EDUCATION AND TRAINING FOR CONSUMER PARTICIPATION IN HEALTH CARE

FINAL REPORT OF PROJECT

Prepared by Global Learning Services Pty Ltd for the
Consumer Focus Collaboration

A Consumer Focus Collaboration publication

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

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

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

For information on the availability of the publications, contact the Information Manager, National Resource Centre for Consumer Participation in Health, ph: (03) 9479 3614 or freecall 1800 625 619.

The Consumer Focus Collaboration publication series is available free of charge on this web site: http://nrccph.latrobe.edu.au

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FOREWORD

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

The Consumer Focus Collaboration publication series provides practical tools to support 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 this active partnership between consumers of health care and those who provide that care.

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

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

Consumer Focus Collaboration
June 2000

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Chapter 1: The context for the project

A. THE CHANGING CONTEXT OF HEALTH CARE

Changes are happening in health care. They have been brought about by demands from an increasingly educated population, by resource constraints leading governments to ensure that care is provided efficiently and effectively, and by increasing concerns about the safety and quality of the services provided. Technological advances in clinical care and in health information management are also leading to increasing demands on health professionals. These factors are all putting pressure on the health care system to be more accountable for its activities and on health care practitioners to deliver services in a different, more user friendly and more effective and efficient way. In short, a change is underway in the culture of our health care system.

One of the key changes is in the role of the 'patient' or the consumer of health care services. Increasingly, people are no longer content to be treated as passive recipients of whatever is deemed to be good for them. They want to be partners in the decision-making about their own health. And they want to be involved in designing, managing and delivering health care services so as to ensure that they are safe, effective and appropriate to community needs.

The participation by consumers in health care policy and practice is now being recognised and sought as a means of improving the quality of care and making the system more accountable. A growing number of governments and health care providers are now actively seeking the views of consumers about health policy, planning and service delivery and evaluation.

This is gradually bringing about a cultural change in an area that has traditionally been characterised by imbalances power between consumers, health professionals and administrators, particularly in the hospital sector. Some traditional models of health care have also been characterised by hierarchical power structures, where consumers, as patients, were the subject of activities rather than active participants. Under this model, health care systems were designed and managed by health professionals and administrators without input from those on the receiving end of services.

The differences in the knowledge base of consumers and providers has only recently been recognised, with the importance of the contribution of the consumer view being more widely recognised. It is clear that the future difficult decisions around health care rationing and usage of expensive technology will require the consumer as much as the provider or administrator perspective.

B. CONSUMER PARTICIPATION

The importance of people participating in the planning and implementation of health care has been recognised in a number of international declarations. In 1978 the World Health Organization's (WHO) *Declaration of Alma-Ata* set out a vision for primary health care, which stated unequivocally that 'people have the right and duty to participate individually and collectively in the planning and implementation of their health care' (WHO 1978). In 1986 the WHO's *Ottawa Charter on Health Promotion* promoted consumer empowerment in health care as a central element of achieving improved health and well-being in a society (WHO 1986). This was reiterated in the recent *Jakarta Declaration on Health Promotion in the 21st Century*, which also recognised that improving the capacity of communities for health promotion requires practical education, leadership training, and access to resources (WHO 1997).

In Australia the importance of consumer participation in decision-making in the health system has been recognised in a number of reports and initiatives of the Commonwealth Government, including:

- provision of funding for the establishment and running of a national peak consumer organisation, the Consumers' Health Forum of Australia (CHF)—a key function of CHF is to nominate consumer representatives to Commonwealth Government health-related committees;
- the publication of a background paper for the National Health Strategy examining the need for improved public participation in health system decision-making (National Health Strategy 1993);
- the work of the Review of Professional Indemnity Arrangements for Health Care Professionals (PIR), which identified increased consumer participation in health service planning and delivery as an important overall strategy in a Commonwealth response to its work (PIR 1994, p174; PIR 1995 p207);
- the Commonwealth Government's Task Force on Quality in Australian Health Care in 1995-1996, which drew a direct link between developments in individual care and systemic change (AHMAC 1996);
- the establishment in 1997 of the Commonwealth Department of Health and Aged Care's Consumer Focus Strategy which is now driving some critical processes to facilitate improved consumer participation in health care; and
- the Report of the National Expert Advisory Group on Safety and Quality in Australian Health Care in 1999 drew attention to the need for national action to further foster consumer participation in the health care system (NEAG 1999).

While there has been some increasing enthusiasm for consumer participation at the policy level, there are still significant systemic barriers to the full involve-

ment of consumers in health care decision-making. A major study by Mary Draper (Draper 1997), which looked at involving consumers in improving hospital care, identified five types of barriers, which were listed in full in the Project's Consultation Paper, the body of which is included as attachment A to this report. Most of these are about the culture of health care and the perception of consumers by providers and administrators. Others show lack of knowledge about the real life situations of many health care consumers, which influence the physical, emotional and financial capacity of consumers to participate fully.

Draper's report used the term 'working partnership' to describe the sort of relationship that is needed for consumers to be able to participate effectively. She pointed to the importance of education to achieve this:

> ... consumer participation is about participating, it is an active working relationship, it is ongoing and dynamic, and it can take place in a range of ways.
>
> It is about clinicians and consumers becoming aware of each other's perspectives; about changes in service delivery, about good working relationships in which issues can be resolved, about sharing problems and finding lateral solutions, about developing better communication and respect for each other. It is a process of mutual adjustment. It is a 'powerful tool for change'. It is about Hirschman's concept of 'voice.'
>
> But it is a process which requires commitment, appropriate skills and time to develop trust in the process.' (Draper 1997, p75)

C. THE EDUCATION, TRAINING AND LEARNING CONTEXT

Education and training were once thought of as primarily a process which children and young adults were taught in a school or other formal training institution. There was limited availability of training at other points in life, except possibly additional vocational training to keep skills up to date.

Learning is now recognised as a dynamic and active concept which is a lifelong activity. In our complex society, where information is changing constantly and rapidly, it is no longer expected that we can be taught everything we need to know at some point in our lives (if this, in fact, were *ever* a possibility!). Rather people are recognising and developing their own ability to learn through everything that they do. This means recognising that learning occurs in both formal and informal situations (such as everyday life experiences) and is something that we do throughout life.

It is also now recognised that learning, even at an unconscious level is a cyclical process. This involves the stages of undergoing an experience, reflecting on that experience, making decisions about how to do it differently next time and then testing out the different approach at the next opportunity. Individual

people tend to learn in different ways and may have preferences for their approach to learning, though this is not the only way they learn. For example, someone may have a preference for learning through reading about something, but where the activity being learned involves physical action, they may, in fact, only learn by trying to do it *after* they have read about it.

To use some examples relating to consumer participation, some people prefer to learn from a concrete experience and to reflect on that. These people usually enjoy debriefing and mentor-based learning. Others prefer 'trial-and-error' or active experimentation, for example by joining a committee having been prepared ahead by a course giving them a range of strategies to try in the new situation.

A life-long learning approach recognises that learning occurs in many situations such as an educational institution, workplace, home and community generally and that there are many different techniques and methods that can be used to learn, both formal and informal. Thus people are no longer thought of as 'empty vessels' to be filled with knowledge by experts (Freire 1970). This approach recognises, instead, that people learn together through sharing their knowledge and experiences. It also underpins many of the new management models involving 'learning organisations' (Senge 1990).

The approach also strongly values what are called 'learning partnerships' where key stakeholders work together. Learning partnerships may take the form of team learning within an organisation, the use of forums or workshops involving stakeholders working together or initiatives as large as the United Nation models of Learning Cities.

D. LEARNING AND HEALTH CARE

In health care, professionals are trained in a particular way, and a particular culture has developed around that training, perhaps most marked in the medical profession. They are trained in their basic disciplines through undergraduate courses at university. Further postgraduate training may then occur. For example, medical practitioners undergo further hospital based training once they begin their mandatory pre-registration hospital practice. They then undergo vocational training in the specialty of their choice under the auspices of the appropriate medical college. Once vocationally trained and registered to practice, health professionals are usually required to show evidence of continuing education and quality assurance activities in order to maintain their professional standing.

Health administrators may have a more diverse career pathway. Some are specifically trained in health administration; some are health professionals by

background; others come from entirely different sectors. Their prior learning is therefore likely to be more diverse.

Consumers on the other hand come from a wide variety of areas in the general community, and reflect its diversity and varying education and learning backgrounds. Those who want to contribute through membership of committees and participating in workshops and other forums, can lack confidence in their ability to put their issues forward. They will often actively seek training or advice from other consumer representatives to give them the skills and confidence they need. Some consumer organisations have responded by developing training programs for their representatives. However they generally do not have sufficient resources to provide comprehensive training programs for all consumer representatives.

As consumers, administrators and health professionals increasingly join together to work on different facets of health care so they bring together their combined formal and informal learning and knowledge. Many health committees have evolved into 'working partnerships' over a period of time. Trust has developed, and respect for the experience and knowledge of others is slowly leading to changes in some aspects of health care.

However, in many other areas providers are nervous about working in this way and do not understand the value of consumer participation. Administrators feel it is just another thing they are asked to do, and don't understand the rationale. On the other hand, consumers are wanting to be involved but feel their experience is not valued and do not always feel skilled enough to be able to put their issues and concerns on the table.

The skills required by health professionals, administrators and consumers, if consumer participation is to be effective, are not easily learned through any of the modes of training and education commonly used 'to teach' either consumers or providers. These include some of the prerequisites to really effective partnerships, such as trust-building and dealing constructively with power and knowledge differentials. Often consumers and providers will come to a participative process with all kinds of unspoken assumptions about each other, many of which may be based on a particular earlier experience, which has reduced their level of trust.

If the process for participation is not effective and, in fact, a positive learning experience for all concerned, existing assumptions and prejudices about each other can be aggravated, and hamper improved relationships and effective partnership building.

This report looks at how training, education and learning for consumers, health professionals and administrators to enhance participation in health care policy,

planning, service delivery and evaluation can be made more effective. Our program of research is set out in chapter 2 of this report and the examples of different resources and case studies of relevant education and training are set out in the separate *Resource Guide*. Chapter 3 of the report summarises what our research found and our analysis of the issues. Chapter 4 sets out principles for the future and how problems which have been identified through this project might be overcome to ensure that education and training for consumer participation and, from this, the effectiveness of health care policy, planning, service delivery and evaluation is enhanced.

Chapter 2: The consumer participation education and training project

A. INTRODUCTION

The Consumer Focus Collaboration (CFC) was formed in 1997 following the *Final Report of the Taskforce in Quality in Australian Health Care* in 1996 (AHMAC 1996). The goals of the CFC are to:

- facilitate the provision of high quality information to consumers in appropriate formats;
- facilitate active consumer involvement in health service planning, delivery, monitoring and evaluation;
- improve health service accountability and responsiveness to consumers; and
- promote education and training that supports active consumer involvement in health service planning and delivery.

In the late 1990s, the CFC took up the issues of education and training. It recognised the need to understand and foster the sorts of skills that are needed to enable consumers, providers and administrators to participate effectively in 'working partnerships'. It designed and commissioned this project to:

- identify the key characteristics of successful education and training methods to prepare health consumers, administrators and providers to create partnerships across health care;
- describe examples of education and training for consumers, providers and administrators which are successful in doing this and include these in resource guides; and
- identify key issues and gaps in education and training for the various stakeholders.

This project was one of eight related projects commissioned by the CFC. Information about the CFC and the other commissioned projects are at attachment B.

B. OUTLINE OF THE PROJECT

The project team consisted of people who had experience and expertise in consumer participation, health promotion and education, health care delivery and education and training. Team members are listed in attachment C. Our multi-disciplinary approach allowed us to engage with both consumers and providers

of health care as well as drawing on expertise relating to education and training for partnerships. The project has included a particular emphasis on the development of a range of skills such as collaboration, communication and negotiation, which are necessary for consumers, health care providers and administrators to work together more effectively.

Using our combined expertise we conducted a literature search looking at local and overseas examples of consumer and provider training in consumer participation, and the theoretical and practical issues to be addressed to determine best practice features of education and training for consumer participation. Preliminary consultations were held with a range of key stakeholder organisations to identify what resources were available or which case studies of this type of training or education was known to them. The team also surveyed a wide range of organisations to see what programs existed in Australia in addition to those identified in the literature. A consultation paper on the issues identified in the first phase was produced and distributed in electronic and paper format. To ensure that as many different groups and individuals were able to be included, the team also conducted a number of focus groups with people working in the field and with special interest groups of consumers and providers.

A separate resource guide has been developed, and this was workshopped with selected stakeholders to consider its content and usability. Changes were made to take account of the concerns raised. The project has also been supervised by a CFC Steering Committee, which has included representatives from the Commonwealth Department of Health and Aged Care and all the key stakeholder groups. The members of the steering committee were:

- Mr Julian Hamon, Commonwealth Department of Health and Aged Care
- Mr Lou McCallum, Consumers' Health Forum
- Ms Kate Silburn, National Resource Centre for Consumer Participation in Health
- Ms Elizabeth Foley, Royal College of Nursing Australia
- Dr Johnathon Phillips, Committee of Presidents of Medical Colleges
- Dr George van der Heide, Queensland University of Technology

The steering committee and the wide range of stakeholders who have responded to the work have provided invaluable assistance to the project and we are very grateful for all their efforts.

This chapter summarises how the project has been undertaken.

C. THE LITERATURE SEARCH

Using a range of search engines and publication databases in the areas of health and education, such as Medline, PubMed and ERIC, the team trawled the literature available on consumer participation to identify academic articles, books and web sites, which may have been of interest to the project.

Overall, there were few articles in academic journals which dealt with training and education for consumer participation in policy-making, planning, service delivery or evaluation of health services for either consumers or providers. There were many articles which looked at improving consumer participation in decision-making about their own health care. There was also quite a number which talked about what providers needed to do to be better partners with people who used their services, almost invariably from the individual doctor/patient perspective.

However, when it came to publications which were central to our concerns, they were relatively scarce. Those which we found were used to prepare the consultation paper at attachment A, and the resource guide itself. There are also separate reference lists for this report and the resource guide, which include most of the documents we found.

There was little on the training and education of health administrators on the facilitation of consumer participation in health services, though we have drawn material and lessons from some of the literature about successful establishment of partnerships and other participation arrangements in other sectors (eg community-based school boards, business organisations).

D. THE PRELIMINARY STAKEHOLDER CONSULTATIONS

The initial phase of the information gathering stage of the project included a series of face to face or telephone interviews with representatives of a cross section of stakeholder organisations from the consumer, provider and health administration sectors of the health industry. The purpose of the consultations was to gain an overview of current education and training activities related to consumer participation in the planning, delivery and evaluation of health services. A list of the organisations consulted is at attachment D.

Each organisation was approached initially by telephone to briefly introduce the project to a key person in the organisation. A letter confirming an appointment was sent out to the nominated representative(s) together with a paper introducing the project. A copy of that paper is at attachment E.

The purpose of the interviews, in the early stages of the project, was to obtain an overview of current activities of relevance to the project. The end result is the list of resources and case studies described in the resource guide.

The consultations found many examples of activities for consumers which provided information on health care services and on maintaining a healthy lifestyle, which sought feedback from consumers on the delivery of health care and which gave consumers an opportunity to provide input to the development of health care services. With a few notable exceptions, most of these were found not to include any formal education and training components. At one end of the spectrum the intention was simply to better inform consumers. At the other the intention was to fully involve consumers in partnership with providers in health care delivery.

For providers, the consultations found relatively few examples of education and training activities which have more effective participation by consumers as their purpose. A number of examples were found where providers and consumers were working together to improve the quality of health care, sharing similar objectives and learning from each other in the process. In some courses of initial training, consumer representatives are called on to meet with students to discuss health care from a consumer perspective. In one case consumers were actually delivering training as university tutors. Most subsequent training seems to relate to the development of technical skills rather than skills in forming partnerships with consumers.

