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Concerns about being a Health Consumer Representative: Results of a South Australian Study on Consumer Perspectives

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Community and consumer participation is strongly advocated as a way to help shape health systems and health services to become more inclusive, accountable, responsive to community and consumer needs, and to improve health outcomes. Involving consumer representatives on committees is one partnership-style method of bringing a consumer perspective into health system and health services decision-making processes. Many consumer organisations are invited to provide consumer representatives to be members of committees. A study was conducted to identify the concerns of health consumers when they are required to take on the role of being a consumer representative on committees. Focus group interviews were conducted using a series of scenarios and questions as a discussion guide. Forty-eight participants were involved in eight focus group interviews in metropolitan and regional South Australia. General concerns covering seven key areas emerged, as well as more specific concerns relating to particular roles representatives may be required to undertake. This study highlighted particular areas of concern for consumer representatives that can be utilised in developing supports to increase consumers' effectiveness, capacity and confidence to fulfil the representative role. It also highlighted that the capacity building process for consumer participation needs to be a joint partnership between the health sector and consumer organisations, rather than be seen as solely the responsibility of individual consumer representatives.

Key words: *Consumer representative, Consumer participation, Committees, Consumer concerns, Consumer training*

Community participation has been featured significantly on the international health agenda for the past three decades since the publication of the Alma Ata (World Health Organization, 1978), and the emergence of the new public health movement that has strongly advocated for individuals and communities to have more control and involvement in decision-making in areas affecting their health and wellbeing (World Health Organization, 1986; Baum, 2002; Wallerstein, 2006). Community refers to “a local neighbourhood, suburb or town, or a group of people who have common interests or problems they want addressed. They may share social or cultural backgrounds or hold similar aspirations” (National Resource Centre for Consumer Participation in Health, 2004, p. 1). Community participation is widely promoted as a fundamental principle of primary health care, which, when coupled with empowerment, contributes to reducing inequities in health, alleviating social exclusion and improving health outcomes for individuals and communities (World Health Organization, 1978; Baum; Wallerstein).

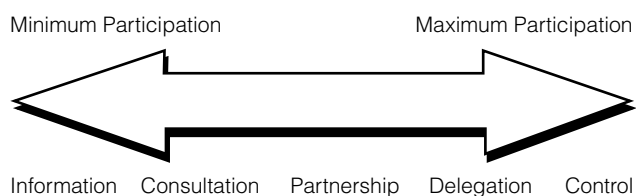
In recent years there has been an increasing

recognition and acceptance of the value of involving health consumers in decision-making to help shape health systems, and to assist health services to become more inclusive, accountable, and responsive to health consumers and broader community needs, whether at a policy level, health service level or individual care level (Government of South Australia, 2003; Johnson, 2001; Commonwealth of Australia, 1993). Consumer participation in health services has been closely linked with the safety and quality agenda within health services, and seen as an integral component of ensuring improvements in the quality of care and service delivery, and reducing the risk of adverse events (Australian Council for Safety and Quality in Health Care, 2003; The Australian Council on Healthcare Standards, 2002). The term “health consumer” refers to “people who either directly or indirectly make use of health services. Consumers are as diverse as the full range of people living in contemporary Australian society” (Consumer Focus Collaboration 2002a, p. 4). Actively involving health consumers in the

health system and health services gives consumers a “voice” and is congruent with a democratic approach to participation (Commonwealth of Australia, 1993). Participation by health consumers in decision-making contributes to establishing an environment and the mechanisms needed to make the health system and health services more responsive and accountable to the community. The Commonwealth of Australia (1993, p. 5) states that adopting a democratic approach promotes three principles; these are: “public participation, a focus on consumers and communities, and an open system”.

Over the past 30 years there has been an extensive literature developed on the concept of democratic health consumer participation that recognises the importance of different levels of participation and its link to power in decision-making. As identified in Figure 1, Shand and Arnberg (1996), like Arnstein (1969) and Brager and Specht (1973), propose participation as a continuum of choices based on power in decision-making for consumers.

