?

1.4 How has the hospital involved community and consumers in a needs assessment? Are the strategic directions responsive to those identified needs?

1.5 Who are the leaders, champions, or staff delegated with the responsibility for consumer participation? Are they easily identifiable within the organisation?

1.6 Does the hospital have key consumer policies in place, such as:
   - consumer rights and responsibilities
   - complaints
   - consumer access to information
   - consumer participation?

1.7 How do consumers find out about:
   - their rights and responsibilities
   - how to make a complaint or commendation
   - accessing information
   - information about how they are able to participate in the hospital?
   How are these processes monitored and evaluated?

1.8 What staff education programs are in place to support the implementation and maintenance of these consumer policies?

1.9 What organisational resources have been allocated to support the incorporation of community and consumer views into strategic and service planning and review?

1.10 What training and supports have been provided or accessed to enable consumers to participate effectively?

1.11 Does the hospital have a consumer participation evaluation plan in place?

1.12 Is consumer participation incorporated into job and position specifications?
<table>
<thead>
<tr>
<th>Section 2</th>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.13</td>
<td>Are consumer participation efforts and achievements incorporated into performance management and staff recognition processes?</td>
</tr>
<tr>
<td>1.14</td>
<td>Is community and/or consumer input a part of key organisational decision-making processes?</td>
</tr>
<tr>
<td>1.15</td>
<td>How does the hospital recognise the contribution of consumers to the organisation?</td>
</tr>
<tr>
<td>2.1</td>
<td>Has the department/ward identified who its consumers are?</td>
</tr>
<tr>
<td>2.2</td>
<td>Has the department/ward identified the purpose and mechanisms for involving consumers?</td>
</tr>
<tr>
<td>2.3</td>
<td>Does the department/ward have a consumer feedback and participation plan in place?</td>
</tr>
<tr>
<td>2.4</td>
<td>How are organisational consumer policies reinforced as part of department/ward management processes?</td>
</tr>
<tr>
<td>2.5</td>
<td>What resources are allocated at a departmental/ward level for enabling consumer feedback and participation?</td>
</tr>
<tr>
<td>2.6</td>
<td>What types of strategies are used to involve consumers in decision-making about care processes and service improvement at the department/ward level?</td>
</tr>
<tr>
<td>2.7</td>
<td>Does the performance review of staff incorporate attitudes towards, and achievements in, consumer participation in care processes and service improvement?</td>
</tr>
<tr>
<td>2.8</td>
<td>Are staff supported to attend staff development programs about consumer participation and consumer policy issues?</td>
</tr>
<tr>
<td>2.9</td>
<td>What links and feedback mechanisms are in place with other departments/wards and services/groups outside the hospital to ensure consumer satisfaction with continuity of care?</td>
</tr>
<tr>
<td>2.10</td>
<td>How have consumers participated in the development and evaluation of care pathways and consumer education/information resources?</td>
</tr>
<tr>
<td>2.11</td>
<td>Does the department/ward have effective working relationships with key support/community groups associated with the consumer profile of its department/ward? Are staff aware of the key consumer issues for these groups, and do they have processes in place to jointly address these issues?</td>
</tr>
<tr>
<td>2.12</td>
<td>How does the department/ward report on its consumer participation activities and outcomes? Has accountability for taking action on consumer feedback been built into this reporting process?</td>
</tr>
</tbody>
</table>

**SETTING A DIRECTION FOR CONSUMER PARTICIPATION**

**Where do you want to be?**

Effective participation requires clarity about objectives before strategies are chosen. This means discussing what the organisation wants to achieve from participation, what motivates participants, what the various agendas are (by different people for different reasons) and how it should be organised. There is a direct link between reasons why participation is encouraged and supported, and the approach and strategies that are employed (Draper 1997). This link is often overlooked by an uncritical reliance on technique.

It is not unusual for an agency to employ a technique, such as setting up an advisory committee or conducting a patient satisfaction survey, without first asking why they are doing it—other than a belief that this is how you add consumer participation. This approach is likely to fail. For example, if you want participation because you are...
committed to quality outcomes for new migrants in your catchment area, then your strategies will need to be designed accordingly. You will make sure that you understand the cultural factors that are important, such as having translated material and interpreters as needed. An advertisement in English in the newspapers inviting members of this cultural group to a focus meeting is unlikely to be effective.

Building capacity and/or involving consumers?
As this section shows, the level of consumer participation that is possible in any organisational setting depends partly on the capacity of that organisation to seek, support and respond to consumer involvement. It follows from this that advocates for consumer participation need to consider whether their efforts will be most effective in focusing on building the capacity of their organisation or on engaging with consumers. It is not an either/or choice but a question of getting the balance of effort and investment right. You need to consider what is the correct balance for your situation at present and how this might change over time and as your strategies roll out.

The following checklist incorporates the planning questions raised in this section. It can be completed together with a small group of consumers and key workers or by yourself. As you work through the checklist, write out your group’s answers to the five groups of questions. These provide you with a clear set of agreed strategic directions, which you can take forward into the next stages of selecting your strategies and preparing for implementation.
**PLANNING CHECKLIST**

Write down answers to the questions below. This will assist you as you think about strategies. Answering the questions in the right hand column will help you identify which of the options in the middle column fits your situation best. By doing this you will address all the crucial issues for a scoping document for your consumer participation initiative.

<table>
<thead>
<tr>
<th>Crucial issues</th>
<th>Options</th>
<th>Key questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1: Clarifying your aims and objectives</td>
<td>To: Assess acceptability of services to consumers, Improve service delivery, Evaluate some aspect of service, Design a service, Get broad service feedback, Assess needs, Increase democracy, Improve health outcomes</td>
<td>• What is the nature and origin of the issue or problem? • What matters need to be discussed and decided? • What are the possible options and likely contentious issues? • Are there any genuinely non-negotiable issues? • How does this relate to your organisation's role and goals? • What are the aims of participation? • What information is to be sought from the process? • Why is the consultation taking place at this time? • Have the objectives and limits of participation been clearly conveyed to participants?</td>
</tr>
<tr>
<td>2: Identifying the consumer groups you want to involve and assessing prior involvement</td>
<td>Are you seeking involvement from a particular group (ethnic, issue based, locality, defined by disease condition, health status, lifestyle factors, patient status, care)? Are you seeking involvement from consumers in general? What involvement by which groups has there been to date?</td>
<td>• Who is the consumer? • Who should be involved (eg particular consumer organisations)? • Do specific population groups need to be targeted (eg people with disabilities)? • Is there a need for wider involvement in addition to the 'immediate' consumer, for example, the families, support networks or carers of consumers? • How should the participants be selected (eg articles in newspapers; selected from short-list; merit process)? • Is there a need for internal agency consultation? • What are the differing needs and issues of participants? • How do these affect the consultation process? • Is there a consumer advocate? Have they been involved? Should they be involved? • Have consumers been involved already or in the past? If so, what were the outcomes?</td>
</tr>
<tr>
<td>3: Assessing the capacity of your organisation</td>
<td>The team/unit is willing to explore participation, The team is not sure about participation, The team is negative about participation, Management is willing to support participation, Management is not sure about participation, Management is negative about participation</td>
<td>• What might you need to do to build commitment? • What might you need to do to build management support?</td>
</tr>
<tr>
<td>Crucial issues</td>
<td>Options</td>
<td>Key questions</td>
</tr>
<tr>
<td>--------------------------------</td>
<td>------------------------------</td>
<td>-------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>4: Identifying the</td>
<td>Locality</td>
<td>• What links between consumer participation activity in sections of your</td>
</tr>
<tr>
<td>organisational focus</td>
<td>Region</td>
<td>organisation are needed?</td>
</tr>
<tr>
<td></td>
<td>Hospital ward</td>
<td>• Depending on your aims, you will need to be clear about how far down the</td>
</tr>
<tr>
<td></td>
<td>Division</td>
<td>participation road your destination lies.</td>
</tr>
<tr>
<td></td>
<td>Department</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Do not know</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Information seeking</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Consultation</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Partnership</td>
<td></td>
</tr>
<tr>
<td>5: Checking time and</td>
<td>Need to act now</td>
<td>• What are the implications of your time scale and resource level for the</td>
</tr>
<tr>
<td>money parameters</td>
<td>Short-term process</td>
<td>strategies you use?</td>
</tr>
<tr>
<td></td>
<td>Medium-term process</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Long-term process</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Resources are needed for</td>
<td></td>
</tr>
<tr>
<td></td>
<td>childcare, travel costs,</td>
<td></td>
</tr>
<tr>
<td></td>
<td>sitting fees, clear</td>
<td></td>
</tr>
<tr>
<td></td>
<td>information, room hire,</td>
<td></td>
</tr>
<tr>
<td></td>
<td>interpreting and translating</td>
<td></td>
</tr>
<tr>
<td></td>
<td>material, food and drinks</td>
<td></td>
</tr>
</tbody>
</table>
STRATEGY SELECTION

The key resources you need to select an appropriate set of strategies are:

- your awareness, knowledge, skills and experience
- your answers to the checklist questions
- the table of strategies at the beginning of section 3
- the detailed descriptions of strategies in section 3

Read through the list of strategies in the table at the beginning of section 3. As you do so, note any that you think are appropriate to your aims and objectives. For more details on the strategies, look up the ones you are interested in by going to the page number in section 3 that is found in the right-hand column of the table. Then:

- think about how your strategies might work together to increase their effectiveness; and
- check each strategy for the degree of participation you want. Remember that a strategy that involves a stronger form of participation means your organisation has to have the capacity to respond to that degree of involvement. To help you with this, the strategies are listed in order of increasing strength of consumer participation.

Remember also that you should not be limited to just one strategy. For example, if you elect a strong form of participation, such as partnership, it will need to be supported by information-seeking and consultation strategies.

Your aim at this stage is not to finalise your consumer participation strategies. Rather you are collecting a first-pass selection of possible strategies that might suit your needs. Be prepared to include some that might be marginal. As you follow the process set out below you will examine your draft collection of strategies and you may decide to cull some of them from your plans. Others you may wish to modify or augment to enhance their effectiveness. You may also find you need to revisit your initial selection and reconsider some you excluded. You can do this at any point.

Check that your proposed strategies are appropriate to the issues and consumers

It is important that you consider how your strategies are to be delivered. If you can, consult with consumers about the strategies you are considering. However, if you find that you have selected strategies that rely on resources or conditions that you cannot provide (eg trained mediator or extensive use of interpreters or bilingual workers) you may need to reconsider these strategies and perhaps refer back to the table to look at strategies to increase these aspects of organisational capacity.

Remember that your strategy selection should not only be driven by the degree of participation you want. For example, you also need to consider the consumer group you want to link with, the issues that concern them and your organisation, any existing links or networks you may be able to use and a host of other issues.

Check available resources and expected results

The next step in reviewing your selected criteria is to check that you can reasonably expect them to deliver the outcomes you want with the resources you have available.

The checklist that follows covers the eternal issues of time, money and outcomes. If you find your strategies do not satisfy these criteria, then you need to revisit, revise and possibly reject those strategies in favour of ones that do.
RESOURCES AND RESULTS CHECKLIST

Formulating the timetable:
- Is the consultation/participation process ‘one-off’ or ongoing?
- Is the timetable realistic?
- What are the time constraints?

Estimating resources:
- What resources and personnel are required?
- Is there a need for staff training or external personnel?
- Have funds been allocated to meet the cost of the process and the expenses of participants?

Outcomes:
- Are the outcomes clear?
- How will the outcomes be documented?
- How will the information gained be used?
- How will decisions reached be implemented?
SUPPORTING CONSUMER PARTICIPANTS THROUGH THE PROCESS

It is vital for the sustainability of any consumer participation process to ensure that consumers will be supported. The outcomes your organisation gains from consumer participation depend in part on the investment it is prepared to make in encouraging and supporting consumers to go on providing the inputs you are seeking. One way to enhance that investment is to identify the constraints to participation for consumers and ensure that your planning and implementation of strategies includes means to overcome them.

Draft an evaluation plan

Evaluation of your consumer participation activities is essential if you and your organisation are to learn from the experience and continually improve your practice. It is also vital in helping you argue the value of consumer participation to the organisation and to the community. Before you finalise your consumer participation strategies it is essential that you develop your evaluation plan. Evaluation can be built into your activity from the outset. Evaluation is dealt with in more detail in section 5, however at this stage you should know:

• What are your expected outcomes? Are they documented?
• How will your actual outcomes be measured?
• How will you incorporate the experience and learnings of both consumers and providers in your evaluation?
• What your evaluation budget is and where it is coming from.

Write up your consumer participation activities action plan

Include:

• a description of the issue or problem you are addressing
• your objectives
• the participants you wish to involve
• the strategies you have chosen and key issues for implementation
• timelines
• budget and personnel required and
• an evaluation plan.

Because you have already addressed these issues and documented most of them, this should be a straightforward process of pulling all the elements together.

Congratulations. You are ready to choose the strategies that will suit your current circumstances. Before you do so, you may find it helpful to look at some examples of selections of strategies made to address particular situations, depending on need and circumstances:
### SOME EXAMPLES OF STRATEGY SELECTION

<table>
<thead>
<tr>
<th>Purpose</th>
<th>Strategies selected</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identify priorities or needs for a community</td>
<td>Surveys, project groups, in-depth consumer interviews, submissions, complaints, focus groups, patient forums, nominal group technique</td>
<td>A mix of strategies is used to target the diversity of the community. Strategies need to enable both data collection and tools to discuss the results of research with consumers.</td>
</tr>
<tr>
<td>Provide information and seek dialogue about a new service</td>
<td>Promotion and campaigns, round tables, publications, public meetings, seminars</td>
<td>Broad-reaching dissemination approaches, supplemented with targeted dialogue.</td>
</tr>
<tr>
<td>Measure acceptability of service</td>
<td>Surveys, research, evaluation of service, in-depth interviews, focus groups, phone-ins, support groups</td>
<td>Mix of strategies which supplements written surveys and research with other approaches to target those for whom traditional surveys may not be appropriate. Again an emphasis on discussing the results of research with consumers is important to get informed comment and to understand the feedback when it is received.</td>
</tr>
<tr>
<td>Identify risks/problems in service</td>
<td>Complaints, hotlines/phone-ins, workshops, submissions, patient forums, focus groups, support groups, surveys</td>
<td>Supplement complaints data with other information from dialogue with service users, using a range of strategies to enable barriers and risks to be identified.</td>
</tr>
<tr>
<td>Engaging culturally diverse consumers</td>
<td>Support groups, telephone surveys, phone-ins, consumer advocates, promotions, information to consumers about services (in appropriate languages), charters (translated) consumer representatives, bilingual workers, culturally appropriate venues etc</td>
<td>Barriers to participation often reflect barriers to access, so overcoming one set of barriers may be needed to identify others.</td>
</tr>
<tr>
<td>Involving consumers in planning services</td>
<td>Submissions, consumer councils, consumer representatives, policy round tables, consultative committees, consumer participation policies, consumer input into organisation policy, partnerships in service planning</td>
<td>Consumer representation on committees is usefully supplemented and supported by other strategies to get broader input and ownership.</td>
</tr>
<tr>
<td>Starting from scratch</td>
<td>Consumer participation policies, consumer representatives, publications, information to consumers, charters, support groups, complaints, suggestion boxes (organisational capacity tool), assessment tool</td>
<td>Use of existing resources and structures both within and outside organisation can help to lay foundations for planning more participatory approaches. Whatever level of participation you aim for, you should try to get a mix of information provision and participatory approaches, and try to canvass views broadly through strategies such as surveys as well as facilitating detailed dialogue on some issues (eg focus groups, consumer representatives).</td>
</tr>
</tbody>
</table>
SECTION 3: THE TOOLS CATALOGUE

How to use this section

This section includes comprehensive descriptions of 43 strategies and techniques that can be used for consumer participation. Don’t try to read it through from start to finish. Use the strategy selector table below to work out what sorts of strategies you need for your particular situation and focus your time and energy just on the ones you need.

The strategies are listed and numbered in the table and in the detailed descriptions that follow in order of ascending degrees of strength (or power sharing) of consumer participation. In general, the higher the strategy number the more power consumers are taking, though of course there are overlaps and some of the rankings depend very much on context.

For each strategy there is information on its usefulness, its limitations and a description of the process and how to use it. Many have links to more detailed and specific information that can be found elsewhere in the resource guide and in other places. These are marked by symbols.

![Refers you to useful references](image)

![Refers you to other related sections of this guide](image)

As you go through the strategy selector table and the detailed descriptions you will begin to build up a suite of strategies that you can then discuss with your team and, of course, with consumers themselves.
<table>
<thead>
<tr>
<th>Strategy</th>
<th>Degree of participation</th>
<th>Key attributes</th>
<th>See page number</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Publications, media releases and displays</td>
<td>Supports consumer participation</td>
<td>Written with no requirement for dialogue, but can provide information on how consumers can participate.</td>
<td>23</td>
</tr>
<tr>
<td>2. Information to consumers about service and treatment options</td>
<td>Supports consumer participation</td>
<td>Written and oral information to consumers presented in an accessible and understandable way explaining treatment choices and likely outcomes, with pathways for asking and getting answers to questions.</td>
<td>25</td>
</tr>
<tr>
<td>3. Patient charters</td>
<td>Supports consumer participation</td>
<td>Written patient rights and customer guarantees that specify service conditions and provide pathways for complaint and possibly redress for consumers if these are not met.</td>
<td>26</td>
</tr>
<tr>
<td>4. Human resource development for consumer participation</td>
<td>Supports consumer participation</td>
<td>Job design, recruitment, orientation and training to support consumer participation.</td>
<td>27</td>
</tr>
<tr>
<td>5. Consumer-friendly administrative procedures</td>
<td>Supports consumer participation</td>
<td>Reviewing and reforming administrative communication with consumers to encourage consumer participation and partnerships for health.</td>
<td>29</td>
</tr>
<tr>
<td>6. Volunteers</td>
<td>Supports consumer participation</td>
<td>Unpaid workers who also often have close contact with consumers and the opportunity to get consumer feedback. However, training, supervision and support will be required as for paid staff.</td>
<td>30</td>
</tr>
<tr>
<td>7. Evaluation of services</td>
<td>Supports consumer participation/ information seeking</td>
<td>Essential component of consumer participation. Many methods. See section 5 for a detailed description.</td>
<td>31</td>
</tr>
<tr>
<td>8. Project groups</td>
<td>Can be information seeking or consultation</td>
<td>Instigated by organisations to advise on specific issues and/or to guide a project. Time limited. May be used to demonstrate the value of consumer participation to key players.</td>
<td>32</td>
</tr>
<tr>
<td>9. Research</td>
<td>Information seeking</td>
<td>Different models depending on values and approach. Outcomes research, qualitative research, action research and clinical epidemiology can overlap with consumer participation.</td>
<td>33</td>
</tr>
<tr>
<td>10. Surveys</td>
<td>Information seeking</td>
<td>Means of gathering information. Agenda set by organisations. Scope of information limited. Quantifiable, but you need to know what you want to ask.</td>
<td>34</td>
</tr>
<tr>
<td>Strategy</td>
<td>Degree of participation</td>
<td>Key attributes</td>
<td>See page number</td>
</tr>
<tr>
<td>----------</td>
<td>-------------------------</td>
<td>----------------</td>
<td>-----------------</td>
</tr>
<tr>
<td>11. In-depth consumer interviews</td>
<td>Information seeking</td>
<td>Extended, semi-structured (usually) face-to-face interviews. Provide rich information from selected consumers. Useful as a follow-up to surveys to explore particular issues and/or for specific population groups, but time consuming.</td>
<td>36</td>
</tr>
<tr>
<td>12. Focus groups</td>
<td>Information seeking</td>
<td>A semi-structured group interview with 6–8 people for 30 minutes to 2 hours. Can be invited on basis of who they are and what they can contribute to discussion. Interactions among participants can help explore issues rapidly and in-depth. Used for information collection focused on a specific issue (not for decision-making). Provides rich information, but may not be representative of all consumers.</td>
<td>40</td>
</tr>
<tr>
<td>13. Submissions</td>
<td>Information seeking</td>
<td>Oral and written presentation of views. Dialogue limited. Can attract consumers who are organised and in a position to put in a submission. But less articulate/literate, non-English-speaking background and/or socially disadvantaged consumers may be excluded.</td>
<td>44</td>
</tr>
<tr>
<td>14. Delphi technique</td>
<td>Information seeking</td>
<td>Formal process using a series of mailed surveys to selected individuals. Used for building consensus across consumers with conflicting views. May be useful for particular groups of stakeholders on specific contentious issues, but relies on good literacy skills.</td>
<td>45</td>
</tr>
<tr>
<td>15. Nominal group technique</td>
<td>Information seeking</td>
<td>Small group process for clarifying priorities. May be useful for consumer involvement in identifying priority issues, allocating scarce resources etc. However, does not allow for much in-depth exploration of the issues.</td>
<td>46</td>
</tr>
<tr>
<td>16. Suggestion boxes</td>
<td>Information seeking</td>
<td>Easy to implement, but may be limited in obtaining useful feedback. May attract negative and unhelpful comment. Only for use in conjunction with other strategies. Limited to those with time and literacy skills.</td>
<td>47</td>
</tr>
<tr>
<td>17. Hotlines and phone-ins</td>
<td>Information seeking</td>
<td>Information gathering. Relies on publicity and the phone being attended. Works best with skilled staff or volunteer to answer. Attracts respondents fairly indiscriminately.</td>
<td>49</td>
</tr>
<tr>
<td>18. Complaints handling</td>
<td>Information seeking/consultation</td>
<td>Response to consumer feedback and complaints. Valuable resource because restricted to consumers who have identified possible area for service improvement. Requires staff understanding of value of complaints.</td>
<td>50</td>
</tr>
<tr>
<td>Strategy</td>
<td>Degree of participation</td>
<td>Key attributes</td>
<td>See page number</td>
</tr>
<tr>
<td>----------------------------------------------</td>
<td>-------------------------</td>
<td>--------------------------------------------------------------------------------</td>
<td>-----------------</td>
</tr>
<tr>
<td>19. Responding to consumer initiatives</td>
<td>Information seeking/consultation</td>
<td>How your organisation/team responds to inquiries or requests initiated by consumers. Developing clear policies, processes and skills to be 'response-able'.</td>
<td>53</td>
</tr>
<tr>
<td>20. Workshops</td>
<td>Information seeking/consultation</td>
<td>Working meeting usually of 8–12 consumers, possibly with providers to share information and to develop a shared approach to a specified issue. Participants usually have been selected on the basis of particular skills, knowledge or experience. Requires informed participants.</td>
<td>54</td>
</tr>
<tr>
<td>21. Consumer advocates/consultants</td>
<td>Information seeking/consultation, partnership</td>
<td>Health care organisation employs person to consult with consumers and advocate on their behalf for service improvement.</td>
<td>55</td>
</tr>
<tr>
<td>22. Promotions and campaigns</td>
<td>Support consumer participation, may include consultation and/or partnership</td>
<td>Ways to get information out. Can be innovative and creative and can involve consumers, possibly through consultation in planning and partnerships in implementation.</td>
<td>56</td>
</tr>
<tr>
<td>23. Search conferences</td>
<td>Information seeking/consultation</td>
<td>Meeting of 30–50 invited people. Investigates a subject/issue in a planned manner. May use discussion paper as starter. Asks specific search question. Wide range of views canvassed. Answer(s) expected as outcome.</td>
<td>57</td>
</tr>
<tr>
<td>25. Discussion papers</td>
<td>Information seeking/consultation</td>
<td>Written presentation of information for discussion. No dialogue involved unless structured. May, however, be used as precursor to public meetings or other discussion.</td>
<td>59</td>
</tr>
<tr>
<td>26. Public meetings and forums</td>
<td>Information seeking/consultation</td>
<td>Audiences usually over 20 people. Meeting structured to canvass views, debate an issue. Representatives nominated by consumer groups/associations. Open to public.</td>
<td>60</td>
</tr>
<tr>
<td>27. Input into needs assessment process</td>
<td>Information seeking/consultation</td>
<td>Cyclical planning process. Input may be requested by organisation using any of the information seeking or consultation strategies listed here. If a permanent planning cycle, then can use standing committees with consumer representatives.</td>
<td>65</td>
</tr>
<tr>
<td>Strategy</td>
<td>Degree of participation</td>
<td>Key attributes</td>
<td>See page number</td>
</tr>
<tr>
<td>----------</td>
<td>------------------------</td>
<td>----------------</td>
<td>----------------</td>
</tr>
<tr>
<td>28. Seminars and conferences</td>
<td>Information seeking/ consultation</td>
<td>Instigated by organisations to explore ideas/issues. May cost and so be restricted to those who can pay. Audiences over 20 people. Format structured. Informal or spontaneous input may be restricted, tending to give providers/professionals more air-time than consumers/community.</td>
<td>66</td>
</tr>
<tr>
<td>29. Consumer councils and reference groups</td>
<td>Consultation</td>
<td>Structure and role prescribed by organisation. Input to whole of organisation. Made up of consumers who advise the organisation. Need to ensure and support consumer representatives links with appropriate constituency. Reps need to have tenure long enough to learn to be useful, but not so long they become part of organisation.</td>
<td>67</td>
</tr>
<tr>
<td>30. Policy round tables</td>
<td>Consultation</td>
<td>Invitations to discuss policy items. Structured. Convened to advise on the development of specific policy.</td>
<td>69</td>
</tr>
<tr>
<td>31. Consumer representatives on your committees</td>
<td>Consultation</td>
<td>Informing, training and supporting, consumer representatives. Ensuring they have a relationship with their constituency. Clarifying their roles and the terms of reference of the committees they sit on. A medium- to long-term investment.</td>
<td>70</td>
</tr>
<tr>
<td>32. Recruiting consumer representatives</td>
<td>Consultation</td>
<td>Clarifying objectives for having consumer representatives, developing clear and effective processes for finding and selecting the people you need.</td>
<td>72</td>
</tr>
<tr>
<td>33. Consultative/advisory committees</td>
<td>Consultation</td>
<td>Usually up to about 15 members. Role: to provide input on an issue/subject on the basis of expertise about an issue/experience. Members can be appointed or elected. Usually limited terms.</td>
<td>75</td>
</tr>
<tr>
<td>34. Patient forums</td>
<td>Consultation</td>
<td>Patients invited to focus on an area/issue. Usually structured.</td>
<td>76</td>
</tr>
<tr>
<td>35. Consumer participation policy</td>
<td>Supporting consumer participation/ consultation/ partnership</td>
<td>Consumer participation policies provide an organisational context to support greater consumer participation and guide the development of multiple strategies across the organisation to increase capacity as well as to foster consumer involvement.</td>
<td>78</td>
</tr>
<tr>
<td>36. Access policies and processes</td>
<td>Consultation</td>
<td>Formal process. Participation structured. May be part of planning or resource allocation consultations, or may arise out of lack of use of services which providers believe are needed. Various consultation techniques may be used.</td>
<td>82</td>
</tr>
<tr>
<td>Strategy</td>
<td>Degree of participation</td>
<td>Key attributes</td>
<td>See page number</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>-------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>-----------------</td>
</tr>
<tr>
<td>37. Consumer input into organisation/team policy</td>
<td>Consultation</td>
<td>Formal and informal. Includes consumer representatives, management committees, planning groups, planning processes, policy development process. Includes consumer advocacy as ‘outsiders’ to a policy development process.</td>
<td>83</td>
</tr>
<tr>
<td>38. Facilitating mutual support groups</td>
<td>Supporting consumer participation/consultation/therapeutic partnerships</td>
<td>Support to assist consumers on their terms about their issues. Groups can be consulted about service improvement. Clinicians can enter into partnership with groups as expert advisers.</td>
<td>86</td>
</tr>
<tr>
<td>39. Negotiation partnership</td>
<td>Consultation/partnership</td>
<td>Consumers and providers work together to develop a written agreement as a basis for future process. May be part of a consumer-initiated participation. Requires clarity of objectives and good communication skills.</td>
<td>88</td>
</tr>
<tr>
<td>40. Networking</td>
<td>Consultation/partnership</td>
<td>Informal relationship-building with people who have common interests or goals. Will include building links to consumer organisations, advocacy groups etc.</td>
<td>90</td>
</tr>
<tr>
<td>41. Partnership of consumers and providers</td>
<td>Partnership</td>
<td>Structured cyclical planning process with specified role for consumers in shared decision-making with providers. Process and outcomes are a shared responsibility. Usually the result of years of development of consumer participation and a strong consumer focus and culture in the organisation.</td>
<td>92</td>
</tr>
<tr>
<td>42. Community development</td>
<td>Partnership</td>
<td>Organic and flexible. Focus on process as well as outcomes. Scope for creative ways to facilitate participation. Support and partnership with consumers about their own issues. Going where the community energy is.</td>
<td>98</td>
</tr>
<tr>
<td>43. Community control</td>
<td>Community control</td>
<td>Community elects board of directors. Management reports to board. Strong primary health care orientation with public health and social justice advocacy, but likely to involve conflict management.</td>
<td>100</td>
</tr>
</tbody>
</table>
1. PUBLICATIONS, MEDIA RELEASES AND DISPLAYS

KEY ATTRIBUTES

Supports consumer participation. Written information with no requirement for dialogue, but can provide an invitation to consumers and information on how they can participate. Best used as an adjunct to other strategies.

