A CONSUMER FOCUS COLLABORATION PUBLICATION

Consumer Participation in Accreditation

PROJECT REPORT

CONSUMER PARTICIPATION IN ACCREDITATION: PROJECT REPORT

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CONSUMER PARTICIPATION IN ACCREDITATION

PROJECT REPORT

Prepared by Enduring Solutions

on behalf of the consortium involving:

Enduring Solutions Pty Ltd, Australian Council for Healthcare Standards, Quality Improvement Council, Women's Hospitals Australasia and Children's Hospitals Australasia, Health Care Consumers' Association of the ACT, National Rural Health Alliance and Australian General Practice Accreditation Ltd.

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.

FOREWORD

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

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

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

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

The resource guides, reports and issues papers that make up the publication series have been designed to provide

health care consumers, service providers and managers with ideas and information about how to work together in partnerships.

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

Consumer Focus Collaboration

August 2001

CONTENTS

CONTENTS cont'd.

EXECUTIVE SUMMARY

Accreditation is increasingly being recognised as an important tool for improving the quality and safety of the health care system in quite a direct way. This project provided an opportunity to show how consumers could be engaged effectively in this new agenda, from the very beginning. The main purpose of this project was to explore and develop best practice relating to consumer participation in accreditation, either at the health facility level or as reviewers and surveyors in an accreditation team.

The preliminary assumptions of the project were:

- that involving consumers in the accreditation cycle has the potential to bring about service wide improvements in quality;
- that involving consumers as reviewers would impact positively on the consumer participation focus in accreditation agencies; and
- that such participation may encourage services being accredited to increase the extent of consumer participation in all their activities.

The outcomes of the pilots in this project were consistent with these initial assumptions.

The project included a literature and internet search, an international e-mail survey of accreditation agencies and detailed telephone interviews with consumers, surveyors and facilities that had experience in these areas. The findings of this research are summarised in Chapter 2. A draft Resource Guide was produced from this research, and four pilots were then established to look at how to implement what appeared to be best practice and to find out what was needed to maximise the benefits of consumer participation in this process. The pilots and their findings are set out in Chapter 3.

The project research showed that internationally there is limited experience with health care consumers as accreditation reviewers and surveyors. The project built on the broader work of the Consumer Focus Collaboration and Australian consumers in its work on consumer participation on accreditation preparation and implementation committees in health care facilities. However, this project has broken new ground for consumers as surveyors and reviewers in general health care accreditation. It has been an innovative development in the Australian context, and lays good foundations for future developments in accreditation.

The recommendations from the project and the outline of best practice are set out overleaf.

Achieving longer term cultural change in health care

Recommendation 1: Some longer term evaluation of the Accreditation Project's pilot sites should be undertaken by the Consumer Focus Collaboration, possibly through the National Resource Centre for Consumer Participation in Health, to determine what longer term changes occur from increased consumer participation in accreditation.

Recommendation 2: State and Territory governments should develop, or provide increased funding for existing, community based consumer representative training programs that provide training for health care consumers to participate at a systemic level in health care, including accreditation. This should become a requirement under the next Australian Health Care Agreement.

Recommendation 3: The Commonwealth should consult directly with health accreditation agencies regarding the inclusion of consumer reviewers/surveyors in general health care accreditation. If agreement is reached, the Commonwealth should work with the States and Territories through AHMAC initially and then through the next Australian Health Care Agreement to require the inclusion of consumer reviewers or surveyors in general health care accreditation.

Recommendation 4: A set of draft national guidelines about the payment of consumers and the reimbursement of their costs of participation should be developed. Such

draft guidelines would need to be considered and endorsed by consumers and State/Territory and Commonwealth governments and then given effect through the provision of supplementary funding to meet these costs.

Consumers and accreditation – refining the process

Recommendation 5: Requirements for adequate consumer participation in the management, planning and delivery of health care need to be built in as minimum standards in all accreditation processes, which will be acceptable for Commonwealth, State, Territory and health insurance funding purposes.

Recommendation 6: Accreditation agencies that operate in health care should review their own processes to ensure that they are clear about the role to be played by a consumer surveyor or reviewer, including their role in the report writing process and the tasks that consumers are to undertake within the accreditation survey or review. Where accreditation agencies are already using existing consumer surveyors or reviewers, they should be involved in this role definition process.

Recommendation 7: Some modest financial assistance should be provided by Commonwealth and State/Territory governments to accreditation agencies to establish formal and consistent evaluation processes relating to consumer participation, to enable lessons to be learned 'across

agencies' and to ensure quality documentation of experience in the use of consumer reviewers and surveyors.

Recommendation 8: Accreditation agencies should review their surveyor/reviewer training to determine whether it is appropriate to wider implementation of the use of consumer surveyors.

Recommendation 9: Accreditation agencies should review their own processes to ensure that the workload expected of all participants is reasonable and that unnecessary and inappropriate paperwork is reduced.

Recommendation 10: Accreditation agencies should introduce requirements for the use of more direct consumer feedback in accreditation surveys and reviews, such as public meetings, sample surveys of service users and focus groups in different areas.

Recommendation 11: Accreditation agencies should develop protocols covering the interviewing of current patients by consumer surveyors/reviewers, as well as some questions that can be used to obtain direct feedback from the patients at the time of survey or review.

Recommendation 12: Accreditation agencies should determine whether a consensus approach to report writing allows the views of consumers to be adequately reflected in a review or survey report, or whether it is necessary to consider having a formal way of building the views of

consumers into any reporting back or feedback to a facility, even when there is not a common view across the team.

Recommendation 13: Accreditation agencies need to ensure that a consumer surveyor has access to expert advice on both clinical and consumer issues to support them in their role as consumer surveyors and reviewers.

Consumer participation training and resources

Recommendation 14: A 'train-the-trainer' package to assist health care facilities in training staff and consumers in effective consumer participation, particularly for consumer participation in effective quality improvement and accreditation processes should be developed. This could be undertaken by the National Resource Centre for Consumer Participation in Health with adequate funding from Commonwealth and State/Territory Governments.

Recommendation 15: The Resource Guide for Consumer Participation in Accreditation should be made widely available as soon as possible and the summary of Best Practice in Consumer Participation in Accreditation set out below should also be made widely available.

Best practice in consumer participation in accreditation

- You need to have the right person for the right job - to achieve this the roles and expectations of consumer representatives must be clear at the time they are recruited.

- All accreditation team and quality improvement committee members need appropriate skills and experience to effectively work together.

- All members of the accreditation team or quality improvement committee need to understand the role and expectations of consumer representatives and of other team or committee members.

- Participation by a consumer representative in accreditation must not be used as a substitute for that of a health professional – consumers bring their own experience and expertise, as do health professionals.

- Effectively managing the diverse membership of quality improvement committees and accreditation review teams is a skilled task, requiring leadership and sensitivity to the spoken and unspoken concerns of members.

- The different perspectives, experiences and skills of all team members, including consumer representatives, need to be acknowledged and valued by all members of the team or committee.

- Consumer participation is enhanced by the active support of senior managers who develop and drive a comprehensive consumer participation strategy within a service or agency.

- Consumer participation is enhanced when providers work in partnership with an accountable and representative consumer organisation.

- All members of the committee or team, including consumers, must be treated with respect and trust, and as equal members in the accreditation process.

- Consumer participation needs to be supported and adequately resourced.

- Consumer representatives should be able to represent the views of a wide range of consumers, and be accountable to them through appropriate mechanisms such as consumer organisations.

- Appropriate training, orientation and information should be provided for all team and committee members, and specific additional training or assistance for both consumer representatives and other members should be provided as required to ensure the effective operation of the team or committee.

- Consumer participation needs to be a continuous process, not a one-off event. Consumer involvement in accreditation processes should be reflected in their on going involvement in the operation of the agency or service.

CHAPTER 1: BACKGROUND TO THE PROJECT

A. INTRODUCTION

This is the Final Report of a nine-month project, commissioned by the Commonwealth Government as part of its Consumer Focus Strategy and has been overseen by the Consumer Focus Collaboration (CFC). The purpose of the project is to develop resources and strategies to enhance the effective involvement of consumers in health care facilities' accreditation review processes. It is part of the CFC's broader objective of strengthening consumer participation in the planning, development, monitoring and evaluation of health care services.

B. THE FOCUS OF THE PROJECT

There are a number of ways in which consumers can be directly involved in accreditation of health care services, including:

- as a member of a team of reviewers who are assessing a service;
- providing input to the development or evaluation of standards and criteria for accreditation;
- as a member of the quality improvement or other team with responsibility for preparation, management or change implementation within the service which is

seeking accreditation, either before or after an accreditation review has occurred;

- provision of feedback to the service and/or the review team about the quality of the service which is seeking accreditation eg through focus groups, public meetings, interviews or feedback surveys; and

- as a member of a management board, advisory council or other internal committees in the accreditation agency.

The CFC required that this project concentrate on two of these – consumers as members of the accreditation review team and as members of quality improvement committees and other accreditation-related committees within health services.

It was a preliminary assumption of the project that involving consumers in the accreditation cycle has the potential to bring about service wide improvements in quality. It was thought that involving consumers as reviewers may also impact positively on the consumer participation focus in accreditation agencies. It was also thought that such participation would encourage services being accredited to increase the extent of consumer participation in all their activities. The outcomes of the pilots in this project have been consistent with these initial assumptions.

C. CONDUCTING THE PROJECT

The project had two stages - stage one included a literature search, an international survey of accreditation agencies and interviews with participants in the reviews and surveys in mental health services through the Australian Council of Healthcare Standards (ACHS) and the Quality Improvement Council (QIC).

This stage resulted in the preparation of a draft Resource Guide to assist accreditation agencies, managers and clinicians in facilities being accredited and consumers participating in accreditation. It also resulted in an Interim Report (key findings of which are included in Chapter 2 overleaf) and the planning of 4 pilot projects. The pilots sought to trial the involvement of consumers in accreditation processes in a range of settings and across different parts of the accreditation cycle. We looked in particular at how these pilots could achieve best practice and set out some draft steps to help with this.

Because of the timing and resource constraints of the project and the timing of different ACHS and QIC reviews, we were limited in the range of sites we were able to choose for the pilots. The pilot sites did not include a major capital city tertiary hospital or a rural and remote location. However, we were able to include a large public hospital in a regional area, a private hospital in a capital city, a community health service which had a significant Aboriginal community in its population, and a combination public/private hospital in a

capital city. The details of the pilots, why we chose the sites we did, and a summary of the individual findings of the pilots are set out in Chapter 3. The information in this report about the pilots has been deidentified to allow a more frank discussion about the lessons learned in the pilots. The draft Resource Guide was used in these pilots and sent out for comment from a range of other stakeholders. A final version of the Resource Guide is available from the National Resource Centre for Consumer Participation in Health.

The four pilots took place over a relatively short period (between 4-6 months) and from the lessons learned over that time, we expect changes to continue over the next 6-12 months and hopefully longer. We provided a detailed evaluation report on the pilots to the CFC, and the main findings of that report formed the basis for our recommendations in Chapter 4.

CHAPTER 2: REVIEW OF CURRENT PRACTICES

A. INTRODUCTION

The project conducted a focussed literature search as well as a survey of agencies and interviews with consumer surveyors and reviewers, non-consumer surveyors, consumer representatives and managers and clinicians who had participated in accreditation processes, particularly in the mental health arena.

This chapter summarises the methodologies and findings of each of these parts of our research for this project, as well as including a summary of the overall findings, which were used in the development of the pilots.

B. THE LITERATURE SEARCH

How we did it

We searched a range of databases, including PubMed, Sociological Abstracts, Medline Lexis and Medical Industry Today for terms such as 'consumers and accreditation', 'quality assurance and consumers', 'accreditation programs', 'consumer participation in accreditation', 'consumers in accreditation' and 'quality improvement'. This process yielded some 50 journal articles of possible relevance.

On inspection, many of these were about better ways of receiving consumer feedback (eg improvements to consumer satisfaction surveys), rather than getting consumers involved on quality improvement committees or in accreditation processes as surveyors or reviewers. Others were about the arguments for greater public accountability through accreditation by public availability of results and better reporting of this data to consumers, including how to get people interested in looking at quality. Many looked at how this data could be made understandable and not misleading for consumers eg through 'report cards'. This left us with a handful of articles, which we have drawn on in the following section.

Of particular interest to us in this work and the survey work has been the differences in philosophies both about accreditation and consumer involvement in accreditation between different countries. Not only did this come out in our research, but a separate issue of the International Journal for Quality In Health Care in June 2000 entitled 'External evaluation of health care'[1] emphasised this as well. A small example of how pervasive are the differences was provided in the article on the interpretation of the ISO 9000 standards in health care across a range of jurisdictions[2].

1 ISQua. *International Journal for Quality in Health Care*. 'External evaluation of health care" - Charles Shaw (Guest editor), volume 12(3), June 2000; pages 167-271.

2 Sweeney J and Heaton C. "Interpretations and variations of ISO 9000 in acute health care" *International Journal for Quality in Health Care*, volume 12(3), June 2000: pages 203-209.

What we found

Consumer participation as surveyors and reviewers in accreditation , save for a few small exceptions, is a new concept both here and overseas, and so there is little written about it in the current literature.

Historical developments

Discussion in the literature of the need for consumer input into accreditation and quality processes has a long history, particularly in Australia, with much of this commencing in the 1970s. For example, a 1986 article in the Australian Clinical Review said:

> The distant, poorly organised grumbling of health service users during the 1970s is beginning to be recognised and listened to by health professionals and planners and managers today. ... At this stage, the various consumer representatives have not directed much attention to the debates associated with quality assurance. Nevertheless, it is not too early to ask: 'What is the proper role for the consumer in quality assurance?' There can be no serious argument as to whether the consumer (patient, taxpayer and elector) has a right to take an interest in the systems which are supposed to maintain standards of care.[3]

[3] Legge D, "Quality assurance: what is the consumers' role?" in *Australian Clinical Review*, December 1986, page 190.

That same article identifies the kind of things for which a consumer may be the best judge of quality including 'promptness, consideration, privacy, dignity, adequate information, participating in decision-making, informed choice, access to personal information and confidentiality.'[4] However, there were few articles progressing much beyond this level of generality at that time.

Protecting the public interest in accreditation

In the US, much of the literature we looked at took a different consumer perspective on the accreditation and quality improvement processes. Much of the US effort has gone into devising 'public interest' protection processes, where consumers are involved in designing standards, considering accreditation reviews which are done by teams of experts and participating in public meetings during an accreditation review. There has also been much discussion about public access to accreditation survey results and public information on quality in hospitals.

The US literature reflects this, both in the reports and the journal articles. The 1988 Office of Technology Assessment report *The Quality of Medical Care - information for consumers* puts this in a specific cultural and historical context:

[4] See note 3, page 193.

In recent years, a number of forces have combined to promote consumers' role in evaluating medical providers. Efforts to advance consumers' interests are occurring throughout society, and changes within medical care are part of that societal trend. More specific to medical care are changes in policies designed to inject greater price competition into medical care. According to competitive theory, consumers who are sensitive to both price and quality will bring these considerations to bear as they select health insurance and medical providers. ... Purchasers of medical care (individual consumers, employers, health insurers) need to know about any differences in quality so they can weigh quality along with cost in making decisions. Furthermore, payment changes have raised the concern that physicians and hospitals facing restricted budgets and low payment rates will skimp on the services that they provide to the detriment of their patients' health. Congressional interest in public information on the quality of medical care predated these new policies, but these payment changes, especially within the Medicare program, have heightened the interest.[5]

[5] US Congress, Office of Technology Assessment. *The Quality of Medical Care: Information for Consumers"*, OTA-H-386. Washington DC US Government Printing Office, June 1999, page iii.

