

Community and consumer participation in Australian health services-an overview of organisational commitment and participation processes

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Abstract

This article briefly describes recent initiatives to improve consumer participation in health services that have led to the establishment of the National Resource Centre for Consumer Participation in Health. The results of a component of the needs assessment undertaken by the newly established Centre are presented. They provide a 'snapshot' of the types of feedback and participation processes mainly being utilised by Australian health services at the different levels of seeking information, information sharing and consultation, partnership, delegated power and consumer control. They also allow identification of the organisational commitment made by Australian health services to support a more coordinated approach to community and consumer feedback and participation at different levels of health services such as particular emphasis on determining the presence of community and consumer participation in key organisational statements, specific consumer policies and plans, identifiable leadership, inclusion into job descriptions, allocation of resources, and staff development and consumer training. Discussion centres around four key observations and some of the key perceived external barriers.

Introduction

There is a growing recognition of the importance of health consumers being more actively involved in their own health care as well as having a broader role in health service development (National Health Strategy 1993). Active consumer participation is being increasingly linked with improvements in the quality of health care and improved health outcomes, and as a result is being encouraged by Commonwealth, State, and Territory governments. In response to the 1995 study on quality in Australian health care (Wilson, Runciman and Gibberd et. al.), where it was identified that 16.6% of admissions were associated with an adverse event of which up to half could have been preventable, the Health Ministers established the Taskforce on Quality in Australian Health Care. A recommendation from the Taskforce Report (1996) was to redesign health care processes and systems to have a strong focus on consumers. Following the Taskforce Report two groups were

formed in 1997 - the National Expert Advisory Group on Safety and Quality in Australian Health Care and the Consumer Focus Collaboration.

The National Expert Advisory Group on Safety and Quality in Australian Health Care was established to build on the work of the Taskforce and provide expert advice on safety and quality in Australian health care to Health Ministers. It recently released its Final Report to Health Ministers making recommendations about significant safety and quality matters that would benefit from national coordination (July 1999). One of the priority areas recommended for national action was to support increased consumer participation in health care.

The Commonwealth established the Consumer Focus Collaboration. This Collaboration has membership from consumer and professional organisations, and Commonwealth, State and Territory Health Departments. It was established to develop strategic alliances and projects that would promote the development of a more consumer-focused health care system. The establishment of the National Resource Centre for Consumer Participation in Health is supported by the Collaboration and funded by the Commonwealth Department of Health and Aged Care with endorsement by the Australian Health Ministers' Advisory Council. Other consumer-oriented projects that have been supported by the Collaboration, and funded by the Commonwealth Department of Health and Aged Care, are being linked to the National Resource Centre but undertaken by different consultants. Examples are the development of 'tool kit' for consumer participation, scoping of training for consumers and professionals in the area of consumer participation, and models of providing consumer health information.

In addition to the formation of these two groups, studies were commissioned from the Commonwealth. The Draper and Hill report (1995) titled *'The role of patient satisfaction surveys in a national approach to hospital quality management'* supported a national approach to consumer feedback aimed at improving the expertise available and the quality of patient satisfaction work. This report also identified the problems with pursuing a unitary measure of satisfaction and recommended a broader approach to measuring satisfaction and using patient feedback. Hospitals were identified as lacking expertise in regard to patient satisfaction and feedback methods. They recommended that a 'clearinghouse' be established to support health services to encourage community and consumers participation at different levels as a key factor in improving the quality and effectiveness of health services.

The report by Draper (1997) identified many good projects being undertaken by hospitals in the area of consumer feedback and participation, but most of the activity was at the level of consumers providing feedback rather than health professionals working with consumers as active participants. It also identified that most projects tended to be short term. This study indicated that health professionals needed to become aware of the broader range of methods of developing 'working partnerships' with consumers and that hospitals needed to develop overall consumer participation strategies, rather than doing a procession of ad hoc projects. There appeared to be congruency with the findings emerging from the abovementioned reports and the long term views of the organised consumer movement that there was the potential for a more active role for consumers within health care and service development (Consumers Health Forum 1996).