Written information can be material your organisation has prepared itself, or you may also perform a useful role in collecting and disseminating material on particular issues of concern for your consumers. Publications, media releases and displays are not mechanisms for consumer participation in themselves. However, they can provide information to support consumer participation and can specifically encourage and invite consumers to be involved. Robert Gann has developed a typology of five categories of health information which he calls the 5–C model.

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
</table>
| Consumer information            | Information to enable consumers and carers to access health services available to them, including:  
   • description of services and costs  
   • method of access and  
   • their rights when accessing these services. |
| Citizen information             | Information to enable citizen involvement in health care policy, planning and purchasing including:  
   • studies and statistics about health status  
   • health data on resident populations  
   • health surveys  
   • reports on community consultations which articulate needs and wishes of local people  
   • health strategies—national, state and regional. |
| Choice information              | Information to enable consumers and carers to participate in decisions on their treatments, including:  
   • information on illness and treatment available  
   • patient versions of clinical practice guidelines  
   • evidence based treatment information weighing up benefits and risks (outcomes information). |
| Coping information              | Information to enable consumers to cope with disability and long-term health problems including:  
   • information on self-help groups and their programs  
   • information on community health services and their support programs  
   • information on how to cope with specific conditions  
   • information about treatment advances and clinical trials for specific conditions. |
| Community health promotion      | Information on establishing and maintaining healthy lifestyles  
   promotion information                                                                 |
   Including:  
   • goals and targets for national health improvements  
   • information on nutrition, exercise, birth control and sexuality, HIV, drugs and alcohol  
   • public health information. |


For many consumers though, publications alone may not be appropriate for these limited goals. The effectiveness of publications depends on consumer literacy, motivation, access at the right time, availability in community languages, cultural value of written
material and appropriate and accessible writing and layout styles. When concerning
treatment and treatment choices, publications should be provided to augment per-
sonal communications, and not as the primary channel for giving information. At an
organisation level, publications should be considered as part of a wider spectrum of
information-giving strategies that in turn may initiate dialogue with consumers.

Media releases can help raise public awareness of a wider consultation process by
your health service. However, check that the media you use will reach all the popula-
tion groups you want to involve by finding out the demographic profile of their
audience. Similarly, public displays may be a good way of reporting back findings of
a consultation process or of putting up a proposal for community or consumer con-
sultation. They constitute information giving and an invitation for further involvement.
Both may be very effective as part of a wider consumer participation program with
multiple strategies.

**CASE EXAMPLE**

**West Gippsland Healthcare Group Health Information Project**

The West Gippsland Healthcare Group, Warragul, is a rural health service with
hospital, primary care and residential aged care facilities. The service executive
initiated the health information project by establishing a working party to review
written information provided by the hospital to the community and to identify
resources needed to assist them in this project. The membership of the working
party comprised representatives from patient bookings, community relations,
medical records, nursing, administration and the customer service areas. The aim
and objectives of the project were to:

- design a mechanism for the development of consumer information;
- set standards, guidelines, policy and agreed procedure; and, most importantly
- develop consumer information that was customer-focused and allowed for
  informed decision-making for the consumer regarding their care.

Early in the three-month project it was obvious there was a huge amount of infor-
mation being circulated but there was no uniformity in information provided or
its presentation and no consumer consultation in the development of information
resources. The working party used ‘front line’ staff to estimate the sort of infor-
mation consumers needed to know. Focus groups were considered but not used
because of a lack of time. Other organisations were also consulted.

In establishing an appropriate style and use of language, the Service improvement
package for the development and review of written health information from the
Women’s and Children’s Hospital in Adelaide proved a useful resource.

The next phase was piloting of the information with a group patients. A second
aspect of the project was to develop a process for the development and review of
all written health information. The working party reviewed the guidelines from
the Women’s and Children’s Hospital in Adelaide and recommended these guide-
lines be adopted by the group.


Undated, Service improvement package for the development and review of written health information, Women’s
and Children’s Hospital, Adelaide.

**Section 3, Consumer-friendly administrative procedures**
2. INFORMATION TO CONSUMERS ABOUT SERVICES AND TREATMENT OPTIONS

KEY ATTRIBUTES

Supports consumer participation. Written and oral information presented to consumers in an accessible and understandable way explaining treatment choices and likely outcomes with pathways for asking and getting answers to questions.

Information to consumers about their treatment options and how to contribute to their own care is most likely to be effective in improving their satisfaction and health outcomes if it is part of an ongoing, two-way communication process with providers. Sophie Hill (1999, p16) cites McIver as arguing that information provision should be viewed as a continuum, from informing to educating to empowering. This means information strategies have to be designed to fit the purpose required. Hill goes on to propose seven design principles for strategies to provide information, advice and support. Such strategies should be designed:

- to enable the consumer (who becomes the patient) to be as knowledgeable about their health and treatment as they wish to be, in addition to having at least a basic level of knowledge of what will happen;
- to reduce the anxiety associated with being ill and requiring treatment;
- to enable the person to participate in decision-making associated with that treatment to the extent that they wish, and to provide a supportive environment for discussion and choice where there are uncertainties associated with treatment and recovery;
- to allow the person and their family to have quiet and unrushed times to make decisions and to talk over troubling issues;
- to allow the person to participate in their treatment in an atmosphere of privacy and sensitivity;
- to prepare the person (and their family or carer) to plan and prepare for the experience of being in hospital and for life after hospital; and
- to assist and where necessary educate the consumer to care for themselves where they wish to or have to.

In developing a framework, or guidelines to ensure that patients are provided with the information they need at an appropriate time and in an appropriate fashion, you should analyse the process that a consumer or patient is likely to go through. One way to do this is to use a focus group of experienced consumers.


Section 3, Focus groups
3. PATIENT CHARTERS

KEY ATTRIBUTES

Supports consumer participation. Written patient rights and customer guarantees that specify service conditions and provide pathways for complaint and possibly redress for consumers if these are not met.

A fine concept, but what does it really mean? Many services now have some charter of patients’ rights or customer service guarantee as a consequence of pressure from state and federal funders. In theory this seems a potentially useful tool for ensuring standards of quality and accountability. However, you should be cautious.

• If the guarantee is really for the benefit of your consumers they should be involved in its development.
• The specifics of service that are guaranteed should be measurable and represent real indicators of overall consumer focus and standards of care—not micro-indicators that can skew your organisation’s performance in a perverse way. It could mean, for example, that no one waits more than five minutes to be assessed by the triage nurse in A&E, because that is in your service guarantee, but then they have an average wait of an hour to see the doctor.
• There should be incentives for staff and the organisation to deliver according to the guarantee—and sanctions for non-delivery.
• Service guarantees also tend to be very individually focused. That may mean they draw resources away from services which target the whole community. When you draw up guarantees think at the whole community level and to whom you will be accountable.
4. HUMAN RESOURCES DEVELOPMENT FOR CONSUMER PARTICIPATION

KEY ATTRIBUTES

Supports consumer participation. Job design, recruitment, orientation and training to support consumer participation.

There are four main strategy streams for human resource development to support consumer participation:

- job design
- recruitment
- staff orientation
- staff training

When possible, the filling of vacant positions provides an opportunity to redesign job roles to integrate support for consumer participation. Kathy Alexander (1992, pp52–3), in reviewing the consumer focus of the Adelaide Medical Centre for Women and Children (now Adelaide Women’s and Children’s Hospital) comments:

> The recruitment, selection, orientation and development of the organisation’s people is the key to cultural change. The values of the organisation in terms of the rights of consumers to actively participate in planning and improving services at the individual and broader policy levels must be present in its workers. Public relations is the job of every staff member. For this reason the organisation must actively seek to attract employees with a commitment to consumer participation and skills in its development. All position descriptions should incorporate these personal skills and attributes and selection panels should seek confirmation of this.

> An orientation program for new staff has, as its primary objective, clarification of the organisation’s values to the new employee and the setting of a clear organisational expectation that new staff will share those values. It should also motivate employees, as a valued component of the organisation, to proactively seek consumer participation as a means of improving services. New employees must understand that although they may not be providing service directly to a patient, they are probably providing a service to someone who is, and that they are, therefore, an important component of service to the patient.

Staff development programs are a major organisational tool for cultural change among existing staff. Training in Continuous Quality Improvement approaches to service has the potential to develop a consumer orientation to service. However, Continuous Quality Improvement does not fully address social issues, which are also important obstacles to consumer participation. Staff require an understanding and sensitivity to cultural and social diversity and to issues of social justice. Some consumers will not provide input, no matter how much Continuous Quality Improvement is ‘practised’ and no matter how dissatisfied with the service they are. Staff education and development should attempt to increase staff sensitivity to the possibility of professional value bias in service provision and its affects on culturally and socially diverse groups in terms of their access to care. Staff training should aim to increase staff skills in individual and group interaction processes with consumers as a major strategy in ongoing consumer participation, particularly with minority and socially disadvantaged groups.

Cultural awareness raising and consumers training staff

Cultural sensitivity is an important tool for increasing opportunities for consumer participation by people of migrant backgrounds and Aboriginal descent. Staff training is just one way of addressing the issue. Many Australian health services have employed as trainers Aboriginal people and those of non-English-speaking background to work with their staff to advise on how to improve communication. A number of resources
are available to assist organisations working with particular consumer groups, staff
groups and cultural settings. More generally, consumers may prove excellent trainers
for staff. They have experienced what it is like on the other side of the fence and can
use those experiences to great effect in making staff aware of the key issues for con-
sumers and how you might begin to acknowledge and address them.

The following strategies for human resource development have been adapted from
Kathy Alexander’s recommendations for the Adelaide Medical Centre for Women and
Children. (Alexander 1992)

<table>
<thead>
<tr>
<th>Human resource development strategies for consumer participation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. That progressively, as positions become vacant, all position descriptions with direct consumer impact incorporate a commitment to consumer participation and to social justice principles.</td>
</tr>
<tr>
<td>2. That staff selection panels incorporate consideration of recruits’ commitment, understanding and experience in developing maximum consumer participation in their service planning. Protocols for selection panels should be developed to ensure such consideration across the organisation. Where possible, representatives from consumer groups should be included on interview panels.</td>
</tr>
<tr>
<td>3. That orientation programs for all new staff develop a clear understanding of organisational values and expectations in relation to consumer participation and social justice principles.</td>
</tr>
<tr>
<td>4. That a management training program incorporating the principles of Continuous Quality Improvement and consumer focus be developed by a multidisciplinary steering group, managed by the organisation’s executive and targeted to managers at all levels of the organisation.</td>
</tr>
<tr>
<td>5. That staff education sessions be developed with particular reference to principles of social justice and to issues of social and cultural diversity.</td>
</tr>
<tr>
<td>6. That staff training programs are developed to maximise staff knowledge and skill in small group facilitation with consumers.</td>
</tr>
</tbody>
</table>


Service Quality Australia 1999, Evaluation of consumer participation in Victoria’s public mental health, Department of Human Services, Melbourne, pp41–2. This section includes discussions on staff training and job design. They include references to these other resources:

Redfern Legal Centre Intellectual Disability Rights Service 1992, The right to have a say—a kit for consumer participation, NSW.

5. CONSUMER-FRIENDLY ADMINISTRATION PROCEDURES

KEY ATTRIBUTES

Supports consumer participation. Reviewing and reforming administrative communication with consumers to encourage consumer participation and partnerships for health.

Administration procedures are usually designed to suit the needs of administrators. Patients and community people who deal with health services frequently complain of having to provide the same basic information over and over again to almost every new health worker they come into contact with. This often reflects the compartmentalised nature of health service organisation. Departments and divisions have their own systems with their own information requirements. A consumer perspective is a good way to raise awareness of this as a problem, not only in terms of inconvenience and wasted time, but as a potential source of misinformation and consequent risk in terms of patient care. Case studies can be used to highlight the inadequacies of current practices and the need for reform.

At a basic level, your organisation must ensure that it communicates effectively with all its consumers, including those who do not speak English well. Is written information provided in languages other than English? Does your organisation’s policy on the use of interpreters ensure, for example, that family members are not used inappropriately as interpreters?

It may also be useful to look at how your service communicates with consumers in writing on administrative matters. What is the tone of these communications? Is it open and respectful or terse and bureaucratic? Often the form or style, rather than the specific content, may be the major impression left on the consumer. For example, hospitals have been known to tacitly endorse the sending of letters from their research foundations to all former patients, soliciting donations. These have been misinterpreted as bills by some people of non-English-speaking background.

Section 3, Human resource development
Section 3, Culturally appropriate approaches
6. VOLUNTEERS

KEY ATTRIBUTES

Supports consumer participation. Volunteers also often have close contact with consumers and the opportunity to get consumer feedback. However, training, supervision and support will be required as for paid staff.

Most hospitals and health services have volunteer groups who provide a range of services including the operation of kiosks, provision of limited patient support, patient transport etc. In their day-to-day contact with consumers they have the time and often more relaxed circumstances to form open relationships with consumers that can provide valuable feedback to the organisation. Volunteers are partly motivated by a sense of social control and responsibility (ABS Survey 1988, Cat No 4402.4) and this can also be a reason for contributing to consumer participation activities.

Volunteers can be offered the option of involvement in your consumer participation activities by using a community development model. A worker with responsibility for consumer issues meets with the volunteers and explains the aims of the strategy. The volunteers themselves then identify the issues or consumer groups with which they believe they can best work. An approach is developed and outcome goals agreed. One way to make this change of role for volunteer groups may be to change their name. Some health services have established ‘Friends of....’ groups (eg ‘Friends of the Lantana Health Service’) Just as some hospitals have ‘foundations’ to support research and other programs with independent funding, ‘friends’ groups are independent of your service, but work with you, in partnership towards shared goals.

Volunteers can provide important links to your community and other community groups, provide a focus for community support for your service and also form part of the infrastructure you need to support your consumer participants. For example, they can be responsible for running orientation and training programs for your community representatives. This approach may lead to strong partnerships between consumers or consumer groups and volunteers. Giving volunteers ownership of the process increases their commitment and fulfillment. Obviously your service needs to provide resources to support these processes and they take time to develop, but the rewards will be worth it.

Section 3, Community development
7. EVALUATION OF SERVICES

KEY ATTRIBUTES


Because improving health outcomes for consumers is what it’s all about, consumer input at some level is obviously an essential component of evaluating any health care service activity. Consumer input can be simply at the level of patient satisfaction or reported outcomes, but evaluations are considerably enriched if there is also the capacity for some dialogue with consumers. This gives the evaluators the opportunity to ask the really useful questions such as why a service seemed to work well or not, and to explore in more detail how the consumer believes things could have been done better.

Any evaluation process should incorporate a way of gaining some appreciation of the subjective experience of consumers. This obviously does not replace the need for clinical and epidemiological measures, but rather complements these.

The use of case studies with individual consumers can be a valuable way of showing how services may or may not link well together in the context of a consumer’s needs and circumstances. Following the consumer’s pathway in this way can provide insights that cannot be gained from needs studies, throughput and outcome data. It can, however, help you and your planners to make sense of the quantitative information and to know what other questions about service use and outcomes need to be asked.

Surveys, focus groups and other methodologies of consumer participation in evaluation are covered elsewhere in this section, but before these are even considered, it is important to check that your organisation ensures consumer views and experiences are included whenever a health program or intervention is evaluated. Key questions which consumer involvement will help to answer are:

- What difference will this (intervention, program, modification etc) make for consumers?
- How will this be ascertained?
- In what way could the intervention be refined or supplemented to improve health outcomes? For example, the rate of unplanned readmissions following a new surgical procedure might be greatly reduced if staff responsible for discharge planning knew more about the (lack of) home supports available to those who had to be readmitted. One way to do this would be to organise focus groups of randomly selected patients who had to be readmitted, to talk about their experiences.

Most consumers are very happy to be involved in providing feedback for evaluation purposes. However, you need to remember to respect privacy and confidentiality, to be sensitive as to when you seek feedback and how you report to consumers on the outcomes of the evaluation. The sorts of tools used for evaluation with consumers are much the same as those used for planning and other purposes such as surveys, interviews, and focus groups. Refer to these elsewhere in this section and to section 5 for a more detailed discussion of consumer participation in evaluation.

Section 5, Evaluation
8. PROJECT GROUPS

KEY ATTRIBUTES

Can be information seeking or consultation. Instigated by organisations to advise on specific issues and/or to guide a project. Time limited. May be used to demonstrate the value of consumer participation to key players.

When your organisation identifies a particular issue as a priority it may decide to address it in the first instance by establishing a project group or working party. Initially the role may be to advise on the issue and to identify strategies. This may move on to an implementation and monitoring role over time, though such groups tend to be time limited in the first instance. Many of the issues that project groups are set up to deal with will benefit greatly from dialogue with consumers. In fact if the definition of consumers includes the wider community and internal consumers, it is hard to imagine any that would not.

Most of the key issues you need to consider when thinking about consumer involvement in your new project group are discussed in more detail under ‘Consumer representatives on your committees’ and ‘Consumer advisory committees’ later in this section. However, there are some aspects of project groups that are a little different. Because they are focused on a particular issue, your consumer participants need to have a specialised constituency, knowledge and experience. You may or may not be able to find a consumer with an appropriate formal constituency (representing some consumer group) depending on the issue the project group is focusing on.

You need to think fairly specifically about what you want from them before you start to recruit. When you do recruit you need a process to ensure you get who you are looking for. Remember that it can be difficult to be diplomatic in backing away from what appeared to a consumer to be an offer of a role in your group, even if you thought you were just sounding things out.

You also need to be very clear about the role and limits of the group. This can be especially challenging if your organisation sees it as ‘a bit of a fishing expedition’. Consumers are investing their time without payment in most cases and may not be very interested in just fishing.

You also need to make sure consumer members of the group are kept up to date about the ongoing status of the project. If the organisation decides the project has shifted from exploration to implementation, or alternatively has been downgraded or dropped, make sure your consumer members hear about these developments (and preferably are involved in shaping them) at the same time as provider members of the group.

Section 3, Consumer representatives on your committees
Section 3, Recruiting consumer representatives
9. RESEARCH

KEY ATTRIBUTES

Information seeking. Outcomes research, qualitative research, action research and clinical epidemiology can overlap with consumer participation.

Different models of research relate to consumers in different ways, depending in part on values and approach. For example, a clinical epidemiology study on the outcomes of a treatment service for consumers is one source of information that may be used for service improvement. It may also provide a guide to issues for further consultations with consumers, particularly if patient behaviour is a significant contributor to the outcomes and you wish to explore the factors influencing this. This is the focus of much qualitative research. As issues are explored with consumers, research activities may extend this exploration, such as bringing together groups of consumers to discuss an issue of concern. Such a meeting may be used by consumers to demand action for change. This is sometimes called action research.

Evidence-based health care decision-making relies on research into the effectiveness of different procedures, treatments, pharmaceutical products, etc. Qualitative research with consumers should provide opportunities for consultation and possibly future partnership. All research involving consumers should preferably benefit them and certainly cause them no detriment. Consumers should also be informed of the findings. Research methods are varied and can include surveys, focus groups and in-depth interviews.


Section 3, Surveys
Section 3, Focus groups
Section 7, Links to resources
10. SURVEYS

KEY ATTRIBUTES

Information seeking method. Agenda most usually set by organisations. Scope of information limited. Quantifiable, but you need to know what you want to ask.

This section is adapted from Planning Healthy Communities: A Guide To Doing Community Needs Assessment (SA Community Health Research Unit 1991, pp87–171).

Surveys can be used in planning, needs assessment, priority setting and evaluation. The most common form of survey is a sample survey. This saves the cost and time involved in surveying the whole population (a census), by taking a sample from which you can infer information about the wider population. A sample taken from that population can tell us about that population as long as a few basic rules are followed.

Questionnaires

Surveys collect information by means of questionnaires. These can be administered by interviewer face-to-face or by telephone, or they can be sent through the mail to be completed (self-administered) by the respondent. Pilot surveys are used to test questionnaire and survey design and are essential to ensure that:

- there are no unknown flaws in your survey plan;
- the questionnaire obtains the information that you are seeking; and
- information you have obtained can be analysed.

Even if there are no major changes to be made to your survey following the pilot study, generally there will be some comments that help you fine-tune the questionnaire. For example, you might change the wording on some questions or add or clarify terms.

Analysis

It is easy to get carried away with setting up a survey selection and questionnaire design and forget that the information that is collected has to be analysed. Analysis is not something you can do in a couple of hours when the questionnaires are all in. As you work on the design of the questionnaire, it is important to consider how you will analyse the information.

Analysis can be done by hand and, if you are not familiar with computers and have only a small sample, this can be a satisfactory way to do it. However, hand sorting is time-consuming, and if you need the information sorted into sub-groups, eg sex and age, it is cumbersome and prone to error. Analysing the data with the help of a computer is not difficult but you will need a program to sort the data, and you will need someone who is familiar with the program. Analysis using computers involves two separate steps:

- coding, whereby the answers to the questions are transformed or coded into numbers based on instructions on a coding frame. The data is entered into a computer according to these codes; and
- using the computer program to sort the data and perform the operations needed to get usable information.

Reporting back

Although you may want the results of your survey for internal uses such as service improvement or priority setting, it is also important that the information you obtained from consumers is given back to them. This can be done in a number of ways, including publication in local media such as newspapers or newsletters, poster presentations...
in your waiting area, community meetings and so on. But before you begin your survey you need to ask:

**Is a survey the right way to find out what you want to know?**

To answer this question, consider the following points:

- At the beginning look at your area of interest and decide if it is a suitable topic for a sample survey. It might be that the information you require can be gathered more effectively using qualitative techniques.
- While surveys give an understanding of the extent of a problem, or the number of people with a particular point of view, they do not increase understanding of community processes, nor do they identify the underlying causes of problems. For this reason, they are best used alongside qualitative research.
- Surveys can be intrusive or impersonal depending on the type of information being sought, the way the questions are phrased and the method (face-to-face, mail or telephone) being used.
- Because the information that is sought has to be quantified, surveys require specific, clearly worded questions.
- Taking part in a survey can be a frustrating experience for the respondent, especially when the choice of answers is restricted.

**Remember, people cannot provide answers to questions that are not asked.**

When you need to know facts about a population in terms of numbers and percentages that are not available from any existing source, a survey is often the only way of obtaining the information.

**Remember, surveys involving more than 100 people are best suited to collecting factual or uncomplicated attitudinal data. If you want to collect detailed information on attitudes, values and beliefs, qualitative approaches are likely to be more rewarding.**

---

**CASE EXAMPLE**

**The value of piloting your survey**

In a community health needs assessment conducted by the South Australian Community Health Research Unit, a section was included for carers. In the original draft of the questionnaire, they asked carers if their work was causing them:

- to restrict their activities
- financial hardship
- physical illness
- stress.

When they piloted the questionnaire, a community worker pointed out that the list was entirely negative. In the final questionnaire they also asked carers if caring was giving them a good deal of satisfaction. In the survey, more carers said ‘yes’ to satisfaction than said ‘yes’ to any of the other aspects of caring. If this last aspect of caring had been omitted as in the first draft, they would have received a totally different picture of caring.

If you believe that a survey will help you meet your consumer participation objectives and that you have the necessary resources, use an appropriate technical guide such as the Survey Flow Chart Checker (from SACHRU’s *Planning Healthy Communities*).
11. IN-DEPTH CONSUMER INTERVIEWS

KEY ATTRIBUTES

Information seeking. Extended, semi structured (usually) face-to-face interviews. Provide rich information from selected consumers. Useful as a follow-up to surveys to explore particular issues and/or for specific population groups. But time consuming.

In-depth interviews can provide you with very rich information about issues of importance for particular consumers or community members. If these individuals are representative of a wider group of consumers you are trying to engage with, in-depth interviews may help you work out how to do so. For example, older women from a particular migrant community may not be following post-discharge care advice, resulting in avoidable readmissions. Selecting a few of these women for in-depth interviews (using a female interpreter) may provide you with a better understanding of the problem and guidance towards a solution.

These comments are adapted from Planning Healthy Communities (South Australian Community Health Research Unit 1991, pp.219–30).

The interview as discussion

Qualitative research creates a variety of interviewing situations. Researchers are not passive recorders confined to asking straightforward questions and taking down simple answers. Interviews may develop into lively discussions. On the other hand, some people need to be encouraged and prompted to give answers which are as complete as possible. Interviewers may have to take on a provocative role in order to elicit more elaborate responses. A most useful question is ‘Why do you say that?’

Qualitative research demands a certain amount of special preparation and knowledge besides personal relational skills. We need to be alert—ready to follow up interesting and possibly significant viewpoints. Interviewers also need plenty of energy. Interviewing requires your attention for the whole time. Don’t try more than three half-hour interviews in a row. If they are an hour each, do a maximum of two or three per day.

In-depth interviews involve a series of face-to-face, detailed discussions with selected people who you believe represent different sections of your consumer population. This idea of ‘representativeness’ will guide decisions about who to interview. In-depth interviews are more informal and less committed to an agenda than interviews conducted in surveys; however, a semi-structured question guide, framed around ‘key discussion points’, is a useful tool.

Who to interview?

Before you invite people for interviewing, you must be clear about who you want. The question of who and how many will depend on three things:

- the recruiting criteria
- the budget, and
- the subject of research.

All interviewees should be able and willing to contribute substantially to a relatively lengthy and open discussion but, at the same time, you must ensure appropriate representation of the consumers you are aiming to consult. In doing so you need to have some analysis of the group you are trying to find out about. Criteria you may need to consider may include: age, sex, income group, ethnicity, location, household structure and probably some special criteria related to the subject of your inquiry, such as recent use of a particular health care service.
How many people for how many dollars?

For in-depth interviews, you should aim to interview a minimum of 20 people; but bear in mind the following:

- Do you want to generalise to all consumers of a particular service, all consumers of your organisation’s services, or even the wider community your organisation serves or not? Generalisation to a particular group may be sufficient, but if you want to apply your findings more widely you may need to do more interviews.

- How is the data to be analysed? Be aware of the need for considerable time at both preparation and analysis stages, regardless of the means of analysis utilised (manual or computer-based). Remember also that the number of people you interview will affect the costs.

- Time per interview: expect to allocate at least three hours per interview, including travel, and approximately three times the actual interview length for transcription (if the interviews are to be transcribed in full—this, however, may not be possible or necessary). Are there interviews for which we need to employ others—for example, those with non-English speaking respondents? If so, additional expense will be incurred, both for conducting interviews and for translating tapes.

- Representation in relation to budget. Looking again at the timing and budget may force you to trim the number of respondents. The general principle is to leave out those you think will make the least difference in terms of representing the group you are interested in. Use common sense and your knowledge of the consumers with whom you work.

The discussion guide

To carry out an in-depth interview, a discussion guide may be used. This can be a simple list, roughly in the order in which you would like to deal with the topics. A well-constructed list of topics will ensure that all the essential issues are covered. Here is an example of a discussion guide for the health needs of older people.

In-depth interview discussion guide: consumer experience of using Anytown Hospital Accident and Emergency Department

- Introduce yourself and explain the purpose of the interview.
- Warm up: obtain a brief personal history—age, family and education.
- Discussion of issues:
  - Circumstances that led to presenting at A&E Department
  - Nature and severity of illness or injury—self or family member
  - Feelings experienced at the time
  - Reasons and process that led to using A&E. Involvement of other service providers (eg GP, ambulance officer). Usefulness of same?
  - Description of experience on arriving at A&E. Who was seen, how long waiting?
  - Was person admitted? What was outcome? How did you feel about this at the time?
  - Suggested improvements: How could hospital staff have done it better?
  - Did physical facilities influence experience? Was access satisfactory?
- Finishing up: general discussion about emergency care to check that topics of importance have not been missed.
- Future prospects and aspirations.
- Thank interviewee—inform them that they will be sent a short summary of results and encourage any further questions.
This is a guide only, but it should cover most of the issues to allow respondents to explore their health needs and social situations. Notice that:

- You gradually build rapport with the interviewee(s) by asking them to talk about themselves and their families. This helps to create a casual atmosphere. The brief personal history gives a background to what the respondent is going to tell you.

- The topics should follow logically from each other. For example, it is better to have a brief employment history before you come to asking about present health status.

- In the topic guide, be clear about the issues most relevant to your subject of inquiry.

Confidentiality

Permission must be sought from each respondent before tape-recording interviews with them. A signed guarantee should be given to the interviewees which ensures that all information will remain confidential.

Listening skills

In-depth interviews involve a two-way exchange or discussion. You need to get away from the type of interview situation where one person asks questions and the other answers. You must listen intently and encourage the interviewee to suggest items of personal concern and interest. Let them set the pace and, when introducing topics you consider to be vital, always be ready to back off if any reluctance to explore them is evident. Such reluctance may be a signal that your preparatory work has been inadequate.

You should not dominate the topics of discussion; above all, you should never impose your own viewpoints. Wadsworth provides some practical advice about listening skills:

You try and be a Good Listener. You concentrate, are tolerant, empathetic, encouraging, agreeable (in the sense of not projecting a stony face), you go ‘mm’ and ‘uh ha’ to show you are listening. You try and hear. You actually ‘take in’ what you’re listening to. You don’t skip ahead thinking ‘I know what she or he means’—you wait, and ponder it. Are you sure you understand what they meant when they used such-and-such a word? You actually ‘hear’ the unexpected answer—it pulls you up and you think ‘Oh, I had that wrong’; and you ‘hear’ if the answer is unsure, confused or not really relevant, or seems to be just saying what is expected, commonplace or otherwise ‘imposed’ ... and you check it out.

(Source: Wadsworth Y 1984, Do it yourself social research, VCOSS and Melbourne Family Care Organisation, pp30–2)

The flexibility to probe and check intended meanings is vital. Keep asking ‘Do you mean ...?’ ‘Are you sure that ...?’ ‘I’m not sure I got what you were saying about ...’