Consumers as partners in preparing for accreditation

In the early 1990s there was a resurgence of interest in the effectiveness or otherwise of the quality assurance processes in place in Australia. The National Health Strategy[6] (NHS) was critical of existing quality assurance processes and identified the need for greater consumer involvement in them. The NHS said:

> A survey conducted by Renwick and Harvey (1989) found that only a third of hospitals surveyed could be said to have a range of activities which were likely to provide adequate quality assurance. Currently, those quality assurance programs that do exist tend to be closed programs protected by confidentiality, with neither consumer input or consumer accountability, often limited in scope and variable in quality. There has been little consumer input or involvement into quality assurance projects. The main instrument used to gauge consumer views has, to date consisted of patient satisfaction surveys.

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6 See, eg: National Health Strategy. *Healthy Participation - achieving greater public participation and accountability in the Australian health care system*. Background Paper No 12, March 1993 - see chapter 7; and National Health Strategy. *Making it Better - strategies for improving the effectiveness and quality of health services in Australia.* Background Paper No 8, October 1991.

> The design of patient satisfaction surveys has tended to reflect hospital rather than consumer perspectives.[7]

At that same time, Australian consumers were starting to make links between the broader issue of consumer participation and the accreditation process. However, the consumer views from that period were that the processes had a long way to go before consumers would have a role, beyond the satisfaction survey. For example, Krouskos in the Consumers' Health Forum journal in 1992 said of accreditation that:

> It is rare for consumers' views to be incorporated into the evaluation of health care and usually consumer input is limited to views on hospitality services ... Indeed, major accreditation mechanisms not only lack the structural capacity to seek and incorporate consumer perspectives on the quality of care, they are also philosophically opposed to doing so. Consumer views are devalued and discounted on the basis of consumers' supposed lack of competence to comment on 'professional issues'. This same philosophy applies to the peer review model of quality assurance practice,

[7] National Health Strategy. *Healthy Participation - achieving greater public participation and accountability in the Australian health care system.* Background Paper No 12, March 1993, page 35.

which excludes consumers' input on the basis of their lack of 'competency', and the professionals' fear of breaching confidentiality requirements.[8]

By the mid 1990s, there was more attention being given to the broader possible role of consumers in quality of care processes. For example, the Professional Indemnity Review (PIR)[9] saw this role for consumers as extending well beyond the 'consumer feedback' model. The PIR said this:

> 5.43 Apart from their potential as sources of information, health care consumers could also provide an important different perspective in institutional quality assurance activities, such as the overall quality management committee or similar body. Where such committees exist at health regional or area level, consumers could have an important role to play too. Such participation could be an important educational experience for consumers, health care facility management and health care professionals. **The PIR recommends that health care facilities have health care consumer representatives on their various quality of care committees and activities. (Recommendation 55)**

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8 Krouskos D. "Consumers and Accreditation". *Health Forum*. June 1992, pages 15-16.

9 Review of Professional Indemnity Arrangements for Health Care Professionals. *Compensation and Professional Indemnity in Health Care - A Final Report*. November 1995. (PIR Final Report). Available at the following website: http://www.health.gov.au/pubs/hrom/theainsu2.htm, pages 94-98 in particular.

Following this, in its 1996 Report to Australian Health Ministers' Advisory Council, the Taskforce on Quality in Australian Health Care stressed the need to ensure that consumers were involved in quality management at the institutional level. As well as emphasising that consumer involvement in defining, managing and monitoring the safety and quality of health care was a key theme in the Taskforce's recommendations, they went onto say:

> Consumers should be active participants in the broader quality management process. ... The Taskforce also supports consumer involvement in the machinery of quality review in all institutions and organisations. Consumer focused care requires that consumers be represented and participate in quality management.[10]

In 1999 the importance of consumer involvement in quality and safety activities in health care was again emphasised in the Final Report of the National Expert Advisory Group on Safety and Quality in Australian Health Care. The first national action that it endorsed was to support methods to enable increased consumer participation in health care. That Report said:

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[10] Australian Health Ministers' Advisory Council. *The final report of the Taskforce on quality in Australian health care*. June 1996 (Taskforce Report): see para. 4.39, page 36. This report is available on the Internet: http://www.health.gov.au:80/pubs/hlthcare/toc.htm.

> The Expert Group believes that all organisations and people involved in the health care delivery process should be encouraged to involve consumers in key elements of health care planning, delivery and evaluation. ... At a State level, a number of health departments have established high level safety and quality organisations that have consumer involvement and a consumer focus. Models exist in some States of action plans and frameworks for safety and quality that have a significant consumer participation aspect. ... The Expert Group believes that incorporation of consumer perspectives in the development of strategies relating to all other national action areas is an integral part of a national approach to safety and quality improvement.[11]

Current state of play

The Australian Council for Safety and Quality in Health Care formed in 2000 has subsequently made the third priority area in the Council's National Action Plan 2001 to be 'actively promoting opportunities for consumer feedback and participation'. While the plan is somewhat

[11] National Expert Advisory Group on Safety and Quality in Australian Health Care. Implementing Safety and Quality Enhancement in Health Care - National Actions to support quality and safety improvement in Australian health care. July 1999: pages 6-7. This report can be found on the Internet at: http://www.health.gov.au:80/hsdd/nhpq/pubs/qualsyn/neagsyn.htm

non-specific about how this will occur, this project and the lessons learned from the pilots will hopefully provide some useful 'practical tools and approaches which support national roll out of tried and tested models'[12] of consumer participation leading, in the end, to improved quality and safety in health care.

Consumers are starting to be seen as a potential resource in organisations which are seeking accreditation or which are otherwise trying to continuously improve their performance. Where such participation occurs, the form of the committee and its scope varies from facility to facility, and the overall members of the committees vary according to local factors.

Some organisations use their Quality Improvement Committees as the forum for their preparation for accreditation. Consumers are quite often already involved in these committees. Other facilities still establish specific committees to prepare for accreditation. With the growing recognition of the positive impact of greater consumer participation in health care planning, delivery and evaluation, these committees are also seeking to have

[12] Australian Council for Safety and Quality in Health Care. *National Action Plan 2001,* page 22.

consumer members. In some cases, this is required by their purchase contracts or broader governance frameworks.[13]

Bringing consumers into these processes has involved opening up quality improvement processes, which were previously closed. However, it is increasingly recognised that consumers involved in such committees can head off problems and embed consumer-focussed quality into the organisation.

Consumers as members of accreditation survey or review teams

Opening up the process

Just as quality improvement processes in hospitals were often closed, accreditation surveys and reviews have not traditionally been very open processes. For example, in 1996 the Taskforce for Quality in Australian Healthcare, discussed above, criticised the closed nature of most

[13] In the ACT, the purchaser/provider agreement includes requirements relating to consumer representation on committees. In NSW, the Quality Framework requires consumer membership on Area Quality Councils (Appendix D - page 67) and the performance measures for Area Health Service Boards include demonstrated evidence of consumer involvement in assessment of feedback about service delivery as well as broader consumer and community participation (Appendix B - page 55).

accreditation processes,[14] and their lack of publicly available information to help consumers choose between facilities. It went on to say:

> At present, accreditation surveys are scheduled events which are carefully prepared for by the hospital concerned. Conditions and processes within the hospital at the time of the survey are not necessarily those which are routinely in force. Surveys focus on structure and process within the hospitals and health services, rather than on assessing whether these structures and processes are effective in delivering safe, high quality care.[15]

The Taskforce's recommended alternative was radically different:

> Indicator and accreditation information from individual institutions should be publicly available. Accreditation should be a continuous process, with regular review of the functioning of the entire organisation supplemented by a series of unannounced smaller surveys which assess the routine operation of systems in specific parts of the institution.[16]

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14 Taskforce Report - see note 1: paras 3.27-3.37, pages 18-20.

15 Taskforce Report - see note 10: para. 3.27, page 18.

16 Taskforce Report - see note 10: para. 3.29, page 18.

While accreditation processes in Australia have not picked up the open public accountability focus implicit in that model, they have moved generally towards accreditation being a continuous process and incorporating greater consumer involvement. In Australia, accreditation agencies have been pioneers on the concept of consumer reviewers.

Consumers as reviewers in mental health

The introduction of consumer reviewers in Australian accreditation agencies occurred first in a small way in the Fertility Society almost 10 years ago, but it has only started to spread more broadly recently in the mental health service area. This was in response to the National Standards for Mental Health Services (NSMHS), established by the Australian Health Ministers' Advisory Council (AHMAC) as part of the National Mental Health Strategy. The strategy has guided policy in the mental health area since 1992. The standards were first published in 1996.[17] They stress among other things that consumers and carers of people with mental illness must be involved in the planning, implementation and evaluation of mental health services.[18]

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17 *National Standards for Mental Health Services* 1996 Australian Government Publishing Service (AGPS) Canberra.

18 Commonwealth Department of Health and Family Services. *National Standards for Mental Health Services - Supporting Quality in mental health care in Australia*. Pamphlet undated - see Section 3 under Summary.

The Australian Health Care Agreements, which cover the arrangements between the Commonwealth and the States and Territories include specific components related to mental health. These include the requirement that mental health services will implement the NSMHS and also that the jurisdictions will maintain mental health consumer advisory bodies in each state. For example, clause 85 of the ACT agreement states:

> The Australian Capital Territory agrees to maintain a mental health consumer advisory group to provide open and independent advice to the Australian Capital Territory Minister and the Australian Capital Territory Department on mental health issues.

The AHMAC National Mental Health Policy Working Group has determined that the implementation of the standards is to be confirmed by external review and that the criteria for such external reviews are:

- a review process should include a broad consultation strategy which includes feedback from consumers, carers, staff, stakeholders and management;
- review personnel are critical to the outcome of the review and mental health services should only be surveyed by a team with appropriate mental health expertise; and
- consumer surveyors should be included on review teams.

In some jurisdictions, the State or Territory Mental Health Units have indicated that the external review is to be conducted as part of any accreditation process which the service is undertaking.[19]

Two of the major accreditation agencies in Australian, the Australian Council on Healthcare Standards (ACHS) and the Quality Improvement Council (QIC), have introduced consumer surveyors or reviewers into their survey teams for in-depth mental health service reviews. At the time of finalisation of this Report, 23 in-depth mental health facility surveys using consumer reviewers had been done by the ACHS and 9 had been done by the QIC. The ACHS had 12 trained consumer surveyors. By May 2001, QIC had trained 15 consumer reviewers in Queensland, 20 in NSW and 15 in Tasmania, but were only able to use around half of them, due to a significant number of trainees 'dropping out'.

Use of consumer surveyors or reviewers in the broader health care accreditation environment may well follow in the near future, depending upon the requirements of funding agencies, Governments and the results of the pilots in this project.

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[19] Australian Council on Healthcare Standards. *External Assessment of the National Standards for Mental Health Services Using the Australian Council on Healthcare Standards(ACHS) Evaluation and Quality Improvement Program (EQuIP).*

How we did it

We decided to contact a range of bodies, both health related and those otherwise involved with accreditation, to see how they involved consumers. We searched the internet using a range of search engines, including Excite, Google, Medisearch, MedHunt and NLM Lexis. We used the following search phrases: quality improvement, accreditation, consumers and accreditation, consumers and accreditation programs. We then contacted by email the 48 agencies which looked like they may be relevant and enclosed a 'proforma' questionnaire for their completion. We also contacted a number of specific agencies which we were aware ran accreditation programs, including the Soil Association of the UK and National Childcare Accreditation Council in Australia.

The proforma asked the name of the organisation, its location, the nature of the industries being accredited, a description of the accreditation process, how consumers were involved either as surveyors/reviewers or within the facilities being accredited, what training is provided, what costs were paid for, whether the organisation had evaluated the effectiveness of consumer involvement and the effects on and implications for the organisation of involving consumers. The organisations contacted covered a range of nations, including the USA, UK, Canada, a number of European countries, New Zealand and Brazil.

We received only nine responses, even after repeat contacts. The UK based responses were from the Soil Association, Health Services Accreditation and Clinical Pathology Accreditation (UK). The US based responses were from the Joint Commission on Accreditation of Healthcare Organizations (JAHCO), the Commission on Accreditation of Rehabilitation Facilities (CARF), the Commission on Accreditation of Allied Health Education Programs, the American Council on Pharmaceutical Education and the Continuing Care Accreditation Commission. We also received a response from the National Childcare Accreditation Council, based in Sydney.

We also became aware of other bodies in our discussions about the project or our general research, and we followed these up as well. These included:

- the Institute for Healthy Communities Australia (IHCA), which is the Queensland based licensed provider of the QIC Program. IHCA is a non-profit body providing best practice accreditation products services and advice for the Health and Community Services Sector in partnership with other leading agencies;

- the UK based Health Quality Service, which runs an ISQua Alpha-accedited accreditation program in association with the King's Fund, and can accredit NHS Trusts, independent hospitals, hospices and Primary Care Services;

- the French national health accreditation body the Agence Nationale d'Accreditation et d'Evaluation en Santé, which involves consumers at a number of levels, including during the self-assessment period, for interview in the accreditation survey, and in the reporting phase,[20] and

- the Australian Resource Centre for Hospital Innovations information package 'The Applied Business of Accreditation Coordination and Project Development'.

What we found

The philosophical approach of different organisations to consumer and community involvement varies significantly between countries and between agencies within countries. For example, many US health care agencies focus their efforts on the 'public interest', with consumer bodies being established to monitor the activities of the accreditation agency from the perspective of the 'public interest' or 'public' representation being included on the board of governance. The actual work of accreditation reviews in these cases is almost always undertaken solely by health professionals.

[20] Pazart L, Brunaeu C, Mounic V, Boulongne M, Petit J, Lachenaye-llanas C. "Consumer Involvement in the Accreditation Process of Health Care Organisations in France", from presentation at the 2000 ISQua conference.

An example of both these kinds is the US Joint Commission on Accreditation of Healthcare Organizations (JACHO). JACHO has six public members on its 28 member Board of Commissioners, whose task is to represent the public's interests in the activities of the Commission. It has a separate Public Advisory Group on Health Care Quality, which was established in 1999. The 20 member group was formed 'to help JACHO define public expectations for quality in health care and offer insights for improvements in the accreditation process.'[21]

The United Kingdom (UK) Health Services Accreditation (HSA) organisation uses a different model for accreditation, with consumers mainly being involved in standard setting. The accreditation 'review' is not a single event, but rather a model where different surveyor/reviewers can attend at different times to 'attest' the standards. For HSA to be satisfied that the facility has achieved a specified standard, two people from a specified list need to attest to its achievement. Attestation visitors can include consumers, where they fit into one of the

[21] Joint Commission on Accreditation of Health Care Organizations. *The Joint* Commission's *Commitment to Public Accountability.* Pamphlet JCAHO 5/00: page 4. Further information on the work of the Joint Commission can be fund on its web-site: http://www.jcaho.org.

specified categories, but there is no separate category for service users. The 'public interest' approach is reflected in the use of prominent public citizens, such as the mayor, local clergyman or newspaper editor, for attestation. It is also possible that a consumer could attend as the chair or other executive member of the local community health council. This model does not really recognise the unique perspective that users of services can bring to the review process.

