The evidence supporting consumer participation in health
Foreword

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

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

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

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

The Consumer Focus Collaboration would like to thank those involved in the preparation of this statement, including: Dr Anne Johnson, staff of the National Resource Centre for Consumer Participation in Health, Ms Sophie Hill and the Collaboration working group (Ms Mary Draper, Mr Matthew Blackmore, Dr Bill Pring, Ms Elizabeth Foley, Ms Jenny McMillan, Dr George van der Heide and Ms Jenni Paradowski).

Consumer Focus Collaboration
May 2001
The evidence supporting consumer participation in health

In many countries, there are strong social and political reasons why governments and health professionals are responding to consumers' requests to be more involved in the wide range of decisions that need to be made about their health care, from individual through to system-wide levels. Many health care consumers, in fact, consider it to be their right that they be included in various decision-making processes and that they are provided with information and other resources that enables them to participate. Beyond these factors, there is also a growing interest in the link between consumer participation activities and improvement in the quality and safety of health care.

The Consumer Focus Collaboration supports the following statements:

• Active consumer participation in decision-making in individual care leads to improvements in health outcomes.

• Access to quality information facilitates decision-making and supports an active role for consumers in managing their own health.

• Active consumer participation leads to more accessible and effective health services.

• Effective consumer participation in quality improvement and service development activities in health services is achieved through the adoption of a range of methods.

• Effective consumer participation uses methods that facilitate participation by those traditionally marginalised by mainstream health services.

• Active involvement of consumers at all levels of the development, implementation and evaluation of health strategies and programs is integral to their success.

This document provides an overview of some of the evidence that supports the above statements. It is not intended to be a comprehensive literature review; it makes judicious use of established practice and authoritative opinion in areas where research results are not yet available. Nonetheless, the document provides compelling support for the value of consumer participation in individual care, health service development and policy development for the broader health system.
**Consumer participation in individual care**

- Active consumer participation in decision-making in individual care leads to improvements in health outcomes.

- Access to quality information facilitates decision-making and supports an active role for consumers in managing their own health.

There is a growing recognition that consumers have enormous potential to influence their own health outcomes if they are involved actively in shared decision-making and provided with quality information and appropriate self-management tools. All of the studies cited below relate to improved health outcomes for people with chronic diseases; they recommend that consumers should become full partners with their health care providers because not only it is their right, but also because health care is delivered more effectively and efficiently if this occurs.

Acting on the conclusions from a Cochrane systematic review Lahdensou found strong evidence that when adults with asthma are active participants in their care, undergo self-management education, and are supported by written action plans, they have reduced hospital admissions, emergency room visits, unscheduled visits to the doctor, days off work or school, and nocturnal asthma. The cost effectiveness studies have shown that approximately $11.22 can be saved for every $1 spent. Similar results have been obtained by the Stanford University School of Medicine with their randomised controlled trial of 952 patients with heart disease, lung disease, stroke, or arthritis undergoing a chronic disease self-management program. A study by Kaplan, Greenfield & Ware proved that people who were more actively involved in the management of their diabetes achieved more effective control of their blood sugar levels.

Shared decision-making is gaining more and more support as a strategy for increasing the effectiveness of treatment. For example, in a 1979 study by Schulman, people with hypertension were shown to benefit if they were allowed to adopt an active rather than passive role in care. England and Evans reached the same conclusions in a more recent study of people with hypertension. A study by Fallowfield, Hall, Maguire & Baum showed women with breast cancer were less likely to suffer depression and anxiety if

---

The evidence supporting consumer participation in health

...treated by a doctor with a more participative consultation approach. The authors were cautious about this result and concluded that many women wanted more information about the relative benefits of potential treatments. A review by Breemhar & van den Borne concluded that shared decision-making and more active involvement of consumers in their health could increase consumer perceptions of control, which in turn could improve health outcomes.

In a systematic review of 17 randomised trials of the role of patient decision aids in improving decision-making and outcomes it was concluded that decision aids improve knowledge, reduce decisional conflict and stimulate patients to be more active in decision-making without increasing their anxiety. Decision aids are defined as structured detail and specific information on treatment or screening options and outcomes to aid decision-making. Evidence provided by several researchers conducting meta-analyses concluded that providing consumers with support and detailed information about their diagnosis and treatment increased their emotional well-being and assisted in their physical and emotional recovery.

---


Consumer Participation in Health Services

- Active consumer participation leads to more accessible and effective health services.
- Effective consumer participation in quality improvement and service development activities in health services is achieved through the adoption of a range of methods.
- Effective consumer participation uses methods that facilitate participation by those traditionally marginalised by mainstream health services.

In general, a service designed and delivered with an understanding of the views and needs of those who are to use it is more likely to effectively target these needs. It follows that involvement of consumers in health service planning, delivery, monitoring and evaluation is likely to result in services which are more accessible and appropriate to service users. To ensure services are appropriate to the broad range of users, a variety of methods should be utilised in facilitating their participation.

The main body of research and evaluation about consumer participation in health services has been oriented to understand the value of different methods of obtaining consumer views. The work by Draper & Hill emphasised that patient satisfaction surveys as a singular method of obtaining consumer input were useful as a measure of acceptability, but limited in achieving quality improvements in health services. This report recommended that additional input from consumers was needed to support quality improvement activities using a range of methods to involve consumers at different levels of health services.

Other research has indicated that attempts to target services to the views and needs of consumers can be beneficial. The results of a study by Bechell, Myers and Smith show that the hospital units that were more patient-centred were associated with statistically significant better outcomes than those that were less patient-centred. The authors define patient-centred care as involving the patient in treatment decisions; increasing patient communication with providers and patient understanding of what to expect from treatment plans, recovery, and aftercare; and involving family members in care. They also address the cost implications of patient-centred care.