Analysis guidelines

The purpose of analysis is to examine and interpret critically all of the information you collected, to clarify any outstanding issues, and to establish themes—or perhaps even the absence of themes. As you listen to the tapes the first time, you should be sensitive not only to general emerging themes but also to areas of ambivalence, and perhaps confusion.
Transcription of tapes is a costly and time-consuming exercise, and should be kept to a minimum. However, if the intention is to use computer software such as Ethnograph or NUD*IST for the analysis, transcription may be essential. However, if you have done the interviews yourself, listening to the tapes should be sufficient for getting all the important points on paper.

There are disadvantages to in-depth interviews.

- They are time-consuming. You should expect to spend from two to four hours on each interview to enable you to cover all the issues outlined in your topic guide. If you are interviewing 20 people, that would take a total of about 60 hours.
- It may be difficult to find respondents who have a good knowledge of the issues you are concerned with and who are prepared to be interviewed.
- They can very quickly provide a mass of information which is not easy to sort and analyse unless you use such tools as the semi-structured interview schedule or, careful note-taking, or unless you carefully focus discussion around a few key topics.
- Without considerable skill on the part of the researcher in building rapport with a very diverse group of people, interviews may result in data from a relatively select sample of confident, articulate people—who may be the ones least needful of community services.

However, in-depth interviews, especially when combined with fieldwork observation, yield valuable information, and rewards can be high and well worth the effort and time spent. In particular, less structured interviews may yield opportunities for exploring underlying thinking patterns and ways of talking about health related issues which may be of particular concern to those directly involved in the health improvement activities of your organisation.

12. FOCUS GROUPS

KEY ATTRIBUTES

Information seeking. A semi-structured group interview with 6 to 8 people for 30 minutes to two hours. Can be invited on basis of who they are and what they can contribute to discussion. Interactions among participants can help explore issues rapidly and in-depth. Used for information collection focused on a specific issue (not for decision-making). Provides rich information, but may not be representative of all consumers.

This brief guide to focus groups is adapted from Planning healthy communities (SA Community Health Research Unit, 1991). Focus groups bring together up to 10 (but more usually 6–8) people to talk about an issue. Focus group interviews allow respondents to discuss things among themselves, with the researcher monitoring and guiding the discussion. It is important to note that focus groups are not problem-solving sessions or decision-making groups. They are essentially group interviews. Increasingly, focus groups are being used to explore health-related beliefs and behaviours in diverse groups.

The key advantages of focus groups are:

- Very efficient collection of qualitative data. In one session, the evaluator can collect information from eight people instead of only one.
- Data quality control. False or extreme views tend to be discouraged by the group process.
- Interaction between the participants means that issues get explored in greater depth than is possible with individual interviews.
- Participants tend to enjoy focus groups and feel they have made a worthwhile contribution for relatively little effort.

The disadvantages are:

- The number of questions that can be asked in one session is limited. Because you get responses from a number of people to any question, it is unlikely that you will be able to have more than five questions for eight people in one hour.
- Focus groups require a facilitator with good group work skills. The facilitator must ensure that the discussion is not dominated by one or two people, that the group stays on the issue and actually answers the questions, and that the quieter members are encouraged to have a say.
- Focus groups require resources and time spent on recording and analysing the data. Sessions should be tape recorded (or video recorded) and someone should be present to assist the facilitator and to take notes. Notes assist greatly when analysing the tape recording in identifying who the speakers are. It is usually not necessary to transcribe the tape recording; however, it is important that it is carefully analysed and the key messages and themes extracted and written up in a comprehensive report.

The main limitation of focus groups is that, as with in-depth interviews, the information obtained is only what participants say they do or believe in. Further, a group leader may draw out opinions and feelings that may be exaggerated in order to make an impression on other people in the group. These limitations notwithstanding, well-run focus groups can be one of the most efficient ways of getting in-depth feedback from consumers, especially if they are of a particular population group or type and the focus group is in relation to a particular service activity or issue.
Recruiting people: How many focus groups?

You first need to decide how many focus groups you need to discuss the issue you are exploring. This will depend in part on what other consumer participation strategies you are using, but as a general principle, the number of focus groups you organise will depend on the number of different consumer groups that have distinct needs in relation to the issue at hand. For example, different age or gender categories, racial or ethnic origins, socio-economic status or geographic locations may produce different focuses in relation to a discussion on access to community mental health services.

Thus we recognise that consumers are diverse with different—and often competing—interests and with unequal access to resources. We should not forget that when we use the term consumer or consumer needs, we are referring to groups of people with significantly different problems and needs.

Participants

Remember that you must select people who are not only knowledgeable but are fairly open. They must be able to express their feelings to the researcher and also in front of a small group of people, and be prepared to respond to what other participants say.

You can invite the participants yourself, or you can pass the word around and ask people in your team or organisation to look for suitable participants for you. It is important for you to be explicit about your recruitment criteria and the nature of the focus group.

Also, remember that there is no magic formula for a successful focus group. You will try your best to recruit the right participants, but it is difficult to predict how they will interact in a group discussion and you should be prepared to repeat the exercise with a new group of participants if the original members do not seem to interact well or if insufficient information emerges.

The role of the facilitator

The aim of a focus group is to provide a situation in which meaningful and sustainable discussion can take place. The discussion involves the participants and the facilitator in two ways: there will be a flow of ideas between the participants and the facilitator, and among the participants.

In focus group discussions the function of the facilitator is to probe significant points raised by the participants and to ensure that the discussion is proceeding in a meaningful and orderly manner. The probing role of the facilitator is very similar to that of the researcher in an in-depth interview. We can ask participants to elaborate and we can pursue issues to a satisfactory conclusion. Facilitation of a focus group requires good group work skills. If you are not an experienced group worker, find someone in your organisation who is.

Note that the one person who definitely should NOT act as facilitator is anyone who is involved in providing services which may be under discussion. This puts both facilitator and participants in difficult positions and either discourages discussion or sets up a conflict.

If you are to act as facilitator, you may find the following points useful.

- **Concentrate**—Complete concentration is necessary in order to pick up significant points from the discussion.

- **Use a topic guide**—The guide should include your list of interview questions. Make sure that the topics cover all the important issues relevant to the subject.

- **Set up the rules**—At the start of the session the facilitator should introduce themselves and their assistant and explain the purpose of the interview. They also explain that their role is to keep things on track, make sure everyone gets a chance
to speak and to watch the clock. They clarify that there is an expectation of confidentiality on all that is said in the group. The facilitator will not be divulging any identifying information about what is said and neither should they. The facilitator should pause and get agreement for this and also permission for tape recording (or video) and explain that the tapes will be destroyed once the report is written.

- **Probe**—Probing, such as asking a participant to elaborate on a significant point, is essential. If a participant says that he or she is not happy with the podiatry outpatients clinic, ask for reasons. Were there specific incidents which made him/her feel that way?
- **Provoke**—Sometimes you may need to take on a provocative role in order to elicit more detailed answers. For example, you may tell older participants: ‘Yesterday I talked to some older people in the shopping centre and the general feeling was that the hospital should spend more on looking after old people in their homes and less on surgery for cancer. What do you think?’
- **Highlight and reflect**—You can encourage discussion by emphasising a participant’s contribution and reflecting it back to the group. It is quite likely that when an idea is too sensitive or unpalatable to other participants, it will be glossed over by the group. You should bring the idea to the attention of the group.
- **Encourage everyone**—You should try to make sure that every participant in a group has a chance to have a say. The tendency is for one or two individuals to dominate a discussion, and it is difficult to avoid this. You can encourage responses from quieter participants by passing questions to them.
- **Elaborate**—You can also do this by elaborating on what has been said and then bringing it to the group for discussion: ‘Now Sarah’s idea implies that we should do away with the neo-natal intensive care unit, because, as she says, this city already has one that could cater for all and we would be better off putting the resources into home and community based birth and child and maternal health services. I would like to pass the question to the whole group. Start from this side of the table, with Jane’ . . .
- **Look for clues for further research**—Keep brief notes on observations made during discussions. Above all, note reactions of participants when key issues are being talked about as supplements to oral information.

**Observers or not?**

In consultations with hospitals and health services held for the development of this resource guide, we noted with some concern that it seems to be common practice for clinicians and other service providers to sit in as observers on focus groups of consumers discussing services provided by those health workers. This is not recommended. There are a number of problems with this practice that make it unlikely you will get a really useful outcome:

- Many consumers are likely to feel inhibited about saying what they really think when the health workers are present.
- A few consumers may take it as an opportunity to vent feelings of anger towards the health workers.
- While health workers certainly should not join in the discussion to argue their case, they are likely to feel angry too, if they get ‘dumped on’ with no right of reply.

Focus groups as used in the market research industry (which is where the tool was developed) don’t have interested observers sitting in and neither should you. If you really need to have observers, then use a venue with a one-way screen, so that observers are not actually in the same room, or just play them the videotape. (You must of course advise your participants and get their permission first.) But there is probably no great advantage in having observers, any more than you would want to read all the returned questionnaire forms from a patient survey.
**Remember**

It is best to tape-record focus group discussions if participants allow. Don’t forget to check the microphone, tape recorder and batteries to prevent a last minute foul-up, and check to make sure it is actually running after you turn it on. Make sure the room that has been booked remains available for use and that it is ready. Provide refreshments, child care and transport for members of the group if they need it.

**Simple notes**

As has been mentioned, it is important to keep simple notes during the discussion, but minimise the facilitator’s note-taking to avoid distraction. It is best if the facilitator has someone to assist them who takes responsibility for note-taking and sits at the back. Notes should identify speakers to help later when you go through the tape.

**Analysis and reporting**

You should avoid the expensive exercise of employing others to transcribe tapes. Moreover, there is an advantage in carrying through qualitative research from beginning to end by yourself or in your team. If you delegate, you may lose the ‘feel’ of the research, which may be vital for your understanding of emerging issues.

It is sufficient to take down the main points from the tapes, and to refer to your notes of each focus group. Your observations of the discussions are part of the data required for constructing views of the consumers and of the settings in which they were elicited.

In the report, do not neglect to record in detail the composition of each focus group: socio-economic, age, gender, ethnicity, and any other social or health characteristics relevant to the subject. If you attempt to draw from these data generalisations about all consumers of your services, the composition of the focus groups gives the reader some basis for assessing their ‘representativeness’.

The key output from your focus group will be the report. It is usually not necessary to provide a transcript of the whole session, but significant quotes are usually provided to illustrate the main points of the report. The report should include the following:

- the research questions you want the questions the group interview to provide the answers to. Note these are not the same as the questions your facilitator will ask at the interview (these are called interview questions). Rather, they are the reasons you are holding the focus group.
- the interview questions that you put to the group during the session;
- a summary of the answers to the interview questions;
- analysis and discussion of these answers; and
- answers to the research questions that emerge from your analysis and discussion.

**Remember, all social research is about getting some indication of the wider social processes taking place in society. This should be reflected in the language used in the report. Write tentative rather than absolute statements.**

Because the information you get from focus groups is confined to people’s beliefs and expressed opinions, it is important to see it in the context of other social circumstances and to use methods, such as observation of the participants’ reactions in discussion, and your own growing understanding to gain a broader view.

Morgan D 1988, *Focus groups as qualitative research*, Qualitative Research Series no 16, Sage, USA.
13. SUBMISSIONS

KEY ATTRIBUTES

Information seeking. Oral and written presentation of views. Dialogue limited. Can attract consumers who are organised and in a position to put in a submission. But less articulate/literate, those of non-English-speaking background and/or socially disadvantaged consumers may be excluded.

Submissions are usually associated with formal inquiries or investigations leading up to the presentation of a report with recommendations for some specific course of action. Submissions are sometimes sought by governments and government departments when developing new policies. They have several advantages. They publicly demonstrate a commitment to democratic processes. They are cheap to elicit and written submissions become part of the public domain and can be used in writing reports.

However, they are not a particularly appropriate tool for health services seeking to enhance consumer participation. They tend to limit involvement to groups with the good literacy skills, resources and access to adequate information to be able to argue their case convincingly. In practice this may mean that those consumers you most need to hear from, including those with worst health outcomes, greatest social disadvantage, poor English literacy skills and greatest isolation, are excluded from the consultation process. Seeking submissions from well organised groups or other agencies may, however, be useful as part of a wider consultation process which includes other more accessible strategies for those less prominent members of the community.

NSW Health 1998, Community consultation and participation resource kit for area health service managers and project leaders, draft, NSW.

Section 3. Public inquiries and hearings
14. DELPHI TECHNIQUE

KEY ATTRIBUTES

Information seeking. Formal process using a series of mailed surveys to selected individuals. Used for building consensus across consumers with conflicting views. May be useful for particular groups of stakeholders on specific contentious issues, but relies on good literacy skills.

The Delphi technique was developed by the Rand Corporation to provide reliable predictions about the future of technology. It is also a means for arriving at a consensus among groups of stakeholders with diverse and conflicting views. It involves a series of mailed questionnaires to carefully selected individuals. After each set of responses, the person conducting the technique summarises the responses (retaining anonymity at all times) and provides this feedback and a further questionnaire. The process continues until competing opinions converge. The participants never meet and individual responses remain confidential.

This approach moves more towards the field of consultation techniques rather than participation strategies. It is frequently used to resolve divergent views among experts on a particular issue. Its weakness is that its technical approach may not deal with underlying stakeholder power issues or value conflicts—so an apparent resolution may not extend beyond the immediate content issues. In addition it is not suitable for stakeholders who do not have good comprehension and writing skills. The nominal group technique (see below) may be more suitable in most consumer participation settings, although Delphi may be useful with particular groups on particular issues. A more detailed description of the Delphi technique appears as a tool in this resource guide.


Section 3, Nominal group technique
15. NOMINAL GROUP TECHNIQUE

KEY ATTRIBUTES

Information seeking. Small group process for clarifying priorities. May be useful for consumer involvement in identifying priority issues, allocating scarce resources etc. However, does not allow for much in-depth exploration of the issues.

The nominal group technique is a process by which a group of people can clarify their priorities on a selected issue, which encourages the participation of the less assertive members of the group. The process also allows issues to be placed in order of priority.

The following steps are an example of the nominal group technique.
1. The purpose of the group meeting and its process are explained to participants.
2. Participants are asked to record their ideas on separate cards. For example, if the group was considering the needs of carers of people with mental illness, a group member may have written on four of their cards: 24-hour telephone support and advice line, 24-hour mobile crisis team, access short-term residential care as respite, carers’ support group.
3. The cards are collected from all members of the group and sorted into categories dealing with similar topics. In the above example these might be: support and advice, needs of non-English speaking people, carers, crisis services, respite, managing medication.
4. The topic areas are then listed with the specific needs grouped under each.
5. The group members are then allowed three votes and can allocate these to the three topics they believe are the most important.
6. The votes are then counted and the topics placed in order of priority.

The main advantages of this process include the involvement of the more reticent group members, an outcome that reflects the opinions of the whole group, and its ease of operation. Also, it can be conducted relatively quickly (approximately 2–three hours should be allowed). The rules for running the groups, such as ensuring that participants are relaxed, are much the same as for focus groups. One way of running the process is to use a large sheet of butcher’s paper headed with each of the topic areas, with the specific needs listed underneath. The voting in stage 6 can then be done by giving each participant the same number (say 10) of coloured sticky paper dots. They then allocate their votes by sticking their dots on the appropriate sheet and next to the needs they see as highest priority. This is sometimes referred to as the ‘dotocracy’ technique. Its main disadvantage is that later voters may be influenced by the developing dot distribution and may manipulate the process by allocating all their dots to a particular issue because of this knowledge. The main disadvantage of the nominal group technique overall is that it only allows for minimal exploration of those issues that emerge as the most important; also, some group members may have good reasons for regarding particular issues as the most important one, but which, in the group process, do not rank highly.


Section 3, Delphi technique
16. SUGGESTION BOXES

KEY ATTRIBUTES

Information seeking. Easy to implement, but may be limited in obtaining useful feedback. May attract negative and unhelpful comment. Only for use in conjunction with other strategies.

The use of a suggestion box and little else is the stereotype of a token approach to consumer participation. This is not to say that suggestion boxes are not a useful and valid tool in the consumer participation toolkit. It is rather that, if used in isolation, they are likely to be about as effective as a garden trowel would be for building a house. Suggestion boxes have the advantages of low cost and requiring little staff time once they are in place. For consumers, they are fairly anonymous. In some settings such as waiting areas where people have the time to write out a suggestion, they have more use than others, such as an ambulance service, where the timing and circumstances are not conducive. One other problem is that for some services people are likely to have time on their hands (to write a suggestion) before they receive the service rather than afterwards when they may have something to say about the treatment they just received.

However, the main limitations of suggestion boxes are that they require reasonably good written expression skills (and the confidence to put pen to paper) and that they are essentially a one-way method of communication, rather than a dialogue. The requirement for literacy skills will exclude many socially disadvantaged consumers—and these tend to be those with the worst health. You can encourage a dialogue by asking consumers to leave contact details so that they can talk through their concerns with a staff member, but few tend to take up this option.

Suggestion boxes can be made more effective by:

- having a focus or issue for suggestions. This can change, say month by month, and there can be a display near the box explaining the importance of the issue and what the organisation needs to know from consumers;
- ensuring that suggestion boxes are not used as the only method for getting consumer feedback, but are part of a wider consultation plan with multiple strategies; and
- placing them in a position where people have the time and facilities to write their suggestions.

Having a suggestion box with little guidance as to what information is being sort and no other strategies leads to few suggestions, some of which may be abusive, and the likelihood that those in your organisation who are sceptical about consumer participation will say ‘I told you so!’ Don’t risk it. Treat suggestion boxes as a minor consumer participation accessory, not as a main strategy.

The following approach to using suggestion boxes has been adapted from Bringing in the Voice of Consumers, Women’s and Children’s Hospital, Adelaide, 2nd edn, 1999, pp28–32:

1. If you have no other ways, a simple starting point can be a suggestion box or a visitors’ book prominently located and brought to the attention of consumers.
2. If you want to set up a consumer feedback mechanism like a suggestion box or a general comments book, put the idea as an item on your next unit meeting agenda for discussion. The commitment of all staff to any idea is critical to its success.
3. Make sure that you discuss as a team what might best encourage consumers to tell of any negative experiences they might have of your service.
4. Form a working group of staff and consumers to provide advice and suggestions about how your unit should respond to negative feedback and complaints.

5. Deal with or respond to negative feedback from individuals by making personal contact with the concerned individual. Listen openly to their experience and ask them what they would have wanted to be different. If you leap in first to defend or explain your service, the consumer will nor feel ‘heard’ and may leave feeling angry and dissatisfied.

6. Remember that people who have the energy to complain may have the energy to be active consumers in your service development and improvement efforts.

7. Be aware that complaints from individuals may be symbolic of a bigger issue in your unit.
17. HOTLINES AND PHONE-INS

KEY ATTRIBUTES

Information gathering. Relies on publicity and on the phone being attended. Works best with skilled staff or volunteers to answer. Attracts respondents fairly indiscriminately.

Hospitals and health services may wish to invite general community and consumer comment, suggestions and complaints on their role and activities by publicising the provision of a free (1800) hotline which is a permanent feature of the organisation’s consumer and community liaison. There are a number of benefits to such a facility:

- Provided people know about it, it is a very accessible means of putting forward ideas or issues, especially for those who have limited mobility.
- It is a cheap and ongoing means of feedback on your service (see ‘Complaints’). The calls can be categorised and a database developed to show trends in what consumers like and don’t like about your service.
- It provides you with an opportunity to resolve consumer dissatisfaction.

However, hotlines only work if people know about them and use them. They must be supported by an information strategy (include the number and a brief description of what it is for on a fridge magnet in your inpatient information kit and on the back of appointment cards, on a huge sign on your main building, etc).

Phone-ins are about specific issues and are short-term strategies to find out public opinion on particular issues or perhaps on proposed changes to your organisation or its services. Like hotlines, phone-ins only work if people know about them. Because they need this additional publicity they are not used as a stand-alone strategy, but as an adjunct to a wider community consultation.

For both hotlines and phone-ins, you should remember that your callers are not a randomly selected sample of your consumers or community. They are the people who have been motivated to call. That reflects a combination of opportunity and the strength with which their views are held. So do not expect them to represent the views of the wider population. They may, however, provide you with some insights into why people who hold those views do so. They may also provide a source of people who can be referred into other avenues of consumer participation such as focus groups, committees or patient support groups.

CASE EXAMPLE

In 1993 a community participation organisation, the North West Suburbs Health and Social Welfare Council, conducted a public phone-in on the issue of use of interpreter services in the South Australian health system. The phone-in was called a ‘Speak Out’ and was held on a Saturday. Volunteers from many languages of people who were being surveyed attended in shifts to take the calls. The ‘Speak Out’ had been promoted widely on community radio programs and community newspapers. Language radio programs in Vietnamese, Spanish, Greek and Italian ran a segment on interpreter issues and listeners were invited to call the station with their issues. The strategy of a phone-in was complemented by a survey of consumers and health workers. A total of 474 people were surveyed across Adelaide. For some it was a chance for them to speak out: ‘This phone-in is the first chance I have had to complain’. The information gathered generated action for change.

(Source: North West Suburbs Health and Social Welfare Council 1993, Speak out on interpreter services in the South Australian health system, Health Commission)
18. COMPLAINTS HANDLING

KEY ATTRIBUTES

Information seeking/consultation. Response to consumer feedback and complaints. Valuable resource because restricted to consumers who have identified possible area for service improvement. Requires staff understanding of value of complaints.

Complaints represent a source of consumer participation that is often not well used by hospitals and health services. While consumer complaints policies and procedures are usually in place, they may not always be consumer-friendly or well used. There is often a tendency for processes to become slow and bureaucratic. From a consumer’s point of view they may look intimidating or like a lot of hassle. For the provider there may be an element of defensiveness that also discourages consumers from complaining.

It is possible to do it better. The key features of a consumer-friendly approach to complaints is to provide a speedy and personal response from a person who is trained and authorised to solve the problem. In addition, your organisation’s staff should be able to identify and follow up consumers who are dissatisfied, but who have not formally complained. It is important that complaints are handled in ways that are culturally appropriate and in ways that are as easy as possible for the person making the complaint. A useful reference is the Australian Standard on Complaints Handling AS4269–1995.

Complaints are just one form of consumer feedback, and if you are trying to encourage consumer participation, then you should also be trying to encourage consumer feedback—including complaints. Complaints also have the advantage of being cheap (but not free). It is very important to remember that if you change your organisation to be more consumer-focused and to encourage your consumers to complain, the level of complaints should rise initially. It may seem strange, but this increased level of complaints is a sign of success. You now have clear directions for change and improvement from your most important stakeholders.

In the private sector complaints are seen as a message from consumers who, if dissatisfied, are likely to go elsewhere in the future. For hospitals and health services, however, consumers often do not have the option of going elsewhere. This means that complaints are all the more important in improving service quality. In service industries in general, it has been estimated that only 3.7 per cent of dissatisfied customers actually complain (Barlow and Moiler, 1996). That means 27 dissatisfied customers behind every single complaint. Complaints represent highly valuable intelligence for service development.

A well handled complaint:
• tells you what you are doing wrong
• fosters a learning organisation
• enables you to make appropriate adjustments
• leads to a positive image with service users
(Source: Kilner & Were 1997, p25)
**To use complaints:**
- The organisation must have the right culture to accept complaints as positive.
- There should be a short written complaints policy, publicly available.
- Staff should be well trained in complaints handling.
- The process of handling complaints needs to be culturally sensitive.
- Handling of personal complaints should not be neglected.
- The organisation should aim to become ‘complaints friendly’ and learn to seek out and welcome complaints (*ibid*, p25).

**Responding to consumer complaints: an exercise**

This exercise can be conducted by a facilitator working with your team or other groups of up to about 12 staff. The total number involved should be a multiple of three if possible. With larger groups use a second facilitator. You will need about one-and-a-half hours. The aims are to:

- demonstrate the advantages of using a complaints friendly approach with customers;
- familiarise your staff with the key elements of such an approach; and
- explore your own organisation’s/team’s current approach to complaints.

(*Adapted from Kilner & Were 1997, p26–7*)

**Stage one**

1. Participants are given index cards and asked to spend five minutes writing down one occasion when they complained about a poor service or product and did not have the complaint resolved satisfactorily—it can be either a commercial or non-commercial situation.
2. Participants stay together in the whole group but take turns role playing customer and organisation in trios.
3. The person who wrote the complaint card takes the role of the employee who handled the complaint badly, a second person role plays the customer and the third person role plays an employee who follows the recommended approach.
4. The scenario is first acted out using the original unhappy experience as a guide.
5. Then the scenario is acted out again using the complaint handling process recommended by Barlow and Moiler (1996), going through each step in order:

   Step 1. Say thank you for the complaint
   2. Explain why you appreciate the complaint
   3. Apologise for the mistake
   4. Promise to do something about the problem immediately
   5. Ask for necessary information
   6. Correct the mistake—promptly
   7. Check customer satisfaction
   8. Prevent future mistakes.
Stage two

You may wish to take a break between stages one and two. Stage two shifts the focus to complaints handling in your own setting. If you have a large group you will need to break up into smaller groups to answer the following questions. Otherwise they can be brainstormed in a large group. In either case have a period of consolidation at the end of each question to draw together and write down (on flip chart so all can see) your collated views.

6. How does your organisation view consumers’ complaints?
7. How do you talk about complaining consumers? What does this say about the culture and attitudes in your workplace?
8. Does your team/organisation treat complaints as a valuable source of information?
9. How do you, your team, your organisation, use complaints?
10. How does your team/organisation (and staff) tell people not to complain?

Kilner D and Were K 1997, Pursuing customer satisfaction in the human services, Social Options Australia, Adelaide.

19. RESPONDING TO CONSUMER INITIATIVES

KEY ATTRIBUTES

Information seeking/consultation. How your organisation/team responds to inquiries or requests initiated by consumers. Developing clear policies, processes and skills to be ‘response-able’.

While health care organisations are often seeking ways to recruit consumers for involvement in their organisations, in many cases it is the consumers who make the initial approach. Sometimes this is as an individual which can be dealt with under ‘Complaints’; if they are asking for a continuing involvement, through membership of a volunteers or a ‘Friends of …’ group, this can be dealt with the tools for ‘Volunteers’.

If it is a consumer organisation that has made the approach, then, depending on the issue, it is likely that your response needs to come from your organisation. Use this checklist to see whether you are on the right track (refer also to the tools dealing with ‘Negotiation’).

1. Identify the right person in your organisation to be talking to the consumer group. If possible use someone with an existing relationship with the group who will be able to continue that relationship. Your negotiator also needs to have good knowledge of the issue in question and sufficient seniority in the organisation to be able to effect changes if needed.

2. Be clear about what you are trying to achieve. Follow these steps in order:
   • Meet with the group and listen carefully to what they say. Acknowledge the issues that they are arising without making any commitments at this stage. Seek clarification and more detail. Try to find out why this is a problem (or perhaps an opportunity). Who does it affect? How does it manifest? Which aspects of your service are involved etc? Is there a range of views within the group or just one position? Explain that at this stage you are just seeking information.
   • Meet with the relevant managers in your organisation. Explain to them the concerns of the consumer group. Work with them to brainstorm possible solutions, and to identify options that would be acceptable to the organisation. Ensure your options include ways in which the consumer group will be involved in the process from this point on.
   • Go back and talk with the consumer group. You may wish to take relevant managers from your service with you. Explain that you and your colleagues have developed a number of options. Present your options and ask for comments, suggestions and alternative ideas. It is important that you explore their concerns and ideas with them and demonstrate to them that the organisation values their views. You may need several meetings before you reach consensus on what is to be done. Resist the temptation to go for quick technical fixes to be implemented along with a polite brush-off. This is not just problem-solving. It is a valuable chance to build a partnership that will be a resource for future initiatives.
   • Once a plan of action is determined, ensure that members of the consumer group are involved in the implementation process. Make sure the results of the changes are monitored and evaluated and reported back to the consumer group.

Section 3, Negotiation
20. WORKSHOPS

KEY ATTRIBUTES

Information seeking/consultation. Working meeting usually of 12–25 consumers, possibly with providers to share information and to develop a shared approach to a specified issue. Participants usually have been selected on the basis of particular skills, knowledge or experience. Requires informed participants.

Workshops are structured, working meetings usually of 12–25 consumers with providers to share information and to develop a shared approach to a specified issue. The aim is to produce a plan or program of recommendations. Participants usually have been selected on the basis of particular skills, knowledge or experience. Workshops can provide an opportunity to sound out alternative policies or programs, to get feedback and to refine proposals. For example, a workshop might be used to consult consumers about the architectural design of a new health care facility; or to consult people from different ethnic groups about their perceived barriers to using your health service; or to consult consumers about their views of what service priorities should be in a climate where savings have to be made to the budget of a health service.

It is important that participants are well informed on the issues and can present a variety of particular perspectives (such as those of particular consumer groups). For this reason they may be representatives of consumer or community organisations. The people from your organisation should be flexible, prepared to listen and able to express themselves clearly and concisely. It should be clearly understood by all that the purpose of the workshop is not to make final decisions, but rather to develop recommendations for your organisation’s decision-makers. This can be done in pre-workshop written material and in the facilitator’s introduction on the day. Those present at the workshop have a common aim of exploring all aspects of the issue and presenting a comprehensive report of their findings.