In some US organisations relating to accreditation for people with disabilities, the approach is much more similar to that which we are adopting in this project and in the area of mental health in Australia. This approach differs from the 'public interest' approach outlined above, in that it accepts that consumers bring a unique understanding that is as valuable to a service, in many ways, as the perspective of an independent health professional.

For example, the US Commission on Accreditation of Rehabilitation Facilities (CARF) accredits mental health, alcohol and drug programs, medical rehabilitation services, employment and community services, adult day services and assisted living services. It includes people with disabilities as surveyors in their reviews. Sometimes these people also have professional skills in the field, but not always. One of their programs also uses consumers to interview consumers of the service to be accredited to gather information prior to the surveyors going 'on-site'.

Consumers are also involved in their standard development processes and on the Board of Trustees.

ISQua

We also contacted the Melbourne-based International Society for Quality in Health Care (ISQua), which is developing a program for the international accreditation of health accreditation services called 'ALPHA' (Agenda for Leadership in Programs for Healthcare Accreditation). They have draft International Standards for Health Care Accreditation Bodies. The standards and the principles under them include 'a clear requirement for patient involvement in care and patient rights' and a 'customer focus'. What these terms mean in practice varies from jurisdiction to jurisdiction, and does not necessarily imply 'consumer participation' as is discussed in this report. For example, in some situations, health facilities may not see the consumer as their customer, but rather the health insurer or even the doctor who chooses to treat patients in the facility, as we found in one of the pilot projects.

Alpha requires an accreditation body to have its own national standards assessed against these international standards. When this project started, ISQua was in the process of undertaking a quick survey of national accreditation bodies throughout the world, which among other things, asked them about consumer involvement in their processes. The survey showed that consumers were involved in standard development, technical

committees and boards of management in 10 (63%) of the surveyed organisations. One additional organisation (in Argentina) had indicated that it had invited consumer involvement but it had been declined.[22]

D. INTERVIEWS WITH HEALTH SERVICES AND CONSUMERS

Given the relative dearth of information in the published literature about the particular elements of consumer participation in accreditation of concern to this project, we supplemented information gained from the literature search with a series of interviews with:

- consumers who had been involved in accreditation as surveyors or reviewers;
- consumers who had been on the accreditation team within a health service seeking accreditation;
- health services which involved consumers on their accreditation team; and
- members of review teams which had included a consumer as a member.

[22] Information provided by Ms Lee Tregloan, Executive Office of ISQua.

Most of these people were identified through the accreditation agencies which are part of the project consortium – particularly the Australian Council on Healthcare Standards and the Quality Improvement Council. Others were contacted through the Women's Hospitals Australasia, Children's Hospitals Australasia, consumer organisations and personal networks.

The interviews were loosely structured around a set of questions, but allowed interviewees to raise issues not covered by the questions. The experience of the majority of the people who were interviewed was in relation to mental health services, reflecting the leading role taken in involving consumers in accreditation in this area and it also involved interviewing a consumer with the organisation that has the longest record of involvement of consumers, the Fertility Society.

The composition of the 26 interviews were:

- six facilities where consumer reviewers had been involved in the ACHS accreditation survey;
- seven consumer reviewers - four from the ACHS mental health surveys, two from the QIC mental health surveys, one from the Fertility Society's accreditation system for assisted reproduction facilities;
- eight survey members or ACHS team leaders, where a mental health consumer had been involved; and

- five consumer representatives who were involved either in internal hospital accreditation or quality improvement committees or who were otherwise involved in the accreditation process.

The interviews focussed heavily on the mental health area because that was the only type of accreditation which was using consumer surveyors or reviewers. The interviews were also generally ACHS focussed, except for two QIC consumer reviewers. QIC's diversified management system made it somewhat more difficult to locate other team members for interview. At the time of the interviews, ACHS had only trained eleven consumer reviewers as their first 'trial' in the area, and QIC had three reviewers in NSW and some pilots in other States, which have subsequently resulted in several more QIC reviewers. The consumers we interviewed had done between one practice and four actual surveys, which gives some idea of the relative 'newness' of the process. We interviewed all but one of the ACHS consumer surveyors who had done either a practice or actual survey.

We interviewed consumers who had reviewed rural facilities, and we also interviewed a member of a rural consumer network, about the broader issue of consumer involvement in quality improvement committees in the rural and remote context.

ACHS contacted the consumer surveyors, survey teams and facilities where mental health consumers had been used in the accreditation survey to seek their participation in the project, while at the same time protecting their privacy if they chose not to respond.

QIC trained a significant number of consumers in three states while our project was happening, and yet more than half of these are not available to be reviewers. Unfortunately, due to the timing of our project and the interview phase, we were not able to interview any of those who had 'dropped out'. It would seem to be a useful field of inquiry for the future, particularly since retention does not appear to date to have been as much of a problem in the ACHS recruitment process.

The information gained from these interviews is set out below. While we recognise that the views are drawn from a small group of consumers, surveyors and institutions, these were the only experiences of the use of consumer surveyors and reviewers available at the time. They formed a useful background to the resource guide and our use of consumer surveyors/reviewers in the pilots. We have reported their views without trying to 'match' them with others on the same reviews to see whether other team members shared the views of individual team members. We have tried to let their voices speak as much as possible without editing or judging.

Consumers as surveyors and reviewers

Most of the consumers who had been involved as surveyors or reviewers reported the experience as being a positive one, where they had felt they made a valuable contribution to the review process, and that their involvement had encouraged a greater consumer focus. Most were consumers of mental health services, two were carers, and one was a reviewer with the Reproductive Technology Accreditation Committee of the Fertility Society .

In the ACHS program, people had been recruited as consumer surveyors through a variety of means. Some were nominated through services they used, or worked with as a consumer consultant or advocate, some were nominated by government agencies and others were nominated by consumer organisations. All consumers had undergone training provided by the accreditation agency. The consumer surveyors and reviewers felt that more training would have been helpful, because at times they felt a bit out of their depth. They didn't know or understand the 'jargon' or terminology and the acronyms, and felt they were expected to look at things like consumer rights but not at some of the 'technical' and 'care' issues.

The consumers reported feeling at a disadvantage because they didn't have computer or report writing skills, and weren't used to managing large amounts of paper. They

would have appreciated training in these areas, and in interviewing and observation skills. They also felt the need for more training on just how a survey is conducted, what to look for and what verification means and involves.

Although the experience was generally seen by consumers as a positive one, some felt that they were there as 'junior partners'. One made a point of mentioning that she felt the partnership with doctors in the mental health survey or review area was really working at that level. Consumers also generally felt that most of the surveyors were welcoming and helpful, with some reporting that there was only an occasional surveyor 'not wanting to know' the consumer.

All felt they had played a positive role, particularly in relation to imbuing a consumer perspective in the review. All felt that they had looked for things and asked questions which would not have been investigated if they had not been on the team. Some had facilitated consumer and carer focus groups or had interviewed consumers of the service. They felt that the people in the focus groups and the interviews were more relaxed with the consumer surveyor and were more ready to talk to them.

One consumer reported that some junior staff had indicated that they felt more comfortable talking to the consumer rather than the other members of the team – a psychiatrist and a nurse - whom they found somewhat intimidating.

All consumers spoke of the heavy workload in the lead up to the review, and the intensity of work during the review. The importance of the team leader managing workloads and ensuring that breaks were scheduled was emphasised.

They all spoke of the importance of being part of a wider network of consumers and of the usefulness of prior experience as a consumer representative or advocate.

They all saw their involvement as positive – 'other people are learning to work with consumers' and 'it's wonderful to see that the system is actually listening to consumers'.

One consumer made the point that better training is needed for the facilities being accredited. If they understood what was required of them, the job of the surveyors would have been easier. For example, they spent a long time making presentations with not enough detail, and not enough time for the surveyors to verify what they had been told.

Members of review teams which had included a consumer surveyor

We use the term 'surveyor' here, as all our team member interviews were with ACHS team members. There was generally a positive response from other surveyors who had worked on teams which included a consumer.

However, one respondent did raise a number of concerns and questioned the value of having a consumer surveyor.

Most people interviewed felt that the consumer had added value to the review team. They spoke about the way the consumer surveyor had increased the consumer focus of the work of the team. One surveyor said the consumer was invaluable in the interviews with consumers. 'She took the lead role and encouraged people to talk about their experience. Her rapport and empathy helped. Her presence was reassuring, and she added value – because she was seen to be in the same shoes as them'.

Most felt that the consumer had fitted in well to the team, and that other members had done their best to make them comfortable. One surveyor stressed the importance of having a 'bonding' session prior to the work of the review getting under way. This helped people get to know each other, and be comfortable working together. However, one surveyor felt that the consumer will always be an outsider in a team of professionals from the 'other side' of care, and felt that the presence of the consumer had changed the team dynamics and restricted some discussions.

It was acknowledged that the review process is onerous and can be exhausting. For people who are ill or have a disability it would be even more onerous. It could even remind people of unpleasant experiences they have had. One surveyor did make the observation that it was an

exhausting process for people who have not done reviews before, but for some consumers it could be like 'a near death experience – observing other people's experience and reflecting on your own – they may need support to work through this'.

Training was generally seen as both essential and currently adequate. However, there was some concern, even from those who were enthusiastic about consumer involvement, that consumers tended to restrict their interest to such things as consumer rights and the extent of consumer participation in a service. One surveyor felt that consumers needed to broaden their interest to include other aspects of the review – but emphasised that experience was essential to develop that skill.

The same surveyor was keen to see consumers have more experience as surveyors, and was concerned that consumers were only surveying facilities in the state in which they lived. He felt that consumers needed to be exposed to health systems in other parts of the country, because this exposure would be invaluable experience for them.

One surveyor raised the question of confidentiality and whether the consumer is bound by professional or work values of confidentiality – there was a fear of the 'enthusiastic amateur' who needed to be shepherded around. He said that there had been a reluctance to let the consumer visit or conduct interviews alone because

of confidentiality concerns, but this was not reported to be a concern by most other surveyors.

One surveyor also questioned whether and how one consumer could possibly represent all consumers.

Consumers on accreditation committees in a facility

The consumers we spoke to were all experienced at representing consumers prior to their involvement in the accreditation team and were familiar with the concept of accreditation. They all saw the experience as being a positive one. However, they had some problems in coming to grips with their role and orienting themselves to the health service, or in particular hospital, environment.

Orientation to the hospital environment was raised a few times as a problem. One consumer said that the most useful thing for her had been to attend a meeting with other stakeholders about health services in her area, where there was dissatisfaction with some aspects of the hospital services – particularly around discharge practices. This was prior to her involvement in accreditation and had not been a formal part of the accreditation process, but it had informed her of some of the problems experienced by people such as community service providers.

While consumers felt welcomed on the accreditation committees, some felt that theysuffered problems from being 'outsiders'. Other committee members were working in the hospital, and were familiar with their own jargon and acronyms. One of the consumers made the point that it is very difficult to understand documents and discussions where large numbers of acronyms are used. He had counted over 70 acronyms in one set of minutes.

Another problem raised was that a large amount of the business is done by email, and that if a consumer does not have a computer at home they are disadvantaged in terms of taking part in discussions by email and in having early access to urgent documents.

One of the consumers had participated in the accreditation process in a large hospital which had established a special accreditation team. Most of the staff in that hospital seemed to treat it as a 'one-off exam' which led to work not being done until the last minute. This meant that for a while the workload became a problem for the consumer. What were meant to be monthly meetings happened weekly, and large amounts of documents needed to be addressed in a very short timeframe. It also meant that quality improvement was not being seen as an ongoing process, and that the culture within the hospital was not being changed.

The consumers felt they had been able to raise issues that would not have been raised by other members of the team, but did not know whether there was much commitment within the hospital to addressing the issues. One consumer noted that the interest from medical staff on issues relating to consumer rights was very weak.

One of the hospitals which involved a consumer is now developing a comprehensive consumer participation strategy which aims to put consumers on all the key quality committees within the hospital, and to set up a network for those consumers. This strategy has the backing of the Chief Executive Officer (CEO) who will attend meetings with the consumers. The consumer suggested that it would be helpful for consumers involved in that hospital to meet with consumers involved in other hospitals in the region.

Overall, some consumers felt that their participation would have been enhanced if they had had some orientation to the hospital, and access to better information. Simple things like a tour of the hospital, explanations about the organisation and location of committees within that organisation, name badges, information about the other people on the committee would have made participation easier and more effective. One of the consumers cited having access to patient satisfaction survey results as possibly being useful.

One of the consumers also made the point that community care agencies have no role in accreditation, nor any means of feeding in to the process. These agencies know a lot about aspects of the hospital service particularly around discharge practices, but this does not seem to be part of the accreditation process.

Health services which involved consumers on their accreditation committee

Those health services which had involved consumers on their accreditation committees saw the experience as being very positive. There were few problems with consumer participation being accepted by other staff members. Attitudes and cultures within hospitals are changing. The CEO of one hospital made the point that consumer participation is 'changing the culture of service delivery' so that consumers are automatically consulted before decisions are made. One quality manager stressed that the questions that the consumer had asked were thought provoking and very useful, and would not have been asked by anyone else on the committee.

There is extensive consumer involvement in one of the services (a mental health service), and they employ consumer consultants who they recruit by advertising in the newspaper. The major criterion is that applicants have had a major mental illness. The hospital 'patients' really value the involvement of the consumer consultants.

It was acknowledged that consumer participation needs to happen early in the process, and that some thought needs to be given to orientation and information, as well as other ways of supporting the consumer representatives.

One hospital had not considered giving any payment to consumer representatives to acknowledge the large workload, on the basis that it would compromise the consumer's independence.

E. SUMMARY OF ISSUES RAISED IN THE RESEARCH PHASE

Some preliminary cautions

It became apparent in the first part of the project that we are at the early stages of learning about consumers as surveyors or reviewers. The involvement of consumers on accreditation committees, either before or after an accreditation review has been conducted, is less novel - among other things, the lessons from consumer participation in committees more generally, which have been documented in other projects of the Consumer Focus Collaboration, apply to this area.

However, there is virtually nothing in the published literature which relates directly to the issues surrounding consumers as surveyors or reviewers - positive or negative. We have had to draw substantially from the direct

experiences of consumers and facilities where consumer surveyors and reviewers have worked in the mental health area. This process has only recently started in Australia, and it would appear to be a new development internationally as well, certainly so far as consumer reviewers for the broader health sector is concerned. Thus the empirical data base we are drawing the issues from is relatively small and affected somewhat by the inexperience of consumers, team members and accreditation agencies.

For example, only a small number of consumers had started working as reviewers when we did the interviews. By September 2000, only about 4 had done a review other than an observation review for ACHS and around 3 for QIC. While some of them had done a number of reviews, their individual and collective experience was still quite small. Even in May 2001, as we write the Final Report for the project, there have only been 26 in-depth mental health reviews involving consumer surveyors or reviewers Australia-wide.