National Resource Centre for Consumer Participation in Health

Within this context, the Commonwealth Department of Health and Aged Care provided funding to establish the National Resource Centre for Consumer Participation in Health (the Centre). The Health Issues Centre, La Trobe University (Australian Institute for Primary Care) and the Women's and Children's Hospital, Adelaide were the successful tenderers.

The Centre has two functions that are closely interrelated. Broadly, its core function is to be a clearinghouse for information about methods and models of community and consumer feedback and participation and examples of 'good practice'. The other is to be a centre of excellence where methods and models of community and consumer feedback and participation are critically analysed, and advice and assistance is provided to health care managers and providers, consumers, community based organisations/groups, researchers and policy makers to develop and implement effective feedback and participation methods. The Centre also has an important role in identifying emerging issues, informing and influencing policy and practice, and supporting and

strengthening commitment to the implementation of processes for effective community and consumer feedback and participation within the health sector. It is important to stress that it is not a consumer organisation, and will not provide consumer representation on committees, nor will it provide a consumer perspective on health issues.

Assessing consumer participation activities and needs

One of the initial projects that the Centre undertook was the conduct of a national needs assessment. The needs assessment was undertaken to inform the development of the Centre's strategic direction and priority areas for action, inform people across Australia of the existence and developing role of the Centre, and develop linkages and networks. It also provided the Centre with an opportunity to study the community and consumer feedback and participation activities being undertaken by different sectors, including the Commonwealth government, State and Territory governments, peak service provider organisations, peak community and consumer organisations, consumer and support groups, and health services.

Whereas the needs assessment included consultation with a range of representatives from these different sectors, this article presents the findings from interviews with health service providers. These findings were analysed in relation to the main types of feedback and participation processes being utilised by health services and the degree of organisational commitment to developing community and consumer participation structures and processes within those health services.

Method

The results reported in this article are part of a larger study that was conducted by the Centre as part of their needs assessment. Staff of the Centre undertook semi-structured telephone interviews with 64 health services across Australia (metropolitan, rural and remote; and hospitals and community health settings), using a specifically designed questionnaire.

Sampling Procedure

The sampling procedure was a combination of a snowballing technique and purposeful sampling of a range of health services (Miles and Huberman 1994; Patton 1990). The snowballing technique ensured that in the initial stages only health services who 'had a local reputation' for undertaking community and consumer feedback and participation were contacted in each State and Territory. This ensured information rich cases. Utilising the second sampling technique, health services were purposefully chosen because of either their location or type of setting (hospitals or community health) to ensure that a broader range of health services were included in the needs assessment.

The initial step in the sampling procedure was to contact members of the Consumer Focus Collaboration who worked in each state and territory health department. They each identified health services that they felt were undertaking work in the area of community and consumer feedback and participation. These health services were contacted and asked if they knew of other health services that should be contacted. Once this process was exhausted, geographical location and the mix between hospital and community health settings was considered.

Data Collection

Each health service was contacted by telephone. The contact person for each health service varied. They were generally Quality Improvement Coordinators or Quality Managers, Directors of Nursing, General Managers or Chief Executive Officers. At this initial contact there was an introductory discussion about the Centre and the purpose of the interview was explained. They were asked if they would be willing to participate or if another person in the organisation would be more appropriate to interview. Once this was clarified a time was made to ring back and conduct the interview. An information sheet was faxed and if specifically requested, a copy of the questionnaire.

The information gathered during the interviews was documented on the questionnaires and any points clarified with the informant during the interview. All information was gathered on a confidential basis with no specific health services being identifiable.

Analysis

The information was initially analysed to identify emerging themes. Descriptive statistics were applied where relevant. Further analysis was conducted using a variation of Arnstein's Ladder of Participation (1971) to categorise the levels of community and consumer feedback and participation in which the health services were engaged. Informants were asked if they wanted to receive a copy of the draft results on which to comment. Those that answered yes were sent a copy with an invitation to comment. All comments were considered in the preparation of the final report of the needs assessment.

Results

The following results are organised into two sections. The first section describes the range of feedback and participation processes utilised by health services at the different levels of seeking information, information sharing and consultation, partnership, delegated power and consumer control. The second section identifies the organisational commitment made by the health services in this study, with particular emphasis on determining the presence of community and consumer participation in key organisational statements, specific consumer policies and plans, identifiable leadership, inclusion into job descriptions; allocation of resources; and staff development and consumer training.