You should consider whether to use an external facilitator. As well as allowing you and your team to participate fully without having to worry about the process of the workshop, this has the added advantage of demonstrating your organisation’s preparedness to have an open process managed by a neutral party. This may help build trust in some of your more cautious or sceptical participants.

Make sure that someone from your organisation takes comprehensive notes and writes up a report of the proceedings that is distributed to all attendees as soon as possible after the meeting. A flip chart is useful to document decisions as you go and provide a sequential record. All agreed positions and recommendations should be carefully documented. If the event is for a full day, provide lunch and allow time for informal networking. In any case, provide refreshments and time for breaks.
21. CONSUMER ADVOCATES/CONSULTANTS

KEY ATTRIBUTES

Information seeking, consultation, partnership. Health care organisation employs person to consult with consumers and advocate on their behalf for service improvement.

The creation of a dedicated staff position or positions as consumer advocate or consumer consultant is a strategy that is becoming increasingly popular, particularly for hospitals and in mental health services and services for the disabled. The recent Evaluation of Consumer Participation in Victoria’s Public Mental Health Services (Service Quality Australia 1999) found that a decision by the department’s mental health branch to provide funding for such positions was taken up almost universally. The authors identified the employment of consumer consultants as one of the key factors vital to effective consumer participation. They noted that while consumer consultant positions were simply ‘tacked-on’ in some cases, with little change resulting, in others the position was ‘the spearhead of enormous change and many improvements’ (p20).

They found a number of important elements seemed to be present when consumer consultants were effective in enhancing consumer participation and consumer-focused organisational change, including:

• having two or more consumer consultants working together;
• consumer consultants working across both inpatient and community services;
• the position being supported by policy, a clear job description, protocols, mentoring and supervision;
• having clear structures both for consumer input and for hearing and acting on that information; and
• having effective linkages between consumer consultants and a wide group of consumers and consumer networks and between the consultants and those managing service delivery in the organisation (p22).


22. PROMOTIONS AND CAMPAIGNS

KEY ATTRIBUTES

Support consumer participation; may include consultation and/or partnership. Ways to get information out. Can be innovative and creative and can involve consumers possibly through consultation in planning and partnerships in implementation.

Promotions are used by organisations to gain support and possibly funding for a particular event, new facility or program. The channels used will increase awareness in the general community but may not be especially effective in reaching particular consumer groups. Increased awareness of a program or event may provide an implicit invitation to consumers and community to be involved in your service, but promotions are certainly not sufficient as a consumer participation strategy in themselves.

Campaigns usually have a particular health issue focus and aim to change the behaviour of consumers or other key stakeholders influencing health outcomes in some way. Because they have a particular health issue focus they may be more effective in engaging consumer interests. A well designed and implemented campaign will operate on a number of levels simultaneously. As well as disseminating information by a range of methods, campaign workers should identify potential allies, consult with them and if possible, develop partnerships. It is very likely that some of these allies will be consumer groups.

Section 3. Publications, media releases and displays
23. SEARCH CONFERENCES

KEY ATTRIBUTES

Information seeking/consultation with 30–50 invited people. Investigates a subject/issue in a planned manner. May use discussion paper as starter. Asks specific search question. Wide range of views canvassed. Answer(s) expected as outcome.

Search conferences are a bit like workshops on a grander scale, but with a role in identifying the key questions as well as working on where to find the answers. They are specifically aimed at building up a common picture of the issues and concerns in a particular area. They are especially useful in areas which previously may have received only limited attention or where data or research is not comprehensive. Search conferences aim at wide-ranging participation in:

• ‘scoping’ the dimensions and attributes of the issue; and
• identifying specific themes and directions for further information collection and consultation.

Workshops to follow up on the identified themes and key questions may be one outcome of a search conference. Health services may wish to hold search conferences inviting consumer groups, other human service agencies, funding bodies and other stakeholders as part of a policy development process.

Writing about search conferences, Bob Dick outlines outlines a possible agenda:

- Introduction and overview
- Optional: community history
- Developing a shared vision
- Wider influences
- Identify stakeholders
- Optional: other information
- Add to the shared vision
- Identify key players
- Set up working parties.

He further identifies four ground rules for a successful search conference. These are:

1. Identify common goals or what most people can agree on;
2. Invite participants to think about the whole community not just the groups they may represent;
3. Ensure that participants use the processes provided; and
4. Ensure that participants do not argue but rather inform one another about views.


Section 3, Workshops
24. PUBLIC INQUIRIES AND HEARINGS

KEY ATTRIBUTES


Health services are not usually in a position to initiate public inquiries and hearings; however, they may have them imposed by government. Public inquiries and hearings usually seek to identify and examine the relevant factors and circumstances relating to a particular government decision or policy; their implementation; or the operation of a particular program or agency. Inquiries and hearings are often conducted in response to dissatisfaction or concerns expressed by customers or members of Parliament.

Often, written submissions are sought first and then public hearings are held which enable those who have submitted cases to be cross examined. While this provides an opportunity to work through the arguments for and against courses of action or policy, it does not provide an accessible path for involvement for most consumers or even for many consumer organisations. As with submissions, the process favours the views of those with money, education and lawyers. Expert views may dominate and the outspoken perspectives of some participants may get over-emphasised.

CASE EXAMPLE

In 1999, the Federal Senate instigated an inquiry by the Senate Affairs References Committee into public hospital funding. Its terms of reference include looking at how ‘within the legislated principles of Medicare, hospital services may be improved’ in respect to adequacy of funding, current practices in cost shifting, impact on consumers of cost shifting, coordination, impact of private health insurance and other relevant matters. The committee is receiving written submissions, and will hold public hearings at which individuals and organisations will be invited to give evidence.

(Senate Committee Office information brochures are available online at <http://www.aph.gov.au/senate/committee/wit_sub/index.htm>.)
25. DISCUSSION PAPERS

KEY ATTRIBUTES

Information seeking/consultation. Written presentation of information for discussion. No dialogue involved unless structured. May, however, be used as precursor to public meetings or other discussion.

Discussion papers aim to broadly outline to the community a proposal or options being considered in relation to particular policies, programs or services. The intention is to encourage broad discussion and responses to the proposals. Parliamentary inquiries frequently initiate discussion papers to facilitate public comment and participation. Discussion papers prepared at the direction of the minister for cabinet consideration are sometimes referred to as Green Papers. (Adapted from Community Consultation and Participation Resource Kit for Area Health Service Managers and Project Leaders, NSW Health Draft 1998)

However, organisations can also use discussion papers as a means of consulting with their consumers and the wider community. This is best done by using a discussion paper as one part of a broader set of strategies. For example, a rural health service may need to take some difficult and important decisions about how it distributes its resources across a number of hospital sites and health centres. There may be arguments for closing some sites and redeveloping others to reflect changing technologies, transport access and demography.

A possible suite of strategies:

1. Local community meetings to explore what the various local communities want from their services and what they might be prepared to trade off.
2. A regional search conference with strong consumer representation could be called to consider the findings of the local meetings and to identify key themes.
3. A workshop of key stakeholders including consumer organisations could then develop a broad list of options for action.
4. The service could then produce a discussion paper that reports what people want, what the key themes are and the possible options. The paper would have to be as brief as possible and written in everyday style (and available in all community languages).
5. The discussion paper would be widely distributed with the invitation to respond through a phone hotline, fax, post and email as well as a series of community meetings across the region.
6. The feedback from these would be consolidated into a report and the final decision made by the board.

Note that you should not release a discussion paper unless:

• there has been a process of consumer consultation in the development of the paper; and
• there is subsequent consultation and a preparedness to change policy direction (from that outlined in the paper) in response to the outcome of that consultation.


NSW Health 1998, Community consultation and participation resource kit for area health service managers and project leaders, Health Improvement Branch and Health Public Affairs, NSW Health, Sydney.
26. PUBLIC MEETINGS/FORUMS

KEY ATTRIBUTES


Public meetings are different from smaller, business meetings. They are often used to present information to an audience, with some opportunity for comments and discussion. More formal public meetings may also provide the opportunities for motions, voting and resolutions, but this requires considerable skill from the chairperson if the attendance is large and energetic. If you hold a public meeting to present information and to elicit feedback you should think carefully about who should chair it and what will be on the agenda. It is usually better to find someone who is not closely associated with your organisation, but who commands the respect of the community and who has the requisite chairing skills. This reassures people that the meeting will provide opportunity for a proper discussion and the airing of dissenting views. Meet with your chairperson well beforehand to develop the agenda.

Good meetings have a number of common points

Meetings that people learn from have these qualities:

- commonly understood goals;
- a clear process for reaching those goals;
- an awareness that people come with their personal pre-occupations and feelings as well as an interest in the subject at hand; and
- a sense of involvement in making decisions and the actions following, which means that all members should participate.

Ensure you have provided sufficient notice, using a range of methods to let your intended audience know about the meeting. Use local newspapers if possible and send formal invitations to those people you feel really must be there. Try and get some idea of the expected numbers so that you nominate an appropriate venue. Arrange for refreshments so that people feel comfortable to stay after the formal proceedings and chat over a cup of tea. Often the most valuable partnerships are started at informal occasions like this. Provide child care and transport for those who need it. Check there is access for people with disabilities.

Making a presentation

Katrina Shields is an experienced community activist and consultant from northern NSW. The following points of advice for making a presentation to a public meeting are adapted from her book In the Tiger’s Mouth (1991, pp70–6).

1. Pitch the presentation appropriately.

   In the preparatory stage, before the actual presentation, give some thought to who your audience is and put yourself ‘in their shoes’. What are their values? What style will allow them to feel comfortable? How does this issue relate to their lives? Are they used to talking about their feelings? Would they have ever been given an opportunity? Have they chosen to attend this presentation or is it compulsory, part of an overall program?

2. Warm-up is important.

   The first few minutes particularly will influence what sort of responses you get; hence you can help your audience by warming them up to sharing and involvement. Welcome the audience and thank them for expressing their concern on this issue by
turning up. You can set the tone by sharing a little of yourself—your personal link with the issue. Sometimes it is important to acknowledge that the material can be hard to face or that it could be distressing. Validate people’s feelings and questions. Create an atmosphere of ‘we are all in this together, and by working together we can find solutions’.

3. Don’t overload people with too much information.
This applies particularly if the information is disturbing. Giving more and more information in itself does not activate people. Give enough information to provide an overview; details could be provided in handouts.

4. Involve the audience.
This is probably the most important principle. Involvement will maintain attention, assist in integrating more deeply what is presented, and lessen isolation. Involvement is enhanced by introducing people to each other, finding out what they really wish to know, and providing opportunities for processing thoughts and feelings together. Consider how the chairs are arranged. For instance, a semi-circle around a speaker rather than straight rows will create a more informal atmosphere and allow people to see each other.

5. Provide hope.
Rather than battering the audience with terrifying information and graphic details of negative scenarios, it is important to leave people with some sense of hope. For instance, emphasising that our public health care services are after all for the benefit of the community implies that it is ordinary people who can be the ones to make a difference. It is empowering to stress that people don’t need to be experts to respond and to become involved.

6. Provide information on how people can be involved.
Prepare handouts to take home with information about local resources, contacts, groups and suggestions for actions the audience could take. Watch out for people needing extra support. Link them up with someone who can spend some time listening to them.
General hints for using meetings effectively

Meetings involving providers with groups of consumers can vary in scale from a clinician talking to members of a small patient support group through to organisation policy forums with large numbers and a relatively formal process. What follows is a more general set of strategies that can be applied to any meeting that aims to enhance consumer participation. It is taken from Resourcing consultation, Best Practice Paper 2, published by the NSW Office of Social Policy, November 1993.

Using facilitators

The effectiveness of meetings can be enhanced by using facilitators. Their role is to provide non-directive guidance in assisting the meeting to come to decisions. Facilitators should ideally have a neutral role in relation to the matters being discussed. It is often helpful for facilitators to work with organisers to design the process beforehand, including formulating the agenda and suggesting forms of participation.

What does the facilitator’s role include?

- Keeping the discussion on topic
- Clarifying and rephrasing complicated or confusing discussion
- Summarising underlying agreement and differences in viewpoint
- Identifying new issues as they arise
- Suggesting options that the parties have not considered

Public meeting presentation checklist

Before deciding what you will include in your presentation, sit down and make sure you have answers to these questions:

- What are your motives for giving this presentation?
- Who are you addressing? What is likely to be their perspective on life and on this issue in particular? What approach/language/environment will be most likely to get through to them?
- What are the three major points you wish people to remember after this presentation?
- What sort of atmosphere will your presentation and venue create? Is it likely to be comfortable and welcoming?
- How do you intend to encourage participation and help people digest the information you offer?
- What else can you do that will contribute towards the empowerment of your audience?
- How can you make the occasion as multisensory as possible? Have you considered including music, comedy or some activity to keep the concentration up?
- What are you offering in the way of follow-up to your presentation? Can you suggest people meet as working or support groups afterwards?
- Is it feasible to do a rehearsal? (Videoing your presentation will give you a tool for refining it.) Who could give you useful feedback?
- What do you as organisers or presenters need to do to look after yourselves during this project?
- Have you double checked the equipment to see that it works well and that you know how to use it?

(Adapted from Shields 1991, pp75–6).
• Ensuring that viewpoints are heard and understood by the group as a whole
• Identifying problems with the group process and attempting to remedy them
• Regulating the pace of the meeting as appropriate
• Managing conflict.

If a facilitator is being used, their background and role should be explained to participants at the beginning of the meeting.

Meeting procedures

Traditional meeting procedures are not necessarily the best approach in consultation. If participants are unfamiliar with such procedures they may be intimidated by the formality. Adopting a less formal structure does not mean that the meeting can’t use some formal procedures. The following procedures may facilitate positive outcomes from meetings.

Agreeing on an agenda and ground rules

A draft agenda should be circulated before the meeting. At the start of the meeting, the proposed agenda is discussed to determine how well it reflects the objectives of the participants. Changes or additions to the agenda are then agreed on. The meeting should also agree about the ground rules, such as whether speakers will be time limited or how much time will be set aside for individual items.

Introduction of items

Items introduced by the facilitator or participants should include a clear definition of the area to be discussed and a statement of what has to be decided. The presentation of background information to the item is often appropriate. Lengthy background documents or discussion papers should be supplied to participants well before the meeting.

Discussion

Ideas, statements of concern and proposals should then be introduced for discussion. These contributions should aim to build on previous statements, rather than repeat them. Try to draw out or invite people to speak who haven’t contributed. Be aware of the possibility of domineering or hostile participants—the conflict resolution strategies outlined later may assist with this problem (see the ‘Recommended resources’ listed in this resource guide.) In the case of controversial issues, summaries can be given of ‘for’ and ‘against’ positions.

Summary of directions

Conclusions or summaries about directions to which the meeting appears to be moving should be given. This is helpful in re-focusing discussion or pulling together a meeting that is becoming disjointed.

Test for consensus

Expressions of concern over the stated conclusions are usually then sought. Listing concerns where everyone can see them may help in working through the issues. Further discussion should then aim to reach a consensus position.

Decisions are agreed or deferred

A decision can be endorsed by the meeting as a whole or deferred to a further meeting or subcommittee if agreement cannot be reached or is not yet appropriate. Consideration could be given to whether small working groups may be more effective than a large meeting. If this approach is taken, responsibility for tasks needs to be clearly defined.
Task allocation

An action or implementation plan can be developed with tasks allocated to particular participants. A timetable should be formulated.

Recording outcomes

The meeting should ensure that major decisions, suggestions and responsibilities are recorded and circulated to participants. Consideration might also be given to communicating outcomes to a wider audience.

Shields K 1991, *In the tiger’s mouth*, Millennium, Newtown, NSW.
NSW Health 1998, *Community consultation and participation resource kit for area health service managers and project leaders*, Health Improvement Branch and Health Public Affairs, NSW Health, Sydney.
27. INPUT INTO NEEDS ASSESSMENT PROCESS

KEY ATTRIBUTES

Information seeking/consultation. Cyclical planning process. Input may be requested by organisation using any of the information seeking or consultation strategies listed here. If a permanent planning cycle, then can use standing committees with consumer representatives.

Decisions about service provision by health care organisations have traditionally been made by service providers and funders without much reference to other stakeholders. More recently the consumer movement and pressure from funders to demonstrate an outcomes base for services has changed this picture. Increasingly decisions about service provision are being informed by a combination of information on population health and illness status, consumers’ priorities and provider advice on the cost and efficacy of available treatments and services.

While many of the strategies described in this section such as surveys and focus groups can be used to ascertain consumer views and preferences about health care needs, consumers should also be involved in making the decisions which the data from those activities inform. Allocation of health care resources is essentially a rationing process and there will always be additional services or facilities to spend funds on. The real question is how to determine priorities from among the many virtuous competing needs. Whether scarce resources should be spent on a liver transplant program or enhanced immunisation coverage is, for example, a question that should not be answered by providers in isolation.

One approach is to establish a health priorities advisory panel. This is really a specialised working group or task force with a majority of consumers but includes representation from service providers and health outcomes and evaluation researchers and with project officer support and resources. The panel works as a group to analyse the available data on health status and services and discusses and debates the alternatives in the light of ethical, efficiency, social justice and service quality arguments. The investment in consumer representatives is significant including the provision of information and training.

The panel has a responsibility to consult widely with consumers and the broader community and to stimulate debate on the issues. As such it may become the focus for political attention if its findings are at odds with current funder priorities.

CASE EXAMPLE

The South Australian health advisory panels

During the early 1990s, three health advisory panels were set up to inform on health care priorities for state government funded services in the Adelaide metropolitan area. Each panel was composed of a majority of consumers who were not employed in the health care industry. Each panel was supported by a small Planning Unit funded by the state government health department. The panels conducted consultations with their communities and service consumers using a wide variety of strategies including surveys, public meetings, phone-ins, shopping centre displays and interviews, submissions from consumer and other interested groups, discussion papers and provider forums. They were informed by epidemiologists, health services researchers, demographers and ethicists. They debated and discussed the evidence and arrived at three sets of priorities for health care services for each of their regions. They identified not only services which they believed should have more resources, but also other health care activities that could be reduced in order to find the needed savings. Their findings (primarily that mental health services were clearly the first priority for additional resources) were not in accordance with the views of the government of the day and the panels and the planning units were subsequently abolished. However, their findings continued to inform debate and planning decisions in the years that followed.
28. SEMINARS AND CONFERENCES

KEY ATTRIBUTES

Information seeking/consultation. Instigated by organisations to explore ideas/issues. May be costly and so be restricted to those who can pay. Audiences over 20 people. Structured format. Informal or spontaneous input may be restricted, tending to give providers/professionals more air-time than consumers/community.

Seminars and conferences often focus on a broad issue or policy and allow for a range of people to present information and ideas. Participants generally include representatives from relevant government agencies, direct service providers, peak non-government organisations and consumers.

A seminar or conference may be a useful tool to encourage community and consumer involvement in a particular issue and may lay the foundation for greater and more focused participation in the future.

Section 3, Search conferences
Section 3, Workshops
29. CONSUMER COUNCILS AND REFERENCE GROUPS

KEY ATTRIBUTES

Consultation. Structure and role prescribed by organisation. Input to whole of organisation. Made up of consumers who advise the organisation. Need to ensure and support consumer representatives’ links with appropriate constituency. Representatives need to have tenure long enough to learn to be useful, but not so long they become part of the organisation.

Consumer councils have been established by some agencies as a mechanism for bringing together representatives of several consumer groups to participate in service planning and evaluation. Consumer councils are designed to:

- evaluate the current level of service performance;
- advise on new or modified services;
- recommend performance indicators of service quality;
- develop quality assurance procedures;
- research consumer needs; and
- draft guarantees of service.

(Adapted from Kennedy 1993, pp6–9)

Consumer councils and reference groups differ from the organisational committees described below (under ‘Consumer representatives on your committees’) in that these are committees, reference groups etc made up entirely or predominantly of consumers and which are set up for the specific purpose of providing consumer participation. It is essential to do your homework before establishing such a body. You need to be very clear and explicit about the following matters.

- The role of the committee, group etc. Written terms of reference must be prepared. What is the scope of their inquiry and advice? What is their role in the organisation?
- Specify the membership, including who they are expected to represent.
- Who they report to and how?
- How will they be appointed and by whom?
- What is the life of the committee? If it is a standing committee, how will new members be appointed? Under what circumstances can members be dismissed?
- What supports will be available to the committee? Will they have a paid executive officer? If so how many hours of their time will be available? Will members have access to research resources, administrative assistance, photocopying, etc?
- What expenses will be met by the organisation? Will sitting fees be paid?

You need to think strategically about how the committee’s findings or advice will be used by the organisation. Is it ready to hear what your group may come up with? How can the links between the committee and the organisation be made as robust as possible? The future of consumer participation in your service and your service’s credibility with consumers may depend on it.

In short, for this strategy you need to be sure that your organisation has the capacity and the commitment to consumer participation to support the committee and to see it through for the long run. One crucial issue is how you maximise the independence of your group. A committee of tame consumers who are captured by the organisation is of no value to anyone. On the other hand, there is a sad, but predictable, tendency for even the best-intentioned organisation to lose patience with critics who bite the hand that feeds them. In some ways, if you have the opportunity to achieve the same
function from an independently resourced group, you are likely to get longer-lived and more courageous feedback.

**CASE EXAMPLE**

**Terms of reference for a consumer reference group**

The Top End Division of General Practice in the Northern Territory is committed to working with consumers and having them involved in the functioning of the division. This has led to the establishment of a consumer reference group, which has the following terms of reference:

- provide information and advice from a consumer perspective to enhance the role and work of the Top End Division of General Practice;
- discuss and comment on the needs of communities in the Top End and issues related to general practice;
- participate in relevant aspects of the strategic planning of the division;
- comment on programs/projects being developed by the division; and
- suggest and support further opportunities for consumer involvement in projects and activities of the division.

(Source: Top End Project pamphlet)

30. POLICY ROUND TABLES

**KEY ATTRIBUTES**

Consultation. Invitations to discuss policy items. Structured. Convened to advise on the development of specific policy.

Policy round tables are joint planning/decision-making forums between government agencies and representative consumer groups. These forums are often ‘one-off’ and convened to discuss a specific policy. Participants often have distinctive complementary expertise related to the policy.

**CASE EXAMPLE**

In 1998 the European ministers responsible for youth held three policy round tables at which the themes of democracy, participation, human rights and solidarity were discussed. Each round table had a specified focus. The chair of the round table invited the speakers, who were from different parts of Europe, to talk about the issues as they saw them. Common themes were drawn together so that a broad and comprehensive view of public policy issues of local, national state and cross-national relevance was developed. The picture that emerged from the round table discussions gave rise to action. Each round table had a chairperson, a researcher and a rapporteur. The rapporteur was responsible for translating the discussions of the round table into a report for the European ministers.

(see <http://www.coe.fr/youth/english/Intergove>)
31. CONSUMER REPRESENTATIVES ON YOUR COMMITTEES

KEY ATTRIBUTES

Consultation. Informing, training and supporting consumer representatives. Ensuring representatives have a relationship with their constituency. Clarifying representatives’ roles and the terms of reference of the committees they sit on. A medium to long-term investment.

A consumer representative is a person/and or group of people who act on behalf of a consumer group or organisation. They take the consumer perspective. Before you decide that having a consumer representative on your existing organisational committee(s) is a key strategy for increasing consumer participation in your setting, pause and reconsider! Professionals and bureaucrats generally feel comfortable with committees and their processes. They are familiar with using committees to make decisions and resolve problems, but most people are not. Most people find committee processes obscure and initially at least, are likely to feel uncomfortable and unable to contribute effectively. If, after going through the analysis and planning process set out in section 2, you are sure you want a community representative on your committee, then ensure you do it properly. Be aware that putting a consumer on a hospital or health service committee is usually a long-term strategy and always involves reciprocal obligations. Using consumer representatives on organisational committees usually means a significant commitment from your organisation in terms of time, communication, support and often training. Done well, this can lead to considerable mutual benefits.

The following guidelines are adapted from Bringing in the Voice of Consumers (Adelaide Women’s and Children’s Hospital 1999, p38).

1. When a community group provides a ‘representative’ for a committee, the community group, the individual and your committee must all be clear about who this person is representing. It is not possible to have one person representing all members of all communities. A community or consumer ‘representative’ can only hope to provide a view which is from outside or from a non-professional perspective, and to undertake to consult with a limited range of people.

2. Many consumer organisations and much consumer participation research suggests that in general you should appoint two representatives, rather than one to organisational committees. This certainly applies in the case of higher committees and boards of management. The additional costs are marginal. The benefits include a broader range of perspectives and most importantly the opportunity for representatives to gain from mutual support and to more quickly gain the additional confidence needed to speak out and contribute.

3. The committee needs to have clear terms of reference and objectives—that is, it needs to know what it hopes to achieve as well as where it fits in the organisation.

4. Ideally, consumers should be involved in the development of these terms of reference and objectives. In the case of a consumer advisory committee, this involvement is essential.

5. In the case of a consumer representative on a hospital or health service committee, the expected role of the consumer and each other member must be clear and documented.

6. Your consumer representative must know and understand what kind of power the committee has. For example, can the committee make final decisions, who decides whether a recommendation is implemented, are there any other decision-making structures within or outside the hospital which may have relevance to the work of the committee?

7. Ensure that the committee has the resources to fulfil its terms of reference and achieve its objectives—for example, accurate information, administrative support, appropriate advice.
8. Remember that an effective chairperson is critical to the success of any committee.

9. Ask consumers what support they need—for example, out-of-pocket expenses, adequate briefing and information on issues as they arise, someone to discuss difficult issues with. They may also benefit from short training courses. A consumer representative kit should be issued with basic information about the organisation, the committee and how it fits in, etc. In addition, generic resources on consumer representation such as *The little purple book of community rep- ping* (North West Suburbs Health and Social Welfare Council 1993) could be provided.

10. Explore with consumers how being a member of this committee will help them achieve what they want. See checklist for consumer representatives below.

11. It is important to choose appropriate consumer representatives for hospital and health service committees. The personal skills to look for in a consumer representative could include an ability:
   - to analyse an issue and judge its effects on consumers and on different sectors of the community;
   - to see short- and long-term outcomes as well as directions leading from decisions;
   - to negotiate on issues to achieve the best acceptable outcome; and
   - to plan the desired outcomes from a committee.

To do the above, it is critical that the consumer representative knows the background to issues with which the committee deals.

---

Consumers’ Health Forum 1999, *Guidelines for consumer representatives*, 4th edn, Lyons, ACT. (This publication is written for the consumer representative who has been nominated on to committees by an organisation and is an essential resource.)


---

Section 3, Recruiting consumer representatives
32. RECRUITING CONSUMER REPRESENTATIVES

KEY ATTRIBUTES

Consultation. Clarifying objectives for having consumer representatives, developing clear and effective processes for finding and selecting the people you need.

The most important prerequisites for successful recruiting of consumer representatives for organisational committees can be summed up as having clear positions on:

• the role of the committee;
• the role of the consumer representatives; and
• the process you will use for recruitment and selection

before you begin any form of recruitment.

These three should be set out in concise, clear documents setting out the terms of reference of the committee, a ‘job description’ for the consumer representatives and the recruitment and selection process. Once you are clear on these you can start recruiting. In doing so, be guided by the role you have developed for the position. From that you will know the consumer constituency you want the person to represent. If that constituency has any formal organisations then you should approach them to explain the role of your committee and to seek nominees. Don’t ask for nominees on the spot. Leave your offer with the organisation for them to use their own internal processes to identify the person they want to put forward.

CASE EXAMPLE

Learning from our mistakes: recruiting for the board

A large regional health service needed new consumer representatives for its board of management. The board arranged for some of its members to seek representatives from among local community organisations. However, neither the board nor the group of members were clear on the process they would follow. They attended some meetings of community agencies and explained the role of the health service and of consumer representatives on the board. However, on one occasion a person selected himself on the evening, on the assumption that he would automatically be appointed. The person was not appropriate and an embarrassing situation ensued which did little for the health service’s relationship with that community group. For the would-be recruiters the lesson was learned: be clear about your selection process and criteria before you approach anyone and consult with the key people in the agencies you approach. Give them your criteria and selection process and leave them to use their own organisation’s processes to select a nominee if they decide they want to.

If there are no appropriate organisations or existing networks, you may need to advertise using local newspapers, letter box drops, community service radio announcements or whatever seems most likely to reach the population you are after. Remember you are looking for someone who will have good links to the population you want represented. Let everyone know the cut off date for nominations. Provide one person to handle all inquiries for the position. Ask intending nominees to contact that person first so that they can explain the process to them.

Alternatively, interested people can be invited to attend an information session. Provide them with a copy of your ‘job description’ and ask them to explain in writing (no more than one page) why they believe they should be taking the role.
You and your team will need to do an initial sift and cull of nominations (assuming you have plenty). Do this using your ‘job description’. Make a check list of essential characteristics. Discard any applicants who cannot demonstrate they fulfil these requirements. You can interview the rest, either individually or using a group process. Make sure your interview panel is fairly small (maximum three) and includes at least one consumer who is already involved with your service. Have your interview questions prepared before you start the interviews. If no one seems right, then wait and repeat the process at a later date, perhaps using a different strategy for spreading the word. Always mail your unsuccessful applicants to explain that their help is not needed at the moment and thank them for their time. You may also put them in touch with other current or anticipated avenues for participation. Phone (and write to) all those applicants you interview to thank them and advise them of the outcome as soon as possible.