Developing effective methods of involving consumers from groups that have been traditionally marginalised is an important way of identifying and overcoming barriers to

---

16 Commonwealth Department of Health and Aged Care, 2000 (b) op cit
17 Draper & Hill, 1995 op cit.
accessing health services by these groups. In Australia, the development of community controlled health services to facilitate access to culturally appropriate services to indigenous people has in effect delegated control to communities themselves to shape and deliver health services to meet their needs. Research by the National Resource Centre for Consumer Participation in Health, undertaken for the Consumer Focus Collaboration, has reviewed the broad range of methods which can successfully be used to harness and act upon the views of marginalised consumer groups in efforts to improve provision of health care services to these groups.

In New Zealand in 1991, asthma clinics were established within a partnership framework, which involved significant Maori management. Initial studies showed that there was a reduction in asthma morbidity amongst Maori people. A further study was conducted to assess whether the long-term benefits of the partnership program extended beyond reduced asthma morbidity and the extent to which any additional benefits may be related to the partnership approach employed by the program. The program was found to have four key benefits: cultural affirmation; improved access to other health services; a greater sense of control for participants; and positive impacts on the extended family.

The work by Alexander & Hicks, which presented a model for involving consumers, community members and health service staff in strategic planning for resource allocation, concluded that developing an understanding of people’s values provides important information to support more equitable and effective decision-making for health services planning.

Evidence also exists which demonstrates the merits of partnerships in care between parents of hospitalised children and nurses in improving satisfaction of parents in their relationship with nurses and the care provided to their child, the confidence of parents to care more effectively for their child in hospital and after discharge, and demonstrates how the involvement of parents can result in quality improvements to organisational policies and practices.

21 Commonwealth Department of Health and Aged Care, 2000, op cit.
24 Draper 1997 op cit.
26 Draper 1997, op cit
Consumer Participation in the Health System

- Active involvement of consumers at all levels of the development, implementation and evaluation of health strategies and programs is integral to their success.

Australia has had great success in the development and implementation of several National health strategies and policies. Consumer participation has been integral to the success of these and has occurred at many different levels utilising a range of methods. The following examples relate to the benefits of consumer participation in two major initiatives.

Consumer led reform has been a keystone in the implementation of the National Mental Health Strategy. There is no doubt that consumer and carer participation and partnership in the design and delivery of mental health services helps ensure more responsive providers, better quality care and more empowered clients.

At the national level, consumers and carers have been included in every planning group established since the Strategy began and considerable funds have been allocated to strengthening their voice in the mental health market place. These initiatives have rippled through to the service delivery field such that these groups now have many more avenues to make their views heard. At the national and State and Territory level, the establishment of a number of advisory groups has been an important element in increasing opportunities for consumer and carer input.

At the local level, it has been important to ensure the involvement of consumers and carers at the ‘coalface’ level of service delivery where they have opportunities to influence the services they receive. Results from the 1998 National Survey of Mental Health Services show that the involvement of consumers and carers in mental health service development is increasing. For example the proportion of mental health service organisations with some type of formal mechanism in place for consumer participation in 1997-98 was 74%. This figure has steadily increased from a baseline of 53% in 1993-94. In addition, 90% of mental health service organisations inform consumers and carers about what to expect from their mental health service and 89% formally seek consumer views on the provision of mental health services.

The Australian response to HIV and AIDS is internationally recognised for its success in controlling the spread of HIV and minimising the impacts of disease. Partnership approaches to policy development, along with bipartisan political support, have been identified as the critical elements of this success. This approach is based on

---


29 Commonwealth Dept of Health and Aged Care, 2001, op cit: 81

developing, fostering, valuing and strengthening partnerships throughout Australia. The principal partnership has been between governments, community-based organisations, affected communities, health professionals and researchers, all working together and learning from each other in developing appropriate policies.

A note on the literature on consumer participation in health

The research on consumer participation is an emerging area and hence the literature is modest in terms of the number of studies and the range of methodologies. The reported research does not often use methodologies such as randomised trials and systematic reviews which are typical of more established research areas in the health field; rather, descriptive studies and process evaluations are more common. However, there is still much to learn, to review, and to experiment with in order to learn the most effective and desirable ways to involve consumers in their health care.

Consumer research in Australia, research conducted by consumers themselves, has always sought to capture and better understand their experiences in their interactions with the health care system. These qualitative approaches need to be incorporated into systematic reviews just as much as the more traditional clinical trials research.

Resources

For all information about consumer participation in health contact the National Resource Centre for Consumer Participation in Health (NRCCPH):

Toll free telephone number: 1800 625 619
Website: http://nrccph.latrobe.edu.au
Address: Level 5, Health Sciences Building 2
LaTrobe University
BUNDOORA VIC 3086
About the Consumer Focus Collaboration Publication Series

The Consumer Focus Collaboration has commissioned the following reports, which are available through the NRCCPH.

- Improving health services through consumer participation – A resource guide for organisations.
- Feedback, participation and consumer diversity – A literature review.
- Feedback, participation and consumer diversity – An annotated bibliography.
- Stocktake of models and approaches to facilitating consumer access to health information – A report.
- Review of existing models of reporting to consumers on health service quality – Summary report and guidelines.
- Education and training for consumer participation in health care: resource guide.
- Education and training for consumer participation in health care - final report of project.

These projects and publications were funded by the Commonwealth Government.
The evidence supporting consumer participation in health