In the hospital setting in particular, however, some examples were found of projects which set out to achieve attitudinal change on the part of providers and establish new and ongoing relationships with consumers. Most of these courses were still about changing the nature of the individual doctor/patient relationship, rather than aimed at broader consumer participation issues. However, some appeared to be influencing the culture of doctors in a broader fashion.

For administrators, the consultations produced little evidence of systematic education and training for consumer participation, although some examples are highlighted in case studies in the resource guide. A number of projects were identified in which consumers, providers and administrators have worked together on aspects of consumer participation. The variety of roles performed by administrators, the range of experience which they bring to the health care services and their mobility both within and into and out of the health sector clearly add to the complexity of devising appropriate education and training activities for this group.

Overall the consultations demonstrated that for all those projects and activities which are designed to improve consumer participation in health care services, relatively few are being well documented and even fewer formally evaluated. The notable exceptions are given prominence in the resource guide produced by this project.

E. THE SURVEY QUESTIONNAIRE

Using contact lists for health consumer and provider organisations provided through the Commonwealth Department of Health and Aged Care and various professional associations in health, the project team distributed some questionnaires to organisations, which it was thought might offer programs of education and training for consumer participation in health care or might be able to direct inquiries to such organisations. The Consumers' Health Forum (CHF) and the National Rural Health Alliance (NRHA) agreed to generate from their memberships also (but not disclose to the project team) lists of selected individuals and organisations whose advice could be sought concurrently by mailing direct through CHF and NRHA.

Some 450 questionnaires were available for return by targeted organisations and 70 useable responses in all were received by late December 1999. Response rates ranged from 10 per cent to 17 per cent for the three distribution types. Respondents included government agencies, consumer and community organisations, health services and professional associations. A list of respondents is at attachment F.

The response rate to the questionnaire was quite low. From the responses and the subsequent focus groups, it is assumed that this was, at least in part, because there was not a lot of knowledge or awareness of education and training for consumer participation among the groups and individuals surveyed. It is also likely to be a direct consequence of the width of the net we cast for the survey—we were aware that we were going 'wide' rather than 'narrow'. This was a deliberate strategy, because of how difficult it had proved to access recent local information through the literature search process. While the preliminary consultations had given us many leads from the key stakeholder groups, we decided strategically to 'test the market' broadly, to give us a better chance of uncovering some of the smaller but significant projects which are taking place. We consider this to have been a successful strategy, even though it probably contributed to a relatively low response rate.

There was also some concern that, with the numbers of Consumer Focus Collaboration projects happening at the same time, contact from each of the projects may have been leading some consumer groups in particular to suffer 'response overload'. However, even with these constraints, there seemed to be a reasonably broad range of responses received—from quite small disability groups to larger professional organisations.

The questionnaire focused on programs provided by the organisation itself; programs provided by another organisation which were seen as having desirable features or outcomes of interest within the project; documentation and/or contacts for such programs; characteristics of successful programs; suggestions for program improvement to address needs more appropriately; views on what

is working best (and least) well in programs; and suggestions for system-level strategies for enhancing program development and delivery. A copy of the questionnaire is at attachment G.

Summaries of the programs identified in responses and the characteristics generally underpinning their success are reflected in the resource guide.

F. CONSULTATION PAPER AND FOCUS GROUPS/ PHONE CONSULTATIONS

The consultation paper was distributed not long after the questionnaire. It include a range of information and questions, which had arisen from the team's preparatory work and was used as the basis for the first round of focus groups and phone consultations. The team received feedback from a number of groups and individuals, both formally and informally on the questions raised in the paper, as well as detailed information through the focus group/phone consultation process.

Focus groups were conducted at two points—in the initial consultation phase and in the piloting of the draft resource guide. Focus groups were undertaken with consumers, service providers, both in separate and mixed groups. Because many of the consumers and health professionals were not able to make themselves available for focus groups, the process was heavily supplemented with in-depth interviews in both phases of the project. This was a highly effective strategy and valuable data was gained. A list of participants in the focus/groups and phone interviews is at attachment H.

The aim of the first phase was to refine the characteristics of successful approaches to education and training (for both consumers and service providers) to enable consumer representatives to participate in all aspects of health care planning, assessment and administration through consultation. In particular the process sought to:

- delineate the types of education that are essential;
- identify the good practice principles of successful approaches;
- identify barriers that may arise, and how they may be addressed; and
- determine any unmet needs or gaps.

The findings of these processes are detailed in the next chapter, with a separate section focusing on the issues in rural and remote health settings.

The second round of consultations and focus groups were used to refine the draft resource guide.

G. THE RESOURCE GUIDE

The *Resource Guide for Education and Training for Consumer Participation in Health Care* is essentially a guide to what other people have done in relation to education and training for consumer participation in health care policy, planning, service delivery and evaluation with some commentary on the processes used and principles that might have underpinned them. The guide is intended for use by consumers, service providers, administrators and educators of these groups. Speaking directly to these groups, the guide says that its aim is:

> to signpost you to the experiences of others, so that you can choose to look at and adapt to your particular circumstances what others have learnt.

The guide does not provide a cookbook formula on how to undertake education and training for consumer participation. As can be seen from the next chapter of this report, there is no single model to suit all purposes. The case studies and resources in parts 3 and 4 point to a diverse range of successful approaches, from which potential users can choose, depending on their circumstances.

The resource guide provides examples of creative innovation where consumers and providers have sought to address the challenge of the new environment of health systems. They offer a typical range of examples of good practice in the implementation of a broad spectrum of education, training, and learning strategies. It does not cover those projects which were not documented.

Part 1 of the guide gives an introduction to the concepts of consumer participation and along with part 2 outlines some of the current thinking about best practice education, training and learning to help potential users to decide the kind of education and training that will best suit their needs. This section also introduces the project's Mindmap for Education, Learning and Training model (MELT), which provides the conceptual basis for the resource guide, and explains some of its most relevant concepts (discussed below in chapter 3).

Part 3 of the guide presents a selection of education, training and learning case studies that have been developed in the Australian context. A key feature matrix categorises the cases by their prime education focus (following our MELT model) for ease of reference.

Part 4 provides a range of approaches to education, training and learning in the Australian health care context. The resources are presented in the form of one-page summaries. A key feature matrix categorises the resources by their prime education focus (following our MELT model) for ease of reference.

Part 5 describes some of the key strategies for education and training in partnership development. This section is designed for those wishing to embark on a more long-term and comprehensive learning pathway.

Part 6 contains appendixes. The guide also has a glossary and a full bibliography.

Chapter 3: What the project found

A. INTRODUCTION

This chapter summarises what our research with consumers, providers and administrators told us. While the information we received was broad, there were a number of consistent themes, which we pick up later in the report. These included:

- the importance of peer support to both consumers and providers in optimising consumer participation;
- the need for both formal and informal strategies to meet the diverse needs for training, education and learning for consumer participation; and
- current inadequate levels of resourcing and other leadership support for education, training and learning about consumer participation.

This chapter then sets out some key developments in learning theory and practice which are particularly relevant to this project and which were identified in our research as significant. We then used this information, combined with the analytical skills of the team to develop a conceptual model for education, learning and training for consumer participation which we have called the Mindmap for Education, Learning and Training (MELT) model.

B. FINDINGS FROM THE SURVEY QUESTIONNAIRE

Respondents to the questionnaire covered a diverse range of groups, as can be seen from attachment F. The vast majority of responses came from consumer groups, rather than providers or health administrators. While their responses varied, the following characteristics were frequently identified as characteristics of successful educational and training programs:

- bringing consumers and providers together;
- containing a mix of information provision and practical exercises;
- based on experience;
- including peer support elements;
- providing information which was relevant to participants' needs; and
- using credible, skilled presenters.

The following needs of consumers were also identified, though these were more about ensuring effective participation. These were:

- the need for provision of ongoing support to consumer representatives;

- availability of funding and resources; and
- commitment and support from providers, staff and management.

These factors are also applicable to service providers as they relate to the long-term sustainability of programs that aim for culture change.

The most common suggestions from the questionnaire responses for enhancing existing education and training programs were:

- more consultation with target groups (ie to identify education and training needs);
- better funding of initiatives;
- greater practicality in the sorts of education and training which is provided;
- more active review or follow-up;
- more attention to the economics of improving program delivery to rural and remote areas;
- better coordination of educational input into program design;
- more targeted publicity on programs; and
- a greater sharing of information and resources for developing consumer-planned and delivered training.

Respondents generally indicated that they had little familiarity with programs provided by other organisations, and had concentrated their energies and resources on their own programs. They had often heard of some successful developments with other organisations and could supply the name of a contact for follow-up, but had little detailed knowledge of the program.

A more supportive recognition and encouragement of consumer-initiated programs by government and the health bureaucracy, with appropriate provision of resources, was seen by a number as a high priority if consumer-group-based programs for empowering consumers for participation in health care decision-making were to succeed.

C. FEEDBACK FROM FOCUS GROUPS AND OTHER CONSULTATIONS

Approaches to education and training

The very terms 'education' and 'training' were problematic for both consumers and health professionals.

- For consumers, the terms had connotations that the professional people were educating and training the consumers, suggesting that consumers do

not have anything to offer to the learning of the professionals. They stressed that reciprocal learning needed to be the fundamental principle underlying all education strategies.

- On the other hand health professionals sometimes had a highly formal definition of education and were less aware of the role of informal learning. The health professionals who were undertaking consumer participation work and those working in community settings were generally open to more multiple understandings of education and training.

The concept of partnership between consumers and service providers was seen as more rhetoric than reality and was significantly critiqued by many stakeholders. It was suggested that to use this term as a basis for education and training may be ineffective and misleading. The terms 'reciprocal learning' and 'dialogue' were preferred terms and the concept 'collaboration' was suggested as a first step towards partnership.

Types and content of education and training required

There was considerable emphasis on the need for a range of types of education and training, including both formal and informal. It was stressed that effective resourcing of training is essential. The future role of the National Resource Centre for Consumer Participation in Health in disseminating information was positively noted.

The need for the following education content areas was noted across the groups. Although the following list may appear to be typical of training for consumers, it was suggested in the professional groups that many health professionals would benefit equally, noting that such training would need to be presented in a relevant manner for each of the health professions:

- how the health system works, from national to local;
- social and ecological views of health, to complement the limited biophysical perspective;
- committee operation and training the Chairs;
- group dynamics;
- communication skills, including assertiveness, active listening, conflict management;
- terminology and jargon-busting;
- emerging issues/new technical skills—for example, how to deal appropriately with commercial-in-confidence papers, how to undertake criteria ranking;
- organisation orientation manuals;

- values clarification and exchange; and
- skills analysis/audit.

Opinions about the way in which education should be delivered also ranged across the full spectrum from the formal to the informal. It was noted that two key principles for effective education are the careful matching of the process to the target group and the use of both formal and informal strategies in any learning plan. The issue of joint training of stakeholders (consumers and service providers) was regarded as not suitable for initial training in consumer participation, because, without any initial training, both groups felt uncomfortable. Joint training was considered more feasible for ongoing training once a relationship had developed. Opinions were divided as to whether training should be certified but there was agreement that some form of certificate of attendance would be desirable for all stakeholders.

The following education processes were suggested, and are listed from the formal to the informal:

- designated curriculum area in all health professional pre-service education;
- accredited TAFE certificate;
- summer schools or short courses;
- conferences, seminars;
- day training—workshops, facts days, seminars;
- multimedia education—Internet, videos, Open Learning television;
- print media—journals, newsletters, fact sheets;
- creative strategies—professional role plays, special purpose games;
- self-paced learning packages;
- action learning;
- dialogue exchange—a structured but informal series of discussions in which differing participants share their perceptions and positions (see for example 'deep dialogue' in Lemon Tree project);
- on-the-job training—on a committee, as part of a consultative forum;
- networking;
- mentoring, mentoring the mentors, briefing, debriefing and re-briefing; and
- peer shadowing—a form of apprenticeship where a new member attends and observes meetings before taking on the role themselves.

Training the trainers: As there has been minimal funding available in this area, there has been little training and support for the community members implementing the training of fellow consumers. Some felt that they would benefit from undertaking a certified 'Train the Trainer' course while others would prefer to have professional supervision available. Professional supervision of the work of unpaid or community agencies has typically been offered by university academics, Lifeline staff and other professional groups as part of their commitment to the development of their profession. A key element of this is to help people to understand how other people learn, so that any training delivered really enhances the learning of participants. Although this issue was not raised by the health professionals, it would be important to consider whether this kind of training would be of equal benefit for health professionals who may have had limited exposure to best practice learning arrangements, but who will nonetheless often be in the position of needing to teach someone something or learn something new themselves.

Training and education good practice principles

All groups described in their own way the importance of acknowledging the particular needs of adults as learners. This included the need to recognise the expertise and experience each participant brought to the learning group, to acknowledge the different types of learners in a group, to provide a non-threatening environment and to provide a range of learning activities.

The importance of matching the training to the particular group was highlighted by a number of respondents. An initial skills analysis was suggested as a way that each participant could assess their own learning needs. In the consumer sector, the recruitment process was seen as an opportunity to begin training as well as informing consumers of the role of representatives. Within institutional settings, conventional survey methods can be used, although if consumer participation has a low priority other strategies may be needed.

The need to match the method of delivery with the target group was consistently noted. No one preferred method was seen as appropriate across the stakeholder sectors. For example some rural consumers noted the inappropriateness of the use of professional presentation packages such as Powerpoint whereas professional groups were more comfortable with that strategy. However there was some agreement that best practice education arises from a close link between an analysis of the learner group and the strategies available. There was an expressed need for access to a wider range of resources.

It was noted that education that used a mixture of concrete examples, creative strategies, information up-dates, the use of key guests etc was most likely to appeal to the diverse needs of learners. It was noted that some groups (for example, medical professionals) expect a more conventional didactic teaching

presentation but that well-designed alternative approaches can be strategically introduced. The range of literacy levels in some learner groups must be addressed. The education needs of learners from linguistically and culturally diverse backgrounds was noted as needing further research.

It was consistently noted that one-off education has a very limited impact. Learning plans need to address orientation education, special purpose learning, learning with other stakeholders and ongoing training and support in order to be effective. The integration of formal and informal learning is also central.

Although evaluation was recognised as an important part of good practice there was concern that only immediate impact evaluation was feasible given current finding arrangements. Long-term evaluation of training was typically informal and anecdotal. There was an expressed need to have separate funding to trial, pilot and fully evaluate new strategies

Both consumer and service provider groups who were engaged in running education, training and learning related to consumer participation noted that they were unable to document their training to a point where it would be useful for other similar settings. There was considerable frustration that they were probably re-inventing the wheel but without separate funding to document good practice training they were unable to share their resources and approach.

Barriers to effective education and training

The barriers to effective education fell into two types—those preventing the beginning of an education response and those arising once a strategy had commenced. The particular barriers faced in the rural and remote settings are dealt with in greater detail later in this section.

There were a range of issues preventing the commencement of an education, training or learning activity including:

- attitudinal barriers
  — such as 'Why should we bother, we are already doing OK!' 'Consumer participation is just a fad!', 'They won't listen!' 'I am already professionally trained.';
- resource barriers
  — problems with finding a suitable location to hold training, lack of funding for leaders and participants' costs (eg childcare, time off work, no money to pay trainers);
- overloading/packing in too much
  — consumers and providers all had busy lives and education, training and learning was seen as an optional extra in many ways;

- time and energy barriers
  — inability to see education as a priority, personal health limitations, competing professional priorities; and
- cultural barriers
  — lack of English and/or literacy, differing relationships to the health system.