**CASE EXAMPLE**

**Recruiting community members for health advisory panels**

Various strategies were used to advertise advisory panel vacancies including shopping centre displays, the local press, and visiting community groups. Information sessions were held in each of the areas advertising the process and calling for expressions of interest for panel membership. A total of 180 people attended information sessions across the three areas. These sessions informed participants of health care planning strategies, the funding of health services and the role of communities in the decision-making process. In addition they were introduced to priority-setting exercises to provide them with some basic understanding of the task of the panels. As a result 120 nominations were received which far exceeded the 36 panel and 24 proxy positions required. Selection processes were then developed.

Two of the panels used an interview process and one used a group selection process where staff and steering group members selected people after observing their performance in two workshops designed specifically for that purpose.

**Consumer representatives checklist**

This list has been adapted from *Bringing in the Voice of Consumers* (Adelaide Women’s and Children’s Hospital 1999, pp46–7). It is designed so that you or a member of your team can sit down with a prospective consumer representative and talk them through the key issues they must consider in deciding if, and how, they wish to take on the role. Do not succumb to the temptation to skip this one. Getting expectations clear at this stage is crucial to getting good results and avoiding disappointment and conflict later down the track. For each item, you are asking the question of the prospective consumer representative:

1. **What are your goals?**
   
   What do you want to achieve in your community, for yourself or your family and friends?

2. **Can the committee help you to achieve your goals?**
   
   How is your involvement on the committee or board going to help you to do this?

3. **Can it happen within your lifetime?**
   
   It’s OK, sometimes even essential, to set yourself a time limit—even if the goals aren’t fully achieved in that time.
4. Will the committee and the organisation support you to participate?
   Will they provide:

<table>
<thead>
<tr>
<th></th>
<th>Yes/No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Childcare</td>
<td></td>
</tr>
<tr>
<td>Sitting fees</td>
<td></td>
</tr>
<tr>
<td>Travel costs</td>
<td></td>
</tr>
<tr>
<td>Other expenses</td>
<td></td>
</tr>
<tr>
<td>Orientation and background information</td>
<td></td>
</tr>
<tr>
<td>A ‘buddy’ to discuss problems</td>
<td></td>
</tr>
<tr>
<td>Clear information when you need it</td>
<td></td>
</tr>
<tr>
<td>Interpreting</td>
<td></td>
</tr>
<tr>
<td>Consumer respite care</td>
<td></td>
</tr>
</tbody>
</table>

5. Do the expectations of the committee suit you?
   When are the meetings?
   How much work will be involved in consulting with your constituency on committee matters?
   How many hours in total will you have to put in per week/month/year?
   How much reading will there be?
   Do you have the skills required?
   If not, how will you get them?

6. What further support do you require?
   Is there an outgoing representative you can talk to?
   Who supports the committee? Is there an executive officer you can talk to?
   Are there other community groups you can consult with or get support from?
   Are there possibilities for attending courses or learning new skills?
33. CONSULTATIVE/ADVISORY COMMITTEES

KEY ATTRIBUTES

Consultation. Usually up to approximately 15 members. Role to provide input on an issue/subject on the basis of expertise about an issue/experiences. Members can be appointed or elected. Usually limited terms.

Advisory/consultative committees can fall into two types: those that involve direct consultation with representative consumer agencies, and those that seek the participation of consumers disadvantaged by traditional consultation processes. A successful advisory committee is one where participants and the organisation are clear as to the scope of participation and how the advice that is offered fits in with broader decision-making processes. This process is aided by written terms of reference for the advisory committee that spell out the purpose of the committee, the nature of the advice sought, how long the committee will meet and what will happen to the advice given. Advisory committee members should receive orientation and support.

Direct consultation with representative consumer agencies
Representative consumer agencies are often well placed to identify relevant consumer interests and consultation participants. Governments often resource agencies to establish consultative committees comprising members of the agency’s constituency for this purpose.

Seeking the advice of consumers disadvantaged by traditional processes
There may be times when the organisation is seeking the advice of consumers who are not represented by consumer organisations. They may be consumers who live in a particular areas, or who have an expertise based on life experience. In this situation membership is sought through advertisements, word of mouth, networks etc.

CASE EXAMPLE

In the early 1990s Sheffield City Council in the UK used advisory groups to develop the city plan. They established both local area advisory groups and specialist groups. These groups covered the areas of young people, Afro-Caribbean communities, Asian communities, women, elderly people, people with disabilities, and parents with young children. They used a range of formal and informal ways to invite people to participate in the consultation. Once formed, the groups were invited to a briefing session where planners gave them as much information as they required about the plan. The groups then met by themselves, with the support of council staff (ie facilitation, transport and small grants). The groups had the space to consider and formulate views on the plan. Once this was completed the advisory groups put forward their collective views to council members. A total of 160 organised groups were involved in the process. Many people who would not usually get involved took part (Reeves 1997, pp333–40).

34. PATIENT FORUMS

KEY ATTRIBUTES

Consultation. Patients invited to focus on an area/issue. Usually structured.

Patient forums are similar to focus groups in that they can be a useful way of hearing the experiences and ideas of consumers. However, forums usually aim to involve a larger group of consumers than focus groups and can include a small number of staff. They are also a useful method for educating people, sharing information about a specific issue or developing an appreciation of different viewpoints.

Forums can be a one-off event or a series of meetings at which consumers and staff discuss a matter of shared concern. In addition to using forums to gain feedback about the care or service consumers have received, they can also be used to gain wider input into organisational decision-making and planning.

How to make a forum work

Generate a list of people to invite based on the consumers, community groups or internal customers you have identified for this project. Alternatively, you can advertise the date, time and purpose of the forum, using your networks and/or media contacts as potential starting points.

Make it attractive and easy for consumers to attend. Provide a meal or light refreshments, free parking and childcare.

Depending on the topic of the forum, you may want to begin with guest speaker(s) formally addressing the group, providing information and sharing knowledge and ideas. This is a particularly useful approach for decision-making and planning forums. Your process should provide consumers with information and the opportunity to ask questions at the beginning of the forum, and then the opportunity to participate in the development of further ideas or action plans through small group discussion.

You should use an experienced facilitator and ensure there are enough people with group experience to act as facilitators for the small group discussions. The conclusion of the forum should include a clear summing up of the outcomes of the forum and you should ensure participants are kept up to date about subsequent progress.

Women’s and Children’s Hospital 1999, Bringing in the voice of consumers, 2nd edn, Women’s and Children’s Hospital, Adelaide.
PATIENT FORUM AGENDA
Adelaide Women’s and Children’s Hospital

7.00pm Welcome and introduction
   Chief Executive Officer, WCH
   • aims of the forum
   • the WCH’s approach to consumer participation
   Chief facilitator takes over.

7.10pm With the person next to you:
   • list aspects of the WCH’s service that most impressed you
   • list aspects that could be improved

7.20pm Larger group brainstorm
   • on large board list all the impressive aspects and all the aspects needing improvement.

7.35pm In small groups (with facilitators)
   • individuals choose their top three issues for improvement
   • each person tells other members of their small group their top three issues
   • the small group selects the top three issues for their group

8.00pm In large group
   Identify the top (up to 10) issues for improvement by collecting the top three issues from each small group.

8.10pm Break—light supper

8.30pm Back into small groups (with facilitators).
   Each person contributes ideas for ways to improve things.

9.00pm Feedback to large group
(Adapted from Women’s and Children’s Hospital 1999 Bringing in the voice of consumers.)
35. CONSUMER PARTICIPATION POLICY

KEY ATTRIBUTES

Consultation. Supporting consumer participation/consultation/partnership. Consumer participation policies provide an organisational context to support greater consumer participation and guide the development of multiple strategies across the organisation to increase capacity as well as to foster consumer involvement.

This is a rare and valuable creature, not to be confused with the more common consumer rights policy. A consumer participation policy endorses the central role of consumer participation in your organisation’s vision and goals. It lays a foundation for other policies, structures and procedures such as the other strategies described in this section. The following advice on developing a consumer participation policy has been adapted from A Stronger Primary Health And Community Support System. Community Participation in Community Health: A PHACS Information Resource 3 (Aged, Community and Mental Health Department of Human Services, Victoria 1999, pp9–15). In its original form, it aims to provide guidance for boards and CEOs in the development of a community participation policy, but the process is equally applicable to a consumer focus and indeed, one policy properly worded could cover both.

Development of participation policy

Developing and implementing a community/consumer participation policy for the service is the clearest way of ensuring that processes and strategies are put in place to make community participation happen. The process of documenting a policy is also educational for staff and provides an easy point of reference for inquiries from community members about becoming involved with the agency. Developing and implementing a policy for the service is the clearest way of ensuring that processes and strategies are put in place that make community/consumer participation happen, rather than just be talked about.

There are many ways in which a board may establish a community/consumer participation policy. The process adopted by boards will depend upon the particular circumstances of the board and the organisation. It is important that the board identify the outcomes it wants to achieve in establishing the policy. It is also possible that existing policies of the board will affect and need to reflect the development of a community/consumer participation policy. Some mechanisms to help develop a policy include:

• setting up a working group of the board to consult with the community/consumers and develop a policy;
• holding a public meeting to seek input on the process and the content of the policy;
• delegating responsibility for developing a draft policy and consultation on the draft policy through the CEO to a staff member;
• sharing ideas with other organisations—don’t reinvent the wheel;
• surveying service users about their views on what should be included in a policy;
• setting a target date for the draft policy to be considered by the board; and
• engaging a consultant to facilitate consultation and draft a policy for consideration by the board.
What should a community/consumer participation policy contain?

A community participation policy should address the following issues:

- The purpose of the policy should be clear. This is often achieved through a concise statement of purpose or aim. For example, the aim of the policy might be to ensure that appropriate processes and strategies are undertaken by the health service to maximise community and consumer involvement with the organisation in the interests of responsive and effective service and best possible health outcomes.

- The policy should be grounded by a set of principles that reflect the value the organisation places on community and consumer participation.

- It should articulate the organisation’s position in relation to:
  1. Participation in strategic planning for the organisation
  2. Participation in service planning
  3. Participation in service delivery
  4. Participation in health decision-making
  5. Participation in service evaluation
  6. Resource allocation and development

- The policy should state who is responsible for implementing the policy. Implementation is managed on an operational level by the chief executive officer of the organisation.

- The policy should state what measures will be taken to monitor its implementation. For example, the policy might require the CEO to report to the board on a regular basis on policy implementation.

- The policy should state when it will be reviewed.

- The policy should state how it will be evaluated. It is helpful to consider what measures or indicators might be used to evaluate the policy.

Using the Ottawa Charter for Health Promotion

Roe (1995, pp117–8) suggests the Ottawa Charter for Health Promotion (published by the World Health Organization in 1986) as a policy basis for building a range of strategies that are appropriate for all health services that have health improvement as their overall goal. She adds the provision of personal care services, including medical care, to the charter’s original five areas of activity:

- providing personal care
- increasing skills and knowledge
- reorienting health services towards a stronger primary care sector
- supporting individual and community action
- creating environments that support health and well-being
- developing policies that value and support health and well-being.

This model highlights the importance of a consumer and community participation policy because such a policy will contribute directly to all six activities. While community health services often have such policies, we are not aware of any hospitals that do.
Policy statement on consumer participation—a case example
(Source: Illawarra Area Health Service)

The Board of the Illawarra Area Health Service (IAHS) recognises that consumer participation is fundamental in the provision of health services and it will encourage consumers to participate. The participation of health consumers in health decision-making is an essential component of the management of the IAHS.

DEFINITION OF TERMS

Consumer: those who use or are potential users of health services as well as those who may be directly or indirectly affected by health services including the family and carers of patients and clients.

Participation: the process of involving health consumers in decision-making about health service planning, policy development, setting priorities and quality issues in the delivery of health services.

The Protocol of Consumer Participation is made up of the following principles, processes and implementation strategy.

Principles

1. Participation of community members is an essential component of continuous quality improvement and the management of the IAHS and is highly valued.
2. The IAHS will provide opportunities at the local and regional level for health consumers to have input into policy development, identifying priorities, planning of health services and quality issues in the delivery of health services.
3. Health consumers are encouraged to provided direction to the participation processes. The IAHS will support this through consumer access to the board.
4. Communication links between the IAHS and health consumers are an effective two-way process. Information is shared and exchanged with health consumers to enable them to participate effectively.
5. A range of networks between the board, health services and the broader community will be established and maintained and accessible to health consumers.
6. The board recognises the need for resources and support for the consumer participation process to enable effective participation of consumers and consumer groups.
7. Opportunities are provided for relevant training and education for health consumers to assist in their effectiveness as consumer representatives.
8. The board recognises that some communities within the Illawarra have special needs and their input into the health service will be supported.
9. Consumer participation in consultation processes will occur prior to final decisions being made with feedback on decisions being provided to the community.
10. Health managers are encouraged to establish and with their staff be involved in health consumer participation processes aimed at establishing active partnerships.
11. Individual health consumers are acknowledged as advocates from the community as well as being representatives of groups.
Processes

1. The Illawarra Area Health Service will support a network of health consumer forums based on geographic areas.

2. A consumer health council will be supported by the health service. The council’s roles will be to:
   — act as an advisory body on consumer issues to the board
   — act as a coordinating body for consumer forums and consumer advisory committees.

   The council will meet at least twice a year with the board.

3. Board members will be informed of local health forum meetings and invited to attend.

4. The IAHS will support consumer and/or community advisory committees which advise specific areas of the health service, such as the psychiatric services community consultative committees (for example).

5. Health consumers will be involved in identifying the needs of the community and be members of service planning committees from the outset.

6. Health consumers will be invited to participate in annual planning processes such as business plan and quality plan preparations.

7. The IAHS widely promotes the consumer participation processes it supports.

8. An annual workshop/conference will be held for health consumers.

9. Training programs for consumers will be developed and provided on a regular basis.

10. Individual health units will be encouraged to involve health consumers in their service and will be recognised for their effort (eg a quality award for consumer involvement).

11. The protocol will be reviewed at least every two years by consumers and health staff.

Aged, Community and Mental Health Department of Human Services 1999, A stronger primary health and community support system, community participation in community health: a PHACS information resource 3, Victoria.

36. ACCESS POLICIES AND PROCESSES

KEY ATTRIBUTES

Consultation. Formal process. Participation structured. May be part of planning or resource allocation consultations, or may arise out of lack of use of services which providers believe are needed. Various consultation techniques may be used.

If a wide range of population groups use your services in the first place then you will be on the road to attracting consumer participants. This is especially the case for population groups who traditionally have found it difficult to use mainstream services. Part of building your organisation’s capacity for consumer participation is improving the access for those population groups with the lowest health status and the highest needs. This in turn may mean you and your team need to find out how your services might be seen by those groups by going out into the community and seeking out relevant community groups. Organisation policies that make these groups a priority will support this sort of process.

What does the feel and appearance of your health service say to consumers?

The physical environment of your hospital or health service has a major influence on consumer participation. As well as the obvious limitations of access which may exclude some consumers or potential consumers from making full use of your services, physical surroundings give messages to your consumers about how you value you them and how they are expected to behave. Barriers like high desks or counters do not encourage dialogue. Uniforms may be intimidating to some people. Cultural sensitivity can be very important. One community health centre consulted with the local Aboriginal community because they were concerned that Aboriginal people did not seem to be using their centre. They found that the people thought the service was not for them and that they would be made to feel uncomfortable if they tried to use it. The health service employed Aboriginal people to work on the reception desk, involved the staff in cultural awareness training and redecorated its waiting area featuring colours and motifs from the Aboriginal flag as part of a successful strategy to increase the use of its facilities by local Aboriginal communities.

What messages do the decor, colours, furniture or paintings on the wall give to your consumers? Does the environment welcome them and acknowledge their culture, or does it say sit down, don’t get too comfortable and keep quiet?
37. CONSUMER INPUT INTO ORGANISATION/TEAM POLICY

KEY ATTRIBUTES

Consultation. Formal and informal. Includes consumer reps on management committees, planning groups, planning processes, policy development process. Includes consumer advocacy as 'outsiders' to a policy development process.

Alexander has argued that the future potential of hospitals in promoting the health of their communities can only be realised if health planners incorporate the views and interests of health service consumers into the policy development and planning processes. This is because the vital policy debates are about the definition of health and the allocation of resources. Professionals, administrators and bureaucrats should not, and probably can not, resolve these issues without strong consumer involvement. Community health services have taken this process much further than hospitals. They have a consumer focus to critique their own role as an organisation. This has meant responding to such key questions as (Auer et al 1993, p166):

• Are our services meeting the needs of those most in need in our community?
• Who aren’t we seeing and what are their needs?
• What is preventing people from accessing our services?
• Are our services/service strategies designed in the most preventive way or in the way we feel most comfortable with?
• How are our communities involved in the planning, delivery and evaluation of our services?

Strategies used to answer such questions have included:

• analysis of service provision data to show who your service is and is not reaching
• identification of community organisations which may represent the groups you wish to involve;
• community development with disadvantaged groups to enable them to be able to choose if they wish to become involved; and
• consumer planning seminar: representatives of consumer groups are asked to make decisions about the allocation of scarce health care resources between competing health issues and to explain the principles which guided their decision.

In some cases community health services have been able to integrate consumer participation with policy development at the highest level by having their communities elect their boards of management. In this way the annual general meeting and election of board members also serves to articulate consumer views on policy issues.

Hospitals can also incorporate consumer participation into policy development. Auer et al (1993) quote Alexander:

'We used mixed team discussion groups to develop a process which the community and staff could participate in, in order to identify issues to put to the board.'

Assuming there is organisational commitment for consumer input into policy development, a number of strategies are possible. Alexander (1995, p111) identifies the need to develop strategies at a number of levels within hospitals:

• strategic planning: deciding what the hospital should do
• service planning: deciding how the services should be delivered
• service delivery: participating in services
• service evaluation: deciding on and participating in the evaluation of services.

CASE EXAMPLE

An approach to the partnership-in-care project using the Ottawa Charter

Anne Johnson, from the National Resource Centre for Consumer Participation in Health, has suggested using the Ottawa Charter for Health Promotion as a model for policies to support partnerships between providers and consumers (Health Issues 1999, p19).

Build healthy public policy
1. Develop family friendly ward and hospital policies that have a philosophical basis that respects the role of the family in their child’s care and facilitates their participation in care.
2. Ensure partnership-in-care is part of the organisational vision statement and wards’ philosophy of care.
3. Ensure standards of care, which reflect partnership-in-care, are developed which support and calculate costs into nursing practice.

Create supportive environments
1. Ensure ward and hospital environments provide appropriate facilities and resources that enable parents to stay with their child and be involved in care, and respect and incorporate the needs of families who choose to be part of the team caring for their child in hospital.
2. Ensure staff are welcoming of parents and negotiate participation in care.
3. Ensure parents are provided with consumer friendly verbal and written information about the ward, their child’s home management and health needs, and community resources.
4. Ensure parents are oriented to the ward environment and routine.
5. Ensure wards are staffed with the appropriate number of staff trained to work with children and families.
6. Ensure nursing staff work effectively as part of a team, as well as provide appropriate care to individual patients and their families.

Strengthen community action
1. Ensure appropriate feedback processes encourage parents to provide information that will assist nurses, other professional groups, hospital management and executive to gain greater insight into what is working and what is not working.
2. Ensure parents are involved in decision making and encouraged to provide feedback which is used to contribute to continuous improvements in their child’s care, changes to the ward and hospital policies and facilities.

Develop personal skills
1. Ensure staff have the appropriate educational input and management support to develop practice and approaches to service delivery which are more oriented to partnership with parents.
2. Ensure parents have the appropriate knowledge and support to work in partnership with staff.
3. Ensure professional forums are conducted to facilitate sharing of information about partnership-in-care and practice and service delivery changes.

Reorientation of health services
1. Ensure results from research, and feedback from staff and parents, are used to facilitate sustainable changes that will enable staff to work in partnership with parents.
2. Advocate for changes in the broader health system that respect the rights of families to be involved in care to a level of partnership.

Based on the learning from the demonstration project and applying the Ottawa Charter, a definition of partnership-in-care emerged that can be applied to all staff caring for children and paediatric hospitals.
38. FACILITATING MUTUAL SUPPORT GROUPS

KEY ATTRIBUTES

Supporting consumer participation/consultation/therapeutic partnerships. Support to assist consumers on their terms about their issues. Groups can be consulted about service improvement. Clinicians can enter into partnership with groups as expert advisers.

Support groups for consumers are well recognised as an effective and efficient way of giving consumers information, emotional support, increased control over managing their health, access to other services and resources and sometimes a means to make a difference in terms of the health issue for the community as well as for themselves. The management of consumer support groups is the role of consumers and consumer organisations, rather than that of providers. However providers do have a role in facilitating the development of such groups and in ensuring consumers are made aware of their existence and how to make contact with them.

The process by which a support group could be set up can follow these steps:

• Providers become aware of common needs, possibly for information and support amongst a group of consumers.

• Providers consult with consumers informally about their common issues and invite consumers, and possibly representatives of consumer organisations, to a meeting or seminar.

• Consumers decide at the meeting to establish a support group. Providers offer support, possibly with a venue and/or expert speakers for meetings as required.

Community health workers sometimes refer to a ‘community development continuum’ (Jackson et al 1989). Under this model providers dealing with individual consumers who become aware of common needs can help consumers take advantage of and develop support groups. These groups gain strength and autonomy from the providers and the provider organisation and may become involved in campaigns in relation to the health issue they are addressing. This may also lead to a more prominent role in services management or to becoming part of a wider social movement, such as the consumer movement.

**CASE EXAMPLE**

**Heart-Throb**

Heart-Throb is a community exercise and support group in metropolitan Adelaide. Group members employ their own exercise instructor and together enjoy regular exercise, social support and recreational activities. The group evolved from a participatory action research project funded by a health enhancement research grant from the SA Health Commission which was used to trial an alternative paradigm for cardiac rehabilitation for people with angina. People with unstable angina who were currently hospital inpatients were invited to attend a discussion about their rehabilitation needs. This group of people, most of whom had years before modified lifestyle factors and complied with medication regimes, still had frequent admissions to hospital with little change in their clinical status.

Flinders Medical Centre Health Promotion Unit staff played a facilitatory role as group members talked about the day-to-day struggles and fears of living with angina. They felt that having opportunities to share their experiences with others who lived with the experience of angina would be more useful in meeting their needs than attending a short-term rehabilitation program run by health professionals. Using the principles of empowerment, partnership and self-help, hospital staff supported the formation of an ongoing support and exercise group. For its members, anxiety and isolation had been constants and the opportunity for new friendships and ongoing support offered new hope. While the group initially met at the hospital, a venue in the local community was soon found. Hospital staff actively supported the group for the first 12 months, and since then it has received a low level of support from the local community health centre. The group highlights the importance of social support and safe exercise and most importantly, the importance of listening to the people who have the knowledge and experience of living with their disease.
39. NEGOTIATION

KEY ATTRIBUTES

Consultation/partnership. Consumers and providers work together to develop a written agreement as a basis for future process. May be part of a consumer-initiated participation. Requires clarity of objectives and good communication skills.

When consumers participate with providers to develop a written understanding or agreement that will be a basis or guide for future process, negotiation is the key strategy. This is especially the case when the perceived interests of providers and consumers may differ significantly. This section has been adapted from Kennedy (1993).

Successful negotiation operates on the following principles:

- Separate the people from the problem—negotiation means working together to solve the problem.
- Focus on interests, not positions—look at the underlying needs.
- Use objective criteria—the solution should reflect fair, objective standards and procedures.

How do you negotiate?

Rose (1987) identifies the following six phases in undertaking negotiation.

1. Preparation
   - List and prioritise your objectives—what are the advantages and disadvantages of these to the other participants?
   - What are the likely objectives of other participants—what are the advantages and disadvantages of these to the agency?
   - Consider what options both the agency and the other parties have—be aware of how various options will meet the agency’s needs. Is it in anyone’s interests to retain the status quo?
   - Be prepared to negotiate the ‘agenda’.

2. Clarifying objectives
   - Establish those areas where interests and objectives coincide.
   - State the context of the agency’s objectives.
   - State the agency’s objectives clearly and simply.
   - Seek a clear statement of the other participants’ needs. Interrupt only to seek clarification. Summarise their statement and reiterate it. Check for confirmation. Ask them about objectives that they would have expected but have not been stated.
   - Determine the essential elements—even though a specific objective may have been stated, the essential elements could be delivered through a number of forms.

3. Making proposals
   - Identify areas of potential agreement.
   - Offer a proposal with mutual elements, eg if a participant is willing to agree to X, then Y could be considered.
   - If a proposal is rejected, ask the other party for a proposal.
   - Do not agree to a proposal too early. It is better to keep the options open as an alternative proposal may develop.
4. Bargaining

- Bargaining involves the exchange of concessions which should get increasingly smaller. This is usually done in incremental stages.
- Concessions should be directed at the real needs.
- Remember the value of the concessions is relative—that is, the participants may have differing views on the value of the concessions.

5. Agreeing

- Summarise the points the parties have agreed and provide a written record to participants.
- If other participants provide a differing written record, then a final version needs to be agreed on.
- If a firm conclusion cannot be reached, aim for an in principle agreement.
- Thank the parties for their commitment to the process.

6. Following up

- Monitor closely the results or implementation of the agreement.
- Arrange to let all the parties know how the solution is working.
- Notify participants if problems in relation to what has been agreed arise.
- Where negotiation fails to produce outcomes acceptable to the parties, it may be appropriate to utilise a dispute resolution mechanism such as mediation.

---

Rose C 1987, Negotiate and win, Lothian, Melbourne.


---

Section 4, Managing the challenges
40. NETWORKING

KEY ATTRIBUTES

Consultation/partnership. Informal relationship building with people who have common interests or goals. Will include building links to consumer organisations, advocacy groups etc.

Adapted from Bringing in the Voice of Consumers, Women’s and Children’s Hospital, Adelaide 1999, pp57–9.

Networks and networking are critical to service development and change. The term ‘network’ describes the formal or informal groups of people who have common interests or goals. Networking is a technique which ensures that people in the network are kept up to date with information and developments about particular issues.

Formal networks are groups of people who may have regular meetings, forums or newsletters to share information and identify, explore and plan collaborative action on issues of common concern. Informal networks exist throughout organisations and communities. They are the source of information about who is doing what, where and with whom. Informal networks can be used successfully to influence the views (and therefore the decisions) of key people in communities and organisations.

Networking is creating links between people so that it is possible to:
• exchange information and ideas;
• support each other; and
• identify common ground or areas of common concern.

Strategic alliances are about forming networks for action in order to:
• deliver particular services, programs or short-term projects;
• influence policy;
• act on common issues of concern;
• achieve the best use of resources and expertise;
• attract resources/funding; and
• ensure unit or organisational survival.

Alliances might be between:
• units within a hospital or health service;
• a unit and part of the higher education sector;
• a unit (or hospital or health service) and a community based health organisation;
• a unit and a community group or organisation(s);
• individual service providers; and
• individual service providers and consumers (internal or external).

In preparation, believe in the value of networking—ie that the best way of providing the best service is by working cooperatively with others to meet common interests and goals.

1. Consider any contact you make with a consumer (internal and external) as a possible opportunity to get or give information and to expand your network of contacts.
2. Approach consumers in a personal and positive manner. This will help to establish stronger links for the future. Make sure consumers know your name and where you ‘fit’ in your organisation.
3. Take every opportunity to convey your team’s commitment to consumer participation.
4. Record the names, addresses and phone numbers of people and organisations and list any ideas or comments they make as well as the date of the conversation.
5. Keep an ongoing information file—this has the potential to save time and can be used again to build upon your information and networks.
6. Regularly review the list to identify emerging themes.
7. Make a list of all the community groups and organisations/agencies providing services relevant to your work. Review your list.
8. Are there potentially valuable groups/agencies missing from your current networks?
9. If yes, make contact to discover common issues and explore possible alliances.
10. Tap into existing networks such as consumer advocacy organisations, self-help groups, professional and community organisations.
11. Keep your networks informed about what you hope to do, what you are doing, your successes and your challenges or issues of concern.
12. The more information you give out, the more you receive.
13. Networking is about communication. Use the available technology—faxes, photocopiers, electronic mail, web sites, telephone and virtual conferencing.
14. Be clear about the purpose of the alliance. This serves to legitimate the alliance and is the basis for the choices and actions you make together around areas of common concern.
15. Be clear about which areas of your work fall within the alliance and which do not. Establish a clear contract together.
16. Your potential allies may have structures, processes, approaches and values different from your unit. It is not essential for partners to have similar approaches. Alliances can be loose; agreed goals and expectations are essential.
17. Foster a relationship of trust through developing agreed goals which lead to action. You should both share equally the potential benefits and risks; the benefits should outweigh the risks for all groups involved.

Women’s and Children’s Hospital 1999, Bringing in the voice of consumers, 2nd edn, Women’s and Children’s Hospital, Adelaide.

Section 3, Partnerships of consumers and providers for service delivery and planning
41. PARTNERSHIPS OF CONSUMERS AND PROVIDERS FOR SERVICE PLANNING AND/OR DELIVERY

KEY ATTRIBUTES

Partnership. Structured cyclical planning process with specified role for consumers in shared decision-making with providers. Process and outcomes are a shared responsibility. Usually the result of years of development of consumer participation and a strong consumer focus and culture in the organisation.

Joint planning partnerships between consumers and providers are a fairly strong form of consumer participation. It is essential for your organisation and your consumer partners to be clear about how the partnership will work.