Consumer Participation in Health Services

All health services reported undertaking some form of community or consumer feedback or participation. Most involved consumers in determining satisfaction with aspects of how care and services were provided. Just over half had involved consumers in some way in designing or redesigning facilities, or planning what types of services should be provided. Approximately one third of services had involved consumers in developing their vision/mission statement, strategic directions and specific policies. Most health services were undertaking some kind of project in which consumers were participating to various degrees.

The following identifies the range of feedback and participation processes used by the health services. The framework used to categorise these processes is a variation of Arnstein's ladder to determine the degree of participation for consumers (Arnstein 1971). Low degrees of participation are defined as being information seeking, information provision and consultation. Higher degrees of participation are defined as being partnership, delegated power and consumer control.

Seeking Information

Most health services sought information from consumers through a variety of processes. Measurement of patient satisfaction through the administration of patient satisfaction surveys was one common approach, but many informants stated that this was quite expensive and while the results provided some useful information, using this method in isolation from other processes was limited. Other types of processes used to seek information from consumers included unit/ward based surveys and questionnaires, focus groups, interviews, suggestion boxes, seeking comments on educational resources being developed, feedback through complaints mechanisms, meetings with consumer groups to gain their perspective on an issue, employment of workers from specific communities to seek feedback from members of those communities, and seeking comments on draft documents.

Information Sharing and Consultation

The range of processes used to share information and consult with consumers was similar to the processes used to seek information. Additional processes used by health services included consumer advisory groups, consumer representatives on committees, development of links with support groups to share information on an ongoing basis, open community forums, and search conferences.

Partnership

Informants often stated that the development of a partnership approach with consumers was the preferred level of participation for health services, though many believed they still had a long way to go in this respect. Establishing partnerships required the development of relationships between service providers and consumers or groups of consumers or the broader community. These relationships were often ongoing.

Different processes were required to develop partnerships than those used in the previous two sections. In particular they involved developing a more active role for consumers. The range of processes used included negotiation of care with patients and their families (partnership-in-care); establishing working groups with consumers, community leaders or support groups for the purpose of joint decision making to improve service delivery or address specific issues of concern; developing partnerships with consumers to plan, implement and evaluate specific projects; employing consumers as consultants; employing consumers to participate in programs or to organise consumer segments of conferences; involving consumers in selecting staff; involving consumers in training staff and students; involving the community and consumers in strategic and service planning; developing consumer and community registers with training of consumers or community members to participate in their preferred ways; and putting in place structures so that consumer councils could play an effective role in decision making in the health service.

Delegated Power

There was very little activity by health services at this level. Health services that delegated power to consumers or community groups tended to have quite well developed relationships with those consumers or community groups. Processes used in this area included a consumer group and health professionals jointly applying for funding to undertake a specific project. The project was then located with the consumer group with input from health professionals at the project management level, and the provision of resources and support by health services so that consumers could identify health issues and then recommend and implement solutions.

Consumer Control

This level of activity was only seen in specific health services with long term residents, or where consumers had taken action together to establish a service, or work closely with an existing service to establish control. The processes used included community or consumer management committees to oversee the running of the health service, develop policies and prioritise resource allocation; and consumers establishing a service in response to a community need.

Organisational Commitment

Organisational commitment to community and consumer participation in health services was investigated in relation to the presence of community and consumer participation in key organisational statements, presence of specific consumer policies, consumer participation plans, identifiable leadership, inclusion into job descriptions for staff, allocation of resources, and staff development and consumer training.

Key Organisational Statements

It was apparent that much of the conceptualisation of organisational commitment to community and consumer feedback and participation was part of the organisations' quality improvement plan, as 75% of informants said that their health service had a statement about 'being consumer focused' or 'providing high quality services to consumers'. This type of statement was either included in the health service's vision, mission, principles or philosophy. Very few health services actually stated that they would 'work in partnership with the community and consumers', or adopted similar statements which identified community and consumer participation as integral to the way they 'did business' or made decisions.