Barriers to continued participation in education, training and learning when implementing a strategy included:

- difficulties with maintaining interest and commitment of participants over time;
- working with very diverse learning groups with differing educational backgrounds and skills often required diverse learning strategies. Given that most consumer courses, in particular, had no funding for the person leading the training, these significant demands often led to burn out;
- lack of training resources;
- maintaining the ongoing support and informal education needed;
- there was a need to providing adequate recompense once participation commences; and
- there was a lack of peer support for the trainer.

The most notable barrier that recurred throughout the consultation was the issue of attitudes and organisational culture. Although education can begin the breaking down of such barriers it requires a whole of organisation approach to produce sustainable change. There were reports of admirable individual commitment to cultural change but there was only one example of a holistic learning organisation approach to improved consumer participation in health. This was in a youth health project that had re-oriented its whole service delivery to a client-centred philosophy. Thus mutual learning became core business, not an optional extra, and the resultant service culture is radically different to mainstream services (see case study 12 in the *Resource Guide for Education and Training for Consumer Participation in Health Care*).

The frequent concern about inadequate resourcing also raised a number of other issues—for example, there were also some concerns about the overly complex reporting arrangements required by some government agencies for very small amounts of money.

From needs and gaps to innovative ideas

The majority of the respondents had creative and feasible ideas on education and training approaches that could overcome existing gaps in the sector. The

thoughtful and lateral thinking we noted in this area is evidence of the high level of commitment and expertise that is relatively untapped at the moment. The following are some of the innovative ideas suggested in the various groups:

- creation of new roles in the health system—for example consumer liaison person who is a two-way educator to the professionals and to consumer groups;
- incentives for education—professional development points for consumer participation courses, Newstart and Comcare acknowledgment of consumer representative training;
- national campaigns—educational mail-out to all health professionals; mail-out to every household on levels of participation in health services (following the notion of citizenship from the centenary projects);
- curriculum changes—from higher education to primary education;
- national funding scheme for consumer participation in professional conferences;
- national awards for good practice consumer participation—with accompanying national community education campaign;
- 1800 consumer line;
- state-of-the-art web site—linking and learning; and
- non-traditional learning programs—pub-nights, field days, combined community needs analysis/community education/community participation.

Education and training issues in rural and remote health systems

The issues faced by consumers in the rural and remote regions of Australia merit particular attention. Although rural consumers share many of the challenges faced by all consumer representatives the recent changes to health service structures have created problems that are unique to that sector. Our contact with people who live in rural areas brought this back again and again to the project team.

Before training and education were available to consumer representatives, most representatives gained their learning by involvement at local levels and then, as they developed greater understanding, these people were able to become representatives on higher level bodies. In the country regions, this meant that representatives could begin by attending local consultations, then join a hospital board, and finally be able to work at state level, should that be their interest. This accumulative learning process brought with it confidence and expertise.

However the recent move to disband hospital boards in favour of regional boards means that this informal learning path is no longer available to consumers. The role of the consumer representative at a regional level is especially technical and requires a level of confidence and experience not readily found. In effect this move has disenfranchised many consumers. Unless addressed in some way, there is a danger that the health system will come to regard consumers as 'not up to the job', rather than acknowledging that it is the system's responsibility to ensure that processes of community representation are achievable and sustainable.

Rural and remote consumer representatives are keen to undertake training in order to increase their skills and effectiveness. However, there are real barriers to their involvement. Rural representatives have to pay high travel and accommodation costs to attend any training. They share the problem of city consumers and professionals that training requires them to miss one or two days of work, with the additional time required for travel often aggravating this. Where rural consumers run farms, their participation in training may in some cases seriously affect their family business, as it does with other consumers who are self-employed or who are working in other small businesses. This problem is not insurmountable—training can be set at times in the rural calendar where extra hands in the family business are not essential, real travel and accommodation costs could be covered and the need for adequate time for papers to be delivered could be accommodated.

The recent joint infrastructure initiative between the Commonwealth Government and the National Farmers Federation 'Networking the Nation' provides another potential avenue for more effective education and support. Once the satellite and computer systems are effectively networked through this program, the delivery of online or televised training becomes feasible. Country areas have a number of committed consumer representatives but, until they are able to access similar information to their city counterparts, their effectiveness may be compromised.

Recent developments in flexible learning and delivery could also be harnessed for rural and remote consumers. Instructional designers are now able to convert face-to-face courses into packages delivered over the Internet or through distance education modules. Rural consumers reported that they had had almost no access to training—these forms of flexible modules would be a valued start.

Through the work of groups such as the Health Consumers of Rural and Remote Australia and the Royal Flying Doctor Consumer Network Group, cost efficient and effective peer learning processes have been developed. Where funding permits, these groups seek to hold regular teleconferences and meet together each year at an annual conference. However, the unavailability of

funding for these activities mean that the teleconferences are often limited to executive meetings and the face-to-face meetings are even more infrequent. Complementing this there is an informal learning system based on peer briefing and mentoring, with some mentoring of the mentors. However this system of peer education is minimally funded. It would be an effective investment to resource such activities across the whole of rural Australia. If there was guaranteed funding for this process, the rural sector could strategically provide real expertise to key bodies rather than depending on the expertise of the few who can afford to subsidise their attendance.

Rural consumers emphasised that it is not enough to bring city packages out to the country. To be effective training must be grounded in local issues. This is a lesson that should be heeded by all developers of education and training. Further they stressed that training should be practical and applicable, and should not assume any particular prior education levels—again principles for all education. Finally rural consumers asked to be considered not as one homogenous group of 'not urban', but as many different groups of consumers—one division suggested the following categories, regional cities, rural towns and remote centres/regions. Again this relates to good practice in any education and training analysis—it is essential to undertake a local needs analysis in order to most effectively plan any educational program.

D. UNDERSTANDING LEARNING

Education and training are elements of a much broader concept called *learning*. It is clear from many of the above views and the information contained in the resource guide that very few of the current processes for learning about consumer participation for either consumers, providers or administrators fit into the traditional picture of school education, which many adults in our community grew up experiencing. As was set out briefly in chapter 1 and in the consultation paper, the way our society now thinks about learning is different.

Three learning strategies will be included here, as they illustrate how a number of the concerns expressed above by participants in our consultation processes have been addressed in the theory and practice of today's life-long education environment. These strategies involve three of the most significant approaches to learning which are being used now. They are expanded in three articles which are included in part 5 of the resource guide. This section provides only a brief summary extracted from these longer articles. They form an important part of the intellectual backdrop to our development of a learning model to enhance consumer participation in health care policy, planning, service delivery and evaluation.

Action and experiential learning

Action learning is a process through which participants learn with and from each other as they work on real issues or practical problems in real conditions. It is usually conducted in teams or sets so that the process facilitates skill in both team and individual learning. The interaction of these two levels drives the learning process. Action learning involves:

- the integration of work and learning;
- experiential learning;
- team learning;
- action undertaken by the group to solve a real problem; and
- reflection by the group on both the problem and the learning process.

The team learning dimension is crucial. Members of the team share addressing the problem, and offer mutual support, advice, and criticism to each other. The process therefore fosters team learning skills and a cooperative, collaborative culture.

The usual components in an action learning program are:

- **the set:** a small group of people, say five or six, who meet regularly—perhaps one day a month or two half-days a month for the prescribed period (eg six months);
- **the task:** the problem given to the set, or decided by the group itself with work shared among members of the set;
- **the process:** that the group adopts when working which is determined by the group (eg the set members may decide to email each other with ideas/observations between meetings);
- a **set adviser** (or facilitator) who helps the group as it works and learns; and
- **duration of program** which is normally from three to six months with reporting on the outcome at the end of the set period.

These components can be applied flexibly and can be varied to suit particular needs and requirements. A key aspect is the support given by the group to the individual.

By integrating work and learning in a team situation, this strategy brings a range of benefits to the participants and to the organisation.

- Team learning skills are refined in a supportive environment.
- A forum is provided where people can share difficulties and problems without fear.

- Problem solving, listening, and communication skills can be enhanced.
- Motivation for ongoing learning can be increased.
- The process contributes to a cooperative, collaborative culture in organisation where staff share insights and problems.
- The process can enhance the creativity of an organisation and its capacity to innovate and respond to changing conditions.

Whether these benefits are achieved depends on how well the process is implemented and facilitated. Participants need a clear understanding of what the objectives are.

Building high-quality partnerships

Partnerships and new collaborative working arrangements are occurring more and more as we move into the new century. Some examples are: alliances of firms; education/industry partnerships; the development of learning cities; networks and communities; and coalitions with a range of stakeholders.

These developments are, to a large extent, a necessary response to characteristics of our society in this new era which has been variously called an information society, knowledge-based economy or risk society. One of the key drivers of these developments is the exponential pace of change, aligned with the key role of modern information and communication technologies, and the impact of a globalised world economy. The cumulative impact of these developments is blurring many familiar boundaries (Davis & Meyer 1998) and making many traditional habits and mindsets obsolete.

In this environment, partnerships have the following benefits:

- stakeholders collaborate in adjusting to change;
- new ideas flow more easily;
- special expertise is shared;
- there is improved feedback; and
- synergies can be created so that outcomes are value added.

Building effective partnerships is often impeded by a range of factors, including:

- inadequate planning and information;
- the reluctance of either party to let go of power and to share power and responsibility;
- inadequate partnership and team skills;

- lack of understanding of how partnerships grow and develop; and
- lack of trust between the partners and dated stereotypes and mindsets.

Each of these barriers, if present, may need to be addressed by strategies that address the barrier so that a partnership culture is fostered. Such a culture will be marked by mutual understanding and trust, open communication, and a commitment to advancing the objectives of the partnership. The existence of the barriers listed above means that a culture change strategy is likely to be needed.

There is considerable evidence from around the world that effective partnerships progress through a number of stages of development with different strategies required in each stage of development if the partnership is not to stagnate and wither. A common finding has been to identify three phases of development in the lifecycle of partnerships and this finding provides a practical approach to planning and developing partnerships. While the stages are given different names in different programs, the following is a useful example:

1. **Start-up:** The 'getting to know you' phase with initial contacts directed at building confidence and trust.
2. **Development:** Joint planning for the partnerships with implementation of the operational phase of the partnership. Strategies are developed for interaction and collaboration.
3. **Mature partnership:** The recognised common interest sustains the partnership. Mechanisms are in place to sustain, review, and extend the partnership.

Key lessons for building high quality consumer/provider partnerships or collaborations in the health sector are that:

- partnerships (and probably collaborations of other kinds) need to progress through a number of phases of development with appropriate strategies in each phase;
- careful joint planning is necessary;
- building mutual understanding and trust is essential in gaining commitment to the partnership or collaboration;
- the objectives of the partnership or collaboration should be clear to all stakeholders;
- there should be regular monitoring and evaluation of progress; and
- shared ownership is essential.

Building learning organisations

All organisations, whether public or private, now operate in an environment where rapid change is the norm. Some of these changes are the same as those which have influenced the growing importance of partnerships and collaborations, discussed above. These include: the impact of globalisation; new information and communication technologies; changes in work and labour markets; and shifts in social attitudes and values. The pace of change has let to the blurring of many traditional boundaries (Davis & Meyer 1998) so that people everywhere are confronted by 'the shock of the new'.

These forces have led to pressures for life-long learning so that individuals can maintain their employability as skill needs change, and maintain their quality of life in a world that combines risk and opportunity in a precarious balance. Consequently the British Government has termed the new era 'The Learning Age'.

In this environment not only must individuals continue learning as the world changes, but so also must organisations and communities. For this reason there has been an international surge of interest in concepts such as the *learning organisation*, the *learning community* and the *learning city*. Examples of these concepts being implemented may be found around the world.

The health sector is subject to these pressures and challenges in the same way as all other sectors of social and economic activity.

Building learning organisations, networks, and communities, in the health sector therefore promotes an opportunity for innovative collaboration and partnership between providers and consumers in addressing the challenge of the new century. There is mutual advantage in this happening so that health systems can be responsive to the challenges and opportunities in this ever-changing environment.

In his influential book on learning organisations, Peter Senge defined a learning organisation as: 'an organisation that is continually expanding its capacity to create its future' (Senge 1990).

This means that a learning organisation must go beyond 'survival learning' and progress to what Senge calls 'generative learning'—learning that enhances our capacity to create. In a learning organisation:

- work and learning are integrated;
- the capacity of staff is continually expanded and developed;

- a culture of reflection and continuous improvement is fostered; and
- the organisation is closely linked to its environment and so is receptive to changes in this environment.

In a health organisation, such as a hospital, health centre or health system, consumer/provider collaboration would be an important aspect of linking the organisation to its environment. Providers and consumers would learn together and would share a commitment to continuous improvement in the work of the organisation.

A number of approaches to building learning organisations have developed around the world and four of these are outlined in part 5 of the resource guide. Common features of these approaches, which could be built into an education and training program for consumers and providers using strategies such as workshops and action learning, are:

- there is a need to develop a shared vision through ongoing dialogue;
- continuous learning opportunities should be created for staff and other stakeholders eg consumers;
- team learning is a necessary strategy;
- systems thinking should be encouraged so that all stakeholders see the big picture ('helicopter vision'), and are sensitive to change;
- personal mastery enables people and organisations to change, to be adaptive and responsive to changing conditions;
- partnership is a key dimension to any learning organisation; and
- there should be systematic provision for review and reflection.

Most learning organisation development has occurred to date in private sector firms, in particular in firms operating in competitive global markets (Watkins & Marsick 1993). These firms understand the need to be receptive to changing conditions, and to be responsive and adaptive in this environment. This has been called 'when giants learn to dance' (Kanter 1989). Health organisations also need to 'learn how to dance' in the conditions of the 21st century, and to have the same agility and responsiveness to change as private corporations. A learning organisation strategy can offer much in this environment in providing a framework for fresh thinking and innovation in addressing this challenge with all stakeholders contributing.

A learning organisation focus provides an opportunity for consumers and providers in health care to develop a new vision for the future together, bringing a wide range of learning strategies into a single learning environment. This, in turn, develops a capacity for health organisations to adapt in the present environment of exponential change. The capacity to work together to bring

about positive changes presents a critical challenge where consumers and providers share a common interest.

E. DEVELOPING A CONCEPTUAL MODEL

The wide-reaching research processes of the project provided a rich source of information for us to consider within this broader education, training and learning framework. The Project team determined, after aggregating all of the identified resources together, and looking at the identified needs of consumers, providers and administrators that a conceptual framework for organising the material was needed.

As part of this development, we identified that our work in this project had been underpinned by a number of important assumptions about the importance of consumer participation, what was require for participation to be effective and the value of learning for all people involved in processes of consumer participation:

- Effective and efficient health care requires consumer participation in the planning, service delivery, monitoring, quality improvement and evaluation of health services. Some of the evidence which supports this assumption is outlined in part 2 of the resource guide.
- Consumer participation in health services benefits the services, their administrators and service providers as well as consumers.
- For consumer participation to be effective, all participants in the process need to respect the different skills and expertise of the other participants.
- Effective participation is facilitated by the development of mutual trust, respect, integrity and goodwill between participants.
- Effective participation can be enhanced through many different forms of learning, including education, training and other less formal 'learning processes.'
- Consumers, providers and administrators of health services can all benefit from learning about the planning, delivery, monitoring and evaluation of health services.
- Consumers, providers and administrators of health services can all benefit from learning the skills necessary for effective participation in collaborative work on the planning, delivery, monitoring and evaluation of health services.

The concept that there are many different kinds of learning applicable in our complex world has found its way into various international statements, which are the education equivalent to the various international health charters and statements discussed in chapter 1 and the consultation paper. For example, the

United Nations Education, Scientific and Cultural Organization (UNESCO) Commission on Education for the 21st century (the Delors Report) proposed a concept of four pillars for education:

- learning to know;
- learning to do;
- learning to understand others; and
- learning to be.