The health check for partnerships reproduced on the following pages is a useful tool for doing this.

Partnerships may draw together organisations with differing histories, priorities and cultures. They may involve groups with different agendas and individuals with differing goals and needs relating to their involvement in the partnership. They may also be established very quickly; to respond to local demands or to meet the criteria for, or timetable of, a new urban regeneration funding initiative. Partner agencies may, or may not, therefore have a shared understanding of the goals, purpose or, indeed, partnership structures.

Exercise

The following exercise has been adapted from An Organisation Check for the Barnsley Partnerships, by Val Harris Training. For further information, contact Val Harris Training, 10 Hall Royd, Shipley, West Yorkshire, BD18 3ED, UK.

The exercise may be used either as part of a training session with partnership/network participants or undertaken by members themselves as part of the process of evaluating network/partnership effectiveness. The checklist should be completed by individuals and then discussed by all partnership members.

GUIDELINES: COMPLETING THE CHECKLIST

Satisfaction rating

These boxes (scored 1–4) give you the opportunity to score your level of satisfaction with the quality of the partnership. Number 1 is the lowest rating; 4 is the highest.

Tick box 1 if for you/your organisation, the partnership ‘simply isn’t working’. Tick box 2 if the partnership works, but there is the need for substantial improvement.

Tick box 3 if the partnership is effective, but there is still room for improvement.

Tick box 4 if everything is perfect.

Comments

Use this space to make notes/observations on the reasons for your satisfaction rating.

Action plan

Use this space to suggest options/actions that might improve the effectiveness of the partnership/network.
### DEVELOPING PARTNERSHIPS CHECKLIST


**Part A: Partnership purpose**

<table>
<thead>
<tr>
<th>Description of management area or policy</th>
<th>Yes, no, don't know or not applicable?</th>
<th>Satisfaction rating</th>
<th>Comments</th>
<th>Action plan</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. All members understand the origins of the partnership</td>
<td></td>
<td>1 2 3 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. All members are clear about the purpose of the partnership</td>
<td></td>
<td>1 2 3 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. The values of the partnership have been clearly set out for all members</td>
<td></td>
<td>1 2 3 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. The partnership has a clear identity</td>
<td></td>
<td>1 2 3 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Members are clear about their role in the partnership</td>
<td></td>
<td>1 2 3 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Members are clear about their responsibilities to the partnership</td>
<td></td>
<td>1 2 3 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Members understand the immediate goals/work of the partnership</td>
<td></td>
<td>1 2 3 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Members are clear about the direction of the partnership over the next 2–3 years</td>
<td></td>
<td>1 2 3 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Systems/budgets are in place to support the training needs of the partners</td>
<td></td>
<td>1 2 3 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. The legal status of the partnership allows it to carry out all its activities within the law</td>
<td></td>
<td>1 2 3 4</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Part B: Communications

<table>
<thead>
<tr>
<th>Description of management area or policy</th>
<th>Action Plan</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The community/other agencies know about our partnership and what it does</td>
<td></td>
</tr>
<tr>
<td>2. Information about the partnership is available in plain language</td>
<td></td>
</tr>
<tr>
<td>3. Information about the partnership is available in community languages and other formats, eg tapes, Braille etc.</td>
<td></td>
</tr>
<tr>
<td>4. Members and others receive enough information to help them work with the partnership</td>
<td></td>
</tr>
<tr>
<td>5. There are clear systems for gathering the views of local communities/other agencies on the activities of the partnership</td>
<td></td>
</tr>
<tr>
<td>6. Systems are in place to gather and analyse feedback from local communities and others</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Comments</th>
<th>Satisfaction rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, no, don’t know or not applicable?</td>
<td>1 2 3 4</td>
</tr>
</tbody>
</table>

---

*Improving health services through consumer participation: a resource guide for organisations*

*A Consumer Focus Collaboration publication*
## Part C: Participation and planning

<table>
<thead>
<tr>
<th>Description of management area or policy</th>
<th>Yes, no, don’t know or not applicable?</th>
<th>Satisfaction rating</th>
<th>Comments</th>
<th>Action plan</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. There is a clear process for the partnership to consult with the local community/other agencies</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. The purpose of consultation is understood and contributes to partnership plans</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. The partnership has allocated adequate funds for consultation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Local/community groups and organisations have been involved in identifying needs</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Partnership members are aware of the barriers to participation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. The partnership has identified ways of overcoming barriers to participation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Forward plans reflect the needs/hopes of the local community and others</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. The partnership is clear about its role in wider (city/regional) initiatives</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. The partnership has clear systems for review and evaluation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Improving health services through consumer participation: a resource guide for organisations
<table>
<thead>
<tr>
<th>Description of management area or policy</th>
<th>Yes, no, don’t know or not applicable?</th>
<th>Satisfaction rating</th>
<th>Comments</th>
<th>Action plan</th>
</tr>
</thead>
<tbody>
<tr>
<td>10. The partnership can communicate the results of reviews/evaluations effectively to others</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. There is a clear planning process</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. All members have a clear understanding of systems for resolving conflicts</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. Partnership members have sufficient resources to meet their/the partnership’s objectives</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. There are adequate systems in place to monitor partnership finances</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. The partnership has a clear view of its future financial/resource needs</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. The partnership has clear systems for monitoring and evaluating work</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. Problems can be identified at an early stage</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18. There are systems in place that can minimise(resolve conflict between partners</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19. The partnership reviews progress on a regular basis</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20. Systems are in place to manage the ‘closure’ end of partnership arrangements</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
CASE EXAMPLE

North Yarra Community Health Service Community Liaison Committee

NYCHS was formed in 1993 through the merger of three existing community health centres. The amalgamation was accompanied by major job losses and a decision to focus on the ‘core business’ of delivering treatment services. This meant that many of the local community groups that had participated in the life of the centres now felt excluded and demoralised. The board of NYCHS was concerned and a community liaison committee was set up, initially with three board members from the three localities. A staff member was appointed to act as community liaison worker to support the committee. The community liaison worker spread the word among the various ethnic and geographic communities that the committee would be holding regular public meetings so that the NYCHS board could be kept abreast of local issues in line with its interest in building partnerships for health. The meetings were supported with interpreting, refreshments and transport.

The committee has discussed a wide range of topics since its inception, including:

- mental illness and its impact on families
- the health needs of the community (a community consultation)
- the impact of outworking on families and communities
- drug issues and the development of a local response
- services provided by local councils
- compulsory competitive tendering
- heart disease and how to avoid it
- the role of the police community liaison officer
- women’s reproductive health.

The committee then went a step further when the NYCHS invited representatives of 18 communities who had been involved in the committee’s public meetings to nominate representatives to meet bi-monthly to provide more detailed input into the governance of the health service. Both these meetings and the regular public meetings, which attract over 100 people, provide regular feedback to the service. As one participant said:

‘When you are here (at the Community Liaison Committee) you know that you are not alone, and you feel part of the community.’
42. COMMUNITY DEVELOPMENT

KEY ATTRIBUTES

Partnership. Developmental and flexible. Focus on process as well as outcomes. Scope for creative ways to facilitate participation. Support and partnership with consumers about their own issues. Going where the community energy is.

Community development is a technique based entirely on community participation. With community development, however, the organisation participates in the community rather than the other way around. Community development workers do not deliver health services as such. Rather they work as a resource for community groups, going where the energy is for change on particular issues and working as a catalyst to help those groups organise and build their power to make those changes.

Community development is an ideal strategy for organisations committed to consumer participation—it provides a resource for those consumers who have participated in your organisation to use the skills they have gained to become involved in other health and community promoting projects that go beyond traditional health care boundaries. Your organisation’s community development workers will help to ensure that your links to community groups are kept strong and that those groups who may be socio-economically disadvantaged (and have the highest health needs) also have a voice.


CASE EXAMPLE

We stopped the tannery

The Parks Community Health Centre in South Australia was particularly interested in lead levels in children because of the predominant industrialisation of the area. A group of local residents came together because of this concern with the community’s health. One of those resident activists, Barbara Sedorkin, tells the story:

It was facilitated by a community development worker from the community health centre, but she was very hands off—she just helped us with what was required. We concentrated mainly on the areas which are extremely industrialised and very polluted. They are known for their toxic industries and the lingering, nauseating smells. We’ve got tanneries with horrific smells as well as flies breeding in the decomposing flesh where they drape the skins over sections in an open shed area. Also, we’ve got a factory that deals with leftover meat from butchers—which during hot summer days has got an odour all of its own. And, further down, we’ve also got Brighten Cement which pumps huge clouds of we-don’t-really-know-what into the atmosphere. A great place to live! The council said that there was reason for some concern but they kept saying that it was zoned for toxic industries—so therefore we shouldn’t be here. But of course, as our photographs showed at a forum that was conducted by Enfield Council, there are houses in between tanneries. There’s a house, then a tannery, two houses, a block of flats and another tannery. The people were there before the industry occurred. They had actually bought here when this was all open land. Since that time, all this industry has cropped up around them. Our main thrust was to get the place rezoned (that’s an ongoing battle) to light industrial. We realise that we can’t get rid of industry completely, but at least we want to get rid of the toxic industries or stop more of them coming along.

The group recruited volunteers by letterboxing, advertising through the local newspaper and through the Parks Community Health Centre itself. From its inception the group had 10 to 15 people. The health centre’s role was to act as facilitators. We actually wrote the reports but David, my husband, typed them and the centre gave us assistance with photocopying, postage and media contacts. They also arranged a one-day media workshop so that we would feel more at ease with communicating with press and television.

Our major project from the beginning was to stop a new tannery from being built. We finally took it to the Supreme Court. I was acting on the group’s behalf (although I’ve got no legal training) because we couldn’t afford a lawyer. We apparently caused so much annoyance that the case was dropped. They were going to build a new you-beaut technologically perfect tannery using a blue chroming process. We found the process was problematic for marine life once it was released into the water system and into the sea. It would also cause problems for workers at the proposed tannery. By lobbying, letters of complaint and our scientific report, we managed to sway the council so that they finally voted against it. When we finally went to court, there were six industrialists from the local area who did not want another tannery, the council and ourselves all against the housing trust that owned the land.

The group has a core of about 10, with a range of ages and backgrounds. Because of family or other commitments, sometimes people drop out until an issue comes along that they have a particular interest in. We’re having a meeting soon to work out our future directions, whether we require a membership drive and our future relationship with the centre. Do we want a community development officer and if so what do we want them to do? Other than photocopying facilities and other office support I believe that the group is off and running and doesn’t need any babysitting at all.

(Adapted from Ryan P 1992, Cases for change: CHASP in practice, Australian Community Health Association.)
COMMUNITY CONTROL

KEY ATTRIBUTES

Community control of health care services in Australia is currently limited to some Aboriginal-controlled health services. These organisations provide primary health care based on a high level of consumer and community involvement and integrated with public health and social justice advocacy activities.

Under this model the community elects a board which has the legal authority for the management of the health service. The community, through the board, determines the service’s goals, objectives and priorities. The responsibility for implementing these rests with a manager and their staff. In theory this model represents consumer participation at its strongest. In practice it is very important to ensure that the community is able to express its views to the board on a regular ongoing basis and not just at election time. It is also crucial that the management and professional health care providers of the service do not set their own agenda despite the views of the board and community.

The community controlled model was endorsed by the World Health Organization in the 1978 Declaration of Alma-Ata as the major strategy to achieve Health For All by the year 2000. Some women’s health centres and community health centres developed models which approached community control during the 1980s and early 1990s, but most of these have since been absorbed into larger, more bureaucratic structures such as area health services.

Under the community controlled model the principles of consumer participation and many of the other strategies listed here are especially important. Community control means that the board and management of the service must ensure that their community and consumers are involved in all decisions of the service. It is not optional the way it is in most settings. Community control may become a forum for differences within the community and conflict must be regarded as one of the processes of participation, to be worked through rather than avoided.


Wronski I 1994, Aboriginal primary health care consultancy: report of survey and case studies of Aboriginal community controlled health services for the national Aboriginal health strategy evaluation, James Cook University, Townsville.


SECTION 4: MANAGING THE CHALLENGES

How to use this section

This section shifts the focus from what strategies you use to how you implement them. It provides some hints on how to ensure your work with consumers is sensitive to their needs and helps to build positive partnerships for the future. We begin by looking at how you can get the most out of your strategies by maximising the ability of consumers to be involved in them. Each of the issues discussed represents an opportunity to get added value out of the process by using it as a means of enhancing consumer participation. If the opportunity is taken in each case the result is likely to be an organisation that is more ‘consumer-friendly’ and has a stronger role as a corporate citizen in its community as well as being more responsive to individual consumers. The section concludes with a look at common problems and barriers encountered by health services using consumer participation techniques and how to prevent and/or overcome them, which links with section 6 on frequently asked questions (FAQs).

Maximising the ability of consumers to participate

No matter what suite of strategies you select, you will have identified a group of consumers whom you wish to involve and you will almost certainly have a fair idea of how you expect to contact them. Some of the barriers to consumers really getting involved are structural and physical access difficulties like just getting to hear about your public meeting, or childcare or transport hassles. Others are the less obvious power differential between provider and consumers, and attitudinal and cultural barriers.

One key factor to keep in mind when choosing locations and venues and organising agendas or presentations is how much formality is appropriate. Many consumers feel intimidated and uncomfortable with formal meeting procedures, men in dark suits and up-market venues such as hotels and conference centres. As a general rule, go for the most relaxed atmosphere possible that will still enable the task to be achieved.

Consult with the potential participants about the levels and types of interaction that are appropriate. Are you familiar with the consumer or community groups in your local community, or the health service of your area? Make a time to meet with members of this group and talk with them. Issues to talk about are:

• what approaches would suit them?
• what times are best?
• how long should the meetings or forums go?
• share with them what you have in mind and see if they think it is the best way of enabling participation.

Resources

Resources of time and money are crucial in enabling or holding back participation. Communities that have high levels of people who are unemployed, benefit recipients, aged or disabled, or belong to ethnic groups experience difficulties in mobilising and maintaining impact. If health services are serious about involving consumer and community groups in planning and evaluation, they need to acknowledge that this will not be without cost.

There are a number of things that health services can do to reduce the costs or compensate for costs incurred. This requires thoughtful consideration of what the cost might be to people who are not being paid to participate. Don’t forget you are being paid and resourced to encourage participation. Don’t take people for granted. Some ideas are:

• Assist with transport costs or provide transport. A community health service in Adelaide has a pool of government cars and these are used in office hours to trans-
port community members to appointments and participatory activities. Taxi vouchers are also used to ensure that transport is not a financial burden.

- Provide participants with some office space and use of a phone and copier. Some health services have a room allocated to community use with desks, filing cabinets that lock, notice boards, an answering machine and meeting space for community members and groups to use.

- Reimburse expenses incurred. These may be the costs of phone calls made at home, or other expenses related to the participation that is undertaken.

- Consider a fee for participants. This is one way of valuing the participation that is occurring. Some health services pay a sitting fee on the basis of the state government rate for consultancies. Other use the Divisions of General Practice rate for consumer representatives. Sitting fees are a contentious issue and one that your health unit will need to talk about to come up with an organisational policy.
PUTTING SUPPORTS FOR CONSUMER PARTICIPATION IN PLACE

What are the constraints to participation and the means to overcome them? What are the most appropriate methods to contact participants and to publicise the consultation? Have accessibility requirements been taken into account?

For example:

- Are venues easily accessible by public transport and for people with mobility difficulties?
- Can transport be arranged where required?
- Are meeting times and locations suitable for participants?
- Are the lighting and seating arrangements suitable to the particular type of consultation? For instance, can the room be darkened for slides or seating reorganised for small group discussion?
- Is care for children, older people or those with disabilities required?
- Has adequate notice of meetings been provided?
- Has participation been actively encouraged through personal contact?

Have social and cultural factors been taken into account?

For example:

- Are there barriers to consultation that may affect participation?
- Are there cultural practices and events which may reduce attendance at meetings held at the same time?
- Has support and advice been obtained from the Aboriginal health coordinator on protocols for consulting with Aboriginal communities?
- Has support and advice been obtained from multicultural health workers who have expertise in working with multicultural communities?
- Can the out-of-pocket expenses of low-income participants be met?
- Do meeting venues provide a comfortable and encouraging atmosphere?
Barriers of power, culture and attitude

The differences in social power between most consumers and most providers is formidable. This is especially the case for individual consumers facing a health crisis for themselves or a family member and when their health issue carries with it some social stigma, such as mental illness or HIV/AIDS. Some of the more commonly encountered barriers include:

- unsympathetic attitudes among some staff to consumer participation;
- attitude of passivity by some consumers and unquestioning acceptance of medical advice;
- different values and perspectives about what is important in health care;
- communication problems associated with use of jargon by providers; and
- a lack of adequate resources to support consumer participation and an organisational assumption that it can be done for almost nothing.

Attitudes of staff and consumers

Obviously there is a full range of attitudes to consumer participation among both groups. Effective communication between providers and consumers is often constrained by either or both slipping into patterns of behaving which are not compatible with developing partnerships. In a typical worst-case scenario, consumers may appear to providers to be deferential and apparently inarticulate, or possibly ill-informed and one-eyed. From the consumers’ point of view, providers may be impatient, arrogant, unable to listen and stingy with information. Some consumers (typically older and with less serious illness) may not want to be involved in their own care at all. Before effective communication can take place providers often need to improve their listening skills, and consumers their assertiveness skills.

Consumers may also be aware of stigma. Self confidence is essential for consumers wishing to mix it with the professionals and for consumers of some services such as mental health, just coming forward to be involved may mean facing stigmatisation.

I have so far tried to avoid using the word stigma, but it is the central issue. To come out as a consumer is to take many risks. Many of those who can pass as ‘normal’ will do so. These are often the better educated, more articulate people who could participate without many of these barriers but, quite sensibly, given the climate of stigma, choose not to. Those who do not have this option or who have issues too big for any closet are the ones out taking the risks and they are perhaps the ones who can least afford to do so ...

This makes it doubly hard to identify as a consumer, as people may have fears and reservations about you without knowing anything except that at some stage you have accessed services.


Providers who are supportive of consumer participation sometimes raise the issue of consumer co-option. This term is used to describe the phenomenon of consumer representatives becoming so focused and entrenched in their role with health services and providers that they are no longer representative of most consumers. Ideally consumer representatives should be replaced reasonably regularly to ensure that a wide range of views with strong links to the grassroots contribute to your partnerships over time. However, this decision obviously involves the organisations they represent and also depends on the resources made available by your organisation for ongoing recruiting, orienting, training and informing those representatives. A low level of resources will mean that individual consumer representatives will tend to remain in place for a long time.
Supportive providers also note that having consumer representatives nominated by consumer organisations is no guarantee that they will have had adequate training, information or support for their role. Some may only be knowledgeable about the one issue for which they have been a consumer. Others may lack the skills and confidence to participate at the level required. A stronger focus on recruitment and training could address these issues, and perhaps opportunities exist for collaborative training and support mechanisms to be developed between providers and consumer organisations.

Culturally appropriate approaches

Consumers bring their culture with them to your health service. It is as inescapable as the culture your service brings to them. This is important for consumer participation because multiculturalism is a way of seeing and experiencing other people and processes. The values, attitudes and practices of your team or organisation present messages to people which they interpret through their own cultural ‘lenses’. Sometimes those messages mean that people from that culture will simply avoid your service. In other cases they may get confused or misleading messages. When you invite consumers into your service through your consumer participation strategies you need to ensure that your invitation and the processes that flow from it are sensitive and appropriate to the cultural diversity that is Australia. Your planners should be able to tell you whether your service is reaching your community demographically. If not, why not?

Because cultural barriers are one of the major factors limiting access to health services it is especially important that your consumer participation strategies engage people from those cultures that experience barriers to accessing your health service. You may need to spend more time and resources on reaching those who use your services least.

To get the local Apex Club on your committee may take a letter.

To get someone from the Aboriginal Community Association will take a lot of time, meetings, building relationships and establishing trust and understanding and, if your aim is reducing health inequalities in your community, then it’s going to be worth it.

Listen to what consumers from different cultural backgrounds say about your service. Use interpreters and be prepared to set up culturally specific advisory and/or support groups. Contact community associations and invite their involvement. They may be able to help you establish support groups and to provide appropriate people for committees and boards.

Enabling factors

There are a range of factors that can enable effective participation. These include:

- a diversity of approaches;
- culturally and age appropriate approaches;
- adequate resources and time;
- information and skills for the participants;
- making sure that participants understand bureaucratic structures and the system in which they are participating;
- clear lines of accountability;
- avoiding jargon and communicating respectfully;
- open and inclusive meetings;
appreciating the circumstances of those participating—both that it is hard work, and that certain environments have ways of working that are exclusive and possibly intimidating;

not over-burdening consumers involved and respecting that they have other very important parts of their lives; and

reporting back so that participants know what came from their involvement.

**SOURCE**


**Embracing the opposition**

Within your organisation there will be opponents to enhanced consumer participation. They will have their own reasons and agendas and their own spheres of power and influence. If you wish to overcome this opposition you may find the most effective way to do so is not to take an oppositional stance. Adversarial gestures are likely simply to lead to an escalation in hostilities. Rather, you need to learn from your opposition in order to incorporate it into your strategies. Consider their strengths and weaknesses.

Just what is it about your consumer participation strategies that they find unacceptable? Can you address that, and still keep your agenda? What do you have in common with them? What can you offer them and vice versa?

Deborah McCulloch (1966) cites the following example of what therapists sometimes call ‘making friends with the resistance’.

A public relations man was hired to persuade the public that sugar is good for us. He made a rough cut of a film that showed sugar as natural—a natural part of life, remember it?

Then he got together representative dentists, nutritionists, doctors and mothers and asked them to critique his film, hard. They did. They told him everything that was wrong with it.

So then he went and made a new version of his film incorporating or taking account of all their criticisms, and when it was released, they had nothing to say.


**OVERCOMING BARRIERS TO MEETINGS CHECKLIST**

**Key questions**
This enables you to review your strategies to maximise consumer involvement.

<table>
<thead>
<tr>
<th>Factor</th>
<th>Key questions</th>
<th>How will you do it?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consumers have been involved in planning.</td>
<td>Are you aware of the constraints to participation and the means to overcome them?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Most importantly, have you discussed your idea for this participation strategy with any consumers to see if they think it would be worth attending, and why/why not?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>What are the most appropriate methods to contact participants and to publicise the consultation?</td>
<td></td>
</tr>
<tr>
<td>People are welcomed and can get there.</td>
<td>Has adequate notice of the meeting been provided?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Has participation been actively encouraged through personal contact?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Have people been invited and welcomed to participate?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Do people know why they have been invited?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Do people know who you are and where you fit into the health unit?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Are meeting times and locations suitable for the participants? Have you checked, for example, to see if there may be other events on at the same time which your potential participants may wish or need to attend?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Do the people you are trying to involve have any particular health conditions which may limit their use of certain venues or times? People with asthma, for example, will be wary of going out to a night-time meeting in cold winter weather.</td>
<td></td>
</tr>
<tr>
<td>Factor</td>
<td>Key questions</td>
<td>How will you do it?</td>
</tr>
<tr>
<td>--------</td>
<td>---------------</td>
<td>---------------------</td>
</tr>
</tbody>
</table>
| People are welcomed and can get there. | Are sitting fees or a payment required? Has this been negotiated with consumers?  
Is there childcare? Is support needed for carers, or people with disabilities?  
Is there disabled access?  
Are venues easily accessible by public transport and for people with mobility difficulties?  
Has transport been provided or have transport costs been covered?  
Is the length of time of the activity suitable?  
Are there food and drinks appropriate to the time of day? | |
| Activities/meetings/events are run in a flexible and suitable way. | Have you talked with the right people about what is appropriate and what might work best?  
If it is a meeting, do participants know the ‘rules of the game’, are the agendas appropriate and of interest? | |
| Decision-making processes are open and transparent. | Is it clear to participants where and how decisions are to be made and by whom?  
When invited, are participants clear where this activity/process fits into the decision-making process?  
Is it clear how and when the activity/process will end, and what the process will be for consumers? | |
# POWER, CULTURE AND ATTITUDE BARRIERS CHECKLIST

<table>
<thead>
<tr>
<th>Factor</th>
<th>Key questions</th>
<th>How will you do it?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Power</td>
<td>Does the process support participants to feel more confident and empowered? How do you know this?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Have consumers been given opportunities to learn skills or attend courses or conferences?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Have consumers been put in touch with other consumers who are involved, or have been involved in the past?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Do the professional workers watch out for in-built biases that may exclude consumers (in talk, conspiratorial winks, etc)?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Are agendas hidden or open?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Is the pace one that is suitable to the participants?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Are consumers asked how they feel about the process and whether anything could be different?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Do consumers know the outcomes of their participation?</td>
<td></td>
</tr>
<tr>
<td>Culture</td>
<td>Has support and advice been obtained from Aboriginal health workers or community groups on protocols for consulting with Aboriginal communities?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Has support or advice been sought from multicultural health workers or organisations on appropriate approaches for particular ethnic communities?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Have jargon and technical terms been minimised and fully explained where they are necessary?</td>
<td></td>
</tr>
</tbody>
</table>
### Culture

<table>
<thead>
<tr>
<th>Key questions</th>
<th>How will you do it?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have the appropriate aids been provided to assist in communication—for instance, the provision of assisted listening devices such as hearing loops for the hearing impaired or sign interpreters for the deaf.</td>
<td></td>
</tr>
<tr>
<td>Have visual methods for conveying information such as slides, overheads, charts and diagrams been considered?</td>
<td></td>
</tr>
<tr>
<td>Do terms of language and examples take account of participants' backgrounds and circumstances?</td>
<td></td>
</tr>
<tr>
<td>Are interpreters and the provision of written information in languages other than English required?</td>
<td></td>
</tr>
<tr>
<td>Is the status of the material provided clear to the participants? For example:</td>
<td></td>
</tr>
</tbody>
</table>

### Attitudes

<table>
<thead>
<tr>
<th>Key questions</th>
<th>How will you do it?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do staff involved in your initiative have the values necessary to work as partners with consumers? If not, how can you support them to acquire these, or involve staff that have them?</td>
<td></td>
</tr>
<tr>
<td>Are the consumers that you expect to be involved able to work with staff in a way that ensures mutual respect and partnership? If not, how can you support them to do so and/or involve those who can?</td>
<td></td>
</tr>
<tr>
<td>Are ‘lay expert’ views appreciated as well as professional opinions?</td>
<td></td>
</tr>
<tr>
<td>Are participants provided with information and skills that they require to be involved?</td>
<td></td>
</tr>
<tr>
<td>Has orientation and background material been provided?</td>
<td></td>
</tr>
<tr>
<td>Is there a ‘buddy’ for consumers to meet with to discuss issues and how the place works?</td>
<td></td>
</tr>
</tbody>
</table>

The two checklists used in this section have been adapted from material contained in The little purple book of community rep- ping (NWSH&SWC 1993), and Bringing in the Voices: making things better (Adelaide Women’s and Children’s Hospital 1999).
**SECTION 5: EVALUATION**

**How to use this section**

This section looks at how organisations and health care providers evaluate consumer participation activities in ways that are congruent with principles of partnership. It covers the definitions of evaluation and reasons for doing it, features of evaluation for consumer participation, tools and techniques, resources and useful links.

Evaluation is the process by which we decide the worth or value of something. It involves a process of reflection on what worked and what did not work and using this information in order to make improvements for the future. Evaluation can be done simply. In fact a lot of what health care workers already do is a form of evaluation, reflecting on practice and modifying their practice on the basis of this reflection. An important part of this consumer participation planning cycle is asking how things have gone and ‘whether we made it’ to where we wanted to go.

**Why do it?**

Organisations evaluate consumer participation in health services and programs for a number of reasons. Foremost of these is that reflection on what works and does not work allows the organisation to shape future participation. This information will strengthen evidence about the benefits of participation and inform you of the strategies most likely to support effective participation. Reflection provides the chance to think back on your participation action plan and see how the plan worked in practice. For instance, did you succeed in involving the groups you intended to? Evaluation also enables you to account for the resources committed to participation and establish the case for future resource allocation.

**What is evaluation?**

‘...evaluation opens up the project’s “black box” and sheds light on the operation and dynamics of the project’ (Baum, Cooke & Murray 1998)

Evaluation of consumer participation is a cyclical process. It starts at the point that the organisation begins to plan their involvement in supporting participation. It involves making judgments about the worth and appropriateness of your strategies for participation and reaching conclusions that will inform future practice. Evaluation of the role
of the organisation and its providers in supporting participation must include an analysis of how the organisation defines successful participation. It should specify the values inherent in this definition and be explicit about which stakeholders share these values and which do not. This awareness plays an important role in the design of the evaluation in determining who is involved, the information that is collected and in shaping the way in which that information is interpreted and reported.

Factors to keep in mind when evaluating consumer participation

- Consumer participation by its very nature can be unpredictable. In the course of consumer participation, activities you set out to achieve will often be adapted as you go along. A rigid approach to evaluation will miss much of the significance of the changes that occur because of consumer participation. Furthermore, consumer participation is a long-term commitment and this should be reflected in evaluation processes.

- Evaluation should reflect the partnership between consumers and providers. Avoid falling into the trap of using empowerment ideas for practice and being the sole expert when it comes to evaluation. How consumer participation is evaluated and from whose values and opinion is critical.

- There are many different views of ‘reality’ in any set of circumstances. This challenges the view that there is an absolute truth that can be pinned down and measured. Evaluation cannot avoid being a value-laden activity—which is why you should be explicit about these values.