Also, in the mental health area, 'consumer participation' has included a mix of carers and consumers - 2 of the 4 ACHS 'consumer' reviewers we interviewed were, in fact, carers of people with mental illness. While carers bring a more user focussed perspective than most health service professionals, it is clear that their perspectives can be somewhat different from that of a direct service user.

Equally the problems experienced by one group as members of review teams may be different from the other. For example, carers may be less likely than consumers to be affected adversely by the intensity of workload expected in some of the accreditation reviews.

Because of the relatively small number of reviews which have been done involving consumers thus far, the experience of other members of the team tend to have been strongly influenced by a single experience (whether that was 'good' or 'bad'). This does not undercut the importance of the information we received from all the people who gave interviews to the Project Team. Rather it reflects the reality of the stage we are at in consumer participation.

The following sections summarise some of the key concerns which were identified at the conclusion of stage one of the project.

Access to information

Consumers on committees raised concerns about their access to information - knowing what to ask for and who to ask was seen as a significant barrier initially to their effective work on the quality improvement committee. After considerable experience, people knew more about what was available and felt empowered to ask questions and seek access to documents which had not been 'volunteered'. However, they felt a checklist of what to

ask for, or a list for services about what to provide, would ensure that they started out better informed.

Conversely, consumers on survey or review teams identified the quantity of information they were forwarded. While most believed they had received the information in time, there was generally a view that the documentation of some facilities left a lot to be desired. Often they were wordy, but the volume of words often had little to do with the value of the writing and its relevance to their task. 'Better quality, less quantity' seemed to be the overall view. One consumer even suggested that facilities be better trained in their document preparation processes, to the benefit of all concerned.

Unresolved attitudinal barriers

In some interviews, it was clear that there were a range of 'perceptions' about consumers, particularly mental health consumers, and some of these reflected the individual's views about consumer involvement more broadly. In some cases, health professionals expressed the view of being 'pleasantly surprised' that there were no problems. In others, where problems did arise or even where no problem had occurred, there was a clear discomfort with dealing with consumers as colleagues.

Where teams were perhaps marginally under-resourced, this lead some team members to express resentment about the consumer's more limited role, particularly where they

had been substituted for an additional health professional. Even where people could see the real advantages of having a consumer on the team, the additional pressures caused by perceived under-resourcing often appeared to lead to criticism of the consumer's role, particularly where the consumer was inexperienced and asked lots of questions.

A small number of health professionals showed a degree of impatience with their consumer team members, and a lack of empathy for the position of the consumer reviewer. This came out even in the interviews with the project team. Where consumers became tired with the intensity of the review process, this lack of empathy mainly came out in the attitude of 'if they can't stand the heat, they shouldn't be in the kitchen' which has traditionally permeated some of the other areas of health care. The attitudes that underpin much of this kind of bravado have been criticised as leading to unsafe practices in health care, including inappropriately long working hours.[23] However it can be a damaging thing for consumers, particularly those who are unwell and whose stamina may be more limited. Planning accreditation

[23] The Professional Indemnity Review for example, drew attention to the impact of medical culture in the area of quality of care - it was hard to acknwledge errors and there was little systemic recognition of the physiological effects of fatigue. See PIR Final Report at note 9: paras 5.12-5.28.

processes requires an awareness that, while it is almost by nature an intense effort for all concerned, the stresses on all can be reduced by good practices such as meal breaks and 'personal maintenance time'. Accreditation agencies need to ensure these are factored into their timetabling for *all* surveyors and reviewers.

Preparation

There seemed to be an apparent need in some cases to better prepare other team members to work with consumers as colleagues. People were often told very little about the skills and knowledge of other team members. Combined with possibly a narrow perception about the understanding and skills of consumers, this sometimes meant that the consumer faced unnecessary attitudinal barriers.

Equally, there appeared to be some 'unspoken' rules, such as dress standards or expectations about attendance at shared meals which were not always made clear to consumers. Some of these were real issues for consumers who may not have otherwise been in paid employment - the expectation that clothing would be of a particular kind may be unrealistic, without some additional financial support.

Timetabling of accreditation process

Almost all consumers and often other team members expressed concerns about the timetabling of review processes. This seemed a particular concern when a consumer reviewer was 'substituted' for a health professional member, particularly if the consumer was not very experienced and so required assistance in some of the tasks, which, with some more experience, he or she would no doubt be able to do unaccompanied.

These issues were particularly evident, where the facilities to be accredited were spread out over a large geographic area. Both consumers and health professionals expressed concerns about this, especially in rural areas, where there were sometimes many kilometres between the different parts of the organisation being accredited. Often these teams were smaller in number because the facility was smaller, but the additional distances which had to be covered were not factored in sufficiently. While accreditation agencies do take these matters into account, it would seem to be important to ensure that experiences of teams about the adequacy of such allowances is fed into the next accreditation review/survey work plan.

Team management

The importance of managing the team as a team was emphasised by a number of interviewees. The use of a pre-Review dinner on the night before an accreditation

review started was seen as a useful thing. In the case of a committee, the use of informal meals and times to chat informally, were seen as crucial to building a sense of team solidarity.

In the case of committees, ensuring that consumers knew who everyone was (given they were often the 'outsider') and understood the structure of the organisation were seen as an important in the team management role. Matching someone up with a committee or team member who they were able and encouraged to ask about things was seen as another useful team management task.

The management of committee or team communication (eg through ensuring consumers had an opportunity to speak and that language used was not full of jargon and acronyms) were also considered to be important team management skills, as was the effective management of disputes.

Confidentiality

There were some concerns which had arisen from failures to be clear about what was and wasn't confidential business in the committee setting. There were also concerns raised about problems which had arisen with a mental health service consumer who had breached confidentiality when they became ill. This had been addressed in the particular facility by the development of a protocol for what to do if someone became ill again,

and by a policy change to ensure that consumer representatives were users of other services, rather than the one in which they were 'repping'.

Some concerns had also been raised about confidentiality in the survey/review process. One health professional mentioned discomfort about whether a consumer could be expected to behave in a confidential manner - that person was not aware that the consumer surveyors had signed a confidentiality agreement as part of their preparation, which illustrates the importance of good briefing of other team members.

Training

While there was general satisfaction with the content of training, there were many suggestions from consumers for a more practical focus. For example, having examples of the different forms of paperwork, letting people do a mock write-up, showing what sort of material may be needed for validation were all given as practical ways training could be made better for consumers.

It also seemed likely that other team members and committee members might well benefit from some training about working with consumers and dealing with consumers as partners and colleagues.

Support

There was an expressed need for recognition of the greater support needs of consumers in their first few reviews. Unlike health professionals who probably had a good broad understanding of the health system, consumers often had many questions of this kind, and answering these took effort on the part of other team members, while no allowance seemed to have been built into the timetabling for that purpose.

Also, there was a recognition that consumers and sometimes carers might need sometimes to deal with difficult emotions, triggered by their work as reviewers from a consumer perspective. The availability of support of this kind seemed fairly ad hoc and seemed to rely on team members being comfortable providing that assistance.

Costs

It was generally believed that while consumers added valuable things to committees and teams, the costs associated with it were either not recognised or not met. For example, there were many examples where consumer representatives on committees were not paid. Similarly, the actual payments made to consumers were likely to be relatively small. In the case of accreditation agencies, sometimes there were additional costs which were not met and time, such as preparation time, was unpaid.

F. BEST PRACTICE FOR CONSUMER PARTICIPATION IN ACCREDITATION

At the conclusion of stage 1, we felt that we were in a position to begin to tentatively describe some of the features of 'best practice' in consumer participation as surveyors or reviewers for accreditation agencies, or as committee members in health facilities in the various parts of the accreditation cycle. It is important to remember that many of these are about good practice generally, not just about consumer participation. Equally, some also apply to other forms of consumer participation generally, not just accreditation. We used these in the pilots as summary guide to participants in looking at what they were doing. They are repeated in their final form in the Executive summary and at the conclusion of the report.

CHAPTER 3: THE PILOTS

A. INTRODUCTION

In its Request for Tender, the Commonwealth set out a number of requirements for the project relating to the pilot stage:

- to conduct and report on pilot studies in which various 'best practice' strategies to effectively involve consumers in accreditation processes have been tested and evaluated in acute care settings and, in a more limited way, in community health care centres;

- to assess and report on the impact of effective consumer participation in the accreditation process as a whole and as a tool for strengthening the participation of consumers in health service planning, development, monitoring and evaluation, with the aim of improving the quality and safety of health care; and

- to assess and report on the costs of effective consumer participation in the review process and provide recommendations for how these costs could best be met.

In addition to the best practice features set out above, the project team developed a draft Resource Guide, which included many practical hints and suggestions, consistent with best practice. One aim of the pilots was to test out the usefulness of the Guide with the participants. We also referred the draft Guide to a number of the interviewees

for their feedback, and to other health professionals and consumers from areas not represented in the pilot sites eg through consortium members such as Women's Hospitals Australasia, Children's Hospitals Australasia and the National Rural Health Alliance. The final resource guide is available separately.

B. THE MODELS

One of the findings of the research stage of the Project was that accreditation must be seen as part of the continuous quality improvement cycle of a health service rather than as a single event. This means that it is also crucial to have consumers actively involved in the pre and post-accreditation review or survey phase. This not only ensures that consumer participation is a central characteristic of a service's continuous quality improvement cycle, but it maximises the likelihood that the involvement of consumers will lead to service-wide quality improvements that are consumer-focussed. Looking at the accreditation process in this holistic manner acts to embed consumer participation into the culture of the service, rather than having it seen as an optional 'add-on'.

We therefore sought to develop models and identify pilot sites which could include consumer involvement in the three phases of the accreditation cycle:

- preparation for an accreditation review or survey;
- participation as a consumer reviewer or surveyor; and
- participation in a post-accreditation review/survey implementation process.

Due to the time constraints of the project, however, we did not consider that it was feasible to have a site which 'did it all'. The cycle of accreditation takes several years. Building up the involvement of consumers in the continuous quality improvement cycle takes considerable time. With a 5-6 month timeframe allowed for the pilots, the best we considered we could do would be to work intensively on each of the stages at different sites, with some attempt to ensure that, if at all possible, there were some sites which 'crossed' the stages.

We therefore developed separate pilots across the 'stages', while also seeking so far as possible to have examples which spread as far across the accreditation cycle spectrum as possible. The four pilots that were developed were:

- Preparation Pilot: A pilot which worked with a health service administration, either within a specific facility or across a health district which involves several facilities, to better involve consumers in their accreditation preparation processes.

- Preparation and Review Pilot: A pilot which combined similar elements to Trial 1, with the use of a consumer surveyor/reviewer as well. The consumer was to be recruited and trained as a reviewer/surveyor as part of this project.

- Review Pilot: A pilot which involved recruiting and training a non-mental health consumer surveyor/reviewer, undertaking a survey or review with the consumer as an accreditation survey/review team member and assisting the team leader accrediting a facility.

- Post Survey Implementation Pilot: A pilot in a health care facility which had recently undergone an accreditation survey, to pilot better consumer involvement in the post-review implementation process.

C. THE PILOT SITES

We worked with two of the major health care accreditation agencies to identify sites where the 4 models could be trialed. Those agencies were the Australian Council on Healthcare Standards (ACHS) and the Quality Improvement Council (QIC), both of which were consortium members for the project.

ACHS and QIC approached services which had recently been surveyed or reviewed, which were to be surveyed or reviewed within the timeframe for the pilots or which

would be in the process of preparing for an accreditation review or survey. They asked the services if they would be interested in participating in the project as a pilot site. They then provided the project team with a list of possible sites, where the services were willing to participate in the project. The team selected the sites which would be the most suitable given requirements of the project and the timeframe available (ie. early October 2000 to early March 2001).

Four sites were eventually selected by the project team, in consultation with ACHS and QIC, and were approved by the Consumer Focus Collaboration. One of these sites was a community health service, and three involved hospitals, one of which was privately owned, one that was privately owned but partly run as a public hospital, and one was a large public hospital in a regional area. Enduring Solutions wrote to each of the sites seeking and gaining their written agreement to participate as a pilot site.

Some limitations

The tight timetable allowed for the project inhibited our ability to select sites which were broadly representative of health service areas across Australia. For example, we were unable to locate a suitable pilot site in a rural area ; all were in metropolitan or regional areas. A major tertiary hospital was also not included, because none were timetabled for accreditation at the time available for the pilots.

Given we also only had four sites and the Commonwealth required three of these to be in the acute sector, our capacity to work with community health services was limited to the one pilot. We also did not carry out any pilots in other accreditation systems used in health care in Australia such as that run by the Australian Quality Council. The Commonwealth also asked that we ensured that at least one of the sites involved a privately owned health care facility.

D. AN OVERVIEW OF THE PILOTS

Involving consumers within the health care facilities

At the start of the pilots, we visited the three sites which were to involve consumers within a health care facility. At each site we met with the Chief Executive Officer (CEO), and conducted separate training workshops with staff and with consumers. A basic training workshop program had been developed for all three sites, but each of the facilities was invited to suggest any changes which were appropriate for their service.

The training programs were designed to be informative and interactive and to encourage participants to raise questions and issues which were of concern to them. Each training session for staff included sessions on 'Why to involve consumers' and gave participants opportunities to identify

opportunities and challenges for their service in working with consumers as well as developing practical strategies. Training sessions for consumers included explanations of the background to accreditation and quality improvement as well as the identification of opportunities and challenges and practical strategies. The contents of the draft Guide were used as a resource during the training sessions, and copies of the Guide were distributed to all participants in the pilots.

Financial assistance was provided to the facilities and to ACHS to meet the costs of participation in the pilots. The facilities at each of the three pilot sites where consumers were to participate within the service's quality improvement activities (Pilots 1, 2 and 4) received a payment of $1,000 for participating in the pilot. An amount of up to $2,500 per site was also allocated to cover the costs of consumer participation, including any sitting fees that may be paid and training costs.

At the end of each pilot we again visited each of those services that had involved consumers and conducted evaluation workshops with staff and with consumers. Those workshops were structured around a set of key questions which were developed in consultation with members of the project consortium. At each of the training and evaluation workshops information was provided to participants about the progress of the other pilots. If problems were raised during discussions, it proved to be useful to discuss strategies and solutions

adopted by other pilots. For example, the formation of a Consumer Representatives Network, with regular access to the CEO in Pilot 4 was used as an example of how consumer representatives can be assisted to work together, and be empowered within the hospital structure. We also interviewed the staff in Pilot 3, where a consumer surveyor had been used.

The recruitment and training of consumer surveyors/reviewers

Enduring Solutions worked with the Australian Council on Healthcare Standards (ACHS) to recruit a consumer reviewer for two of the pilots. Because the accreditation survey for Pilot site 2 was due to take place in December, and the ACHS had a scheduled training session for new surveyors in early November, there was only a short amount of time to recruit and train an appropriate consumer – both for this and Pilot 3.

We therefore suggested to ACHS that two consumers be recruited from the network of consumers in the Health Care Consumers' Association of the ACT (HCCA), one of the consortium members. HCCA has been established for over twenty-five years, and for the last few years has received financial support from the ACT Government to conduct regular training programs for consumer representatives on a range of committees. The organisation therefore had a pool of people who had received general

'consumer representative' training and were experienced in being a consumer representative.