'Learning to be' is directed at the personal fulfilment of an individual, which is a lifelong process of personal development. The notion of four pillars of education also helped us to develop the conceptual model, within which to place all the resource material.

F. THE MINDMAP FOR EDUCATION LEARNING AND TRAINING (MELT) MODEL

Figure 1 sets out the project's conceptual model, which has then been used in the resource guide to arrange the material, to identify the nature of the learning involved in each one and to help users to understand how all the material relates to broader concepts in health and education.

The range of learning strategies given in the MELT model are consistent with the above four pillars of education identified by UNESCO.

- **Learning to know** in the information and knowledge components.
- **Learning to do** in the skill components.
- **Learning to understand** others in the use of team learning strategies such as action learning and other strategies that foster reflective interaction and better understanding of other people.
- **Learning to be** through enhanced informal self-directed learning and other activities that build personal fulfilment, including leadership development.

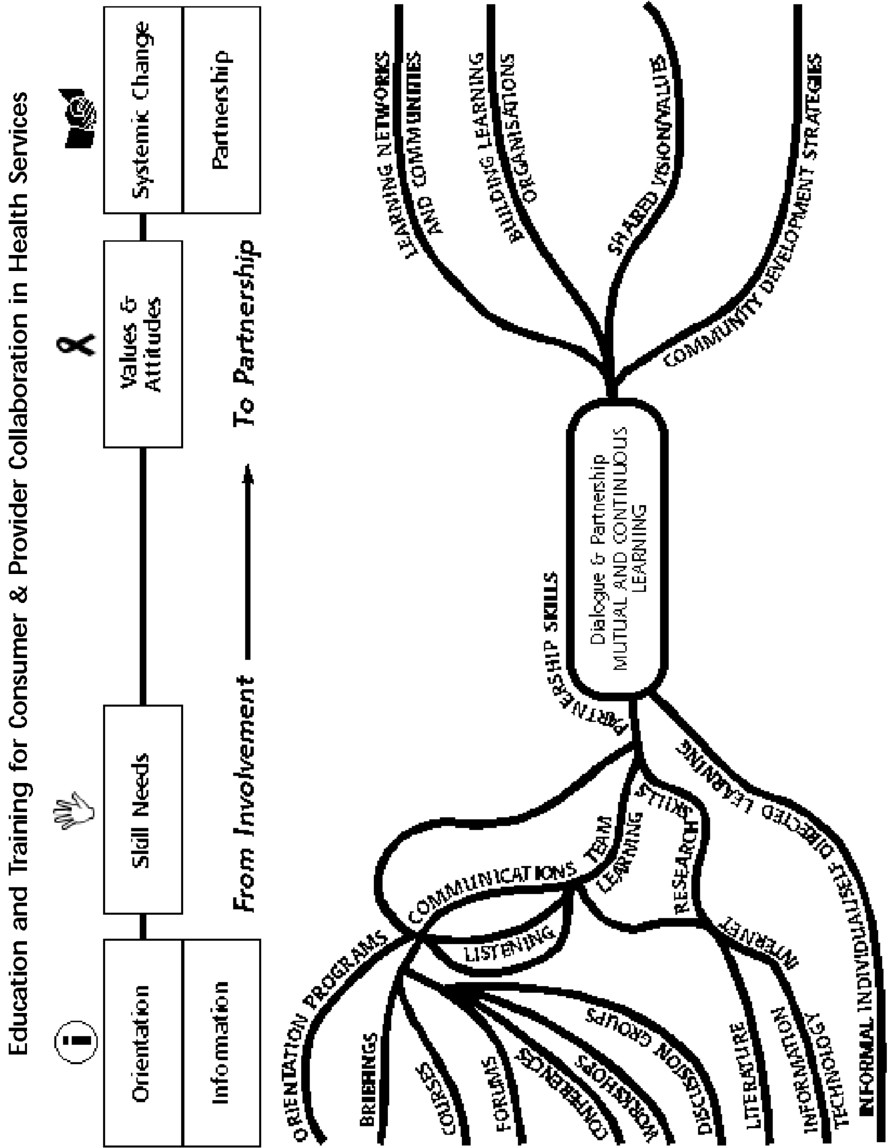
There is no ideal starting point in the model—each learning environment will need to be assessed, and the most appropriate starting point determined. However there is a progression of complexity from the simple strategies on the left through to the more challenging and broad-based changes to the right. In summary, the model emphasises the need for education that:

- meets orientation and information needs—a diverse range of ways of meeting these needs are included in the resource guide, including orientation programs, courses, seminars, workshops, discussion groups, newsletters and forums;

- meets skill needs such as those needed for communication, listening, problem solving, and partnership skills—similar methods to those adopted in meeting orientation and information needs are common with methods such as courses, seminars, and workshops often used, but there is growing use of informal self-directed learning and team learning through strategies such as action learning;
- is directed at attitudes, values and cultural change—strategies in this area are typically based on mutual and continuous learning and may include ambitious change programs aimed at fostering values and systems that underpin and support collaboration and partnership; and
- fosters dialogue and partnership and building organisations and communities that are responsive to changing conditions, so that collaboration becomes a natural process—community development strategies, learning communities and learning cities, learning organisations, and healthy cities strategies have been used to address these objectives.

An effective education and training program will offer consumers the opportunity to learn in one or more of these areas. A number of programs were found that focus on the first two arms of the MELT but very few were overtly working towards big picture cultural change. This is one of the areas where future work is required.

Figure 1 The Mindmap for Education Learning and Training (MELT) model



Chapter 4: Principles for the future

A. THE OVERALL OBJECTIVE OF EDUCATION AND TRAINING FOR CONSUMER PARTICIPATION

The primary aim of education and training for consumer participation is:

> to enable the full and effective participation of health care consumers in the planning, delivery, monitoring and evaluation of health services through the provision of relevant, accessible and effective learning experiences.

The information from the consultations summarised in chapters 2 and 3 identifies many areas where education and training can enable consumers and professionals to work together in the planning, delivery, monitoring and evaluation of health care. Often those who have thought about training and education to make consumer participation more effective have only focussed on consumer needs. However, as the research showed, such programs need to include health service providers and administrators, as well as consumers, because these groups strongly influence how effectively consumers can participate.

For example, health administrators need to understand that there are different ways of involving consumers. At the least satisfactory end, there is tokenism and providing information after decisions are made. One of the resources in the resource guide (see resource 37 in the *Resource Guide for Education and Training for Consumer Participation in Health Care*) provides a number of useful examples of what token participation can include:

- a … committee representative not being given the opportunity to contribute;
- advising … people of a decision and maintaining they were consulted;
- holding a meeting to placate people but not reflecting their opinions; and
- holding a meeting to discuss an issue but not feeding the decisions back.

At the other end of the spectrum, there are mechanisms which give a high level of authority for consumers to make decisions, either through self-determination or representation on decision-making bodies. Between these two ends are various mechanisms to ensure consumers are involved in decision-making to some extent. For example, consultations with consumers can occur before decisions are made and consumers' views can actually be brought into consideration as part of the decision-making process. A table setting out how such different levels of participation can be approached by individual staff members, in a unit and at a divisional or organisational level is

included in the resource guide (CO1, table 1) and is included as attachment I to this report. Often health administrators are influential in establishing decision-making bodies and determining how and when consumer input will be sought in a health care planning, policy, service-delivery or evaluation process. The education of administrators about the most effective means of seeking and obtaining consumer participation in these processes is therefore crucial. If they are not aware of barriers or useful means of facilitating participation, then they may establish processes which are ineffective.

Equally, the education of providers to aid consumer participation is also an important issue. The relationship between providers and consumers in health services long relied on a model where power rested almost completely with the treating health service providers generally and doctors in particular. This model relied for its effectiveness on a significant degree of consumer passivity and on a traditional assumption of trust. As is discussed in more detail below, this relationship has changed significantly over the past two decades. The inclusion of consumers in systemic decision-making and encouraging their input at other levels often requires new skills of health service providers and others. In addition, service provider knowledge of the health system beyond their immediate area of expertise may be quite limited, as may their skills in such areas as evaluation techniques or planning.

Those who were consulted in this project believed separate training and education for the three groups was required in some areas, to overcome initial barriers to communication and to provide some basic skills for consumers, providers and administrators. Longer term more established consumer representative training projects also identified the need, at some point, for joint learning experiences, often built into the participative process itself eg into the establishment and running of a committee. It seemed highly likely that these more complex learning experiences would involve careful planning and management by administrators, which would often have required some in initial training for them as well.

B. PRINCIPLES FOR FUTURE DEVELOPMENT

Introduction

The project team developed a set of principles which are designed to achieve the objective set out above and to reflect many of the issues which have been raised by consumers, providers and administrators in the consultation and research parts of the project. These principles seek to recognise the reality of the lives of consumers and providers as they seek to learn how to develop new ways of shaping the health care system together in a more collaborative manner.

Principles for consumer participation in education and training

1. Participation in any mechanism for the planning, delivery, monitoring and evaluation of health services is best viewed as a learning experience, consistent with the concept of life-long learning.
2. Effective education, training and other learning on consumer participation needs to openly acknowledge the fears and power imbalances in the relationships between consumers, providers and administrators of health services and work towards changing this culture towards a more collaborative one.
3. Any education, training and other learning processes relating to effective participation in the planning, delivery, monitoring and evaluation of health services needs to recognise that consumers, providers and administrators of health services usually have limited time available for these activities.
4. Effective education, training and other learning on consumer participation recognises the diverse learning needs of participants, including those from different cultural and language backgrounds, and that different people learn in different ways, and seek to positively accommodate this diversity.
5. Effective education, training and other learning on consumer participation recognises and addresses affirmatively the economic, physical and social barriers to participation and learning which can arise from poverty, disability, illness, other caring responsibilities and geographical location, as well as inadequate resources.
6. Effective education, training and other learning on consumer participation needs to be an element in main stream education about citizenship and in all health professional and administrator training and education, at the undergraduate, postgraduate and continuing medical education levels

There are examples of education, learning and training experiences which fit within these principles, and which meet a number of the needs of consumers, providers and administrators and these are identified in the resource guide. However, it was also clear from our research that there are a number of significant gaps in current resources as well as other practical problems which mean these principles are not being achieved by current education, training and learning provision for consumer participation.

C. GAPS, PROBLEMS AND SOLUTIONS

The following section looks at how these principles are currently operationalised as well as identifying where current arrangements fall short. Where there are problems and gaps, some recommendations are made to address these.

Principle 1: Participation as a learning experience

Consumer participation in a committee or a consultative process can be a learning experience in itself, if it is set up in a way which consciously seeks to achieve this. In many ways, this can be a highly efficient way for people to learn. Not only does the work required to be completed in the participative process get done, but the participants learn new information, new skills, new ways of relating and even new ways of being—all four of the UNESCO pillars of learning.

The second case study in the resource guide (extracted below) describes the Directors' Education Program at the Loxton Hospital Complex in South Australia.

> At the start of each year one session was dedicated to a needs analysis to ascertain the personal as well as the collective training needs of the group. All consumer representatives, medical and executive staff who attended Board meetings were encouraged to be involved in the needs analysis. The technique used was a face-to-face one where each member wrote down his/her own education needs; individuals then joined to form a small group to share needs. The process continued to larger groups compiling needs. Once the whole group training needs were established and agreed upon, priorities were set by the total group and an annual training plan drawn up. Any member who had a need not accommodated in the collective plan was given the opportunity to have this need met on an individual/small group basis.
>
> The timing of the education/information sessions was also determined by the members. The majority of ours were held prior to a normal Board meeting. We then would have a light meal together before the official Board. This would enable further informal learning and exchange to take place and was an important way for staff and consumers to continue their mutual learning. Attendance at Board education segments was purely voluntary but as our members "owned" the program we always had a very high rate of commitment.
>
> Through this planned approach to education members were not only more informed and confident, but negotiation, communication and participation at Board meetings was heightened. The Board of Directors took a leadership role in education and provided a model for other staff to rectify and develop their own educational and professional development program essential to the provision of effective health care services.

While this program is designed to create a separate 'education' program, it seems to be closely linked into the operation of the board.

The project team has also looked at models which take a more integrated approach and blend together the health and education experience, more closely allied to the 'learning organisation' idea or 'learning partnerships'.

Some characteristics of such a model were described in the consultation paper in the following manner:

- consumers are invited with all other committee members to a joint information session to hear the necessary background information from those seeking the advice of the committee and are provided with a draft terms of reference to consider;
- consumers and all other committee members meet to agree a final terms of reference, or if the terms of reference are set by an external agency, to agree a scope for the work of the committee, a set of outcomes sought to be achieved by the committee and business rules for the operation of the committee;
- committee members participate in an open forum session, where people can have a say about their particular concerns and learn to talk with each other; and
- committee members interact informally, for example, over a meal, afternoon tea or other trust building activities.

Unfortunately, the project team was unable to identify an example which operated in this way, though discussions with various organisations of both consumers and providers has indicated support for such a model. It would seem to be an ideal model for trialing as part of new initiatives arising from this and other Consumer Focus Collaboration projects. It has the advantage of involving all three groups identified in this project, as it requires the development of a program for training the health service administrator to set up such a program, as well as the involvement of consumers, providers and, possibly, administrators in the participative process.

Principle 2: Power, trust and cultural change

The relationship between providers and consumers in health services has long relied on a model where power rested almost completely with the health service provider, especially where they were a medical practitioner. The effective operation of this relationship to a large extent relied on the passive role of patients who placed significant trust in the doctor who was treating them.

The past several decades have seen the growing effects of consumer empowerment in health care, strongly set out by the High Court in the 1992 case of *Rogers v Whitaker* (109 ALR 625, especially 631, where the majority judgment quotes with approval *FVR* (1983) 33 SASR at 193). In this case the Australian High Court endorsed a 1983 South Australian Supreme Court decision, which said:

> the paramount consideration is that a person is entitled to make his own decisions about his life.

This case went onto set out some principles relating to disclosure of risks and provision of information to patients which has been strongly influential in the practice of providing information to consumers. These legal principles have been accompanied by growing expectations among consumers of a professional 'partnership-like' relationship, as well as consumer demands for involvement in decision-making relating to their own care.

These moves towards greater consumer empowerment have been accompanied by a loss of a significant part of the trust relationship, which was once always assumed to exist between all doctors and all patients. In its response to our consultation paper, the NSW Health Complaints Commission suggested some reasons for this loss of trust and its relationship to consumer involvement at the systemic level:

> - The deaths and injury caused by the so called 'deep sleep' therapy conducted at Chelmsford Hospital and the failure of existing licensing and monitoring bodies to act in the public interest led to widespread consumer distrust of the ability of professionals to manage health service delivery.
> - The high rates of adverse incidents in the Australian health system has also undermined consumer trust in the health system.
>
> These examples are only [two] of many that have provided consumers with insights into the existing health system, undermined community trust and provided impetus to have a voice in health service planning and evaluation (correspondence from Mr Bruce Greatham, Acting Director, Complaints Resolution, NSW Health Care Complaints Commission to Dr Barry Cameron, Global Learning Project Team, 20 February 2000).

The combination of these two processes has seen increasing emphasis being placed on publicly accessible complaints bodies, as now required under the Australian health care funding agreements, and, to some extent, a likely growth in medico-legal litigation.

In part 2 of the resource guide, the broader implications of power in language, perceptions, social practices and cultural norms are examined. An example given there of how different people may describe a consumer who chooses not to take the advice of a doctor about a particular course of treatment illustrates the implicit assumption of 'I know best and you don't!', which has been seen by many consumers to characterise their relationships with health service providers. These include 'non-compliance' or a 'lack of understanding', whereas a consumer may simply see it as a 'different life choice.' Consumers often perceive these attitudes as indicating that health professionals do not respect their experience as consumers and do not listen to what they want. This can cause consumers to bring a degree of suspicion and an expectation of

condescension into almost all transactions with certain service providers, which, if left unacknowledged, can thwart the development of more cooperative relations between consumers and providers.