Consumer Policies

There were a range of consumer policies that organisations could have in place to provide the policy context for being 'more consumer focused' or supporting consumer feedback and participation. Approximately 86% (n=55) of health services had a complaints policy (or a complaints mechanism); 78% (n=50) had a policy on freedom of information; and approximately 72% (n=46) had a policy about consumer rights. Only 25% (n=16) stated that they had a specific policy about consumer participation. Informants identified a range of other policies that they believed would support consumer participation, these included policies on patient satisfaction, cultural diversity, consumer feedback, improving performance, consumer/community participation register, and volunteers.

Participation Plan

Just over 50% of health services stated that they had a strategy or plan for involving consumers. On the other hand very few health services appeared to have developed a coordinated approach to involving consumers and only 25% stated they had consumer participation policies. This discrepancy may have occurred because informants often included consumer participation as part their quality improvement plan, or had a specific plan for a feedback or participation process, such as the formation of a consumer advisory group, undertaking patient satisfaction surveys, fulfilling the criteria under the EQuIP accreditation process and developing projects in specific units. While these are all activities that can enhance consumer participation, in the absence of an actual consumer participation plan, these activities often remained isolated and ad hoc and do not appear to impact on change across the organisation or involvement in decision making at different levels of the health service.

Leadership

Sixty five percent of informants identified that there appeared to be strong leadership for consumer participation within their health services. The Chief Executive Officer and/or senior management and/or the Board of Directors generally provided this leadership. People in other portfolios including unit managers, Directors of Community Health Division/Departments, Quality Improvement Consultants/Quality Managers, Health Promotion Consultants/Officers, Consumer Advocates or Patient Representatives, also provided leadership. People working in these positions were usually champions for encouraging high level commitment in organisations, as well as being supportive of staff in their efforts to undertake more community and consumer participation activities. Where informants identified leadership in the health services as coming from either the Board, Chief Executive Officer or a senior manager (or a combination of these), there tended to be a more integrated approach to utilising community and consumer input into decision making at different levels of the organisation. Consumer participation was seen as part of the philosophy of management and care and the 'way business was done and care was provided'. Where informants did not identify this high level commitment and leadership, those health services tended to have staff undertaking ad hoc projects which varied in success, and were not often related to similar activities being undertaken in other parts of the health service. In these circumstances staff became caught in difficult position. On the one hand they experienced an inflexible system that did not support consumer input, and on the other they faced consumers who had become disenchanted because nothing seemed to change despite their efforts.

Inclusion in Job Descriptions

Very few hospitals had requirements to ensure that consumer participation be written into the job descriptions for a broad range of staff. There were some hospitals where there was a person identified as having responsibility for fostering community or consumer participation, this was most often the Quality Improvement Consultant or Quality Manager. Others who had this responsibility were the patient representative or complaints officer, the staff of the community health division or department, or specific project managers. Very few hospitals had a position or portfolio with the specific responsibility for coordinating community or consumer participation across the organisation.

This was in contrast to community health services, where responsibility for community and consumer participation was more likely to be integrated into the roles of a range of staff positions, rather than being the responsibility of one or two individuals. In these types of health services, promoting community and consumer participation was stated as being essential to the role of most staff.

Allocation of Resources

In hospitals, resources were generally allocated to community and/or consumer participation through existing budgets for surveying patient satisfaction and quality improvement. Community health services tended to integrate resources for community and consumer participation into 'normal' service provision. In both hospital and community health services project workers were at times employed to undertake some consumer-oriented activities. These activities were often undertaken with external funds for time limited periods and were often located in one area of the service.

Some health services had allocated specific funding to establish consumer advisory groups, run focus groups, establish committees, undertake community activities, undertake periodic consultation, reimburse consumer expenses, support volunteers and undertake needs assessments for their catchment area. Some identified that they had shifted resources in response to their observations and that some strategies were more successful than others. For example, one hospital identified that they were getting the same type of information every year from their patient satisfaction surveys, so they shifted the resources into running focus groups which enabled them to engage more effectively with consumers.