We discussed this with HCCA, and put forward two names to ACHS. These people were interviewed and accepted for the ACHS training program in early November 2000. This two day training program was designed for all new surveyors and covered all aspects of being a surveyor. It was not specifically tailored to training consumer surveyors. Following the two day training course, and prior to their participation as a full surveyor in an accreditation team, the two consumer surveyors joined, as an 'observer', an experienced ACHS accreditation survey team undertaking a review of a health care facility. This was the same process used for mental health consumers and for ACHS trainee surveyors more generally.

We kept in close contact with the consumer surveyors during their training period. At the end of each the two pilots involving consumer reviewers, we met with them to evaluate their experience. We also interviewed, by teleconference, the surveyors who had worked with the consumers on both their observation surveys and their full surveys.

At the conclusion of the project, we met with ACHS to discuss the experiences of, and lessons to be drawn from the involvement of consumer surveyors.

E. SUMMARIES OF THE PILOTS

A separate detailed report of the pilots was prepared for the Commonwealth on a confidential basis. We include a summary of each of the pilots and our assessments of each of them here.

Pilot 1: Developing consumer participation prior to accreditation

This pilot worked with a health service administration across a health district which involves several facilities and different kinds of health services to better involve consumers in their accreditation preparation processes. The model had the potential to test consumer participation processes in a number of different contexts, but within a consistent management unit.

Pilot 1 involved a community health service, which included health services such as aged and adult health; child, youth and family health; child, adolescent and adult mental health; sexual health; indigenous health; oral health; alcohol and drug; Breastscreen; home care; and aged care assessment. The focus of accreditation activity was to be on QIC accreditation of the integration framework. It provided an opportunity to test out consumer involvement in accreditation in a range of community health settings.

There did not appear to be any prior experience of directly involving consumers in their policy, planning or evaluation activities. Key activities in this pilot were the initial briefing for staff, training workshops for staff and for consumers, the separate evaluation workshops for consumers and staff, and discussions with the CEO.

Assessment of Pilot 1

Pilot 1 was the pilot where consumer participation has made the least progress. The pilot had made a promising start. There was clearly a high level of commitment to consumer participation from the CEO and there was an encouraging level of attendance and interest at the training workshops. Discussions with staff had suggested that there was also some commitment to involving consumers throughout the service. The large number of consumers (around 20) who attended the consumer training workshop seemed to indicate that, while specific responsibilities had not be assigned to them, consumers were generally interested in participating and we believed that the pilot had significant potential to lead to greater consumer participation in the service.

However, we were concerned at the lack of progress that seemed to have been made after the consumer training workshop. For example, there appeared to have been no follow-up of the participants from the original consumer training workshop, and no committees involving consumers had been established. We were also concerned

that there appeared to be a lack of continuity in staffing responsibilities for consumer participation. For example, there was no one except the CEO who we were able to ring to find out where individual areas were 'up to'. While there was strong commitment from the CEO, there were too many demands on that individual's time, and there was not a person with central, day-to-day responsibility for coordinating or driving the project. Many of the staff who had attended the training workshop did not attend the evaluation workshop, and nor did they contact us at any point to discuss problems. Staff who attended the evaluation workshop had not attended the earlier training workshops, and seemed unfamiliar with the concepts and practices of consumer participation.

Progress with the pilot was possibly also impeded because the service's preparations for the accreditation review are only now getting underway, with the appointment of a staff member to coordinate accreditation preparations, even though the review is expected to take place later this year.

It may also be that the service's lack of any prior experience in full consumer participation may have increased uncertainty among the staff, and impeded progress in this pilot. While staff who attended the training workshop seemed to have found it useful, the strategies discussed did not seem to have been implemented, apart from recruiting the consumers to attend the consumer training workshop. At the evaluation

workshop for staff, it was clear from those who attended that there was a level of uncertainty about why consumers should be involved, and little understanding of the practicalities of how to do it.

In addition, the consumers who were involved were largely inexperienced in consumer participation within the health service. The consumers from the indigenous health service were the clear exception here. It was clear that they saw their participation as being essential to helping the service to identify and provide the sort of services their community needed. However, there was little evidence of effective communication between these consumers and the service through forums other than the pilot.

Another factor which may be absent from this pilot is the presence of a broadly based consumer organisation, which may have helped to facilitate consumer involvement by providing one point of contact for staff, and by acting to support consumers who wanted to participate. Staff did not seem to have any experience of working with consumer organisations, and did not take up our suggestions about making contact with consumer organisations, who could have nominated and supported consumers to participate in particular aspects of the service.

While progress has been slow, we believe that it is still possible for consumer participation in the service to be developed, and that as its preparations for accreditation get into full swing, then opportunities are still there for consumers to be involved.

Following the evaluation workshops we discussed our concerns with the CEO by telephone. The CEO agreed that progress was slow, and that staff had been slow to act on the outcomes of the training workshop. We suggested that there should be one person with responsibility for coordinating consumer participation across the services. We participated in a telephone hook up with the managers of the services at their regular meeting in early May. We have also made ourselves available to the service for telephone advice and support over the coming months, while they actively prepare for their accreditation review.

Pilot 2: Consumer involvement in the facility and a consumer surveyor/reviewer

We worked with the Australian Council on Healthcare Standards (ACHS) to recruit and train a consumer surveyor who was included in the accreditation team for a 4-day survey. The facility is a major teaching and referral hospital for a regional area. It has around 350 beds and provides emergency, specialist medical and surgical intensive care, and major diagnostic, obstetric and paediatric services.

Consumer advocacy is well established in the area. For many years the region has had a Consumer Advisory Council, which has been supported by the relevant State Government who employs a Consumer Advocate. The Hospital had involved consumers on some of their internal committees, including their quality improvement committee, although the number of consumers who were involved was decreasing. Consumers in the region had received some training in quality concepts and, in the past, had also been sponsored to attend a National Consumer Conference on Quality.

The focus of accreditation activity was around an ACHS survey which was scheduled for early December 2000. By the time the pilot got under way in mid-October the Hospital's accreditation preparations were well advanced.

The project team worked with ACHS to recruit and train a non-mental health consumer surveyor for this pilot. ACHS staff worked with the other members of the survey team to ensure that they understood the role of the consumer surveyor. The chosen consumer was an experienced consumer who had been involved on an Accreditation Preparation Committee as a consumer representative and had undertaken HCCA consumer representative training. She undertook her training survey at a 5-day survey at a large urban hospital.

Key activities in this pilot were the recruitment and training of a consumer surveyor; the recruitment, training

and orientation of consumer representatives to work within the hospital, the staff training workshop; the accreditation survey itself; and the evaluation. Evaluation activities were separate workshops for consumer representatives and hospital staff, and interviews with the consumer surveyor, other surveyors and with ACHS.

Assessment of Pilot 2

We believe that the pilot of consumer participation in a hospital in combination with the involvement of a consumer surveyor demonstrates the potential of this model to be a potent tool for quality improvement. While consumer participation within the hospital's accreditation committees had only just got under way at the time of the survey, the presence of the consumer surveyor looking at the facility from a consumer perspective and getting feedback from the consumer representatives appeared likely to be the start of an effective quality assessment and feedback loop.

The consumers who had just become active in the hospital clearly saw the potential for the consumer reviewer to complement the work they were doing by ensuring that the survey raised issues of concern to consumers. In turn, the consumer reviewer saw the presence of consumers working within the hospital as a means of informing the survey, as well as keeping the hospital services focussed on the needs of their patients.

However, the timeframe available for this pilot only allowed for this to be tested out over a relatively short period of time. The accreditation survey occurred in early December, only a month-and-a-half after the start of the pilot. By the time the pilot started, most of the hospital's accreditation preparations were close to finalisation. While it was possible for some consumers to be involved in the hospital prior to the survey, their influence was limited due to the lateness of their involvement. Nevertheless, it was clear by the end of the pilot that consumer participation in the hospital's post-accreditation survey work was building a head of steam, and had good support from within the hospital.

The commitment from the CEO, the presence of a staff person within the hospital who was responsible for coordinating the consumer participation project, and the involvement of the local Consumer Advocate all contributed to getting this pilot off to a healthy start. The hospital's prior experience of involving consumers also seemed to assist. For example in the training session with staff, they came to an understanding of why there might have been problems in the past, and what strategies they could use to make it more successful in the future.

The recruitment strategy for new consumers was innovative and generally seemed to be working well. This involved a public advertisement, drafted at the first consumer workshop by the current consumer representatives, the Consumer Advocate and the hospital's Quality Manager.

In this workshop the consumers identified the attributes and skills necessary to be a good consumer representative, as well as the non-monetary rewards which came from representing consumers. These were included in the advertisement, which initially attracted responses from 10 people, of whom 7 attended an information session and stayed to become consumer representatives.

Initially, only three applications were received from the information packs sent to the 10 initial respondents. The Quality Manager sought our advice and we suggested ringing the people who had not applied and see what their concerns were. Most felt daunted by the information supplied, but with some reassurances that they would be able to do the job, seven then attended the information session. This indicated the need for a less daunting initial kit, and an easier application arrangement, but otherwise this was a useful strategy, which supplemented people available from the local consumer group.

The development of skills and the qualities required of a consumer representative was well done, and proved to be a useful tool for attracting people's interest while at the same time being clear about what was needed. This was an interesting result of work between the hospital, the consumer advocate and the consumers themselves. Although it had caused friction with the consumer advisory council, this could probably have been overcome with better communication. The importance of having a person or group with whom hospital staff can work if

problems arise was demonstrated in the pilot. The local Consumer Advocate was able to work with the consumers and the hospital to help the process along. Once the Consumer Advocate left, about half way through the pilot, that expertise was no longer available to the hospital. However, they were able to draw on the support and expertise offered by Enduring Solutions, and this again was important in helping with the successful recruitment of more consumers. In addition, another senior person on staff (the Quality Manager) took over the active consumer liaison role when the Consumer Advocate left, so someone remained responsible for this within the hospital.

The involvement of a consumer surveyor clearly had an impact on the accreditation survey, and her presence was appreciated by the consumers working with the hospital and by many staff. She interviewed patients, and raised the issues that they had discussed with her. Generally she was seen to have raised some different issues, and to have bought a broader focus to the survey itself. There was very positive feedback about her interview and interactions with the Aboriginal Liaison Office and an aboriginal community worker, though some other health professionals indicated that they had found the consumer surveyor to be somewhat intimidating. The consumer representatives on the hospital committees felt they would have liked more time to talk with the consumer surveyor. They felt that if a consumer surveyor was to be used next time and the time of interview was limited, they would like

to meet beforehand to look at what were their priority issues and focus on these.

The report of the accreditation survey, which will provide a basis for further quality improvement activities within the hospital, had only just been received as the pilot was coming to a close. Whether lasting change occurs will only really be tested over a longer period of time. None of the participants in the pilot, be they health care providers or consumers, expressed a view that was contrary to encouraging consumer participation. Many of the participants in the pilot clearly saw this as a learning experience, and that more and more would be learnt over time.

There was clearly a lot of openness and enthusiasm about involving consumers within the hospital. Although not all of their experiences had been positive, they were open to learning from the past, and to improving on the ways in which they worked with consumers. Consumers were also enthusiastic and positive about working with the hospital, and also to involving as wide a group of people as possible.

Similarly, on the survey team, both the consumer reviewer and the other team members saw many positive benefits, and were confident that the role would develop over time.

At this stage we believe that consumer participation in the hospital has a promising future. There was a positive response from key hospital staff, and an acceptance that involving consumers is a learning process for everyone. A good relationship has been developed between the consumers and hospital staff and there seems to be a willingness to deal with problems as they arise.

We are also encouraged by the experience of the participation of a consumer with the ACHS survey team. Everyone involved seemed to think that this was worth doing, and that it added a further dimension to the survey process. However, involving consumer surveyors is still very much a 'work in progress', and this pilot has done much to inform participants about effective involvement of consumers.

Pilot 3: Consumer surveyor only

This was the only pilot in a privately owned facility, and it involved the participation of a consumer surveyor in the ACHS Accreditation Survey Team for a 3-day survey. The hospital is a 200 bed private hospital whose facilities and equipment include five operating theatres, a critical care unit, medical and surgical wards, a children's ward, a day procedure suite, lithotripsy, maternity unit and a hospice. It has a cancer centre with consulting and examination rooms, a dedicated day chemotherapy treatment centre, a procedure room and clinical research facilities.

The project team worked with ACHS to recruit and train a non-mental health consumer surveyor for this pilot. ACHS staff worked with the other members of the survey team to ensure that they understood the role of the consumer surveyor. The consumer surveyor was an experienced consumer representative. He had participated in the consumer representatives training program run by the HCCA. For his observation survey he had joined the survey team for a 5-day review of district health service in an outer urban area.

Key activities in this pilot were the recruitment and training (including the observation survey) of a consumer surveyor, the accreditation survey, and evaluation interviews. These interviews included the consumer surveyor, other surveyors involved on the accreditation teams for the observation survey and the Pilot 3 survey, and with staff within the hospital, as well as an interview with the Australian Council on Healthcare Standards.

Assessment of Pilot 3

This pilot demonstrated the potential for the inclusion of a consumer reviewer on a survey team to broaden the focus of a survey. While it was a new experience for the consumer, he valued the training and had learnt from his observation survey, and from the experiences of the other consumer surveyor from Pilot 2. He felt he had been able to raise issues that might not have been covered by the other surveyors, although he felt there was some resistance to what he wanted to put in the report.

The other surveyors also felt that the role was useful, and was worth developing. However, it was clear that the role of the consumer surveyor needs to be developed and clarified. While it is important that the consumer surveyor be able to work across the standards and provide a 'consumer focus' on any of the standards, this generalist approach can make it more difficult for the consumer's voice to be heard. Another option is to make greater use of consumers to look at specific standards eg complaints processes, access to information, 'patient rights' issues, consumer participation in committees etc. Yet another option is to allow for an additional section in the survey or review report, where consumer concerns which don't 'fit' anywhere else can be raised. This option is not considered the best by some because it may see the consumer's input being side-lined, rather than recognised as a main stream accreditation issues. Whichever option is chosen, it needs to recognise the importance of the consumer surveyor having a full voice in the survey, and the power to have their comments put into the written report and any other feedback process.

The hospital had a limited understanding of consumer participation issues more broadly, and some issues arose with doctors and others about the consumer's role, particularly about confidentiality of patient records. Even with these reservations, however, there was quite positive support for the concept of consumer input into the accreditation process, though the organisation at the moment did not seem ready as yet to embark on greater consumer involvement in its management.

There was a different perspective about consumer participation, compared to the other pilots, particularly in the context of the private hospital. The hospital saw doctors and health insurers as 'consumers' of their services with as much a stake, if not more than consumer patients. In addition, there had already been other imperatives driving consumer participation in the pilots in the public sector, which did not seem to exist in the private health care sector. These included overt government commitment to consumer participation in the planning, delivery and evaluation of health services. In the private sector pilot, there seemed to be greater resistance in the facility to including consumers more widely in its management or quality improvement processes, even though it was required by the ACHS accreditation standards.

Pilot 4: Post accreditation implementation

This pilot assisted a facility that had recently undergone an accreditation review to develop better consumer involvement in the post-review implementation process. This facility included both private and public hospitals, private and public maternity suites, a day procedures unit, private and public psychiatric services, 24 hours emergency service, intensive and coronary care units and a specialist clinic. The public division is a 140 bed community hospital, providing a broad range of acute and specialty services. It is also an associate teaching hospital.