The broader changes among consumers have, in turn, resulted in fear in health providers and a lack of trust in consumers, particularly where a provider sees the person questioning their authority. This fear can result in behaviour by the doctor or other health service provider which the consumer sees as angry or patronising. This kind of mutual distrust can be very difficult to manage in an individual doctor-patient relationship, and while it its often difficult for a consumer to leave a health care relationship, in such cases there is at least an option for most consumers that they can choose to go to another doctor (unless, for example, they live in a rural area and there is no other doctor). Where it becomes an issue in a consumer participation process, it can have a devastatingly destructive effect unless both consumers and providers work actively to address the lack of trust.

However, the experience of many of the projects in the resource guide has been that where participation has commenced, understanding and trust can be welcome by-products. The question is whether we can consciously build this learning directly in to the participation process to enhance and possibly even speed up the cultural change process. To do this, it is first necessary to identify the process which is initiated by effective participation.

The process starts with a mutual degree of wariness or possibly differing degrees of fear and distrust. Through participation and effective communication, understanding develops and from this trust follows. Trust itself then creates an environment where greater understanding is possible. At some point, it is highly likely that both participants will find that their greater level of understanding and trust enables them to identify some mutually unsatisfied needs. Participants then base cooperative action on the trust which they have developed and cultural change then starts to occur.

The actual promotion of cultural change in this way requires the trialing of new models which build on the results that have been identified in some of the projects. For example, there are a number of examples in the mental health arena of education and training processes where consumers are hired to help health service providers understand what it is like to be a consumer receiving services. These include the Lemon Tree Learning Project in case study 10 and case study 3 involving consumer tutors in the Canberra Clinical School.

In the later case study, Professor Cathy Owen set out some of her findings which illustrates that this kind of training can influence culture, even though it

also shows that effectiveness may not always result in adoption by others (presumably because they are still working within the old power paradigm).

- The initial concern for the welfare of the consumers working as tutors was unfounded and demonstrated a rather paternalistic view on her part initially.
- The time and intervention required by Professor Owen to devote to the tutors was not as much as expected.
- The relation between student and tutor that developed was invaluable as students began to feel comfortable to share concerns with their tutors about dealing with patients.
- The experience and knowledge that the tutors brought was seen as legitimate and valued by students.
- Other teaching staff in the unit, who had known some of tutors as patients, were surprised and impressed.
- Consumer tutors provided a better caring model for patients compared to that used in the ward in interview training.
- Some other provider disciplines eg nursing, have shown interest in using this approach at other sites, but there has been no local interest among doctors.

Given the importance of cultural change to more effective consumer participation, more methods of learning which enhance this should be developed and piloted. It may also form an important element in the model set out under the discussion of principle 1.

Principle 3: Time constraints

The reality is that consumers and health care providers are all generally extremely busy. For consumers, their participation is often in addition to their work or caring commitments. Where they are ill or have a disability themselves, they may have additional time constraints imposed by their illness or disability. When they are also a member of a consumer group or support organisation (a characteristic, which, it appears, assists their participation to be more effective, probably because their participation in this group provides them with some level of peer support), their time is further limited. While health professionals and administrators are more likely to be participating in their working time, they may see any associated training, education or learning which takes additional time as 'just another chore' in an extremely busy day.

All this means that education, training and learning which expect either consumers or providers to put aside significant periods of time over an extended period are unlikely to be attractive or sustainable.

The greater the integration of the learning experience into the participation experience, the more likely it seems that time constraints on both consumers and providers will be addressed. Other options which appear to be attractive to both groups and which provide time flexibility are mentoring (including follow-up phone calls from a more experienced colleague); briefing and de-briefing approaches (including, for example, those which take place in an informal setting, such as over a cup of tea or coffee); and peer support (for example, morning tea with other colleagues who can assist in the process).

Principle 4: Diverse learning needs

While the materials included in the resource guide show how diverse available education, training and learning resource are, it was noted in the earlier discussion of the MELT model that there was more material of the information and skill-building kind available, but lesser amounts which relate to cultural change and personal development in this area. The diversity of material provides a better chance that a consumer or provider, who is seeking to find something to help them learn about some element of consumer participation, will be in a better position to find something appropriate from among those resources brought together by the project.

The importance of diverse learning material and strategies is emphasised in the theories about learning. Chapter 1 in this report briefly refers to the different ways of learning and part 2 of the resource guide provides a more detailed outline of both the concept of a learning cycle and of multiple intelligences. In summary, the learning cycle has been used to explain the basic process of how an adult learns. David Kolb (Kolb 1984), for example, suggested that people learn in four ways:

- through immediate concrete experience (an affective way);
- through observation and reflection (a perceptual way);
- through using abstract concepts (a thinking way); and
- through active experimentation (a behavioural way).

Most people have a preferred way to learn. but in fact, these four ways of learning can feed cyclically into each other. It is argued by educational theorists that if a person can learn how to learn in each of these ways then they will be better able to pursue lifelong learning. Another important shift over the last decades is the recognition there is more than one form of intelligence (Gardner 1993). These different intelligences have been described as emotional, verbal/linguistic, musical/rhythmic, mathematical/logical, visual/spatial, body/kinaesthetic, interpersonal and intrapersonal intelligence. To meet the likely needs of consumers, providers and administrators for learning experiences, this

explains why these must be diverse and dynamic to support the range of learning abilities and preferences.

One gap which is clearly identified in our research was that of education, training and learning material to assist consumers from a non-English speaking background or from other culturally diverse groups in our community, including Aboriginal and Torres Strait Islander people. There is an urgent need to address the shortage of such resources.

Principle 5: Addressing the economic, physical and social barriers to learning

This principle more frequently affects consumers than providers, though the issue of lack of access to appropriate and relevant education for both groups in rural and remote locations is well-recognised. Consumers and providers in rural and remote areas are particularly disadvantaged by their isolation and the time and costs associated with travel that is required not just for education and training in participation but, for consumers, in relation to participation itself. Innovative ways of meeting the consumer participation education and training needs of rural consumers and providers are a high priority.

The barriers associated with differences in power and knowledge were discussed earlier under principle 2. Practical ways of addressing jargon and of providing a basis of shared information can go some way towards addressing the practical problems for consumers in these situations, though more is needed to tackle the real difficulties faced by both consumers and service providers in achieving cultural change.

Some of the other practical barriers for consumers for accessing education and participation are similar. For example, in both situations consumers (and providers) have a need for physical accessibility. This may be to the building or facility where the training, education, learning or participation is to occur. It may be a need for the course materials for learning or for the meeting documents for participation to be accessible by a blind person.

The lack of access to and inadequacy of funding to develop educational, training and learning materials and processes was seen as an immense barrier to their success and proliferation. In some cases, where special grants had been made available, there was few resources available to fund their continuation, even where they had proved effective. In the case of professionals, this was often not such a problem, because it was possible to use mainstream training and education resources to continue the projects and build them into continuing or primary professional education courses, for example through a Division of General Practice, tertiary institution or professional college.

However, there were no such alternative sources for consumer training outside that which may be provided by an institution, which was seeking their participation in one or other areas of work of their facility. The absence of a funding source often meant that consumer trainers were not able to be paid and had to provide any assistance on a voluntary basis. While this may have been possible for one or two events, it was not seen as a sustainable way to maintain a long-term supply of effectively trained and informed consumers. This was particularly so, while training materials and instruction manuals were still being developed. The lack of documentation of a number of projects led the team to leave them out, even though it is likely that they may have provided some useful lessons. The comparison of available material from the mental health area versus the broader health care area illustrates the difference between well-funded programs and those which limp by on small grants. The National Mental Health Strategy was the funding source for many of the best documented consumer training assistance, and there were more examples of new and innovative education and learning strategies in this area as well. Ongoing support for consumer training, and sufficient initial financial support to document the information provided in training and education, and to evaluate its effectiveness over time are important priorities for all areas of health care.

Another important issue for consumers relates to the costs of participation in education and training. Often consumers are volunteers, and some have limited income due to their health problems. They will often be sitting on committees or in other consultation processes where most of the people present are being paid to be there and often being paid quite well. A similar situation may well arise with participation in training or education. Administrators need training to understand that consumers may well need financial assistance just to meet their travel costs and that these need to be met on the day, because the level of disposable income of someone who may be on income support may be very small indeed. Denial of reimbursement of costs may preclude such people from participating at all.

The question of consumer payment for participation arises in relation to training and education as well. In the case of participation, the consumer brings valuable experience to the table and this has economic value for the facility, so payment for their time is an important acknowledgment of that value. Sometimes, this principle is modified to provide payment to consumers, only if they are not otherwise remunerated for that time eg through their employer continuing their wages to support their participation. However, in the case of education and training, it is arguable that a consumer who participates in learning in these areas gains skills and knowledge, and so gains an economic benefit by so doing. It is equally important to remember that the overall aim is to foster effective consumer participation and improve health service planning, delivery, monitoring and evaluation. There can be economic as well as

social and ethical reasons why a health care facility or organisation may believe that the provision of financial assistance to pay consumers to attend training and/or to meet any costs associated with the training or education is in its best interests as well.

Principle 6: Mainstream learning about consumer participation

It was clear from the discussions with health educators and clinicians involved in the education and training of health service providers and administrators that there was little, if any, formal education or training included about the systemic importance of consumer participation in the planning, delivery monitoring and evaluation of health care services. Nor were trainee health service providers taught any skills about how to optimise the effectiveness of consumer participation. The closest most courses came to providing such education was in the training now being done to enhance individual health service provider/consumer relationships, usually in a therapeutic setting. It would seem desirable if this could be extended to encompass learning about consumer participation at the system level.

There were also issues raised by some professionals about the culture of medical education in many places. Comments were made that in some institutions, teaching techniques themselves encouraged an individualistic, competitive approach to learning and did not encourage listening and valuing the experience of others, particularly patients. There were examples given of personally belittling experiences used to 'harden' students. Such an education process for professionals seems unlikely to teach the kind of skills which will facilitate consumer participation.

Equally, there are arguments that many of the skills necessary for active and effective consumer participation in health care planning, delivery, monitoring and evaluation are the same ones needed to be a flexible, adaptable person for full community participation in and out of paid work in the 21st century. The skills which are necessary for life-long learning, active learning and learning organisations are not specific to health care, but are important life skills which should be built into broader community education, at least in the secondary schooling level if not before hand. The inclusion of consumer participation and facts about the operation of the health system in primary school education may also result in more informed citizens in the future.

D. PRIORITIES FOR FUTURE ACTION

To better achieve the objective set out above, within the framework of principles the project has put forward, we believe that there are a number of priorities for future action by the Commonwealth, States and Territory Governments

and other stakeholders, if education, training and learning processes to enhance consumer participation are to be most effective.

Action 1: Sustainable resourcing

As a first step, there is real need for sustainable resourcing from all levels of government and, where appropriate, other funders (eg organisations seeking consumer participation):

(a) to document projects, models and materials which have already been used to enhance consumer participation in health care planning, service-delivery, monitoring and evaluation;

(b) to evaluate the effectiveness of the different projects, models and materials;

(c) to develop more educational, training and learning materials and processes;

(d) to provide financial support for consumers to enable their participation in these activities; and

(e) to regularly update the resource guide so that it will continue to be a useful source of information on 'good practice.'

One specific option raised by consumers was the need for special funding to pay for or assist consumers to attend key conferences in health care.

Action 2: Scarcity of education and training for particular groups

There is a range of groups, for which education, training and learning resources to enhance consumer participation in health care planning, service-delivery, monitoring and evaluation are scarce or non-existent. These include resources for:

(a) health care administrators generally;

(b) consumers and providers from non-English speaking backgrounds and other cultures; and

(c) rural and remote consumers and providers.

Given the importance of health care administrators to the establishment of effective processes for consumer participation, the project team considers this a high priority area for action. For example, funding could be made available for a collaborative project between consumers and medical administrators for the preparation of materials for health administrator training about effective consumer participation.

The project team also considers the effective involvement of consumers in the many geographically distant locations where health care is provided in Australia as an important health equity issue. Again, funding is required for a specific collaborative effort to develop materials and a number of pilots to see education and training can best to enhance the participation of rural and remote consumers (eg through bodies such as the Rural Health Alliance, specific rural consumer bodies, the Flying Doctor Service). Examination of the effectiveness participation and self-determination models used in Aboriginal health services might provide some different models for other rural and remote health services.

There was an absolute shortage of information about training and education to ensure the effective participation of consumers from varied cultural and language backgrounds. Given the range of sensitive religious and cultural issues, to which health care gives rise, it seems an important 'missing element' in our increasingly multicultural society. The barriers to participation of many of these groups are formidable. The project team believes this makes the development of models and materials in this area important priorities as well. The project team's experience in other areas suggest that there are effective ways to involve people from culturally and linguistically diverse backgrounds in health care system decision-making, though the methods which are currently used most frequently such as public consultations or participation on committees may not be most appropriate in these circumstances. Once again the development and piloting of some models is an important priority.

Action 3: Building education and training into participation processes

The project team considers that there is a strong need for models of education training and learning to enhance consumer participation, which can be consciously built into health care planning, service-delivery, monitoring and evaluation processes. By recognising the need for separate and combined learning, as well as building these processes into learning collaborations, there is a much greater likelihood of cultural change.

To achieve this, bureaucrats and others who are establishing committees, which are to involve consumers, need to learn the best ways of building these learning experiences into the structures and processes that they set up. They also need to recognise that learning is required for all participants and to implement processes which are based on the principles used for building effective collaborations and partnerships in other environments.

There is a scarcity of case studies or resources which achieve this more integrated approach and yet it seems more likely to fit in with the time constraints of both consumers and providers. The development of some simple 'how-to'

training for bureaucrats and health administrators and the conduct of some pilots of these integrated training and participation experiences is another priority area for action.

Action 4: Cultural change

The project team also considers that there is a significant need for the development of projects, material and models which can achieve cultural change in health care, and in the relationships between consumers, providers and administrators. The project consultations identified a shortage of educators and materials which sought to do this and there was little information available about how effective any methods were in doing it.

One option which the project team considers useful is to work with bodies and organisations already involved in cultural change in health care institutions, For example, the Australian Council of Healthcare Standards (ACHS) has good standards in relation to consumer participation, but there appears to be few skills in evaluating the effectiveness and operation of these standards in that organisation. There are no consumer surveyors and little understanding of how to measure outcomes in this area. The development of training about effective consumer participation for this and other quality and health care management training organisation may help with more rapid dissemination of cultural change in this important area.

The investigation of how to effectively bring about cultural change in health care could be a focus for future effort, with many parts of the health system likely to benefit from such research. Equally, organisations involved with cultural change in health care could start looking more closely at these issues themselves. Impetus for this could come from Commonwealth promotion of the findings of this project.

Action 5: Some strategies to achieve change for the health system

The funding of specific projects which address some of these high priority areas is one approach which the Commonwealth has used effectively on other occasions, eg through the Consumer Focus Strategy and the National Demonstration Hospitals Program. The Consumer Focus Collaboration should consider all these recommendations for action, in particular actions 2 to 4 above, which set out some immediate priority areas for consideration.

However, there are other more proactive strategies which could also be adopted. The Commonwealth has a direct interest in effective consumer participation. It could therefore engage with other groups such as ACHS, health management training services and other bodies to look at ways of educating

them about consumer participation and its crucial role in high quality health care. It could use the release of the work of this project as a starting point for this more directed approach to engage the interest of these groups.

Action 6: Information dissemination

There is a need for an effective information dissemination process for the resource guide from this project and from all of the other outputs from the Consumer Focus Collaboration process. The project team found the identification of important Commonwealth materials from programs such as the National Mental Health Strategy and the National Demonstration Hospitals Program difficult to locate through conventional literature search processes. Many of these came to light instead through consultations with the stakeholders.