Figure 1: The Shand-Arnberg Participation Continuum (1996, p. 21)



The level of “partnership” has long been advocated as an important level of participation for the health sector to attain, as it is not until this level of participation is reached that health consumers can have a role in decision-making which can challenge the power base of professionals within the health system and health services (Draper, 1997). Partnership in decision-making can be achieved through the formation of “formal” decision-making forums such as consumer advisory boards and consumer representatives on committees (Bishop & Davis, 2002). The involvement of consumer representatives on committees is one of the most common vehicles for partnership-style participation (Bishop & Davis), and a more democratic way for consumers to participate in decision-making within the health system and health services (Consumers’ Health Forum of Australia, 2001). Consumer

representatives can provide direct and unfiltered views and enable a two-way exchange. They are often invited onto a committee to represent the interests of a constituency of health consumers, such as special interest groups formed around a disease or health issue, or consumer advocacy groups that have a broader interest in health policies and system changes. A consumer representative nominated by and accountable to an organisation of consumers, and required to represent the formal views of a particular group and report back to that group, is different to a consumer nominee who is not required to represent the views of a constituency and is not accountable to that particular group (State of Victoria, Department of Human Services, 2005).

Consumer representatives, more often than not, have to participate in committees dominated in number by health professionals, health administrators and/or health policy-makers. Consumer representatives often have different (though legitimate) views and interests to other committee members, because they are putting forward a consumer perspective and protecting the interests of consumers (Consumers’ Health Forum of Australia, 2001). The potential for consumer representatives to feel marginalised and in conflict with the dominant professional views in these committees is significant. Because of this, the consumer representative role can be daunting and quite stressful.

Health consumers come from a variety of backgrounds in the community and reflect its diversity. Without undervaluing the wealth of expertise and experience health consumers bring to the consumer representative role, the need to identify and address their concerns about being part of more formal committee procedures—and undertaking an often complex role as a health consumer representative—is vital to providing them with the support they need to participate effectively in these roles. To maximise the value of consumer representatives’ input into committees there needs to be consideration of any concerns they may have about being required to undertake this type of complex role.

In recognition of these issues, health consumers and health consumer organisations/groups alike have acknowledged the need for consumer representative training and support. The Consumer Focus Collaboration (2000c) report titled “Education

and training for consumer participation in health care. Final report of project” identified that training and support was required for people taking on a consumer representative role, but there was a lack of comprehensive training programs for all consumer representatives. In addition, the review of its consumer representative program by the Consumers’ Health Forum of Australia Inc. (2002) indicated a real shortfall in support and training for its nominated representatives to address their concerns and needs.

Health Consumers Alliance of South Australia Inc.

The Health Consumers Alliance of South Australia Inc. (HCA) is an independent state-based peak health consumer organisation that aims to contribute to strengthening the voice of consumers in the health system in a range of areas. These areas include:

- Policy advice to government
- Consumer education, training and support
- Consumer nominee program
- Participation in health system reform
- Assistance to hard-to-reach groups in lobbying and advocacy (e.g., Indigenous, mental health and rural and remote consumers).

Developing a consumer nominee program to respond to requests from government and health services for consumer representatives is seen as a core role of HCA, as is providing consumer education, training and support. This involves a range of different committees for the Department of Health, government review groups, professional bodies and various types of health services such as hospitals and community health centres. To underpin the development of a training and support program for members participating as consumer representatives for HCA as part of their consumer nominee program, the HCA Management Committee supported the conduct of a research project to determine the best ways to maximise the impact of these consumer representatives on various government and health services’ committees. The research included identifying consumer representatives’ concerns, training and support needs and identifying resources/programs

that were available or needed to be developed to meet their concerns and training and support needs. Funding was obtained through the SARNet Research Bursary, under the auspices of the Flinders University Primary Health Care Research, Evaluation and Development (PHC RED) Program, funded by the Australian Government Department of Health and Ageing.