It has a number of other characteristics, which meant we could look across the spectrum of consumer involvement in accreditation. This facility has recently undergone an accreditation review including an in-depth mental health review with a consumer reviewer. Consumers have been involved in the quality improvement activities in the hospital's mental health services for several years. In addition, the facility had a consumer involved in their Quality Improvement Committee leading up to accreditation. They are also keen to more actively involve consumers in the implementation of the findings of the accreditation review.

They were keen to look at using the post-review implementation phase as a cultural change process. They are particularly keen to look at some of the consumer participation education strategies for their clinicians as well. The pilot project had strong commitment from the Chief Executive Officer, and implementation of the project was the responsibility of the Quality Development Manager.

The facility had an established relationship with a local broadly based consumer organisation which has extensive experience in training consumer representatives and placing them on government and service-related committees. The consumer who was involved in the hospital's Quality Improvement Committee was nominated by that organisation, there were a number of other consumer representatives trained through the

consumer organisation and working on hospital committees, and the hospital had had extensive discussions about consumer involvement with the consumer organisation's project officer. The consumer representative on the Quality Improvement Committee had been a member of that committee for a considerable period prior to the pilot starting.

The report of the accreditation survey was received in January 2001, and an action plan for the hospital was prepared, which effectively became the focal point for this project. Key activities of the pilot included the recruitment and training of consumer representatives, a staff training workshop, a joint meeting between consumer representatives and staff, and separate evaluation workshops for consumers and staff.

Assessment of Pilot 4

While consumer participation in the post-accreditation survey quality improvement activities of the facility is still in the early stages, it appears to be having some success. Staff and consumer representatives both have a very positive attitude to working together, and are gaining an appreciation of each other's skills and knowledge, as well as constraints. This project is very much a learning experience for all participants – or as one participant put it – 'it's a work in progress'. Changes are being made as problems are identified, and there is good communication between the individuals involved in the pilot.

There was strong commitment to effective and comprehensive consumer representation from the senior level of management. This sent a very clear signal throughout the hospital that consumer participation is important. The Chief Executive Officer's (CEO) support and commitment to regularly meeting with the consumer representatives is also going to be an important means of empowering the consumers because they will have access to the CEO if problems arise that cannot be sorted out at lower levels of the organisation.

We believe that having one single person within the hospital who developed a consumer participation strategy, and who had responsibility for implementing it was crucial. The Quality Development Manager (QDM) provided leadership to the staff, and support and encouragement to the consumers. The QDM coordinated the hospital's consumer participation activities, and liaised with the local consumer organisation as well as Enduring Solutions.

The involvement of the consumer organisation with a staff person responsible for a consumer representatives program assisted enormously with this pilot. The consumer organisation has worked closely with government over a number of years and has developed considerable experience in nominating consumer representatives to a range of government and service committees. It recruits consumer representatives from a broad range of consumer organisations in the area, and

runs regular training programs for those representatives. The hospital was able to work with the consumer organisation to recruit representatives who had already received some broad training and to discuss strategies for enhancing consumer participation within the hospital.

During the course of the pilot it was acknowledged by the hospital that the requirement in the ACHS accreditation standards was a critical driving factor in their consumer participation strategy and their willingness to participate in this project.

Prior involvement of consumer participation in the hospital's mental health service provided useful experience for the hospital to draw upon in the course of developing the hospital wide strategy. Staff were able to learn from the experiences of others, and the hospital's close working relationship to the mental health consumer representative provided a useful demonstration of the benefits of working together.

At this stage it looks as if consumer participation is progressing well, and that consumers will continue to be represented on quality improvement activities within the hospital's structure. The issues seem to be not so much about whether consumer participation will stay, but how they can learn from, and improve on, what they have done already.

The hospital has demonstrated a strong commitment to involving consumers and is working with the local consumer organisation to strengthen its partnership both with individual consumer representatives and between the two organisations.

F. TIMEFRAME FOR THE PILOTS

The pilots were conducted over a period of 5 to 6 months, from October 2000 to February/March 2001, and included the Christmas-New Year period. This was a relatively short time frame to test out the practicalities of involving consumers in processes which are unfamiliar and often confusing to them. Equally, for some facilities, the active involvement and understanding of consumer issues among health service providers who had not worked in this way with consumers before was a challenge. Preparing for an accreditation survey or review and waiting for the accreditation team to prepare the accreditation report and provide it to the facility takes several months. This, in turn, affected what could be achieved in the timeframe allowed for the pilot projects.

One of our recommendations is that a further follow-up review be undertaken early in 2002, when facilities have had a chance to 'settle in' and fully establish the processes that the pilots commenced. More lessons could no doubt be learned at that point, both about the changes in the facilities, and about the durability or otherwise of the

changes these pilots commenced. In addition, it will then be timely to identify what has worked best in relation to consumer participation. It will only be in the long term that some of the questions posed by the Commonwealth about the effect upon health service quality of consumer participation in accreditation can be properly assessed.

G. COSTS OF THE PILOTS

Consumers on committees

While money was available for the payment of sitting fees for consumers on committees, there was inconsistency about whether or not these were paid or only expenses were reimbursed. In some cases, pre-existing arrangements for sitting members were seen as precluding an offer of payment and this was generally accepted by the consumers in that pilot. In some cases, consumers clearly stated that they didn't want to be paid, so the costs were considerably variable. Even where a sitting fee was offered, the take up rate was variable. Consumers who were on low incomes and incurred expenses in participating were generally happy to accept reimbursement of costs, but even this varied. In all the pilots involving consumers on committees, the consumer costs per project were less than $500 (sitting fees and reimbursement).

In addition to these costs, there were direct costs of consumer participation and of the pilot in particular to the organisations, such as:

- catering and venue hire;
- photocopying, stationery;
- advertising costs;
- additional staff time in setting up the processes;
- administrative costs eg phone calls etc.

These ranged between $500-$1,000 per pilot, depending upon whether the service had its own conference rooms, whether it advertised for consumers or used other networks and what other variables existed between them.

Additional costs, which we built into our costs for the project were training and workshop facilitation costs. In the pilots, these included travel costs, which could probably be avoided if local trainers were available. At a minimum, when getting started, we consider that a facility should budget on 3 half-day workshops (one for staff, one for consumers, one joint meeting). The total cost of these 3 training workshops would be expected to be around $1,200 - $2,400, (ie $400-$800 per half-day workshop) depending upon the duration, number of trainers, number of times the workshops were to be repeated and other special needs required by the site.

These costs were 'pared down' to the minimum for the project, and it may be that commercial trainers would have a different charging rate. However, these costs are indicative. The development of some train-the-trainer packages that build on and use the Resource Guide might well be a useful, cost-effective 'next step' in encouraging consumer participation within facilities.

Some costs for access to advice to address problems may also need to be 'built in' as we provided some support of this kind. The quantity varied between projects, but it often helped address significant issues before they became a problem. The Resource Guide provided valuable assistance for those who were setting up consumer participation on quality improvement and accreditation committees inside facilities, so this can address basic needs in this area.

Consumers as surveyors or reviewers

The costs of consumers as surveyors were more significant. Training costs (not including the general 'consumer representative' training which was undertaken outside the project) for the ACHS consumer surveyors were around $1,000 each, which included a $200 per day honorarium, travel, accommodation and meal costs. There were also the costs associated with the 'practice surveys'. These were significantly affected by the duration and location of the surveys, and ranged between $1,650 - $2,100.

Likewise, the survey costs were dependent upon the number of days and the location. Consumers were paid at the same level as other 'independent' (non-employed) surveyors, at $200 per day. Given that surveyors often spend 10 hours or more per day working, and are not paid for the extensive preparation time required, this is not a particularly generous level of payment. Nonetheless, consumers were at least paid the same rate as health professionals on the team. For an accreditation agency, the costs are essentially those of having one additional surveyor, because it is not possible or appropriate for a consumer surveyor to be 'substituted' for someone required to have health professional or health management skills. As these costs are passed onto a facility, there is a need to ensure that facilities are clear about what benefits they can gain from having the consumer reviewer/surveyor present. This issue is discussed further in the next chapter.

CHAPTER 4: FINDINGS OF THE PROJECT AND RECOMMENDATIONS

A. INTRODUCTION

The four pilots of consumer participation in different phases of the accreditation process provided important lessons about consumer participation. Even where the pilots had not gone as well as we had hoped, there were important lessons available from them. This chapter summarises the lessons learned from the pilots. With our preliminary research findings and the experience we have had with the Resource Guide, these also form the basis for our recommendations.

B. GOOD FOUNDATIONS FOR EFFECTIVE CONSUMER PARTICIPATION

Three of the four pilots involved consumer participation within a health care facility. Pilot 1 was where consumer participation had made the least progress. Pilots 2 and 4 were making good progress as the pilots drew to a close.

The three pilots allowed us to look at the participation of consumers in different settings, where different factors were at play. The training programs and evaluation workshops provided for staff and consumers were basically the same. We have been able to compare and contrast the ways in which the facilities went about

involving consumers, and to identify factors which affected the course of the pilots. The pilots clearly demonstrated that effective consumer participation involves much more than simply finding a consumer and placing him or her on a committee. As we drew comparisons between what had happened in the four different pilots, we were able to identify factors that we believe can influence the successful participation of consumers in accreditation and quality improvement processes.

None of these are really surprises – it is 'hardly rocket science' as one senior manager said. However, we found the following four features to be strong foundations for successful consumer participation. This is not to say that effective consumer participation is not possible without these. Rather, if a facility wants to have the best chance for long term success in implementing consumer participation across its organisation, particularly in the core areas associated with quality improvement, these 'features' can really help.

Strong and active commitment from the CEO

This was evident in all three pilot sites. It was clearly a significant factor in Pilot 4, where the CEO had sent strong signals throughout the organisation about consumer participation by appointing a senior manager to drive the process, and by committing to meeting with the consumer representatives on a regular basis. There was also good CEO commitment at the Pilot 1 and 2 sites.

Pilot 2 had also appointed a senior manager to drive the consumer participation process, and while Pilot 1 certainly had strong CEO commitment, it did not have one person within the service who was responsible for driving and coordinating consumer participation.

A senior staff person responsible for developing, driving and coordinating a consumer participation strategy

We saw this as an essential factor in ensuring that the commitment from the CEO is driven throughout the organisation. It was present in both Pilot 2 and Pilot 4. However, it was not present in Pilot 1, and it seemed to us that without that 'driver', staff were not motivated or encouraged to pursue something that they had little experience in, and where their comfort levels were low.

The presence of, and relationship between, the service and a broad, representative and accountable consumer organisation

The hospital in Pilot 4 acknowledges that their access to a broadly based consumer organisation with experience in nominating, training and supporting consumer representatives had been important for them. The hospital in Pilot 2 had worked with the local Consumer Advocate, and with some consumer representatives who were associated with the local Health Consumers Advisory

Group. Although there were some tensions in the relationship with the Advisory Group itself, the presence of the Consumer Advocate and the knowledge of the consumers themselves were very useful in helping the hospital to recruit and work with consumer representatives. By contrast, the Service in Pilot 1 had few existing relationships with consumer organisations, nor did they form such relationships during the course of the project. Rather, they attempted to recruit consumers from among their clients. While the level of interest from those clients was high, there did not appear to have been much success in keeping them involved.

External requirements for consumer participation

The requirements of external bodies such as accreditation agencies or funding bodies for consumer/community participation in the services seems to be an important factor in motivating the services to involve consumers. The pressures on people who work in health services are such that without some external requirement, consumer participation may not be a priority. This was perhaps most clearly illustrated in Pilot 4 where it was said 'If that imperative wasn't there, you wouldn't do it. You're so busy keeping your head above water – if you don't have to do it, you don't.' It remains to be seen whether and how the Service in Pilot 1 will respond to the QIC requirement for consumer and community participation as its accreditation review preparations get under way.

C. CONSUMER PARTICIPATION IN HEALTH SERVICE ACCREDITATION COMMITTEES

In addition to these four foundations, there were other supporting factors that were important influences on the relative success of the three pilots.

Prior experience of consumer participation within the facility

Having some experience in working with consumers was a contributing factor to how well the facilities were able to work with consumers. In the mental health area of the hospital in Pilot 4 there was already a strong working relationship between the hospital and consumer representatives. This working relationship was evident in the workshops we held with staff and with consumers, and the experiences and lessons that had been learnt in that area were discussed and drawn upon in implementing the wider consumer participation strategy. In addition, the hospital had had a consumer representative on its quality improvement committee, and were very comfortable with the role he had played.

The hospital in Pilot 2 had also had some prior experience of working with consumers, and, while it had not all been positive, they were keen to learn from the experience and to adopt strategies which might strengthen consumer participation. On the other hand, the service in Pilot 1 had not had much experience in this area, except in their

indigenous health programs, which had a local consumer advisory council.

Training and other opportunities for learning

Training for consumer participation was seen as important for both staff and consumers in the three pilots. In one pilot we also trialed a joint training session, where we facilitated an 'active learning' discussion between staff and consumers about problems of common concern.

For staff, the training provided through the pilot primarily helped staff to understand why consumer participation in quality improvement activities was important, and to identify problems and a range of strategies to capture opportunities and overcome the barriers. The staff who participated in both the training and evaluation workshops seemed to have appreciated and benefited from the training. It gave them the chance to talk about their fears, and to work through them with the people doing the training and other staff, and later with the consumers themselves.

The training provided for consumers aimed to provide basic information about accreditation and quality improvement activities. It also allowed them to identify opportunities and barriers, and explore strategies for dealing with problems. While appreciating this, the consumers also emphasised that other forms of learning were as important. They include learning from other

consumer representatives through a range of activities such as consumer representatives networks, involvement in a consumer organisation, access to training programs run by consumer organisations, and mentoring or 'buddy' systems where more experienced representatives 'coach' a new consumer representative. Many of the consumers emphasised that a lot of learning happens through their actual participation in a committee, and that this learning is helped if they have access to other representatives who they can discuss issues and problems with.

The importance of training and committee experience as potential 'relationship/trust building' was emphasised, both where training had been joint and separate. For example, in Pilot 2, a good relationship was developing between some of the hospital staff and the consumers, and it was clear that this relationship was important in enabling consumers to get to understand the hospital, and for the hospital staff to understand consumers concerns.

Staff and consumers in Pilot 4, who had participated in the joint workshop in addition to their separate training sessions, saw the opportunities to talk together about a range of issues outside of a committee setting as also being important for their learning about consumer participation and as an important part of 'team building'. The experience of the three pilots suggests that topics that would usefully be covered in meetings between consumer representatives and staff would be expectations and roles of representatives, representativeness of consumers,

confidentiality of information, and creating trusting relationship.

Information and orientation

Both Pilot 2 and Pilot 4 demonstrated the importance of providing information to consumers about the service within which they were going to work. However, information needs to be thought about in the broadest sense. Orientation sessions or processes for consumers are as important as the provision of written information.

The Quality Development Manager in Pilot 4 had developed an orientation kit for the consumers. During the pilot, however, it was clear that while the consumers appreciated the information in the kit, there was a need for more information, as well as some orientation to the physical and cultural environment of the hospital and to its policies. In Pilot 2, an information kit had been developed for new consumers and an orientation session had been held. These were clearly very useful. While the amount of information provided had originally been overwhelming for the new representatives, it was something that they were working through and using as a reference once they started working on their committee.