Good web-based indexing and reference sites would be one way of achieving this, and it is expected that the National Resource Centre for Consumer Participation in Health will play an important role in ensuring this material is at least easier to locate in the future.

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Attachment A: Body of consultation paper

EDUCATION AND TRAINING FOR CONSUMER PARTICIPATION—A CONSULTATION PAPER

A. INTRODUCTION NOVEMBER 1999

This paper provides a basis for consultations and focus groups for stakeholders in the Education and Training for Consumer Participation Project being undertaken by Global Learning Services for the Commonwealth Department of Health and Aged Care. More details of the project and the background to the project in the Consumer Focus Collaboration, can be found in Attachment A, Introduction to the Project.

In summary, Australian health care policy and practice is seeking to create effective partnerships between health care consumers, providers and administrators and to encourage greater consumer participation in health care. Such arrangements are believed to lead to a health care system which responds better to consumer needs and to result in better outcomes, and sometimes, even in lower costs. The notion of partnership in health care began at the individual doctor/patient level, as is discussed further below. However, equality and mutual obligation, which are key components of partnership, are also important for consumer participation in health system decision-making.

Health care has traditionally been characterised by imbalances of knowledge and power between consumers, health professionals and administrators. It has also been characterised by hierarchical power structures, where consumers as patients were the subject of activities within the system, rather than active participants. Given this historical legacy, all players require assistance to gain the necessary knowledge, skills and attitudes to create effective partnerships.

This project is seeking to:

(a) identify the key characteristics of successful education and training methods to prepare health consumers, administrators and providers to create these partnerships across health care;

(b) describe examples of education and training for consumers, providers and administrators which are successful in doing this and include these in resource guides;

(c) identify key issues and gaps in education and training for the various stakeholders.

The project team has undertaken a literature search looking at local and overseas examples and the theoretical and practical issues which need to be addressed to determine best practice features of education and training programs in these areas. It is currently surveying a wide range of organisations to see what programs exist in Australia, in addition to those identified in the literature.

This paper brings together some of this work to provide a basis for focus group and stakeholder discussions of the issues. A final report for the project will bring together results of these consultations, the research and the survey data to identify the key characteristics mentioned in (a) above.

B. PARTNERSHIPS AND CONSUMER PARTICIPATION IN HEALTH CARE BACKGROUND

The World Health Organization's (WHO) 1978 *Declaration of Alma-Ata* set out a vision for primary health care which stated that:

> The people have the right and duty to participate individually and collectively in the planning and implementation of their health care …
>
> Primary health care … requires and promotes maximum community and individual self-reliance and participation in the planning, organisation, operation and control of primary health care, making fullest use of local, national and other available resources; and to this end develops through appropriate education the ability of communities to participate.[1]

In the 1986 Ottawa Charter on Health Promotion from the World Health Organization, consumer empowerment in health care was seen as a central element of achieving improved health and well-being in a society. The Charter also saw the promotion of health as something which went well beyond individual health care treatment. It involved cooperation and the skills and experience of many different people:

> The prerequisites and prospects for health cannot be ensured by the health sector alone. More importantly, health promotion demands coordinated action by all concerned: by government, by health and other social and economic sectors, by non-governmental and voluntary agencies, by local authorities, by industry and by the media. People in all walks of life are involved as individuals, families and communities.[2]

The means of achieving health set out in the Ottawa Charter were reiterated in the recent *Jakarta Declaration on Health Promotion in the 21st Century*, with health promotion being described as 'a process of enabling people to increase control over and to improve their health.' The declaration goes on to say:

> Health promotion is carried out by and with people, not on or to people. It improves both the ability of individuals to take action, and the capacity of groups, organisations or communities to influence the determinants of health.
>
> Improving the capacity of communities for health promotion requires practical education, leadership training, and access to resources. Empowering individuals demands more consistent, reliable access to the decision-making process and the skills and knowledge essential to effect change.[3]

These international declarations provide a broad conceptual framework in which many other developments in health care can be placed. They provide high level recognition of:

- the importance of partnership, not just at the individual consumer/provider level but to the degree of consumer participation in the system as a whole;
- the need for practical skills development and education to empower consumers and communities to participate in their health care at a systemic level;
- the importance of the active cooperation of health professionals and managers in facilitating consumer empowerment across the health system; and
- the needs of health professionals and managers for skills development and training to work with consumers to achieve the full potential of partnership and consumer participation in gaining better health for all citizens.

Where health systems do not include the active involvement of consumers, they are more likely to driven by the individual concerns of health professional groups, who may or may not have an understanding of what is needed in the community or wanted by service users. This in turn leads to wasted resources, inappropriate health care and consumer dissatisfaction leading to complaint or litigation. It also lessens public confidence in, and support for, the health system more generally.

> Q1: Are there any other international or local developments which you consider important to the development of consumer participation in the health care system in Australia?

The growth of partnership concepts in health care

The past few decades have seen a gradual shift in health care from a paternalistic approach, where 'the health professional knew best' and there was little consultation with the person upon whom the services were to be performed.[4] These changes are part of a broader social shift within our society, which 'acknowledges the fundamental democratic rights of all citizens to be involved in issues that affect them,'[5] In the health care arena, this is perhaps most epitomised by the legal principle of consumer self-determination in health care.[6]

Many of these democratic developments in health care have centred around the concept of partnership in individual consumer/health care provider relationships. However, the establishment of individual partnerships has had an impact on the broader policy discussion in health care decision-making. Partnerships are recognised as useful and desirable for both consumers and health professionals at the systemic level. For example a recent British Medical Journal editorial said:

> The key to successful doctor-patient partnerships is therefore to recognise that patients are experts too. The doctor is, or should be, well-informed about diagnostic techniques, the causes of disease, prognosis, treatment options and preventive strategies, but only the patient knows about his or her experience of illness, social circumstances, habits and behaviour, attitudes to risk, values and preferences. Both types of knowledge are needed to manage illness successfully, so both parties should be prepared to share information and take decisions jointly.[7]

All of these same sentiments ring true for consumer participation in health care decision-making at the systemic level.

Consumer involvement in systemic decision-making

There has also been growing recognition of the need for public participation in health system decision-making in Australia over the past decade. For example, in 1993 the National Health Strategy looked at the need for improved public participation in health system decision-making and a public process of debate concerning the priorities of the health system.[8]

More recently, the Task Force on Quality in Australian Health Care in 1996 drew a direct link between the developments in individual care and systemic change.

> There is a broad social change in the direction of a more active consumer role in health care. Individuals expect decision-making to be more of a partnership between provider and consumer. At a broader system level the expectation is that consumers will participate in quality definition, monitoring and feedback.[9]

In her 1997 report on models of consumer participation in Australian hospitals Mary Draper uses the term 'working partnership' to describe this sort of relationship and indicates the continuing importance of education and training to achieve this:

> … consumer participation is about participating, it is an active working relationship, it is ongoing and dynamic and it can take place in a range of ways.
>
> It is about clinicians and consumers becoming aware of each other's perspectives; about changes in service delivery, about good working relationships in which issues can be resolved, about sharing problems and finding lateral solutions, about developing better communication and respect for each other. It is a process of mutual adjustment. It is a 'powerful tool for change'. It is about Hirschman's concept of 'voice'.
>
> But it is a process which requires commitment, appropriate skills and time to develop trust in the process.[10]

Most recently, in the July 1999 Report of the National Expert Advisory Group on Safety and Quality in Australian Health Care entitled *Implementing Safety and Quality Enhancement in Health Care*, attention was drawn to the need for national action to further foster consumer participation in the health care system.

> The Expert Group recommends that national action continue to be taken to research, develop and disseminate methods to enable informed consumer participation in health care service delivery, planning, monitoring and evaluation at all levels, including strategies to improve the quality and accessibility of consumer health information.
>
> The Expert Group believe that incorporation of consumer perspectives in the development of strategies relating to all other national action areas is an integral part of national approach to safety and quality improvement.[11]

Partnership and participation—the common threads

The importance of individual care partnerships and the greater recognition of the need for consumer participation in systemic decision-making are philosophically interrelated. Both recognise that health care exists because of the health needs of consumers, rather than seeing health care's existence as an end in itself. Therefore, they both seek to develop new, constructive relationships

between consumers who need services and health professionals and administrators who provide these services.

Both concepts are built on assumptions about mutual recognition of the expertise and knowledge that each party brings to the relationship. Both rely on a shared understanding of the issues to be considered as part of that relationship. Both require a move away from adversarial, hierarchical models of behaviour and the growth of mutual trust and respect to work most effectively.

The traditional hierarchical system in health care has placed the consumer at the bottom of the decision-making and control ladder. This is opposite to the position that would be expected, given that consumer need is the principal reason for the system's existence. Both partnership development and the growth of consumer participation are part of the transition of the health care system to one where decision-making power and responsibility reside more firmly with those whose lives are most directly affected by those decisions—the consumers of health services.

In the end, however, the concepts of 'partnership' and 'participation' are not interchangeable. Tensions can arise between them, where the interests of consumers and providers or administrators do not coincide. This issue was identified in the Lemon Tree Learning Project, discussed more fully later:

> … we have become increasingly unhappy with [partnership] as our driving concept. Over the past twenty months we have come to realise that staff and consumers do not necessarily have the same agendas. Staff are workers. Consumers are trying to get on with their own lives which may or may not have much to do with the services they receive for their 'psychiatric stuff.' Staff are (or should be), by definition, work-focused when they are at work. That is, they are meant to be there *for* consumers who are trying to recover. This does not make for easy partnership. The very unequal power relationships between the two groups, the history of paternalism; the 'reserve powers' which our society gives to professionals to withhold liberty, to forcibly inject; etc all militate against the development of relationships which can truly be described as *partnership*. Therefore as the project progressed over time we found ourselves increasingly using the language of collaboration rather than partnership.[12]

While the issues of deprivation of liberty for psychiatric patients make the tension between partnership and participation even clearer, the same underlying tensions can exist in almost all other health care decision-making processes. However, as a concept, partnership provides a useful bridge between paternalism and full consumer participation.

Q2: Do you consider that the concept of partnership is a useful one for consumer participation? What do you see as the benefits and limitations of the concept?

Barriers to participation and partnership development

While there is often theoretical enthusiasm for consumer participation at the policy level, there are still significant systemic barriers to the full involvement of consumers in health care decision-making. Consumer participation in health care can range from very low level involvement where consumers are simply provided with information but have little capacity to influence decision-making to, at the highest level, consumer sovereignty, where all decisions are made by consumers often in cooperation with professionals and administrators, but with the final decision resting with consumers.

It is probably true in many health care organisations and systems that health care administrators and professionals are much more comfortable with lower level participation than with consumer sovereignty. For example, in relation to consumer feedback on quality in a hospital, the most frequently used tool is the patient satisfaction survey. Mary Draper describes these as the low end of the involvement spectrum:

> Many of the methods used by hospitals to obtain feedback from consumers, such as patient satisfaction surveys, continue to treat consumers as passive recipients of hospital services and reinforce traditional professional and authority relationships.[13]

Among other things, the lack of consumer focus in these surveys arises because consumers are seldom involved in their development. The failure to recognise the specific expertise of consumers and to value it in health care decisions acts as a real barrier to consumer involvement in this and other areas. Health administrators and health professionals simply don't think of involving consumers at the systemic level. Sometimes, where they are required to have consumers involved, they are unclear about the purpose of involving consumers. This can be a frustrating exercise to all concerned and can lead to ineffective use of consumers on committees. For example, not all consumers and consumer representatives bring the same skills, and a clearer statement of the reason for involving consumers can help maximise the chances of getting someone with the most appropriate skills and experience.

> For example, if a hospital or network wanted to get consumers on a board of management or its sub-committees as part of its strategic planning, they would need to find consumers with expertise in thinking through issues from a policy perspective, and with some authority to represent other consumers. On the other hand, if a hospital ward or area was looking at improving its service delivery, it might seek to involve the

relevant clinical illness consumer group, as well as consumers who are currently or have been recently involved with that ward or service delivery area[14].

There are also barriers which are about the culture of health care and its perception of consumers, as well as an ignorance about the real life situations of many health care consumers, which influence the physical, emotional and financial capacity of consumers in their participation. Mary Draper's study identified 5 factors which can act as barriers to consumer participation and she provided some examples under each which give a useful summary for the purposes of this paper. They are:

- Organisational factors
  - — bureaucratic delays
  - — lack of understanding of multiple responsibilities of consumers
  - — lack of adequate notice of meetings
  - — travel and time
  - — issues not followed up or reviewed
  - — the considerable time put in by consumes does not always have tangible results.
- Communication factors
  - — inadequate information
  - — use of jargon, both bureaucratic and clinical
  - — absence of courtesy (calling consumers by first name and everyone else by formal title).
- Consumer factors
  - — lack of confidence by many consumers
  - — caring responsibilities
  - — consumers bad experiences elsewhere.
- Power/status factors
  - — perceived undervaluing of consumer input
  - — perceived inflexibility of some doctors
  - — unequal power and resources.
- Language and cultural barriers
  - — for people from non-English speaking background
  - — cultural barriers for indigenous people.[15]

For people who are ill themselves or who are caring for someone who is ill, they can also be so intensely involved in day-to-day care decisions that it may be difficult for them to represent the views of a broader range of consumers. In addition they face the constraints imposed by their own ill-health.

Other practical difficulties include access issues for people with disabilities, such as access to reading material for people who are sight impaired and physical access to meeting places for people in wheelchairs. There are also the costs of participation, which for consumers can be considerable eg lost earnings, costs for getting substitute care, travel costs. Consumers are often also seen as 'free resources' next to professionals who may well be highly paid:

> Barriers to participation are generally major issues among consumers who can feel them quite acutely … Issues around feeling valued rather than disregarded, get tangled together with resentment over costs, and can easily contribute to people feeling exploited by professionals. It can also be humiliating to underscore differences in status by having to ask for access to things like information, phones, and reimbursement for out-of pocket expenses which have not been offered.[16]

These financial barriers effectively preclude the participation of consumers who are affected by poverty, but are an impediment to even those with higher incomes.[17] The actual success of consumer representatives in some areas has brought with it other barriers to the sustainability of that participation. As Hilda Bastian said:

> As support for consumer participation increases, so too do the demands and expectations placed on representatives. When I first started 'consumer repping' back in the early 1980s, representatives were basically just trying to legitimate their presence, and even just get themselves taken seriously. Now they can find themselves expected to write sections of reports or pamphlets for consumers, or any other number of tasks. While this is progress in many ways, it also places new stresses on representatives, and clearly requires an ever broadening range of skills beyond knowing how consumers feel about their health care. This blend of increasing professionalisation coupled with the expectation of volunteerism is creating great stresses.[18]

These time and money constraints are also issues for consumers in relation to training and education for their roles. These same constraints are often said to also affect the capacity of health professionals and administrators to attend training of this kind.

Q3: What do you see as the main expectations of consumers for training and education for their roles as consumer representatives in health care and the main barriers to their obtaining this training?

Q4: What do you see as the main expectations of, and barriers to, the participation of health care professionals and health care administrators in training and education to assist them to facilitate consumer involvement in the planning, delivery, monitoring and evaluation of health services?

In a decision-making environment, where full consumer participation was a reality—for example, where there was shared understanding and a more equal power distribution—all committee members would be able to facilitate each other's involvement. For example, in future, consumers could have a greater capacity to influence and even 'facilitate' the more effective involvement of health professionals and health administrators in decision-making. However there are significant barriers to such a mutual active role at the moment.

Q5: What do you see as the main ways of enabling, and the key barriers to, consumers, health professionals and health administrators assisting each other to better participate in the planning, delivery, monitoring and evaluation of health services?