- Consumer participation is about the complexities of human relationships and power sharing. Evaluation tools need to be both robust enough to inquire and sensitive and respectful to those involved.

Evaluation as dialogue

Yoland Wadsworth (1998) has written much about ways in which human service workers can evaluate what they do. In a recent conference paper she outlines the importance of stakeholders (community and providers) ‘coming to the table’ to talk about ‘that which is of value, merit, worth or significance’ (ibid, p11). She calls this evaluation as dialogue.

An inspiring example is her work over a period of six years with a psychiatric hospital and consumers. When she began her involvement, the consumers and the staff had very different views about the issues needing attention. They also did not share an understanding of each other’s views. They met separately, took notes and exchanged them between the groups. Over time they moved to a position where the staff sought feedback from consumers and than talked to consumers about this feedback. This progressed even more to a point where other ways were established for people to talk with and understand each other. These methods included ward-based trials of consumers working with staff and consultants who acted as facilitators of the conversations and monthly meet-ings where 20 staff and consumers tried out ways to talk to and understand each other.
EVALUATION CHECKLIST

There are many different techniques for evaluation. Consider the following checklist:

- Clarify why the evaluation is being done and how the results will be used. Who is involved in setting the evaluation agenda?
- Establish what level and type of evaluation can be done. Is the timing right to do a formal evaluation? Has the service or activity had time to develop so you can really assess its value?
- Consider the commitments of consumers and providers and the time and the money available for evaluation. Consider the skills of consumers in matters of evaluation. Consumers may need skill development in evaluation and may also have other pressures on them, which will dictate how much time and energy they have for involvement in evaluation. The factors about supporting participation outlined in section 4 also apply to evaluation. These include the provision of childcare, transport, costs to be involved, translated material, respite and so on.
- Determine who will do and manage the evaluation. Determine in partnership with consumers how they may best be involved in the evaluation. Consider also the ethical issues of confidentiality and respect. These issues will shape how you interpret what has happened and what you do with the information collected.
- Plan the evaluation design and the way in which information will be collected. Will you use a method that seeks to understand new things or do you want to check out whether the aims and objectives of a program have been achieved, or both? These purposes for evaluation will be achieved through different approaches.
- Determine how the analysis and reporting will be done. Are there particular requirements of the funder or organisation that will be expected in the evaluation report? How do these mesh with the expectations of the consumers/consumer groups involved? If accountability is foremost to the consumers involved then this will determine what is written up and how material is presented.
- What are the political implications of how and when an evaluation is conducted?
- Ask yourself:
  — how things could be improved
  — how could we do more of what we are doing right?
  — how can we let go the things we don’t want to be doing?
EVALUATION DATA COLLECTION TOOLS

There is a range of tools that can be used to collect data for evaluation. Some of these are formal and planned while others are informal. Both qualitative and quantitative methods can be used.

The type of tool you use will depend on what type of evaluation the organisation requires. Time, money and skills are also determining factors. Providers can collect the data and consumers can also be involved in the data collection. These questions need to be thought through before the tools are chosen.

- Documents—keeping and analysing records such as journals, minutes of meetings, annual reports, newsletters, newspaper reports
- Story telling—sharing the narratives of what happened, why, what this meant to different consumers and other people involved and what can be improved
- Focus group interviews and discussions
- Informal feedback—this can include snippets of information heard or received (eg comments about how consumers experienced a meeting, feedback about how things are run or how consumers/providers feel, ideas about what works or does not work, suggestions for improvement)
- Observation—what is observed and reflected upon along the way (eg whether people are satisfied, happy, angry, quiet, frustrated, whether they attend, speak when they come to an advisory meeting, appear more confident, do not come back, what cultural groups are involved and not involved)
- Face-to-face and telephone interviews
- Self-completed questionnaires
- Photos
- Statistics
- Complaints
SECTION 6: FREQUENTLY ASKED QUESTIONS

How to use this section

In the course of developing this guide, the authors consulted with service providers and found that a number of questions kept arising from those interested in consumer participation. These have been collected and reproduced in this section with short answers and links to relevant parts of the guide and any other resources we are aware of. They are listed in alphabetical order by a keyword.

ACCESS ISSUES

• How do we gain access to consumers who rarely have a say?

We need to make a planned and concerted effort to do so. It is a tried and true reality that those who participate are likely to be better educated and better off than your average consumer. As Bates and Linder-Pelz (1990) put it: ‘The trouble with the pluralist choir is that it sings with a middle class accent’. For health services this is a particular problem, since those with the worst health status and greatest health care needs are also likely to be those with multiple social disadvantage and least voice in the system. Your responsibility is to introduce equity into your consumer participation processes. Essentially this means putting much more effort and resources into reaching those whose voices are not usually heard. It also means ‘working smart’ by being culturally appropriate. This can mean supporting and employing bilingual workers and Aboriginal workers to link with their communities, using their local venues rather than expecting them to come to you, and using different strategies like participant peers working alongside street kids to understand and respond to their health care needs.

Section 4, Managing the challenges

COMMITMENT

• What is our commitment to community participation?

• How do we know how ready we are to go and how far?

It is probably useful to think about this at two levels. The first is: who are ‘us’? Who is the team or group who has the commitment? Is it management? How much of your organisation do they/we encompass? Even if you and a few others are passionately committed to consumer participation, you won’t get far without getting wider support first. This does not mean that you do not work to get things to happen. Experience has shown that small changes can demonstrate the importance of participation and that ‘success can lead to success’. The second question is: how high and wide is policy and resource support for consumer participation? That gives you an indication of how likely the seeds you spread are to produce vigorous change.

Section 2, Assessment
CONFIDENTIALITY

• How can we discuss confidential information in front of consumers?

Confidential information can fall into the realm of organisational information and patient information. In respect to patient information, clear policies and procedures are needed to protect confidentiality. Consumer representatives who may be involved in such discussions should have gone through a process of orientation, training and education that clarifies the rights and responsibilities of their role and includes guidance on confidentiality. If consumer representatives are regarded as part of your organisation, your consenting arrangements etc should reflect that. In most circumstances discussions can avoid the use of identifying information. Consumers may also find themselves in situations (ie board meetings or committees) where they are asked to respect confidential information about the organisation's functioning, such as financial information or yet-to-be-released plans for change. As with any of the members of the committee, the consumer is faced with dilemmas of confidentiality. Again, orientation, training and education that clarifies the rights and responsibilities of their role and includes guidance on confidentiality is required.

CONSUMER REPRESENTATIVES

• Should we have a consumer representative on our committee?

That depends on what you want your committee to achieve and also who the consumers are. It is useful to remember that one consumer representative is almost always not a good idea, especially on a committee of health professionals. Most committees will exist in order to direct or advise on some function of the service, or a health issue. There will be consumers of that function, or concerned with that issue, but they may be internal to the organisation or they may be community members, patients, carers or others. First clarify who the relevant consumers are. Then think about how long a time scale is involved. Often, especially for external consumers, effective participation develops over time. Ask also why you want consumer representatives on the committee. What about other strategies for consumer involvement? They may be more appropriate to your purposes. Go through the planning steps in section 2 before you decide. Then check the strategies on consumer representatives in section 3.

CONSUMER ROLES

• What is the role of the consumer?
• Who are my consumers?
• Who are the consumers we want to see participating?
• Do we agree?

Supporters of consumer participation see the consumer as an active partner with providers in achieving their shared goals. These goals can be about an improvement in individual or family health and well-being, or be broader and may be in terms of population health, community capacity for health or building social capital. You may also be part of an organisation with ‘internal’ consumers such as medical and nursing...
staff being consumers of the biomedical engineering department. Watch the traps inherent in talking about consumers in this way. If you share the view that involving consumers and listening to their feedback can lead to improved services you will identify just who the relevant consumers are and seek their participation.

Virtually all consumers can be involved in some way, at some time, depending on the strategies for involvement. In supporting consumers for representative roles, however, you should think very carefully about what the organisation requires, what room you have to accommodate different views and what you are offering. In short, be very clear about the role of the committee, role of the consumer representative and the parameters of the participation. If you do not have agreement across your organisation as to the role of consumers, you should ensure that you offer involvement that you can deliver on, within the specified parameters. You should also continue to have those discussions within the organisation to develop an agreed position on consumer participation and to formalise that in a written policy.

Appendixes A, B, C

Section 4, Managing the challenges

COST

• Where are the funds coming from?
• How do I find them?
• Do we have to pay?

Consumer involvement should be part of the normal costs of services just as occupational health and safety or quality assurance are. However, when public services generally, and health services especially, are under tight financial constraints, advocates of consumer participation may be told they are in the position of having to argue for resources that can only come from reducing service provision.

Consumer participation does cost, not much, but it does cost—and if resources are not adequate, then results will suffer. Because the benefits of consumer participation are for the whole organisation, the organisation should be encouraged to regard consumer participation as a priority worth funding. One sure-fire way for managers to build resistance to the ideas and values of consumer participation is to instruct their teams to institute consumer participation with no additional resources.

This resource guide does not tell you how to find funding. It does, however, provide some evidence you may want to use in arguing for those funds. At a broader policy development level, some providers have suggested that funding formulas could be developed that reward strong consumer participation, just as case mix rewards throughp
DIFFICULT CONSUMERS

• How do I handle the really difficult consumer?
Carefully, with patience, consistency and clarity. Some consumers may be motivated by anger over a perceived injustice done to them by your organisation or by some other part of the health care system. Others may be focused on a single issue. Here are some pointers:

— Ensure their roles and responsibilities have been made clear. Do not allow uncertainties or ambiguities to set up unrealistic expectations. Explain the organisation’s position and the limits of consumer involvement very clearly.

— Be a patient and good listener. Hear and acknowledge what they are saying—and acknowledge you understand they are angry and disappointed and why.

— Consider what they are saying, not just how it is said. They may be unreasonable. They may be very distressed. They may be all these things and still have a valid point. Try to avoid a win/lose situation as this does not leave much room for the consumer to feel in any way ‘empowered’.

— If the person is a representative for an organisation, take the issue up with the organisation. Explain to them your difficulty in working with the person. Make it their problem as well as yours.

Read up on communications skills and maximising consumer ability to participate.

DIFFERENT PERSPECTIVES

• Aren’t we all consumers?
Clinicians and administrators sometimes suggest that specific consumer input is not needed as they themselves are also consumers and can somehow put on their consumer hat to get this input. While empathy with consumer viewpoints should be encouraged, this argument fails to recognise competing perspectives, interests and degrees of influence. A provider is primarily driven by the interests and experiences he or she has and cannot have the perspective of a consumer who approaches the system from a user’s perspective. Unfortunately it is not as simple as switching hats, and something important to a consumer may be taken for granted by a provider or administrator and vice versa.

DISAGREEMENT

• How do we respond when consumers put forward ideas we don’t agree with?
• What if they ask for something we can’t afford?
• What if their agenda and that of the organisation are incompatible?
• How do we align consumer participation with the overall direction of the organisation?

When consumers put up ideas you don’t agree with, be pleased. It probably means you are getting input you could not have got without consumer involvement. If you have set up the process properly the consumer view will be considered along with others and after exploration and discussion, a decision will be made. Because you have made the process clear and the rights and responsibilities of participants are all up
front, there should be no problem. If consumers are asking for something you can’t afford, it’s because you didn’t tell them what was in the budget to begin with. If the process was transparent they would not be asking you for unrealistic outcomes. They might, on the other hand, be lobbying the government to get your organisation better funding.

You must do everything you can to ensure that the consumer agenda being put forward is well informed (including information only providers will have) and representative of the wider range of consumers and community. If it is, and your agenda and the agenda of your consumers are incompatible, your organisation will not survive long in its current form. Your organisation exists to meet the needs of its consumers, not the other way around. The real question is ‘how do we align the organisation to encourage consumer participation?’

Appendixes A, B, C

EVALUATION
• How do we evaluate the status of consumer participation?
Consumer participation can be evaluated in the same way as other services and activities. Indeed, it is important that the same principles which inform your practice also shape how you view and act to evaluate your work. Always ensure the evaluation includes the views of consumers on the value of the process and outcomes.

Section 5, Evaluation

EVIDENCE BASE
• Is consumer participation evidence based?
Yes, there is ample evidence that consumers who are more active in planning and implementing their health care have better health outcomes. These are mediated through better-informed diagnosis and treatment and a beneficial effect of increased power in health care decision-making. See section 7 for links to evidence.

Section 7, Resources
GETTING IT RIGHT

• How do I get it right?
• How do I get a tick for consumer participation?

Read the resource guide. Talk with your team. Hold a meeting. Decide on your strategies. Do it. There is no right way to effect consumer participation. There are no perfect strategies. The nature of consumer participation is that you and you consumer partners will learn by doing. The process will evolve with you. It should be flexible and dynamic, but within clearly defined guidelines, which of course you and your partners can change down the track if that seems appropriate. You get it right by doing it together. You are not alone.

Section 2, Assessment and planning

INCREASING LEVELS OF PARTICIPATION

• How do I move from consultation to implementation?

Your consultation or involvement with consumers provides you with insights about your organisation and its services. How and if those insights are translated into changes depends on a number of things. Firstly, does your organisation have the capacity to hear and act on what consumers have said? Your consultation process should have been managed so that you and the consumers have a clear understanding of what change the organisation sees as possible from the consultation. The organisation should have made a commitment to the process and acceptance of its outcomes on the basis that they fall within these previously agreed limits.

If, for any reason, your organisation is not able or willing to follow through with implementing the findings of the agreed process, you may need to take an incremental approach. Are there lesser levels of implementation that may be possible? Is there a further process of consumer participation or partnership with additional stakeholders that could move implementation further on?

You may find it useful to consider the management micro-climate you work in. If there is little support for implementation of consumer participation strategies or findings in one area, you may want to look for a more supportive management environment elsewhere. One of the positive things about the complexity and fragmentation of our health care services is that this also means they include a wide variety of management styles and values.

DEALING WITH DIFFERENT VIEWS

• How do we work with consumers groups with different points of views?

There will always be a divergence of opinions across consumers (and providers, for that matter). What is important is to explore and understand that divergence and find out why it exists. Why might some sorts of services be more important for some groups rather than others? Use your communication and group skills to tease out the real points of agreement and difference. What are the underlying needs and values that are driving the differences? That is where qualitative strategies such as in-depth interviews and focus groups are really useful. If you can get down to that level you have a much greater chance of developing a consensus for moving forward. At that point you may want to use negotiation skills to work out a written resolution, or people may be able to accept the existence of a difference. There are no guarantees. Make sure that you show respect for the values and views of all participants, even if at the end of the
day, your organisation will not act on them. Most people will accept this, just as they accept that an election result will not necessarily go the way of their vote.

Section 3, The tools catalogue, Focus groups, In-depth interviews, Negotiation
Section 7, Resources

ENGAGING CONSUMERS

• How do we engage one-time users of services?
  Depending on the nature of the contact and the consumers, telephone or postal surveys may be possible. If it is in relation to a particular service, such as accident and emergency, you could conduct a telephone survey (say a random sample of users over the last three months). You could then follow up for more qualitative detail by using in-depth interviews with selected consumers and/or by recruiting a focus group from those surveyed to explore some of the issues that emerged in the survey.

Section 4, The tools catalogue, Surveys, Focus groups, In-depth interviews

HOW DO I BEGIN?

As this guide explains, assessment and planning are essential before launching into consumer participation. Section 2 provides information on the steps involved in planning and selecting strategies for consumer participation. Go through the ten steps outlined in section 2. By the time you have completed step 10 you should know what to do to make a start. If not, go back and go through sections 1 and 2, doing all the exercises and checklists.

Section 2, Planning

I’M ONLY ONE PERSON—WHAT CAN I DO?

• How can consumers help me to achieve our goals?
  Network. Get support. Find like-minded people in your organisation. Form alliances. Find funding. Read sections 1 to 4 of the guide and talk to your colleagues.

Sections 1 to 3
Section 3, Networking
INFLUENCING MANAGEMENT

• How do I ‘manage up’?
  1. Provide models of good practice in consumer participation through focused, time limited project work so that you can demonstrate the real benefits in terms of service improvement and health outcomes.
  2. Use your networks to build strategic partnerships so that your allies will help to convince your managers of the need for consumer participation.
  3. Keep your managers informed of the developments in consumer participation at other highly regarded health service organisations.

• How do we get managers (at a range of levels) to come on board?
  1. Build consumer participation responsibilities into managers’ job descriptions.
  2. Identify consumer participation performance indicators and specify them as management goals.
  3. Organise seminars for managers on how to manage using consumer participation.
  4. Provide models of good practice in consumer participation through focused, time-limited project work so that you can demonstrate the real benefits in terms of service improvement and health outcomes.
  5. Use your networks to build strategic partnerships so that your allies will help to convince your managers of the need for consumer participation.
  6. Keep your managers informed of the developments in consumer participation at other highly regarded health service organisations.

   Section 3, The tools catalogue, Human resource management, Training, Projects, Networks

INFORMATION

• What information do we need to provide to consumers to enable them to be effective contributors?

The answer to this question depends on what your expectation is of ‘contributors’. The greater the degree of participation, the greater the information provided and the greater the potential contribution from consumers. Some strategies, based on information collection such as written surveys, may require the consumer to be given very little information. At the other extreme, if you want shared control of a service, than consumers need just as much information as their provider partners—and even more training and orientation. Look over the strategies table in section 3. As you move through the table more information is needed as the level of participation increases.

Section 4 shows how information needs to presented in ways that are appropriate and accessible for the consumers concerned.

   Section 3, The tools catalogue, Table of strategies
   Section 4, Managing the challenges
LETTING GO
• How do prevent consumer participants from becoming dependent on the organisation?
• How do I disengage from consumer participants at the end?
• How do I let consumers go when the money runs out?

Consumers who participate in your organisation rightly expect their involvement to be a two-way street. They are working with your organisation for a variety of purposes and they should also be getting some of their own needs met. Sometimes the interaction can get out of balance. If the parameters are not clear, or if particular consumers continue as representatives for a very long time and this role becomes central to their lives, disengaging may be more difficult. This is particularly the case if there has been consumer co-option, where the consumer starts to identify more as part of the health services than as part of a consumer constituency.

Your organisation can minimise this problem by having very clear roles and responsibilities for consumer representatives, including fixed terms of office and procedures for appointing and removing members. A continuous process of recruitment and training can provide a pool of potential consumer representatives so that new people are always waiting and the risk of co-option is dramatically reduced. Of course this means a resource commitment, but you get what you pay for.

If you have consumers involved in a project which is limited in time and funds, your participating consumers need to know this from the outset. The secret to avoiding disappointed or angry consumer partners when the money runs out is to be totally honest from the outset about the funds and any other limits to their involvement that you are aware of. They may choose to lobby your organisation or your funder, and they have every right to do so, but if you have avoided setting unrealistic expectations you will avoid unnecessary disappointments. Your consumer participants are your partners in service development. If you are keeping information from them you are not treating them as partners and you are unlikely to get full value out of the partnership.

KEEPING CONTROL
• How do we contain consumer participation?
• Will it open a Pandora’s Box?

Each consumer participation strategy and your wider organisational approach to consumer participation is controlled by your policies and procedures. You avoid getting out of your depth by only going in as deep as you want. You specify just how deep that will be to consumers and providers before you implement the process of information collection, consultation, partnership or whatever. Consumer participation is not the same as consumer control. Involving consumers in the planning, implementation and delivery of services is not going to lead to a consumer driven chaos any more than the right to vote has led to anarchy.
MEETINGS

• I held a meeting and no-one came.
• How do I get them to come?

Why did you call a meeting? Were there other strategies that might have been more appropriate? There could be a lot of reasons why consumers did not attend, especially if other needs had a higher priority. First, review section 2 and check that a meeting was the best option.

If a meeting was an appropriate strategy, check the following: Who did you want to attend? Was your publicity well designed and delivered? Were the venue, time, transport access etc acceptable to the people you were trying to reach? Did you ask them beforehand? Was the atmosphere right? Was the meeting you planned culturally acceptable to the consumers? Were interpreters provided? For more detailed checklists, go to section 4. Follow the guidelines to see if a meeting is the best option and then use the checklists to maximise involvement.

ORGANISATIONAL STRUCTURE

• What do we need to change about structures and the way we do things so those consumers can be effective?

We need to listen and we need to be ‘response-able’. Health care services are often steeped in bureaucratic traditions that obstruct consumer participation. Features may include:

• hierarchical structure
• focus on professionalism, economy, efficiency, regular routine tasks
• rules and regulations
• maze-like structures
• bureaucratic concept of patients

Health service organisations often have fragmented structures. By making our services more open to consumer input at all levels and across all departments and divisions we encourage system-wide dialogue and out of that dialogue come the ideas for changes to structures and processes that enable consumer focus to develop. Trying to make changes to organisational structures may be too hard in the first instance. Build in a variety of consumer participation strategies into your existing structures and then work with the ideas for structural reform that emerge. This way consumers become partners in that change process right from the start.

Section 2, Planning
Section 3, The tools catalogue, Administrative procedures
Section 4, Managing the challenges
PARTICIPATION AT THE CLINICAL LEVEL

• How do we involve consumers at the clinical level?

To involve consumers in this area you must have the support and involvement of key members of your clinical team and agreement on the approach you will take as a team. The following 10 steps provide a guide:

1. Provide the individual and/or carer with information which describes the nature of care, reasons for care, duration of care and possible outcomes.
2. Invite the individual and/or carer to participate in their care.
3. Negotiate with the individual and/or carer what care will be provided.
4. Identify the roles that the health professional and the individual and/or carer will take on in the provision of care.
5. Provide information and education to the individual and/or carer to support the knowledge and skill needed to safely and confidently provide care.
6. Provide guidelines as to what changes in the condition of the adult or child need to be reported to the health professional.
7. Provide access to appropriate resources to the individual and/or carer to be able to implement care.
8. Identify with the individual and/or carer any other support they require to effectively participate in care.
9. Regularly reassess the level of individual and/or carer participation and renegotiate care as appropriate. Decide how regularly with the individual and/or carer.
10. Document individual and/or carer participation in the patient’s unit records.

Section 3, Partnerships of consumers and providers

RECRUITING

• How do I find consumers (especially rural/remote)?

Consumers are the people who use your service and the community that depends on it being there. They shouldn’t be too hard to find. The real question is: ‘How do I consult with them?’ Many consumers won’t want to join your advisory committee but some will. They also may not feel as though they have much to contribute. They may need to have the role described to them and to have assistance in identifying what skills they can bring to the committee. However, there are many other ways to involve consumers. In rural and remote settings where people must travel a long distance to use a service and are not interested in coming in to town for committee meetings you need a different approach. For example, you could do a series of in-depth telephone interviews conducted in the evening when people may be more likely to have the time.

First think about why you want to involve consumers and which consumers you are trying to reach. Go through the steps in section 2 and select strategies appropriate to your needs. If you want to recruit consumer representatives to your committees, then check out the advice in section 3 on recruiting consumers.

Section 2, Strategy planning
Section 3, The tools catalogue, Recruiting consumer representatives
REPRESENTATIVENESS

• How do we know they’re representative?

By checking their constituency. You should know why your consumer representatives have been sought out in the first place. You should have a specific population group or perspective you are aiming to gain from them (such as young people with non-insulin-dependent diabetes, for example). They should also be able to demonstrate a constituency. This could be formal (‘TeeNiddm Inc.’) or informal such as knowing a network of others with the same problems and with links to organisations or other networks. To check out your consumer representatives’ constituency, ask them who they have consulted with in reaching their opinions and what the views of others have been on the issue. If they represent a formal organisation ask them about that organisation’s position on specific issues.

Section 3, The tools catalogue, Recruiting consumer representatives
Section 4, Managing the challenges

RESOURCE ALLOCATION

• How do we involve consumers in resource allocation?

To do this, you first need a resource allocation process of which they can be part. That process should be ‘rational’ and transparent. The criteria used to make decisions, the information provided to the decision-makers, their process and outcomes should be open to public scrutiny. Consumers should be involved in such a process. Consumers working at this level need considerable orientation, training and information. They should have input from clinicians, evaluators and epidemiologists. They also need resources in order to consult with the wider community, because resource allocation affects the whole community, not just specialised constituencies. Public forums to float various broad resource allocations options may be useful. There are a number of strategies in section 4 that could be relevant.

Section 3, The tools catalogue, Consumer councils, Input into needs assessment, Delphi technique, Search conference, Partnerships, Policy round tables

SUPPORT

• How do I get support for my role in promoting consumer participation?

This is challenging, but essential, especially if you are an isolated advocate of consumer participation. Develop and use your networks. Seek out sympathetic people in your health service. If you cannot find support in your own team or organisation, find it from colleagues in other organisations. Use the telephone, use email. Use the National Resource Centre for Consumer Participation to contact people in other organisations who are trying to do what you are. Talk to them.

Section 3, The tools catalogue, Networking
Section 7, Resources
SUSTAINABILITY

• How does an organisation maintain and sustain consumer participation processes?

Organisations have a crucial role in initiating and maintaining consumer participation processes. They often act as catalysts to begin the process (though of course it may be initiated by consumers themselves) and they have a continuing role in providing the essential resources and facilities to keep it running. However, it should be expected that their investment will be greatest at the beginning and scale down to a maintenance level over time as consumers and consumer groups come on board. One of the most important activities for sustaining consumer participation is ongoing orientation and training for consumer representatives. By having a range of consumer participation strategies running, consumers have the opportunity for involvement at all levels, from volunteers driving patients to clinic appointments to sitting on the board. A continuous training program also means there is a pool of consumer representatives able to work with you at a high level of understanding and team skills. The problem of representatives who remain in place for years and lose contact with their constituency is also minimised. There are also a number of practical and cultural issues which, if addressed, increase sustainability.

Section 4, The tools catalogue, Consumer representatives
Section 5, Managing the challenges

TECHNICAL

• We’re talking about strategic/technical issues—what can a consumer contribute?

What the consumer can contribute is an appreciation of how the changes in treatments or services associated with the strategic and technical issues may affect outcomes. A consumer representative who is in touch with their constituency and who has the training and information to take a broad view based on improving health outcomes should be able to appreciate the likely appropriateness of technical changes. After all, there will be other professionals in the group who will not fully understand some of the technical issues too. A consumer view should inform technical and strategic choices, and should also monitor the impact of those choices and report back.

Section 3, The tools catalogue
Section 4, Managing the challenges
TIME

• Where do I find the time?
   If throughput and cost control remain the dominant drivers for your organisation, it will be difficult. Consumer participation does take time and the real rewards also require a long-term commitment. If you do not have the time and your managers will not give you the time, then it may be best to focus on building a policy foundation that will give consumer participation legitimacy in your organisation. Once that is done your managers will have to find time for consumer participation. Review the strategies on building capacity for consumer participation, especially developing a consumer participation policy.

Section 3, The tools catalogue, Developing a consumer participation policy

VOLUNTEERS

• How much can you expect from volunteers?
   Ask them! There is no reason why volunteers cannot be linked into a seamless continuum of consumer participation right through to chair of the board, provided the policies and supports are in place. See the FAQ on sustainability. Review the strategy on volunteers in section 3.

Section 3, The tools catalogue, Volunteers

WHAT IF ORGANISED CONSUMER GROUPS ACT AS GATEKEEPERS, EXCLUDING OTHER CONSUMER VIEWS?

You have a problem. If you suspect this may be the case, try to find out if the gate can be kept open through better communication, training and support. Section 4 on 'Managing the challenges' may be of assistance. You can also use some of the strategies in section 4 to check out other sources of consumer views for the particular constituency of concern. If they are not congruent with the views expressed by the representative, you should be asking why. If you are aware that organised consumer groups and the consumer representatives are not able to represent the constituency you are seeking and/or, lack the knowledge or skills to contribute usefully, then you should raise the issue with the person concerned and with the organisation. Do not forget that the consumer group has its own life and identity outside your organisation and that a respectful dialogue is important at all times. There are plenty of precedents with service providers and large organisations acting as gatekeepers. You may also want to contact other consumer groups and discuss the issue of representation with them. However, just because a view expressed by a group or representative does not correspond with your own or that of the rest of the committee, it should not mean that you presume it is not representative of other consumers. Do your homework carefully on this one.

Section 3, The tools catalogue, Consumer representatives
Section 4, Managing the challenges
WHAT IF YOUR CONSUMER REPRESENTATIVES AREN’T PERFORMING WELL?

What you do about this depends on why it is happening. Talk to the person. Ask them how they are finding their role. Do they need additional training, information or support? Do they find the structure or processes of the group or committee are causing them problems? Can these be addressed? Do they have another consumer representative they are working with? They should. If you have addressed these and still have a problem, talk to them about their constituency. What contact do they have with it? Are they linked to a formal organisation? Have you talked with them and the person about how you could improve their representation? If they are not performing and know it and you have done all the above, it is unlikely that they will want to continue in the position. Is there an alternative role that would be more suitable that you can offer them? If the problem persists you need to consider how long the person has to run with their appointment and whether it is worth trying to remove them first. Hopefully you have done your homework and have a clear statement of the roles and responsibilities of the consumer representative which includes term of office and procedures for appointment and replacement.

Section 4, Managing the challenges

WHAT CAN A CONSUMER TELL US THAT WE DON’T ALREADY KNOW?

Consumers are the experts on how treatment and other services are received and experienced. They can tell you about how different social and environmental settings impact on the effectiveness of services. They can tell you why some services get used and others don’t. They can tell you how it feels to be on the other side.