In Pilot 2 the orientation session for consumers was received very positively, and was seen as a key briefing point for the consumers who attended. The Quality Development Manager in Pilot 4 met individually with all

the consumer representatives prior to them becoming involved, and had talked to them about the hospital and, where they wanted to, a site visit was organised. This had worked variably, with staff often being rushed and unable to really assist the consumer representative to get a 'better feel'. At one of the training meetings in the pilot, a suggestion was made that consumers participate in the orientation sessions for new staff. Consumers supported this idea because they felt it would help them to understand the hospital culture and environment. Staff also saw this as desirable and symbolic of the organisation's commitment to real partnerships with consumers.

Support and advice for staff working within the facility

The availability of support and advice for staff, particularly those charged with implementing a consumer participation strategy seems to be an important factor. This is often breaking new ground within a facility and is a new area of responsibility for many staff. Staff generally do not have experience or training in consumer participation. Therefore, the ready availability of advice on what to do, or how to do it, when a problem occurs seems to be helpful. This was particularly evident in Pilot 2 where the loss of the Consumer Advocate halfway through the pilot had left a gap in the advice and support available to the Quality Improvement Coordinator in the hospital. While our telephone advice was helpful, the

Coordinator missed the local on-the-ground availability of assistance.

Support for consumers working on committees

It was clear from the three pilots that effective consumer participation also requires ongoing support for the consumers working on the committees. In this section we have already discussed the importance of training, information and orientation for consumers, all of which are important means of support. Their links to a consumer organisation is also an important means of providing support, and advocacy where required. This was lacking in Pilot 1, where there was little evidence of formal or informal support for consumers, either from a consumer organisation or from the facility itself.

In Pilots 2 and 4, there was good support from the relevant consumer organisation or advocate as well as from the two health care services. In Pilot 4, the hospital had taken responsibility for supporting the consumer representatives to work together through facilitating their meeting as a consumer representatives network within the hospital. While consumer participation in Pilot 2 was still in its early stages, the representatives had been able to meet together at the orientation session, and were continuing to network through the evaluation workshop.

Another important 'support' that was strongly supported in the pilots was having more than one consumer representative on each committee. In Pilot 4, the pilot had started out with the intention of involving just one consumer on each committee. The hospital were reconsidering this because on a couple of occasions the consumer had not been able to attend a meeting, and it was evident that this left a gap in their consumer participation strategy.

It was clear that the consumers themselves would welcome having more than one representative on each committee, because it provided them with support, and they would feel less isolated and responsible if they could not attend a meeting, particularly if they were ill. In Pilot 2, the less experienced representatives were teaming up with experienced people on the committees. This was encouraging new representatives to learn from those with more experience and was generating more confidence in putting consumers' perspectives forward. In fact, the hospital in Pilot 2 had decided to place 3 consumer representatives on their new post-accreditation implementation committees.

Recruitment of consumer representatives

The three pilots demonstrated three means of recruiting consumer representatives. Pilot 4 recruited through the local consumer organisation. Pilot 2 initially recruited through the Consumer Advocate and the local Consumer Advisory Council, and then supplemented this by recruiting

consumer representatives through media advertising. Pilot 1 recruited directly from their clients.

While there was initial success with each of these strategies, the longer term outcomes probably differed because the follow up strategies were different. Pilot 1 had not put any means of support in place for those who had been recruited, except for the training session with Enduring Solutions. Even though at that workshop the consumers had been clear about their support needs and this had been discussed with the service, the follow up commitment required from the service appeared not to have happened.

In Pilot 2, while the new representatives recruited through the media advertising did not have much experience, they were clearly learning through their contact with the other representatives and through the information and orientation provided by the hospital. The representatives were raising issues about how they could be 'representative' and accountable, and starting to devise some strategies to enhance their participation on behalf of their community. The representatives in Pilot 4 were recruited through the local consumer organisation, and were clearly supported by that organisation, as well as by the hospital.

Payment for consumers to participate

As noted above in Chapter 3, opinions about the payment of sitting fees for consumers who participate in quality improvement activities within a health care facility were divided throughout the three pilots. The pilots highlighted significant differences of opinion, among both consumers and staff, about whether sitting fees should be paid.

Many consumers did not want to be paid a sitting fee because they thought that it may compromise their independence or because it would attract people who just wanted to do the job for the money rather than because they were committed to improving the service. Other consumers thought that it was only fair that consumers be paid for their time spent at a meeting, and in preparation for a meeting, particularly where everyone else involved was either participating as part of their employment or otherwise being paid to attend (eg GP representatives are sometimes paid to attend meetings by the Division of General Practice). This would be a recognition by the service that their participation was valued by the service and would provide some reward for the work the consumers undertook. Some of the staff were also concerned that if the health service paid for consumers to participate, it may compromise the independence of those consumer representatives.

However, there was agreement that at the very minimum consumers' costs of participation in a committee should be met by the service. Those costs can include costs of travelling to and from meetings, meals, parking and child or respite care. However, it was clear from the pilots that a great deal of sensitivity is needed within the health care service in dealing with this issue, particularly when the consumers are on low incomes. Many staff are not aware of the daily financial problems experienced by people living on low incomes and of the hardship that can be experienced due to the costs incurred in participating in meetings. It is very important that the costs incurred by consumers are met by the facility, preferably prior to the costs being incurred, or are reimbursed immediately. For some consumers on low incomes, prompt reimbursement literally meant the difference between eating a meal or not. This issue of staff sensitivity to consumers' financial needs could be partially dealt with through formal training sessions. Staff can also be assisted by having access to people in consumer organisations who understood the issues, and who can, where necessary, advocate on behalf of consumer representatives.

Enduring Solutions' opinion is still that payment of a sitting fee is good practice, both because it demonstrates that a facility values the participation by the consumer, and because it puts consumers on a more equal footing with other members of the group. Taking care with selecting a good consumer representative who is

accountable to other consumers will ensure that the consumer's allegiance remains with a consumer constituency, and minimises the risk that they will be co-opted by the interests of the health service.

D. CONSUMERS AS SURVEYORS OR REVIEWERS

Two of the four pilots involved consumers working as surveyors or reviewers on accreditation survey teams. Pilot 3 only involved the consumer surveyor. Pilot 2 involved a consumer on the survey team, as well as the participation of consumers in the hospital's quality improvement activities. Both of these pilots involved surveys of hospitals being conducted by the Australian Council on Healthcare Standards (ACHS). Enduring Solutions worked closely with ACHS on these two pilots, and at the conclusion of the project met with ACHS to assess the conduct of, and lessons learned from, the pilots.

The opportunity to trial the involvement of consumers was important. The pilots demonstrated that it is possible to involve consumers as surveyors/reviewers and that those consumer surveyor/reviewers can add value to the survey. The lessons learned, and issues raised, by the pilots are set out overleaf.

Training

Both consumers attended the two day training session conducted by ACHS for all new surveyors. They were both complimentary about the training and felt that it had been very important in preparing them for their roles.

However, they both felt that, for consumers, there needs to be some extra training. Non-consumer surveyors are generally recruited from people who work within health care services, who have had experience in 'being accredited', and are familiar with the processes, terminology, structures and cultures of hospitals. Consumers, even those with considerable 'in hospital' experience as a patient, are not familiar with the concept of accreditation, or of the processes and standards used to assess a hospital. Both consumer surveyors felt that the extra training should cover topics such as the roles of the consumer surveyor, report writing including how to ensure that the issues they raise get covered in the report, interview techniques, and managing documentation. It could also usefully cover some endurance strategies to help consumers to cope with the enormous workloads and long working hours. They emphasised that this extra training must be aimed at people who have no experience at working within a health care setting. The need for this extra training was also raised by the other non-consumer surveyors who had worked with the consumer surveyors.

After her observation survey one of the consumer surveyors had also felt the need for more information about people's experience of hospital care, and had been able to talk some consumers prior to her full survey. However, she also suggested that accreditation agencies could prepare an information kit, or a reading list of literature about consumers' hospital experiences, which their consumer surveyor/reviewers could use as part of their orientation and training.

Other surveyors who worked with the consumer surveyors felt that the ACHS training needed to cover the role and expectations of the consumer surveyors. They felt that while extra training for the consumer surveyors would be useful, some of the topics nominated, such as interview techniques would also be of benefit to all surveyors. It was also apparent from the interviews with other surveyors that some additional 'transitional training' about working with consumers and the benefits of consumer participation might be needed. Some additional training for team leaders about dealing with the greater diversity of view points which can arise in a team with health professionals, administrators and consumers on it would also seem useful.

Recruitment of consumer surveyors/reviewers

Because of the short timeframe allowed for the pilots, we worked with ACHS to recruit consumers who were experienced in consumer representation and who had

already had some formal training from a consumer organisation. The experience of the pilots suggests that any future recruitment of consumer surveyors would do well to look for people who are experienced in representing consumers, and who are familiar with the range of issues that are important for them. Joining a team of experienced surveyors who work intensively over a period of time suggests that this is not an exercise for people who are new to consumer participation. Rather, it needs people who have experience at working on committees with other stakeholders and who have some familiarity with the sort of issues that are discussed, and are able to advocate for and negotiate on those things that are important to consumers.

The role of consumer surveyors/reviewers

The pilots clearly demonstrated the need for consumer to have a clearly defined role – although exactly what that role is will need careful consideration. In an ACHS survey, each surveyor has their own area of standards to survey. However, in the pilots the consumer surveyors were not given a distinct role or a set of standards to survey. They were encouraged to work across all areas of standards, because all the standards are important for consumers and there are consumer elements in all the standards. However, the identification of consumer elements in each of the standards is really an emerging science/skill. Combined with the very breadth of the

standards, consumers and others were often a little unclear about what was expected of each of them in relation to consumer and other standards.

The consumer surveyors felt that that lack of a clear role also limited their influence when it came to writing the report on the survey. They felt that if they had an area that was 'theirs' to write up, they may have been more influential. On the other hand, there is a danger in confining the consumer surveyor's role to one that has a limited range of standards. We understand that ACHS are currently reviewing their standards, and that this issue may be looked at as part of that process.

The lack of clarity of the role of the consumer surveyors was also a problem for the hospitals being surveyed. Both of the hospitals said that they were unclear about the consumer surveyor's role, and what they should be organising for them. The consumers participating in the Pilot 2 hospital's quality improvement activities were also unclear about the consumer surveyor's role, but were very positive about her presence. They felt they needed to have been better prepared for her, and probably to have had more time meeting with her.

Support for consumer surveyors or reviewers

The pilots raised issues about the support available to consumer surveyors and reviewers, particularly when they are participating in a survey, and where a consumer

may have a different view on an issue than other health professional team members. Some of these concerns may have reflected the inexperience of consumer surveyors and the inexperience of health professional surveyors working with consumers. As mentioned at other points, it is important to ensure that all team members are trained to try to listen and understand each others perspectives and, where at all possible, to seek consensus across all of the team.

In the ACHS model, the normal process requires team members to reach consensus. While this is clearly a desirable outcome, it is not clear what should happen if a consumer does not feel consensus is appropriate, because they are seeing the issue from a different perspective. If a consensus is not possible on all issues it may be desirable to look at other formal ways that consumers voices can be heard.

The consumer surveyor believed it would be helpful to have support available, during a survey, when they are working with health professionals but may need access to some external advice. ACHS surveyors have had access to 'preceptors' who have a range of skills, and who are available to provide advice to surveyors. While the project was still being carried out, there were no experienced consumer advocates who could be available to provide advice to consumers, or to clinicians who are seen to be 'consumer friendly', and who would be willing to be available to consumers. However, this was considered

likely to be an important source of assistance for consumer surveyors. As one of the results of the study, consumer advisers are now available to consumer surveyors, through a sysem of State Advisory Committees, which have replaced the previous preceptor system. The consumer advisers can also provide advice to other team members who may want some advice on consumer-related issues.

Standards

Although issues of standards were specifically not examined as part of this project, some matters about standards were inevitably raised. The principle issue that was raised in the pilot was the application of the standard requiring consumers to be involved within the facility seeking accreditation. This was raised in the Pilot 4 survey which involved the only totally 'private' hospital in the four pilots. In that pilot the consumer surveyor wanted to raise issues about the lack of consumers involved in the facility, and the lack of other mechanisms for obtaining feedback from people who had used the service. This was a standard where the facility had rated itself as having only limited achievement. The raising of this issue by the consumer surveyor had caused discomfort for other surveyors who seemed to think that topic was outside the boundaries for a survey of a private hospital or even that the standard applied more to public than to private facilities. ACHS is clear that its standards apply equally across both public and private facilities, but this issue was raised by team members as a concern about the consumer

surveyor, and by the consumer about the team in the evaluation interviews. It seems it may be an issue that it is important for accreditation agencies to stress in their training of all surveyors and reviewers.

This scenario raises another issue. From time to time, it may be that there are issues that a consumer feels are important that are different from those considered by the other team members. In one sense that is exactly why consumers are being involved, that is, to bring their unique perspective to the accreditation of facilities. It is therefore important to ensure that there is adequate opportunities for consumer views to be reflected back to the facilities, and, where there are a diversity of views within the team, a way to accommodate these in the reporting and feedback processes.

Protocols re interviewing patients

With consumers present for the survey, it provided an opportunity for them to talk to patients actually in the facility. Such activity could provide current advice and potentially could provide an understanding of how some of the theory set out by the organisation is working in practice eg what the patient might know about a consumer's right to complain or to have procedures explained.

The consumer surveyors felt that there should be some specific protocols in place about interviewing patients to

ensure that the patients' privacy and health needs were respected, as well as practices which would allow patients to speak to the consumer surveyors if they wanted to. The development of an appropriate set of questions to address to patients was also considered to be something which would be a useful tool for the consumer surveyors.

Availability of consumer feedback to consumer reviewers

The consumer surveyors found that there was limited opportunity for them to get formal or informal input from consumers or to otherwise hear from consumers. There was a need to allow more focus group input to the survey, and where consumers were involved in focus groups, not to just have a small number of 'hand-picked' consumers who may only give positive input. The consumer surveyors also suggested that meeting with consumer representatives from hospital committees was another potentially useful source of information.

Costs of consumer surveyors

Consumer surveyors involve additional costs. Some facilities may be reluctant to take on these costs, but, in general, there seemed to be an acknowledgment that the surveyor/reviewer brought new insights. As a small pilot (only two surveys) the costs were also higher, because the observation survey costs and the training costs were all counted towards the one pilot survey. Once the

surveyor/reviewer does more surveys, the average cost per survey completed of these 'fixed costs' to the accreditation agency will be reduced.