Addressing the barriers to participation and working partnerships

Many, but not all of these barriers, can be addressed by education and training of consumers, health administrators and health professionals. Even in areas where training cannot overcome the barrier itself, such as adequacy of resourcing for consumer participation, awareness of these barriers can perhaps facilitate better understanding and lead to the development of more successful models of participation.

Some of these barriers can be addressed simply by the provision of information to all committee members—professionals, administrators and consumers alike—about how the system operates. This can provide a common basis of understanding which is fundamental for successful partnerships.

However, effective working partnerships in health care require much more than just shared knowledge—they require cultural and attitudinal change and the modification of traditional power structures to facilitate more even power-

distribution. This type of change is more difficult to achieve. Among other things, it involves:

- a recognition that there are real benefits for health professionals and administrators in the active and full participation of consumers in these processes;
- direct dialogue between with providers and consumers, with each listening effectively to the other;
- establishing trust between providers and consumers, and sometimes, administrators and professionals; and
- development of working relationships where the principles of partnership are honoured by all participants.

Gaining the skills to enable people to listen well to each other and to work together with a common purpose can be much more difficult than simply imparting even complex knowledge. Yet such skills are crucial to achieving the cultural change which is generally necessary for full consumer participation in health care decision-making.

For example, sometimes it may be necessary for health professionals and health administrators to learn that the involvement of consumers in systemic decision-making can have positive effects. These may include the spreading of responsibility for difficult decisions across a broader group and the likely greater community acceptability of the results of processes which have truly involved consumers in full participation.

> Q6: Are there other skills or knowledge that are necessary for consumers, health professionals and administrators to allow them to fully participate in planning, delivery, monitoring and evaluation of health services?

C. A LEARNING CONTEXT

Introduction

There are a range of things which consumers need to learn to be able to participate fully in health care decision-making. The skills and knowledge which may be required for active and effective participation in the various activities of planning, service delivery, monitoring or evaluation of health services can also differ. For example, a broad understanding of the overall health system and financial arrangements between different levels of government may be needed by someone involved with system wide planning, while a consumer working on the evaluation of health services may need some understanding of statistics and evaluation.

Health professionals and administrators may also need assistance to better understand some of these areas. For example, health professionals may know a great deal about their area of professional specialisation, but have very little understanding about how the broader health system operates. Equally, they may have little experience or understanding of evaluation.

All participants may require assistance to be more effective listeners and communicators.

Creating a learning environment

Education and training were once thought of as something which you did as a child and possibly as a young adult in school or other formal training institution. There was limited availability of training at other points in life, except possibly additional vocational training to keep your skills in your original area of knowledge up to date. Over the last half of the twentieth century, the rapid pace of change in our society has resulted in the development of a new learning paradigm, often called 'lifelong learning.'

A lifelong learning approach recognises that learning occurs in many situations such as the workplace, home and community generally and that there are many different techniques and methods that can be used to learn, both formal and informal.[19] This paradigm moves away from the idea that people who learn are 'empty vessels' to be filled with knowledge by experts. It recognises, instead, that people learn together through sharing their knowledge and experiences.[20] It also underpins many of the new management models involving 'learning organisations.'

It also strongly values what are called 'learning partnerships' where key stakeholders work together. Learning partnerships may take the form of team learning within an organisation, the use of forums or workshops involving stakeholders working together or initiatives as large as the United Nations models of Learning Cities.[21]

Learning partnerships are said to evolve over time through a number of stages of development.[22] These stages have been described in different ways but essentially they are:

- a start-up phase: which has variously been called 'coming together' and 'getting organised' in different models but which essentially involves coming together to work out a shared objective and starting to build a relationship;
- a development phase: which has variously been called 'moving forward' and 'towards shared understanding' which involves the growth of trust through participants talking together, properly listening to each other and treating each other with mutual respect as they learn together; and

- a mature partnership phase: which has variously been called 'sustaining the momentum' and 'cycles of learning and reflection' where the focus is on the maintenance of an established relationship and efforts may be needed to prevent the relationship from stagnating and lapsing.

Q7: Do you think that 'learning partnerships' are a useful framework for considering ways of achieving better consumer participation in planning, delivery, monitoring and evaluation of health services?

Q8: How do you think the stages of a 'learning partnership' can be applied to improving the 'working partnerships' between consumers, health care providers and administrators in the planning, delivery, monitoring and evaluation of health services?

Types of learning

At the international level, the UNESCO Commission on Education for the 21st century proposed four pillars for education into the next century.[23] These are:

- learning to know (eg information)
- learning to do (eg skills)
- learning to understand others (eg empathy)
- learning to be (eg self-esteem)

Each of these elements is required for training consumers, health professionals and administrators for more effective participation in health care decision-making. In some ways the learning needed to achieve this is more akin to traditional 'community development activities' than traditional 'education and training', both in the way it is generally delivered and the types of learning that are required. At its core, 'community development' is concerned with enabling and empowering people as they work towards an agreed goal of social change, through a wide range of processes,[24] most of which are informal, non-institutional and not formally considered to be 'education or training.'

Nonetheless, it is argued that such empowerment can bring about profound changes in communities and organisations, because they are transformed as people participating in them are transformed.[25] This is consistent with the paradigm shift in education towards 'lifelong learning' and the notion that a lot of effective learning is informal and incidental and happens as we try new things and exercise new skills.

Q9: How can these UNESCO 'pillars of learning' be applied to formulate training for consumers, health professionals and administrators to maximise the effective participation of consumers in the planning, delivery, monitoring and evaluation of health services?

Q10: What lessons from community development programs might be applied to formulate training for consumers, health professionals and administrators to maximise the effective participation of consumers in the planning, delivery, monitoring and evaluation of health services?

D. SOME EXAMPLES OF PROGRAMS TO FOSTER CONSUMER PARTICIPATION

Introduction

In order to maximise the effective participation of consumers in the planning, delivery, monitoring and evaluation of health services, the learning needs of consumers, health professionals and administrators to achieve this goal must be considered. There are some specific needs for consumers and some for health professionals and administrators. There are other shared needs, many of which relate to the process of working together successfully.

The need for specific training for consumers to facilitate their participation in community committees has been recognised in a range of contexts over the past two decades. This has resulted in the production of a number of consumer training manuals, often in conjunction with projects which have sought to provide skills and knowledge to consumers to be consumer representatives.

However, there appear to be far fewer examples of programs which are designed to assist those who are the traditional members of committees to gain the necessary skills to facilitate consumer participation. Traditional committee members, such as health professionals, administrators and those with a commercial or career interest in an area, are often assumed to know or have the necessary skills to facilitate participation However, the experiences of consumers tend to indicate this is frequently not so.

There also appears to be a limited number of examples of programs in the health field which seek to train those who are establishing committees and decision-making bodies on the best ways of setting up such bodies to maximise their chances of working. More work has been done in other fields, such as training for school boards,[26] and lessons can be gleaned from these fields.

Consumer training

There are examples from the 1980s and 1990s of manuals and training programs for consumers in spheres of community activity, such as committees, school boards or community councils. For example, the manual *Getting Involved—a woman's guide to participation*[27] arose out of a project funded under the National Agenda for Women Grants Program in 1989–90 called *Participation in our community: survival skills for women on committees*. The project ran two series of 8 week programs to develop and increase the skills of women who want to be or who are already involved in community organisations or groups and produced a manual for use by women in the community, community organisations and workers.

In the health sector *The Little Purple Book of Community Rep-ing* is another widely used and popular resource which arose from the North West Suburbs Health and Social Welfare Council's 'Not just a Token Rep' cartoon project, that was funded by the Consumers' Health Forum. The aim of that project was:

> to produce a humorous and accessible guide for people wanting to be community or consumer representatives, a guide which was based on the experiences of people who had actually been community or consumer representatives.

This booklet developed from a series of workshops which identified the greatest needs for consumer representatives were:

- an understanding of group dynamics;
- access to jargon-free information;
- the need for practical support; and
- assistance with 'hanging in there.'[28]

There are more recent examples in the health sector, such as the ACT Health Care Consumers Consumer Representative Training Project or the various mental health consumer training projects, which have been funded under the National Mental Health Strategy, such as *The Kit—A Guide to the Advocacy We Choose To Do.*[29]

Q11: Are there any examples of education and training programs for consumer representatives which you believe exhibit best practice features and could be used as examples for others?

Learning for health professionals and health administrators

To date, education and training for health professionals and administrators has focussed on the development of skills for creating partnerships with individual patients, rather than the involvement of consumers in systemic decision-making. A good example of a manual to assist in individual information sharing and partnership development is *The Care Partnership: Communication and Education Strategies for Health Care Professionals*[30] which was funded under the National Demonstration Hospitals Project. It was developed by the Royal Melbourne Hospital to provide a practical method for designing effective and efficient learning resources for patients and their carers to actively participate in their own health care.

As noted earlier, health professionals and administrators can sometimes lack direct knowledge of the broader health system or have limited skills in particular techniques such as evaluation, just like consumers. However, they are generally much more likely than the average consumer to have a good technical understanding of health procedures and techniques. Equally to work effectively with consumers, they are more likely to require skills in communicating without the use of jargon and listening effectively to people with diverse views.

Another important issue for effective consumer participation is the pervasiveness of hierarchical power structures in health care. Health professionals and administrators need training to increase their awareness of the barriers these structures create to participative decision-making, as well as skills to remove these barriers. Examples of training and assistance for health professionals and administrators in these particular areas are much less common.

A number of examples of innovative provider education and training of this kind can be found the Lemon Tree Learning Project, which is a Victorian based project funded by the National Mental Health Strategy.[31] It sought to develop a number of consumer initiated learning processes around the idea of consumer participation in service delivery. The project team identified the importance of cultural change in effective consumer participation and developed a number of ways to assist in this, including:

- a board game called 'Lemon Looning', similar to monopoly, which is used in (paid) consumer-led provider training sessions to allow providers 'to gain

experience of the consumer perspective as they negotiate their trips around the board and by extension, through the mental health system',[32] and

- the use of two consumer-facilitators to lead discussion groups of up to ten staff, where rather than being 'impartial facilitators' the role of consumers was to 'hold their consumer perspective and introduce it into the discussion when they were inclined to do so'. For example, when a staff person put forward something which may include an assumption which 'violated their own experience as a consumer.'[33]

Another example of this sort of publication is the Consumers' Health Forum's guide to assist Divisions of General Practice to work with consumers.[34]

Q12: Are there any other examples of education and training programs for health professionals and administrators designed to maximise the effective participation of consumers in the planning, delivery, monitoring and evaluation of health services?

Q13: What do you believe should be the best practice features of any such education and training programs, and are there lessons which could be learned from care partnership training initiatives?

Training for the establishment of successful consumer participation processes

It is often assumed that committees can be established and function without any particular assistance and without any specific processes being used to ensure that they function effectively, other than taking minutes. Ineffective consumer involvement has often been one consequence of this *ad hoc* approach. Often a committee will be formed and then someone may think having a consumer member is a 'good idea'. Someone will be invited or nominations will be sought for a consumer to participate on the committee.

While sometimes this approach can eventually produce useful results, often this initial *ad hoc* beginning has negative effects for consumer representatives. Consumers can feel that they were an afterthought to the process, rather than an integral part of it. They may find it difficult to 'connect into' a process which had an existing dynamic and a set of relationships in place before they arrived. They can feel an absence of ownership of the terms of reference and a lack of understanding about the desired outcomes of the process.

Establishing a better process for committee formation and consumer involvement, through development of some best practice principles would seem to be highly desirable and a useful tool for all participants. While there are few examples in health care, some elements of the processes for establishing other forms of community committees, such as school boards and community

councils, could be drawn upon. These can be linked to the various different stages of the 'learning partnership' identified in the previous section. For example, some elements of such a process could be:

- consumers are invited with all other committee members to a joint information session to hear the necessary background information from those seeking the advice of the committee and are provided with a draft terms of reference to consider;
- consumers and all other committee members meet to agree a final terms of reference, or if the terms of reference are set by an external agency, to agree a scope for the work of the committee, a set of outcomes sought to be achieved by the committee and business rules for the operation of the committee;
- committee members participate in an open forum session, where people can have a say about their particular concerns and learn to talk with each other; and
- committee members interact informally eg over a meal, afternoon tea or other trust building activities.

Q14: Are there any examples of education and training programs which provide guidance on how to set up and run successful committees, which maximise the effective participation of consumers in the planning, delivery, monitoring and evaluation of health services?

Q15: What kind of features would you include in such a model program, if you were designing one?

E. CONCLUSIONS

This consultation paper seeks to ask some challenging questions for participants in the health care system. Many readers of this paper will be participants in focus groups and other consultation processes. The questions raised in the paper will form part of the discussion in these forums. The project team is very much looking forward to hearing your views on these and any other relevant issues, which you may consider we have omitted from this paper.

For those who wish to provide written answers to the project team to any of the questions, please forward them to the project team through the project manager or principal author of the paper.

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The input of those who provide feedback on the consultation paper is very important to the project team and will form a valuable part of the final analysis of the project. We thank you in anticipation of your assistance in this important project.

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Attachment B: The consumer focus collaboration and commissioned projects

The following projects were listed as an attachment to the introductory paper, the body of which is included at attachment E to this report. The Consumer Focus Collaboration has subsequently commenced other projects to pursue its aims as well.

Stocktake of models for facilitating consumer access to health information

This project will document the most effective approaches currently available to facilitate consumer access to health information and to draw out the lessons that can be learnt from them. Consumers will be involved throughout the project. The project outcome will describe and assess the available models of access to health information; analyse the core principles, characteristics and key elements underpinning best practice in the area; and establish a baseline against which the effectiveness of future work can be measured.

Support for nurses to involve consumers in their health care

Major nursing organisations are sponsoring this project to develop recommendations for promoting consumer participation, and collaboration between nurses and consumers, in acute health care settings. The project will identify models of best practice, evaluate these through consultation with nurses and consumers, and recommend further strategies to promote partnerships between nurses and consumers.

Supporting the efforts of medical practitioners to involve consumers in health care

The Australian Medical Association and the Committee of Presidents of Medical Colleges are jointly sponsoring a project to work with medical practitioners to support in a practical way their efforts to involve consumers in their health care. The consultant will test existing tools and techniques for consumer involvement to assess their relevance and usefulness in the context of hospital practice. Recommendations will also be made for adapting these tools and techniques for use in other areas of medical practice.

Toolkit for consumer participation

The aim of this project is to provide a practical toolkit of approaches and strategies to assist service providers and consumers to achieve effective consumer participation in the planning delivery, monitoring and evaluation of health care services. The toolkit will present resources, strategies and best practice approaches to assist people at all levels within organisations to undertake their work. The development of the toolkit is to be informed by key elements of recent research on consumer participation in health care; a search conference with a targeted range of stakeholders; and review of the draft toolkit in consultation with partnerships of consumer organisations and service providers. The project is to also produce a supplementary resource for providers which documents other providers' expertise, specific tips and issues arising from the project.

A model for selecting and supporting consumer representatives (Breast Cancer Network)

This aim of this project is to document, from a disease-specific perspective, the recruitment, selection and training processes employed by a consumer organisation (Breast Cancer Network Australia) for their consumer representatives.

Communication and clinical outcomes

The project involves doctors and patients in developing materials to improve doctor/patient communication in elective surgery, tested by a randomised controlled trial. Research on the impact of communication on outcomes shows it is related to patient satisfaction, psychological well-being, functional status, compliance and clinical result. The project seeks to develop ways that both doctors and patients dealing with elective surgery can change aspects of the health system for mutual benefit.