But this is only one part of the value of involving consumers. The point is not just what we as providers can learn from consumers. Rather it is about how we can work with consumers as co-producers of health outcomes, or partners in health development. That means consumers take on a more active role in their own health care and in the planning, implementation and evaluation of health care services. In that role they are informed by their own experiences and networks, and by the expert knowledge of providers. Providers also change their role in response to information from consumers so as to make services more appropriate to consumer needs and preferences. The result is a win-win situation, with more responsible, empowered and healthy consumers and wiser, more grounded and outcomes-focused providers.

Section 7, Resources

WHAT’S THE BEST WAY?

There is no best way—only principles and practice and ongoing dialogue. Each organisation will require its own tailor-made solution. Refer to the FAQ on ‘How do I get it right?’
WHERE IS THE HOME FOR CONSUMER PARTICIPATION IN THE ORGANISATION?

At one level this question is a bit like asking where is the best place for women in the organisation ... and the answer is of course, everywhere. There are so many different strategies and techniques for consumer participation that it can be practised at all levels and across all departments. And doing this has a bonus. The strategies at various levels reinforce and complement each other in a synergistic way. You get more outcome for your investment and there is such a range and a culture of consumer participation that the quality of consumer input improves as consumers learn with practice along with their provider partners.

However, the question has another level which is really about who or what in the organisational structure should be responsible for implementing an increased consumer focus. The answer is the CEO. While the responsibility may be delegated to quality manager or a consumer participation manager, they should report directly to the CEO and should be part of the organisation’s executive. All this should be specified under the organisation’s consumer participation policy.

Section 3, The tools catalogue

WE CONSULT WITH CONSUMERS EVERY DAY—WHY DO WE NEED ONE ON THE BOARD?

We do it because:

- It works. Consumer participation leads to better health outcomes. See section 7 for the evidence.
- It helps us to improve the quality and effectiveness of our services, both for individual consumers and for the population who use us.
- It’s fair. People have a moral right to be involved in important decisions that impact on their lives.

A consumer on the board (in fact there should be at least two) provides a perspective that you will not get through dealing with consumers in a clinical setting. And you need more than just a token consumer representative because issues for consumers are complex, diverse and dynamic.

Section 7, Resources
SECTION 7: RESOURCES

1. LINKS

There are a number of sources of information about community/consumer participation. A key link is the National Resource Centre for Consumer Participation in Health. It is a clearinghouse for information and assistance about consumer participation. The centre will be able to advise about other resources which have been funded through the Consumer Focus Strategy. These include a stocktake of education and training resources to support consumer participation, a review of models of providing access to information for consumers, and research into doctor-patient communication. The resource centre is located at Room 517, Health Sciences Building 2, La Trobe University, Bundoora, Victoria, 3083; phone: (03) 9479 3614 and (03) 9479 3895; fax: (03) 9479 5977; email: m.wohlers@latrobe.edu.au.

There are research units/health information and advocacy organisations which provide useful links. For example:

- **Health Issues Centre (HIC)**, an independent health policy and research centre. It has a library which is open to the public from 9:30–5:30pm, Wednesday to Friday. They are located at Level 11, 300 Flinders Street, Melbourne, Victoria, 3000; phone: (03) 9614 0500; web site: http://www.vicnet.net.au/~hissues

- **Consumers’ Health Forum**, an Australian national peak organisation providing a voice for health consumers in national health care issues. It is the author of a very useful document *Guidelines for Consumer Representatives*. It is located at Suite 3, 3–5 Phipps Close, Deakin, Australian Capital Territory, 2600; phone: (02) 6281 0811; web site: http://www.chf.org.au

- The **South Australian Community Health Research Unit** provides research and evaluation support and advice to a range of people working in the area of primary health care. It is located at The Flats, Flinders Medical Centre, Bedford Park, South Australia, 5042; phone: (08) 8204 5988; web site: www.dhs.sa.gov.au/sachru

- The **New South Wales Department of Health** has copies of major documents and resources on consumer participation. The Health Improvement Branch and Health Public Affairs have produced a resource kit on community consultation and participation; phone: (02) 9391 9815.

- The **Gilmore Centre** (Charles Sturt University, New South Wales) encourages collaborative research and education and training in the area of rural health with specific emphasis on consumer health, consumer participation and empowerment, mental health, youth suicide prevention, health service delivery, indigenous health, health service management, rural public health, and support to the rural health workforce; web site: http://www.csu.edu.au/research/gilmore/interest.htm

- The **Health Consumers’ Council WA** is a community based advocacy organisation with state-wide responsibility. The Council may be contacted by phone: (08) 9221 3422; email: hconc@iinet.net.au; or post: GPO Box C143, Perth WA.

You can also make contact with university libraries or the local health department libraries.

2. PRACTICAL KITS AND ‘HOW TO’ GUIDES

Aboriginal Primary Health Care Project 1994, *Draft Protocols for Consultation with Aboriginal Communities*, Far North Queensland Division of General Practice.

ARTD Management and Research Consultants 1997, Consumer Feedback Package, A self-contained guide and set of tools to assist general practices to manage research projects to provide systematic consumer feedback to the practice, Albany Consulting Group.
APPENDIX A
National Resource Centre for Consumer Participation in Health—Draft Community and Consumer Participation Audit Tool for Hospitals

Preamble
Community and consumer feedback and participation is increasingly being advocated as an important component in decision-making for health service managers and providers. The term ‘consumer’ is defined as users of a health service or potential users. They can be individuals or a group of consumers with a collective interest. The term ‘community’ is broader and can refer to either a particular community group (e.g., culturally determined group, disease-oriented group, or an interest group), or the place where the hospital is located, or catchment area for the hospital. Participation can be at different levels of a hospital (or network/area health board/region) such as in strategic planning, service and facilities planning, policy development, service delivery and care processes, and review and evaluation of care and services. Also, the degree of participation can range from low degrees of participation (information giving and information seeking) through to higher degrees of participation (consultation, partnership and consumer control).

There are various methods and models that can be used to involve the community and consumers. There is no one right way of enabling the community or consumers to participate. However, what is important is that a hospital clearly identifies who its community and consumers are, and what the purpose and mechanisms are for involving them. What is also important for maximum benefit to the hospital, its staff, and those community members and consumers who participate, is that community and consumer participation is part of an overall organisational strategy, rather than a series of ad hoc projects. As such, it is important that community and consumer participation is seen as part of an organisational management strategy as well as part of care processes between individual providers and consumers.

Purpose of the Audit Tool
Many hospital staff have asked for an easy-to-use tool to gain an indication of the level of commitment to community and consumer participation in their hospitals. This Audit Tool has been developed for that purpose. The focus is on management issues at an organisational level, as well as at the department/ward level, rather than assessing the practice of individuals. The design of the Audit Tool has been based on the ACHS’s EQuIP format, as many hospital staff have indicated that they are familiar with this format. Community and consumer participation is an integral part of the EQuIP standards and criteria. Most of the criteria contained in this Audit Tool bear a relationship to the standards and criteria in the EQuIP Guidelines (ACHS 1998).

This Audit Tool can be used by hospitals to determine:
- the level of organisational management commitment to community and consumer participation;
- the range of activities being implemented at organisational and departmental/ward levels; and
- where to go next.

How to use the Audit Tool
How you use this Audit Tool will depend on how your hospital is structured and the resources you have available to undertake activities such as this. Some hospital staff have said that their quality manager or quality improvement consultant would undertake the organisational level (part 1) audit and coordinate the activity across the
hospital, with each department/unit head being responsible for completing part 2 of the tool for their own area. Others have said that it could be part of the patient representative or a project officer’s role, and they would expect that person to interview the relevant people across the organisation to complete both organisational and department/ward levels. Another person said that they would coordinate the activity in their role as quality improvement consultant, but would get staff in each of the departments/wards to complete the audit from their own perspectives. They were also considering asking some consumers who had a long-term relationship with the hospital and different departments/wards to complete some of the criteria that they thought would be relevant to their level of contact with the hospital. In this way they would have staff and consumer perspectives of key management issues. Others have said they would do the organisational level audit and then randomly select some departments/wards and work with them to complete the Audit Tool.

However you chose to use the Audit Tool, it is important that you determine beforehand why you are undertaking the audit and how you want to use the results. It is equally important that you clearly describe and justify your method as part of your report.

**Rating the activity**

This is a self-rating scale and is based on the EQuIP format.

<table>
<thead>
<tr>
<th>LA</th>
<th>Little achievement</th>
<th>EA</th>
<th>Extensive achievement</th>
</tr>
</thead>
<tbody>
<tr>
<td>SA</td>
<td>Some achievement</td>
<td>OA</td>
<td>Outstanding achievement</td>
</tr>
<tr>
<td>MA</td>
<td>Moderate achievement</td>
<td>N/A</td>
<td>Not applicable</td>
</tr>
</tbody>
</table>

**What to do with the information**

Once the information is gathered from the organisational and department/ward audits, it can be analysed and then reported to the board, senior management, staff and consumer groups you may have involved in the audit to enable them to determine where the organisation is positioned with regard to its commitment to, and activity in, community and consumer participation. The results can be used to identify the organisation’s strengths, as well as where the gaps and limitations are. The organisation will then be able to prioritise where the management efforts need to be directed if it chooses to develop an organisational approach to community and consumer participation.
### Part 1: Community and consumer participation—organisational level

<table>
<thead>
<tr>
<th>No</th>
<th>Criteria</th>
<th>Evidence of achievements</th>
<th>Self-rating</th>
<th>Action required and expected outcomes</th>
<th>By when</th>
<th>By whom</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.1</td>
<td>Has community and/or consumer participation been incorporated into the hospital’s vision, values and any other philosophical statements?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.2</td>
<td>Has the hospital clearly identified who their community and ‘consumers’ are?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.3</td>
<td>Has the hospital clearly identified the purpose and mechanisms for involving community members and consumers at different levels?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.4</td>
<td>How has the hospital involved community and consumers in a needs assessment? Are the strategic directions responsive to those identified needs?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.5</td>
<td>Who are the leaders, champions, or staff delegated with the responsibility for consumer participation? Are they easily identifiable within the organisation?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.6</td>
<td>Does the hospital have key consumer policies in place, such as:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• consumer rights and responsibilities</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• complaints</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• consumer access to information</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• consumer participation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>Criteria</td>
<td>Evidence of achievements</td>
<td>Self-rating</td>
<td>Action required and expected outcomes</td>
<td>By when</td>
<td>By whom</td>
</tr>
<tr>
<td>----</td>
<td>--------------------------------------------------------------------------</td>
<td>--------------------------</td>
<td>-------------</td>
<td>---------------------------------------</td>
<td>---------</td>
<td>---------</td>
</tr>
<tr>
<td>1.7</td>
<td>How do consumers find out about:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• their rights and responsibilities</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• how to make a complaint or commendation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• accessing information</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• information about how they are able to participate in the hospital?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>How are these processes monitored and evaluated?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.8</td>
<td>What staff education programs are in place to support the implementation and maintenance of these consumer policies?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.9</td>
<td>What organisational resources have been allocated to support the incorporation of community and consumer views into strategic and service planning and review?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.10</td>
<td>What training and supports have been provided or accessed to enable consumers to participate effectively?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.11</td>
<td>Does the hospital have a consumer participation evaluation plan in place?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.12</td>
<td>Is consumer participation incorporated into job and position specifications?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.13</td>
<td>Are consumer participation efforts and achievements incorporated into performance management and staff recognition processes?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Part 1: Consumer participation—organisational level

<table>
<thead>
<tr>
<th>No</th>
<th>Criteria</th>
<th>Evidence of achievements</th>
<th>Self-rating</th>
<th>Action required and expected outcomes</th>
<th>By when</th>
<th>By whom</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.14</td>
<td>Is community and/or consumer input a part of key organisational decision-making processes?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.15</td>
<td>How does the hospital recognise the contribution of consumers to the organisation?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Part 2: Consumer participation—department/ward level

<table>
<thead>
<tr>
<th>No</th>
<th>Criteria</th>
<th>Evidence of achievements</th>
<th>Self-rating</th>
<th>Action required and expected outcomes</th>
<th>By when</th>
<th>By whom</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.1</td>
<td>Has the department/ward identified who its consumers are?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.2</td>
<td>Has the department/ward identified the purpose and mechanisms for involving consumers?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.3</td>
<td>Does the department/ward have a consumer feedback and participation plan in place?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.4</td>
<td>How are organisational consumer policies reinforced as part of department/ward management processes?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.5</td>
<td>What resources are allocated at a departmental/ward level for enabling consumer feedback and participation?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.6</td>
<td>What types of strategies are used to involve consumers in decision-making about care processes and service improvement at the department/ward level?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>Criteria</td>
<td>Evidence of achievements</td>
<td>Self-rating</td>
<td>Action required and expected outcomes</td>
<td>By when</td>
<td>By whom</td>
</tr>
<tr>
<td>----</td>
<td>---------------------------------------------------------------------------</td>
<td>--------------------------</td>
<td>-------------</td>
<td>---------------------------------------</td>
<td>---------</td>
<td>---------</td>
</tr>
<tr>
<td>2.7</td>
<td>Does the performance review of staff incorporate attitude towards, and achievements in, consumer participation in care processes and service improvement?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.8</td>
<td>Are staff supported to attend staff development programs about consumer participation and consumer policy issues?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.9</td>
<td>What links and feedback mechanisms are in place with other departments/wards and services/groups outside the hospital to ensure consumer satisfaction with continuity of care?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.10</td>
<td>How have consumers participated in the development and evaluation of care pathways and consumer education/information resources?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.11</td>
<td>Does the department/ward have effective working relationships with key support/community groups associated with the consumer profile of their department/ward? Are staff aware of the key consumer issues for these groups, and do they have processes in place to jointly address these issues?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.12</td>
<td>How does the department/ward report on its consumer participation activities and outcomes? Has accountability for actioning consumer feedback been built into this reporting process?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Comments:**
Developed by Dr Anne Johnson for the National Resource Centre for Consumer Participation in Health, with assistance from an Advisory Group made up of Andrea Argirides, Kay Currie, Jackie Kearney, Kate Silburn and Joanne Wilkinson.
APPENDIX B

ORGANISATIONAL CAPACITY ASSESSMENT

(Adapted from Auer, Roe and Repin 1993, p105)

This tool enables you to audit your organisation’s consumer participation focus. There are some options for how you reflect on these questions. You may prefer to answer the questions as a group and in that case you should consider using a facilitator. If you can not answer these questions then, before you move on, spend some time thinking and talking with your colleagues about participation, your motivations, skills and values and the organisation in which you work.

With staff and community members/consumers (separately or together), review the extent to which the following critical factors for effective participation are present or absent in your organisation.

Decide on a rating (0–10) for each. A rating of 0 would indicate that factor is completely non-existent in your organisation. A rating of 10 would indicate that there is no need for improvement for that factor. Mark your score for each item.

1. Is there a policy commitment to consumer participation?

   0 1 2 3 4 5 6 7 8 9 10
   low medium high

2. Are there appropriate organisational structures for consumer participation?

   0 1 2 3 4 5 6 7 8 9 10
   low medium high

3. Are there identifiable processes and procedures for policy development and decision-making?

   0 1 2 3 4 5 6 7 8 9 10
   low medium high

4. Are consumers/community currently involved in the organisation?

   0 1 2 3 4 5 6 7 8 9 10
   low medium high

5. Are there adequate resources to support participation?

   0 1 2 3 4 5 6 7 8 9 10
   low medium high
6. Are time lines long enough to allow consumer participation to develop (minimum of two years)?

0 1 2 3 4 5 6 7 8 9 10

low medium high

7. Is there a two-way flow of information between consumer groups/communities and organisations?

0 1 2 3 4 5 6 7 8 9 10

low medium high

8. Does the organisation have a willingness to share power?

0 1 2 3 4 5 6 7 8 9 10

low medium high

9. Does the organisation provide attitude and skill development—management for staff and community/consumers?

0 1 2 3 4 5 6 7 8 9 10

low medium high

10. Is there a critical mass of enthusiastic people who support consumer participation in the organisation?

0 1 2 3 4 5 6 7 8 9 10

low medium high

11. Are there appropriate measures of effectiveness used for consumer participation strategies?

0 1 2 3 4 5 6 7 8 9 10

low medium high

What your score means

Your total score gives an indication of your organisation's capacity for enhancing consumer participation. Scores on individual items provided a guide as to where you may need to concentrate your efforts:

- 110 and over—theoretically possible. Have you talked with the consumers involved in your service?
- over 80—your organisation is already well focused on consumer participation and has an environment that is likely to support new consumer participation initiatives.
- 60 to 80—it is likely that there are some measures in place and plenty of opportunities to do more.
- 40 to 60—while there may be opportunities for initiating new consumer involvement, there may still be some significant work to do in improving the capacity of the organisation for consumer participation.
- below 40—the organisation is not supportive of consumer participation in its current state, and the focus should be on organisational development efforts.
APPENDIX C

ASSESSMENT OF WORKFORCE CAPACITY AND SETTING

Assessment of your organisation and workforce’s achievements in relation to key elements for effective participation can provide you with a picture of its readiness for further consumer participation. It will also provide some clear indications about those aspects that may need particular attention and where threats and opportunities may lie. There are three levels to the assessment process. Assessment of the wider organisational capacity (culture, policy, structure and processes) is dealt with in section 2 by the resource centre’s Audit Tool.

Assessment of workforce capacity (the skills, knowledge, values and beliefs you and your team need to encourage effective participation) and assessment of your situation, or setting within the organisation are dealt with below.

ASSESSMENT OF WORKFORCE CAPACITY

BELIEFS AND VALUES

Practitioners and managers who support participation are likely to express the following types of beliefs and values:

- acceptance that you do not always know best
- willingness to share decision-making authority
- a commitment to empowerment of consumers
- acceptance and acknowledgment of diversity
- acknowledgment that process is as important as the tasks
- acknowledgment of people’s experience as a source of expertise
- ability to participate influenced by the individual’s or group’s level of wellness

Community participation processes are especially challenging to some of the values prized and reinforced in professional health practice and by the rules and regulations of health institutions. Once you step off on a journey of participation, value dilemmas are likely to occur. This means the focus for development is not just ‘out there’ but also internal to yourself. This can be one of the most exciting aspects of participation, but it is also one that obliges you to watch for and understand the hidden dimensions. It is a continuous process that requires empathy.

KNOWLEDGE BASE

There are many and, at times, contradictory reasons why participation is demanded by consumers or implemented by organisations. The clearer you are about what you want participation for, then the easier it is to decide the approaches to use. This is where guiding ideas come into play. Practitioners and managers who support participation require guiding ideas or a framework for establishing:

- the motivations for participation
- who benefits from participation
- knowledge about consumer groups/community
- knowledge about consumer participation methods and strategies
- knowledge about the workings of decision-making processes, influence, and authority
SKILLS

The providers of health care services, programs and policies interact with consumers in a number of ways. These interactions call for a set of skills that may not necessarily be developed through professional education and training. Professional training places emphasis on skills such as professional judgment, analysis and communication of complex and scientific medical information, and achieving tasks in a short time span. Participation requires skills such as:

• interpersonal relations
• communication
• resolving and managing conflict
• flexibility and openness
• humility and reflection
• facilitation
• developing and maintenance of consumer participation strategies

Supporting effective participation means being willing to build open relationships with consumers from different racial, social and economic circumstances from your own. Communication, flexibility and openness are pivotal to this process. It involves being able to listen, encourage, and act upon different ‘voices’. It means that spaces have to be created where people feel that they will be heard and that things will be different because of their participation. It also means learning how to deal with conflict as it arises. Developing these skills requires time:

• to gather with and talk to consumers
• to build different relationships with consumers from the ones you may be used to
• for understanding different views that come from outside of the professional paradigm
• for introspection and analysis.
ASSESSING THE DIFFERENT SETTINGS FOR CONSUMER PARTICIPATION WITHIN ORGANISATIONS

During the consultations that contributed to the development of this resource guide it was pointed out several times that effective consumer participation was possible at any level in a health care organisation provided that two vital criteria were both present:

• an advocate or champion (or group of champions) working in the organisation who was committed to consumer participation and aware of its key principles; and
• a supportive and committed manager who provided resources and an appropriate policy environment.

The tool below describes four types of organisation or sub-organisation situation. For each one there is a description of the relative levels of commitment, the characteristics you might expect to see in that situation and the implications for your strategic approach to building better consumer involvement.

<table>
<thead>
<tr>
<th>Situation description</th>
<th>Commitment</th>
<th>Characteristics</th>
<th>Implications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Optimal</td>
<td>Manager and advocate fully committed to consumer participation</td>
<td>High levels of trust, openness, communication</td>
<td>High potential, focus on involving consumers, multiple strategies, partnerships with outside organisations</td>
</tr>
<tr>
<td>Developmental</td>
<td>Advocate committed, but manager ambivalent</td>
<td>Rhetorical support, but few resources for consumer participation. Advocates spend time and energy arguing the case within the organisation</td>
<td>Advocate may need to focus on changing management attitudes to build organisational capacity. Pilot projects in areas where success can be quickly shown may be one way</td>
</tr>
<tr>
<td>Directed</td>
<td>Manager is committed, but team are not</td>
<td>Top-down focus on consumer participation policies and procedures</td>
<td>Strong emphasis on staff involvement in developing organisation’s vision, goals and strategies. Training and development to equip staff to be involved and to involve consumers</td>
</tr>
<tr>
<td>Contained</td>
<td>Team members are committed advocates, but the manager is opposed</td>
<td>Management focus on efficiency and professionally defined quality</td>
<td>Very difficult situation. Build up networks, make alliances within and beyond the organisation. Find supportive managers at whatever level. Act locally if possible</td>
</tr>
</tbody>
</table>
APPENDIX D

Reference Group for Resource Guide for Organisations

Ms Lynne Evans, Consumer Focus Collaboration

Dr Anne Johnson, Manager, National Resource Centre for Consumer Participation in Health

Ms Betty Johnson, consumer representative, Health Advisory Committee, National Health and Medical Research Council

Ms Colleen Krestensen, Assistant Director, Quality and Consumer Strategies Section, National Health Priorities and Quality Branch, Commonwealth Department of Health and Aged Care

Ms Asimina Peristeri, Acting Director, Health Advisory Section, Health Advisory and Workforce Branch, Office of the National Health and Medical Research Council

Ms Sue Pluck, Consumers’ Health Forum

Mr Andrew Stanley, Director, Policy and Planning (Health), South Australian Health Commission

Australian Consumers’ Health Forum 1988, Guidelines for Consumer Representatives, Canberra.

Australian Consumers’ Health Forum of South Australia 1996, Working with Consumers, A Guide for Divisions of General Practice, Lyons, ACT.


Goodes L and Roe M (undated), Bringing in the Voices, Women’s and Children’s Hospital, Adelaide.


Leitch A 1993, A Guide to Aboriginal and Torres Strait Islander Communities, prepared with the assistance of the Queensland Aboriginal and Torres Strait Islander Staff Network for the Queensland Office of the Department of Human Services and Health.

North West Suburbs Health and Social Welfare Council (NWSH&SBC) 1993, The Little Purple Book of Community Rep-ing, NWSH&SBC, Adelaide (Available from the Adelaide Central Community Health Service; phone (08)8342 0046.)

NSW Health 1998, Community Consultation and Participation, Resource Kit for Area Health Service Managers and Project Leaders, Health Improvement Branch and Health Public Affairs, NSW Health.

Office of Multicultural Affairs, Department of Prime Minister and Cabinet 1994, Consulting the Multicultural Way: Guidelines for APS Managers Consulting and Negotiating with Non-English-Speaking Background Groups, AGPS, Canberra.


South Australian Community Health Research Unit 1994, What is Research? Paper no 1, Research and Evaluation Series, South Australian Community Health Research Unit, Adelaide.

—— 1994, How to Evaluate your Community Health Programs, Paper no 2, Research and Evaluation Series, South Australian Community Health Research Unit, Adelaide.


—— 1994, Health Outcomes in Community Health, South Australian Community Health Research Unit, Adelaide.


3. READINGS


Draper M 1995, *Involving Consumers in Improving Hospital Care: Lessons from Australian Hospitals*, Commonwealth Department of Health, Canberra, AGPS.


Australian Health Organisations Taking Up the Best Practice Challenge, Australian 

Kennedy R 1993, Better Service Through Consultation, Best Practice Paper 1, Social 
Policy Directorate, NSW Government.

—— 1993, Resourcing Consultation, Best Practice Paper 2, Social Policy Directorate, 
NSW Government.

Krestensen C 1990, Common Pitfalls and Oversights in Government Consultation with 
Consumer Groups, Consumers’ Health Forum of Australia, Canberra.

Macklin J 1992, Healthy Participation: Achieving Greater Participation and Accountability in the 
Australian Health Care System, National Health Strategy, Melbourne.

McArdle J 1989, Community Development—Tools of the Trade, Community Quarterly, 
16, pp47–54.

McCulloch D 1966, Creating Influence, or How to Lobby: The 9 Point Plan for Lobbying 
Success, FEM Enterprises and Women’s Electoral Lobby, SA.


Pateman C 1970, Participation and Democratic Theory, Cambridge University Press, 
London.

Patton M 1980, Qualitative evaluation methods, Sage, Beverley Hills.

Quality Management Services (QMS) 1999, ‘Health and Community Services Core Module’ Service Development Workbook, NSW.


Stuart P and Parker S 1999, The Emergency Department—A Consumer’s Perspective, 
Getting it All Together—Improving the Health and Wellbeing of Our Community Through Partnerships, Wakefield Regional Health Service, South Australia.


Weiss CH 1972, Evaluation Research: Methods for Assessing Program Effectiveness, 
Prentice-Hall, New Jersey.

15 Laris P and Verity F 2000, Community Participation: Power, Organisations and Change, 
SACHRU: Adelaide forthcoming.
4. WEB SITES

There is increasingly a wealth of information relevant to consumer participation on the world wide web. The following list has been compiled by the Aged Community and Mental Health Division of the Department of Human Services, Victoria. We acknowledge their permission to reproduce this information.

4.1 Government Agencies

The Quality-Effectiveness Unit of the Acute Health Branch, Department of Human Services, Victoria, Australia, has a web site which includes a page on consumer participation and information with links to other sites:

NSW Health publishes a wide range of materials that are available to the community. Publications may be in the form of a pamphlet, brochure, report or fact sheet. The listing shows titles under various subject headings which may be browsed online:

NSW Health has a multicultural catalogue of materials in various community languages:

Health Services Liaison Association acts as a unified independent voice on matters pertinent to the role of liaison officers by advising agencies at all levels, both government and non-government, on issues relating to patient liaison and patient representation:
http://home.vicnet.net.au/~hsla

Commonwealth Department of Health and Aged Care, National Health Priorities and Quality Branch has a consumer participation page:

Commonwealth Department Health and Aged Care, has a listing of and links to consumer groups:

4.2 Community development

This site covers the processes of community participation and building partnerships between different interests, both ‘real world’ and online:
http://www.partnerships.org.uk/part/index.htm

Online community development resource kit:

4.3 Finding evidence for advocates of consumer participation.

There are many web sites from which you may find the evidence needed to assist you in building support for your consumer participation activities.

Commonwealth Department of Health and Aged Care has a Better Health Outcomes newsletter. See September 1997 and Winter 1999 special editions with a consumer focus:

See also, the British Medical Journal special edition on consumers and participation (September 99):
http://www.bmj.com/cgi/content/full/319/index.htm

The United Kingdom’s Doctors Desk brings together the tools of evidence-based practice on a single screen and includes online medical journals, government information and newspapers:
http://drsdsk.sghms.ac.uk
The Cochrane Collaboration aims to assist people to make well-informed decisions about health care. A comprehensive and reliable source of evidence about the effects of health care. Abstracts available free:


The Consumer Network reflects consumer interest within the Cochrane Organisation:


Consumer participation materials are available at:


Register for the Cochrane consumers’ email group list at sue.pluck@flinders.edu.au

Medline is a free search service to the nine million citations in the MEDLINE and pre MEDLINE databases. Some links to full text articles:


Embase has 6.5 million citations, indexes more European citations than MEDLINE, and has better coverage of pharmacology resources (free searching, charges for full citation):

http://www.healthgate.com/Healthgate/druginfo

PsychINFO is a key database for references in the field of psychology and psychiatry (free searching, charges for full citation):

http://www.healthgate.com/Healthgate/behavior

CINAHL is a database of nursing and allied health (free searching, charge for full citation):

http://www.healthgate.com/Healthgate/nursing

Turning Research into Practice (TRIP) offers a tour of links to medical journals, associations and evidence based health care links. A combination of 18 linked databases, the search engine is limited to looking for words in the titles of reports:

http://www.gwent.nhs.gov.uk/trip

Seeking the Evidence: a protocol outlines the stages by which evidence can be accumulated for evidence based digests, such as those found in the Journal of Clinical Effectiveness:

http://www.shef.ac.uk/~schart/ir/proto.html

Medem provides online health care information. Medem is comprised of credentialed content provided by member professional medical societies such as the American academies and colleges representing asthma, immunology, allergy, pediatrics, psychiatry, ophthalmology, plastic surgery, obstetrics and gynecology, and the American Medical Association.

http://medem.com/

Consumer participation references are available from the National Institute for Social Work, London, United Kingdom:

http://www.nisw.org.uk/pubs/fulltext.html
http://www.nisw.org.uk/pubs/shaping/index.html
http://www.nisw.org.uk/pubs/building/bridcont.html
http://www.nisw.org.uk/pubs/stand/scont.html