In looking at the additional costs of the consumer surveyor, it is important also to remember the comments about the value of the consumer's input which was made by one of the mental health facility managers we interviewed:

> I came to the hospital about 18 months ago and I knew there was a lot to change. But staff – even my management team - were very resistant to change. They felt everything was pretty good. They were even resistant to the process of accreditation. It must have been hard for the surveyors, as some staff refused to talk with them. At the conclusion of the review, the consumer spoke from his heart about what he had seen. He talked about the lack of dignity for people being treated here and the need for very significant change. He said things that I had been saying but THIS TIME, everyone listened. After that, one of the key players came to me and asked could he go and see another facility to see what was happening in other places. Once he came back, he said that he hadn't realised how far behind the facility was, and if the consumer hadn't talked about it, he would not have questioned his assumption that what they had been doing here was the best. He now is one of my best supports in bringing about the changes that are needed. (Facility Manager)

While it should not always be expected that the involvement of a consumer will have this dramatic an effect, it was clear that consumers affected the facility and their team members in sometimes unexpected and usually positive ways. Team members and facilities sometimes reported feeling uncomfortable about the questions asked, and yet generally, after some reflection, they realised that it was because the consumer was looking at the matter from a different perspective, and so the other team members sometimes 'looked again'.

It is also true that the consumers are inexperienced and on steep learning curves - something which is so of all new team members at that time, but particularly so for consumers who are unlikely to have come across the practice of hospital accreditation in their daily lives. It had been found with the mental health consumer surveyors that they became better surveyors and provided more useful input 'over time'. Because of the short duration of this project, the general consumer surveyors did not have that opportunity, but ACHS has been sufficiently satisfied to want to expand out the project and the opportunities for consumer involvement as surveyors in general accreditation surveys.

Availability of consumers

Both ACHS and QIC expressed strong support for wider use of consumer reviewers and surveyors, though their experiences in the mental health area were indicating some important practical issues.

The most immediate one of these was the lack of trained consumer surveyors/reviewers compared to the number of surveys or reviews in which they were needed. This is particularly so in the mental health area, where it is a requirement for all publicly funded services who receive funding under the Australian Health Care Agreement. The relatively small number adds pressure on those who are trained, which can cause health problems, particularly for mental health service consumers who may be sensitive to stress. This in turn causes frustration in accreditation agencies, which may not have sufficient consumers to meet their needs and which may 'lose' trained reviewers/ surveyors at a greater rate than they expected.

Equally the availability of trained consumers with experience in representative roles in health care may be a problem - there are few funded consumer representative training programs currently in place. The availability of a supply of trained consumers can be important to rapid implementation of consumer participation in accreditation - without the experienced trained consumers from the ACT's HCCA it would have been very much more difficult to undertake Pilots 2 and 3. Equally, infrastructure to support the wider use of consumers in accreditation (such as mentors or preceptors) is not yet in place.

Reform of the accreditation process

Consumers indicated a range of problems with the current accreditation processes. This included the quantity of paper work supplied by some facilities, and the extremely long days and hectic schedules expected of surveyors/ reviewers in the validation inspection. These were also accepted by other participants as valid criticisms of the system, but they felt they just 'had to live with it' because 'that was what was expected'. As 'outsiders', consumers did not feel that same obligation to accept what seemed unreasonable to them.

In fact, health professionals who were employed described having to undertake the survey in the day-time and then work at night to do the work still expected of them by their employer. Not surprisingly, some surveyors said that this discouraged many good people from becoming or remaining accreditation surveyors or reviewers.

Given the current consumer participation requirement on accreditation processes for mental health facilities, it would seem to provide an ideal opportunity to 'rethink' these different aspects of the accreditation process and look at different ways of 'doing their business' better. This is particularly so, given the desire by all agencies to base their accreditation processes on a quality improvement cycle approach. Consumers could be very useful in this, because they may have a better idea of what is reasonable not just for themselves, but in the process more generally.

E. THE RESOURCE GUIDE

All participants who used the Resource Guide had found it useful, and some made suggestions for change, many of which have been incorporated in the final version of the Resource Guide. Overall, it was felt that it provided useful information and would be able to be used by accreditation agencies, facilities which were seeking accreditation and consumers involved in accreditation.

Similarly, the best practice features, which were set out in the Interim Report and the Resource Guide were accepted, virtually unchanged by all participants. We sought views on best practice specifically as part of the evaluation, and the list of features were accepted by both providers and consumers as being a useful summary for them. These are repeated in their final form in the Summary of Recommendations in the front of this report and in the section on Best Practice in Chapter 2.

F. CONCLUSIONS AND RECOMMENDATIONS

The involvement of two major accreditation agencies in this project has already led to changes in their processes and the development of a clearer understanding of what consumer participation in health care actually means in practice. For example, the Australian Council of Healthcare Standards is looking very closely at the issue in its current review of the EQuIP program, and the Quality Improvement Council has recently introduced a new

mandatory Essential Requirement relating to this issue. While these actions have arisen for a range of reasons, participation in this project has been important. These recommendations and conclusions do not repeat what the agencies are doing internally, except where it seems these should become characteristics of best practice accreditation in Australia.

Follow-up from the accreditation project

The research and pilots all indicated that consumer participation in accreditation, either in a quality improvement committee where a facility is seeking accreditation or as a surveyor or reviewer on an accreditation agency's team, brings new 'consumer focussed' insights into the accreditation cycle. While the project was too short to judge whether this involvement would lead to longer term cultural change and quality improvement in health services, the preliminary indicators seemed positive.

As we found in the research phase of the project, many of the Australian developments in consumer participation are innovative and have not been tried in many places. There is thus a scarcity of research looking at the effect of consumer participation at the health system level, though there is an expanding literature base on the usefulness for

facilities and individual health care.[24] It would be unfortunate to loose the opportunity to evaluate the longer term effects of this project and to document them. **Some longer term evaluation of the Accreditation Project's pilot sites should be undertaken by the Consumer Focus Collaboration, possibly through the National Resource Centre for Consumer Participation in Health, to determine what longer term changes occur from increased consumer participation in accreditation. (Recommendation 1)**

Development of a greater role for consumers as accreditation reviewers or surveyors in Australian health care accreditation

The accreditation agencies involved in the pilots and which are currently working with consumer participation in accreditation through the National Mental Health Standards both indicated a desire to make more use of consumer surveyors or reviewers outside the mental health arena. The project also led at least one of the agencies to reconsider whether they had an adequate focus on consumer participation in their standards and processes. The lessons from the pilots and from the

[24] *The evidence supporting consumer participation in health*. Consumer Focus Collaboration 2001.

experiences of the mental health consumer reviewers indicate the need for a number of changes to occur to facilitate the expanded use of consumer reviewers or surveyors. The following recommendations address these.

State and Territory governments should develop, or provide increased funding for existing, community based consumer representative training programs that provide training for health care consumers to participate at a systemic level in health care, including accreditation. This should become a requirement under the next Australian Health Care Agreement. (Recommendation 2) Existing examples of this are the consumer representative training programmes of the Health Care Consumers' Association of the ACT and the Healthcare Consumers' Council of Western Australia. This recommendation is designed to address the 'supply' problem relating to trained consumer representatives already identified by accreditation agencies.

The Commonwealth should consult directly with health accreditation agencies regarding the inclusion of consumer reviewers/surveyors in general health care accreditation. If agreement is reached, the Commonwealth should work with the States and Territories through AHMAC initially and then through the next Australian Health Care Agreement

to require the inclusion of consumer reviewers or surveyors in general health care accreditation. (Recommendation 3). To be effective this requires the implementation of Recommendations 2, 6 and 9 BEFORE this recommendation, so that supply problems and practical workload and role issues, all of which are barriers to the implementation of this recommendation, are addressed.

The costs of consumer participation are very real for many consumers, and the policies and practice around it vary widely. While some of this variety is inevitable, given the diverse range of consumers and accreditation participation situations, some formal guidance about what is reasonable, as has occurred in the mental health area, would be very useful. **A set of draft national guidelines about the payment of consumers and the reimbursement of their costs of participation should be developed. Such draft guidelines would need to be considered and endorsed by consumers and State/ Territory and Commonwealth governments and then given effect through the provision of supplementary funding to meet these costs. (Recommendation 4)** This does not mean that payments should be required in all cases - as we found in the pilots, some consumers do not want to get paid sitting fees. However, it would go some way towards acknowledging the significant work expected of consumers and delivered by them in participating in health service accreditation processes, and other management, planning and service delivery in health care.

Requirements for adequate consumer participation in the management, planning and delivery of health care need to be built in as minimum standards in all accreditation processes, which will be acceptable for Commonwealth, State, Territory and health insurance funding purposes. (Recommendation 5). It is fundamental that these indicate that it is the patient or direct health care service user (which in the case of children, includes the carer) that is referred to in these standards.

Accreditation agencies that operate in health care should review their own processes to ensure that they are clear about the role to be played by a consumer surveyor or reviewer, including their role in the report writing process and the tasks that consumers are to undertake within the accreditation survey or review. Where accreditation agencies are already using existing consumer surveyors or reviewers, they should be involved in this role definition process. (Recommendation 6). Once these roles are clarified, or developed in the case of accreditation processes which do not currently involve consumers as surveyors or reviewers, the accreditation agencies should establish formal evaluation processes to refine these in the light of consumer reviewer/surveyor and team experience.

Some modest financial assistance should be provided by Commonwealth and State/Territory governments to accreditation agencies to establish formal and

consistent evaluation processes relating to consumer participation, to enable lessons to be learned 'across agencies' and to ensure quality documentation of experience in the use of consumer reviewers and surveyors. (Recommendation 7) The lack of formal written documentation of new processes such as these often means that the lessons learned are poorly disseminated. Working with accreditation agencies to develop a suitable evaluation framework could also allow accreditation agencies not yet using consumers as reviewers to learn from this project in a fairly focussed manner. This work could be undertaken by the National Resource Centre for Consumer Participation in Health.

Consumer surveyors both in the pilots and interviews suggested a variety of changes to the training provided by accreditation review bodies. We are aware that some changes have already been made in response to consumer feedback on the training. However, there were also other training issues which arose, including the need for training for all surveyors on the role of consumer surveyors as well as specific training for team leaders about working effectively with consumers. **Accreditation agencies should review their surveyor/reviewer training to determine whether it is appropriate to wider implementation of the use of consumer surveyors. (Recommendation 8)**

Changing the accreditation process

There were concerns both about the impact of long hours and heavy workloads on consumer and other surveyors as well as concerns about the volume of paper work and its usefulness to the process. Both of these concerns indicate a need to rethink some of the processes currently used. **Accreditation agencies should review their own processes to ensure that the workload expected of all participants is reasonable and that unnecessary and inappropriate paperwork is reduced. (Recommendation 9)** This business re-engineering process should aim at achieving more cost effective accreditation processes for facilities, while protecting the human resources of the accreditation agency (including consumer reviewers and surveyors) and promoting higher quality health care services. This may involve for example:

- looking at different ways of carrying out surveys;
- a different balance of on-site and paper based processes; and
- a more 'risk management' approach where less emphasis is placed on the accreditation review and survey and more on 'spot checks' and responses to complaints about services.

Consumer surveyors felt there was insufficient direct feedback from consumers about their experiences with the

services they were using and insufficient guidance for them about what to ask and who they could ask. **Accreditation agencies should introduce requirements for the use of more direct consumer feedback in accreditation surveys and reviews, such as public meetings, sample surveys of service users and focus groups in different areas. (Recommendation 10).** Where these have been introduced and used in the mental health area and in overseas accreditation processes, they have provided a good vehicle for discussion between the accreditation team and service users. **Accreditation agencies should develop protocols covering the interviewing of current patients by consumer surveyors/reviewers, as well as some questions that can be used to obtain direct feedback from the patients at the time of survey or review. (Recommendation 11)**

One of the important reasons consumers are considered of value in health care policy, practice and management is that they bring a user's perspective, which may be different from that of the health professionals and managers around the table. While in many cases, it is likely that consumers will be able to gain the support of other reviewers, so that a combined team consensus view will be possible, it may be that on some occasions, the consumer will have a different view. In these circumstances, potential benefits could flow from ensuring that consumer reviewers and surveyors have a way of ensuring that their different perspectives are put formally into the feedback and reporting processes of the accreditation agency. **Accreditation agencies should**

determine whether a consensus approach to report writing allows the views of consumers to be adequately reflected in a review or survey report, or whether it is necessary to consider having a formal way of building the views of consumers into any reporting back or feedback to a facility, even when there is not a common view across the team. (Recommendation 12).

While recognising that surveyors are acting as a team, are independent of the organisation under review, and are experts in their field, nevertheless it is important for consumer reviewers to have some assistance in relation to clinical and consumer issues. **Accreditation agencies need to ensure that a consumer surveyor has access to expert advice on both clinical and consumer issues to support them in their role as consumer surveyors and reviewers. (Recommendation 13)**

Encouraging consumer participation in the accreditation and quality improvement committees of health services

Much of the work being undertaken by the Consumer Focus Collaboration and the National Resource Centre for Consumer Participation in Health is relevant to encouraging the participation of consumers in this way. However, the issue of adequate training tools was one which became apparent as we worked on the project.

Existing consumer agencies could sometimes help, but to ensure some consistency of message, the project team felt that a more active guidance strategy would be appropriate.

A 'train-the-trainer' package to assist health care facilities in training staff and consumers in effective consumer participation, particularly for consumer participation in effective quality improvement and accreditation processes should be developed. This could be undertaken by the National Resource Centre for Consumer Participation in Health with adequate funding from Commonwealth and State/Territory Governments. (Recommendation 14) This recommendation addresses one of the problems we observed - that people who are able to provide training in the skills of consumer participation are not readily available and may be quite difficult to obtain except at high cost in some areas, eg rural and remote locations. However, the development of good 'train-the–trainer' materials could reduce this problem and allow services to equip themselves in an on-going way for this task.

Dissemination of the tools developed in this project

The Resource Guide for Consumer Participation in Accreditation should be made widely available as soon as possible and the summary of Best Practice in Consumer Participation in Accreditation set out on the next page should also be made widely available. (Recommendation 15) Both of these tools were considered very useful by participants in the pilots and by consortium members and will assist in any program of expansion of consumer participation in accreditation.

Best Practice in consumer participation in accreditation

- You need to have the right person for the right job - to achieve this the roles and expectations of consumer representatives must be clear at the time they are recruited.
- All accreditation team and quality improvement committee members need appropriate skills and experience to effectively work together.
- All members of the accreditation team or quality improvement committee need to understand the role and expectations of consumer representatives and of other team or committee members.

- Participation by a consumer representative in accreditation must not be used as a substitute for that of a health professional – consumers bring their own experience and expertise, as do health professionals.

- Effectively managing the diverse membership of quality improvement committees and accreditation review teams is a skilled task, requiring leadership and sensitivity to the spoken and unspoken concerns of members.

- The different perspectives, experiences and skills of all team members, including consumer representatives, need to be acknowledged and valued by all members of the team or committee.

- Consumer participation is enhanced by the active support of senior managers who develop and drive a comprehensive consumer participation strategy within a service or agency.

- Consumer participation is enhanced when providers work in partnership with an accountable and representative consumer organisation.

- All members of the committee or team, including consumers, must be treated with respect and trust, and as equal members in the accreditation process.

- Consumer participation needs to be supported and adequately resourced.

- Consumer representatives should be able to represent the views of a wide range of consumers, and be accountable to them through appropriate mechanisms such as consumer organisations.

- Appropriate training, orientation and information should be provided for all team and committee members, and specific additional training or assistance for both consumer representatives and other members should be provided as required to ensure the effective operation of the team or committee.

- Consumer participation needs to be a continuous process, not a one-off event. Consumer involvement in accreditation processes should be reflected in their on going involvement in the operation of the agency or service.

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