Safety of Australian health services: a community survey

The aims of this project are to determine the prevalence of self-reported adverse events within a representative population of Australians aged eighteen years and over and to determine the community awareness of and perceptions of risk associated with contact with the health care sector. The project should also provide some baseline information about the effects of reported adverse events, and consumer perceptions of health care professionals, the most common causes of adverse events, trends in the safety of health care services, and the reliability of groups that provide medical and health information. The project should provide statistically robust information on: the frequency and nature of adverse events encountered by the Australian community; the relationship between consumer perceptions of adverse events and adverse events identified by expert medical record review; and a benchmark from which future performance of the health care system may be measured.

Attachment C: Team members

Dr Jennifer Thomson *Joint Project Manager*	Management consultant; Policy Adviser, ACT Division of General Practice; Medical Consultant, Australian Medical Association
Dr John Grant *Joint Project Manager*	Director of Global Learning Services; Chair of the ACT Accreditation and Registration Council; previously Deputy Vice-chancellor, University of Canberra
Dr Barbara Pamphilon	Senior Lecturer in Health and Community Studies, University of Canberra
Ms Fiona Tito	Executive Director of Enduring Solutions with the assistance of Ms Kate Moore of Enduring Solutions
Dr Barry Cameron	Former Executive Director, Academic Services/Development, University of Canberra
Mr Peter Kearns	Managing Director of Global Learning Services
Mr Jake Keller	Education and management consultant
Mr David Francis	Managing Director, Caithness Robson Consulting; previously Chief Executive Officer, Curriculum Corporation
Dr Christopher Holmwood	GP supervisor Modbury Hospital; Adelaide Southern Division Mental Health Program Manager

Attachment D: List of organisations consulted in preliminary consultations

The following list of the organisations was developed by the consultants with the assistance of the Commonwealth Department of Health and Aged Care and the Steering Committee.

State health departments
Australian Capital Territory Department of Health and Community Care
New South Wales Health
Department of Community and Health Services, Tasmania
Victorian Department of Human Services
South Australian Department of Human Services
Health Department of Western Australia
Territory Health Services, Northern Territory

Professional organisations
Australian Divisions of General Practice
Australian Medical Association
Australian Medical Council
Australian Nursing Federation
Pharmaceutical Society of Australia
Society of Hospital Pharmacists of Australia
Royal Australasian College of Physicians
Royal Australian College of General Practitioners
Royal Australasian College of Surgeons
Committee of Presidents of Medical Colleges
Royal College of Nursing, Australia
Royal Australian College of Medical Administrators
Health Professionals Council of Australia
National Rural Health Alliance

Consumer organisations
Consumers' Health Forum
Health Issues Centre
National Resource Centre for Consumer Participation in Health
Australian Consumers' Association
Health Consumers' Council WA
Health Consumers of Rural and Remote Australia
Victorian Mental Illness Awareness Council

Education organisations
Committee of Deans of Australian Medical Schools

Attachment E: Introductory paper

AN INTRODUCTION TO THE PROJECT EDUCATION AND TRAINING FOR CONSUMER PARTICIPATION

Introduction

This paper has been prepared to introduce the project to interested people, including health care consumers, health care providers, health administrators and health educators. A list of project team members is included.

One of the important directions for health care policy and practice in Australia is the creation of effective partnerships between health care consumers, providers and administrators. The aim of these partnerships is to ensure a more responsive health care system, with better outcomes for consumers. These partnerships are intended to cover all parts of health care, including planning, delivery, monitoring and evaluation of health services.

However, such partnerships don't form automatically—particularly in health care, where the traditional model of service has been characterised by imbalances of knowledge and power. Health care consumers, administrators and providers all require assistance to gain the necessary knowledge, skills and attitudes to successfully create effective partnerships.

This is the first part of the information gathering and consultation stage for the project. We will be asking you to tell us:

- about those education and training programs for health consumers, providers and administrators that are fostering consumer/provider partnerships; and
- whom we should be approaching in the next phase of our project when we will be sending out a more detailed consultation paper and conducting surveys and focus groups.

Objectives

The objectives of this project are:

(a) to identify the key characteristics of successful education and training methods to prepare health consumers, administrators and providers to create these partnerships across health care;

(b) to describe examples of education and training for consumers, providers and administrators which are successful in doing this and include these in resource guides; and

(c) to identify key issues and gaps in education and training for the various stakeholders.

Context

The Consumer Focus Collaboration (CFC) was formed in 1997 following the *Final Report of the Taskforce in Quality in Australian Health Care* in 1996. The project is one of a number of projects (outlined as an attachment) that have been designed to progress the goals of the CFC which are to:

- facilitate the provision of high-quality information to consumers in appropriate formats;
- facilitate active consumer involvement in health service planning, delivery, monitoring and evaluation;
- improve health service accountability and responsiveness to consumers; and
- promote education and training that supports active consumer involvement in health service planning and delivery.

The CFC has also overseen the establishment of the National Resource Centre for Consumer Participation in Health (NRCCPH), which has been established to promote partnerships between consumers and other stakeholders. It will act as a clearinghouse, collecting information on consumer feedback and participation methodologies, widely disseminating this information to health care providers and consumers. The centre will also provide advice on and critically analyse new methods and models of consumer participation. This project will liaise closely with the Centre and the Centre will disseminate its work.

Methodology

The project commenced in July 1999 and will be completed in March 2000. Some key dates are:

1999

16 Aug – 10 Sept	Initial consultations with peak bodies
15 Oct	Publish consultation paper
23 Sept – 1 Dec	Conduct surveys, focus groups and further consultations
19 Nov	Present progress report to Consumer Focus Collaboration

2000

19 Jan	Produce draft resources guides for workshopping
19 Jan	Produce draft final report for workshopping
28 Mar	Produce resource guides and final report

The project team will first undertake a literature search and conduct preliminary consultations with key stakeholder groups, receiving responses to the questions asked at the end of this paper.

A discussion paper for wider consultation will be prepared by mid-October 1999. It will take account of the results of preliminary consultations with key stakeholders, information from the literature search and the findings from responses to this introductory paper.

A detailed questionnaire will be forwarded to organisations, which have examples of the sort of education and training which is the subject of this project. We will seek further information through focus groups and interviews with those who appear to be most effective in achieving their aims.

A resource guide which describes examples and outlines the critical features of effective education and training activities for consumers and their representatives which successfully prepares them for participation in health care planning, delivery, monitoring and evaluation will be finalised in March 2000.

A second resource guide which discusses the characteristics of successful approaches to education and training for providers and administrators of health care services to assist them to involve consumers in health care planning, delivery, monitoring and evaluation will also be finalised March 2000.

A final report on the outcomes of the project and possible future directions will be completed at the same time.

Attachment F: List of questionnaire respondents

While some respondents were anonymous, the following lists an extensive range of respondents who were identified.

Australian Capital Territory Department of Health and Community Care
AIDS Council of New South Wales
Association of Pharmacy Registering Authorities
Australian Brain Foundation
Australian College of Road Safety
Australian Council on Healthcare Standards
Australian Council of Professions
Australian Dental Association Incorporated
Australian Institute of Health and Welfare
Australian Medical Acupuncture Society
Australian Speak Easy Association
Bendigo Regional Breast Screen Centre
Caroline Chisholm Centre for Health Ethics
Central Highlands Division of General Practice
Chiropractors Association of Australia
Consumer Health Advocacy Group, Frankston and Mornington Peninsula
Department Families, Youth and Community Care, Queensland
Dietitians Association of Australia
Donor Conception Support Group of Australia
Ethnic Communities Council of Queensland
Haemochromatosis Society of Australia
Health Complaints Commission, New South Wales
Health Consumers' Council WA
Health Consumers of Rural and Remote Australia Inc
Health Professionals Council of Australia
Hornsby Kuringai Division of General Practice
IAHS Consumer Health Consultative Committee
Mid North Coast Health Service
Munro Para Community Health Centre
National Asthma Campaign
North East Victorian Division of General Practice
North West Melbourne Division of General Practice
Northern Rivers Health Service
New South Wales Council of Social Services
Office of Ageing, Queensland
Older Women's Advisory Committee (South Australia)

Optometrists Association Australia
Pharmaceutical Society of Australia
Quality Improvement Council
Redcliffe Bribie Division of General Practice
School of Public Health, La Trobe University
School of Public Health, Queensland University of Technology
Society of Hospital Pharmacists of Australia
Speech Pathology Australia
Sudden Infant Death Association ACT
Tasmanians with Disabilities
Territory Health Services
Victorian Healthcare Association
Victorian Mental Illness Awareness Council
Women's and Children's Hospital, Adelaide
Women's Health Victoria

Attachment G: Questionnaire

PROGRAMS OF EDUCATION AND TRAINING FOR CONSUMER PARTICIPATION IN HEALTH CARE

The Commonwealth Department of Health and Aged Care (DHAC) has commissioned Global Learning Services (GLS) to assist in one of a number of projects designed to progress the goals of the Consumer Focus Collaboration. This project aims to:

- identify the key characteristics of successful education and training programs to prepare consumers, health service administrators and providers to create partnerships across health care;
- describe successful examples and include them in resource guides; and
- identify key issues and gaps in education and training for the various stakeholders.

The project is interested in **programs of education and training for consumer participation in health care** which:

> prepare consumers and representatives for participation in the planning, delivery, monitoring and evaluation of health care services across a range of decision areas from the individual level to system-wide nationally. They may be offered by consumer groups or organisations or by 'service provider' or training bodies.

Consumer participation may include activities such as complaints mechanisms, advocacy functions and partnerships in clinical care planning at all levels as well as other formal and informal exchanges between consumers and providers.

IDENTIFICATION: We have allocated a **unique code** to each Survey form to avoid your needing to provide again the identification, contact details, demographic and other information which we have used in preparing the mailing list for this survey. This code will also be used to produce the reminder (by Email, phone or mail) to those who have not completed and returned the Survey by the due date. We believe that this arrangement will produce the most appropriate balance between comprehensiveness and usefulness while minimising demands on respondents, as it has in a number of our prior studies.

Return Survey to: Dr Barry Cameron, Global Learning Services Pty Ltd,
16/2 Postle Circuit Holt ACT 2615

Phone/Fax 02 6254 0898; Mobile: 0410 421 072;
Email: BazCameron@bigpond.com

PLEASE REPLY BY 15 OCTOBER

Education and training includes formal and informal "hands on" approaches to developing the kinds of knowledge, skills and attitudes needed for effective partnerships.

The programs of interest in this project include:

- education or training for CONSUMERS of health services, to assist them in participating effectively in health care services.
- education or training for PROVIDERS of health services, to assist them in participating effectively in partnership with consumers.
- education or training for ADMINISTRATORS of health services, to assist them in participating effectively in partnership with consumers.

We seek your assistance in the Survey's completion and **RETURN BY 15 OCTOBER**.

1. **What** programs **does** your organisation **provide (or did provide in the past)?**
   Please indicate what you can of each program's purpose and scope, target group, delivery mode, duration, costs, participants' educational level (or prior knowledge/ skills/competencies required)

2. **What** resources/documentation **are available on the programs in 1.**
   (Please list them and indicate the contact details (phone, fax, Email or mailing addresses) for the best person to provide further information or a copy).

3. Which programs **(not just in your** own **organisation but in** others **also) seem(ed) to be** working best/**well?**
   (Please be as specific as you can and provide contact details if possible).

   a) **What** characteristics **underpin their** success **(such as what they try to do and how they go about it)?**

   b) **What** could be done **to make these programs even** more effective?

4. Do you know of any **other organisation** that conducts (or conducted) effective education or training for consumers, providers or administrators to assist them in participating effectively in partnership? Please provide contact details.

5. **What** other programs (not mentioned in 1-4 above) **should the project team seek further information about.**
   (Please provide program title/description, and contact phone, fax, Email or mailing addresses if possible)

6. **Which program(s) operating** elsewhere **would you most** want to put in place **for your** own **special interest group**
   (such as if, for example, some additional resources became available)?

   a) To what extent would these programs need to be changed **to suit your group? What would the changes be?**

7. What **seems to be** working least well **in education and training for consumer participation in health care?**
   (not just in your own organisation but in others also)

   a) Why **is this?**

   b) What needs to be done **to fix it?**

8. What's happening **in education and training for consumer participation in health care that** SHOULDN'T BE?
   (not just in your own organisation but in others also)

   a) What should happen instead?

9. What ISN'T happening **that** should be?
(not just in your own organisation but in others also)

a) Who **should take appropriate** action **on this?**

b) What **should that** action **be?**

10. Which of the following teaching/learning strategies have your organisation's programs **used**, and which would you **like to use** in the future?
(Please mark the appropriate boxes).

Strategy	Have used	Like to use
Introductory training course		
Up-date/refresher training course		
One-off workshop		
Self-directed learning package		
Mentoring		
Seminars & conferences		
Peer learning/network groups		
Community development (how to form issue-based groups, lobby groups and action groups)		
Learning community		
Learning Organisation		
Internet training		
Other (please elaborate)		

11. What have been the **main aims** of your programs, and what will they be in future?

Aim	Current	Future
Improve/broaden knowledge of the focus health issue		
Improve knowledge of the health system		
Improve knowledge of role and responsibilities		
Develop advocacy/participation/representation skills		
Develop meeting/communication skills		
Develop skills to facilitate mutual understanding and dialogue		
Provide peer learning, networking and support		
Build a learning community		
Build a learning organisation		
Other (please elaborate)		

12. Is there any **other information** you would like to provide? eg. examples of good overseas practices; details of organisations which we should contact; examples of good practice from other areas which may be applicable to health care.

13. Any other suggestions **on programs for education and training for consumer participation in health care?**

If this copy of the survey was provided to you as a copy of one sent to someone else (rather than addressed to your organisation directly), please give **YOUR** organisation's name and **contact details**.

Person:

Address:

Phone: Fax: Email:

Thank you for your assistance.

The Global Learning Services Team for the Education and Training for Consumer Participation project for DHAC.

Attachment H: List of focus group and phone interview participants

Health Care Consumers' Association of the Australian Capital Territory
Mental Health Foundation
Barnardos
Health Consumers of Rural and Remote Australia
Royal Flying Doctor Consumer Network Group
Country Women's Association
Carers Association
Adelaide Women's and Children's Hospital
Calvary Hospital Quality Management team
The Junction Youth Health Service
Australian Capital Territory Division of General Practice
University of Canberra School of Nursing

Attachment I: Participation actions in different parts of an organisation (Source: Women's and Children's Hospital, Adelaide)

Degree of Participation (high to low)	Explanation	Examples of Consumer Participation at Different Organisational Levels		
		Individual Staff Member Level	**Unit Level**	**Divisional or Organisational Level**
Consumer control	Consumers/ community make decisions	Self-management of care plan	Consumers decide how to spend refurbishment budget for unit waiting area	A service program is designed and managed by consumers
Partnership	Decisions are made jointly by consumers and staff	• Partnership in Care • Joint development of care pathway • Shared Care Program where GPs are the consumer as well as women	Joint planning session involving staff and consumers	Involving consumers in an ongoing committee, management or advocacy group A consumer/staff steering committee for a new program is set up
Consultation	Consumer views are sought and incorporated into decision-making	Parents are consulted about their preferences for their child's care	Women are consulted about a plan to set up a multi-cultural clinic Regular focus groups or informal meetings, eg a coffee break meeting	Community organisations are consultedabout a proposed change in services
Information Seeking	Staff seek information (*as opposed to opinions*) from consumers	A woman is asked is about her clinical history Gathering informal individual feedback from consumers	A survey of consumer patterns of visiting times Regular surveys, eg written, telephone, interview Compliments and suggestions boards and boxes	GPs are surveyed about their use of discharge summaries
Information Giving	Information is provided to consumers	A family is given information about risks of treatment Responding to consumer complaints and taking preventive action	A brochure on a disease is given to patients attending a medical clinic	Seminars are held to inform consumers about recent advances in clinical care

For more information about different ways to involve consumers, refer to WCH 1999, *Bringing in the Voice of Consumers, A Practical Guide to Consumer Participation* 2nd edn.