Staff and Consumer Training Programs

Despite the existence of policies on consumer rights, complaints, freedom of information and consumer participation, most health services did not conduct ongoing staff development programs in those areas. Often some input in these areas was provided to new staff on commencement of employment as part of an orientation program; when a new policy was introduced; or on an ad hoc basis by staff responsible for specific policy implementation. Other staff development programs that were identified related to cross cultural training, cultural awareness, customer service or continuous improvement. A range of issues appeared to impact on the capacity of health services to conduct staff development programs. These included staff being too busy to be released from the wards/departments, high staff turnover, and no funding available.

Very few health services conducted any training programs for consumers. Those who did generally provided an orientation to the health service for volunteers, rather than a broader training program to equip consumers to participate in decision making in health services.

Discussion

There were four key observations made from the results of this study about organisational arrangements for health services and their commitment to community and consumer participation. First, those health services such as community health services, which have a service philosophy supporting primary health care principles and a social view of health and health care provision, tend to report having more effective relationships with communities and consumers. They also tend to have community and consumer involvement in decision making at different levels of their services.

The second observation was that, where hospitals and community health centres were co-located, the hospitals tend to report more community and consumer participation activity, but this activity is usually undertaken by the staff of the community health centre rather than with or by staff of the hospital. In several instances it was reported that this led to the hospitals not have ownership of the community and consumer issues that arose, resulting in an unwillingness to make changes.

Third, those hospitals that have an organisational commitment to health promotion, or a population health approach to service planning and provision, report to have more effective relationships with their community and consumers than those hospitals without this focus.

Fourth, when there appears to be strong leadership and commitment to community and consumer participation shown by Chief Executive Officers, the Board, and other active champions within organisations, the health services tend to have a more integrated approach to involving the community and consumers in decision making at different levels throughout the organisation. Those health services without a senior level of leadership and commitment appear to have ad hoc projects that are not often able to effect change across the service.

The results of the needs assessment suggest that without the appropriate organisational structures and processes in place most community and consumer activity is ad hoc and presents as a series of unrelated activities, which do not often lead to broader and coordinated organisational change. The results suggest that there appears to be a lack of coordination of, and planning for, community and consumer feedback and participation across the whole service. This conclusion relates mainly to hospitals rather than community health services.

It also became apparent that developing an organisational commitment to community and consumer participation is never the role of just one person, but requires an organisational commitment that is driven and supported from several people at different levels within organisations. Where this did not occur staff often only effected change in their own area, with the extent of change limited because of the broader organisational issues. These findings are consistent with those reported in the study undertaken by Draper (1997).

There appears to be significant interest in, and goodwill towards involving the community and consumers in health services by service managers and providers that participated in the needs assessment. However, it appears that the community and consumers have a fairly passive role in decision making in most Australian health services, and particularly in hospitals. Most of the activity is focused on seeking feedback, providing information and consultation, rather than involving consumers more actively in decision making. For most health services (especially hospitals) information is gathered from consumers so that health professionals can make decisions on how to improve care processes and the way services are provided in particular wards or departments. Very few health services had developed effective working partnerships with consumers or delegated control to consumers to enable shared decision making.

It was also evident that many of the informants had limited knowledge of the different ways in which consumers could participate in health care and health service development. Many were keen to be able to have access to information and advice so they could improve their knowledge and practices in this area. However, lack of knowledge within health services of the different ways in which consumers could participate in health care and health service development was not the only perceived barrier identified in this study. The study also identified other perceived external barriers such as lack of policy direction and incentives from government for services to involve consumers in decision making and the funding policies in some states and territories; perceived lack of evidence of the effectiveness of consumer participation to improve quality and safety and health outcomes; and limited capacity of consumers to participate in health care and health service development. These perceived external barriers are complex issues and require more in-depth discussion, which is beyond the scope of this particular article.

If community and consumer feedback and participation is to become an integral part of improving the quality and safety in the Australian health care system, it is imperative that health services, particularly hospitals, put in place organisational structures and processes to support community and consumer feedback and participation at different levels and broaden their current approaches to working with the community and consumers.

The Centre can play a role in increasing the access of health services to quality information about different methods and models for community and consumer feedback and participation. It can also provide tools and advice to enhance the capacity of health services to integrate community and consumer feedback and participation into strategic, service and facilities planning, policy development, service delivery and care processes, and the review and evaluation of care and services. Finally, it can promote the link between community and consumer feedback and participation and improvements in quality and safety through emerging research and evaluation.

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