Method

Project aim

The overall aim of this research project was to identify concerns, skill areas, and support and training needs for consumer representatives to effectively participate in health services, and at a policy level, in the South Australian health system, on behalf of HCA, and to scope what resources and training and support programs were available and identify where gaps exist. This article reports on one aspect of the larger study—the concerns that participants identified about participating as health consumer representatives who will be representing HCA on various health system and health services committees.

Research approach

An exploratory qualitative approach was used to ensure the findings were grounded in specific real-life experiences and contexts, and to assure their appropriateness and relevance to practical settings (Denscombe, 2003). A series of eight focus group interviews were held with health consumers in metropolitan Adelaide and regional South Australia during August 2004. Focus group interviews were the preferred method because they are an effective approach for exploring differing experiences and perceptions in a structured way, whilst enabling interaction between participants and opportunities for them to express their own views (Patton, 1990). An Advisory Group was established to provide guidance for the research project and consisted of an HCA Management Committee member, the HCA Executive Officer, and two HCA members who were experienced researchers. A researcher was employed for the project, and a consumer (an HCA member) was engaged to contribute to the project and learn more about the research process.

Sampling technique

A purposeful sampling technique was used. The criteria for recruitment into the sample were whether participants had been or were

currently involved in participating as consumer representatives with health services or at a policy level in the health system, or were HCA members who would like to be involved in the future. Participants were recruited through HCA membership using an Expression of Interest to participate in the research, and were asked to self-nominate. Participants were also canvassed through community networks aligned to HCA and through word of mouth. Even though participants were asked to self-nominate, an effort was made to get a mix of rural and metropolitan consumers of different population and age groups through the HCA networks.

Data collection

A series of scenarios and questions were developed by the Project Advisory Group. The use of scenarios and questions was the preferred method for the focus group interviews as they provided structure to support discussions and enabled the discussion to be focused on the potential roles that participants may need to play as consumer representatives for HAC. The scenarios and questions were piloted prior to commencing the focus group interviews, resulting in some amendments to ensure clarity and that the information obtained met the research objectives. Scenarios and questions are in Box 1. All focus group interviews were facilitated by an experienced researcher, assisted by a health consumer who worked in the role of assistant researcher and scribe. The scribe documented the key issues raised by participants on a flip chart. At the end of the discussion for each scenario the researcher asked the participants if the information documented reflected the essence of the discussion. Once a consensus was reached the discussion moved on to the next scenario and the process was repeated.

Ethics

Ethics approval was gained from the Flinders University Social and Behavioural Research Ethics Committee.

Data analysis and interpretation

Data from the focus group interviews were collated into Microsoft Word. Initial themes were identified through content analysis of participants' comments by two members of the Research Advisory Group. They independently read the collated comments

Box 1: Focus Group Discussion Guide

Scenario A

You have been asked to participate on a committee at a health service. There will be a range of people on this committee from the local hospital, doctor's surgery and community health service. You will be only consumer invited to be on this committee.

Scenario B

An issue has come up in a forum which you believe requires broader consumer consultation.

Scenario C

You have been nominated by a particular community organisation to represent them on a committee which requires you represent the group's views and to report back to that group on a regular basis.

Scenario D

You are involved in an advisory group and have been part of a planning forum, but feel that some of the very important issues for consumers have not been taken on board by that health service. It is important that these issues be addressed by this service.

The following questions were used to stimulate discussion after each individual scenario identified above was presented:

Q1. From your experience what skills would a consumer need?

Q2. What would worry consumers most about doing this?

Q3. What supports would consumers need to be most effective?

Q4. What particular training/education would a consumer need to be most effective?

After the abovementioned questions have been responded to for all the scenarios, this final question will be asked:

Q5. Do you know of any training/educational resources available to assist consumers in these roles?

and looked for themes. Data was coded based on the emerging themes. Both members then met and discussed similarities and differences in the themes identified and reached a consensus on them. An iterative process of refinement supported the identification of key themes and areas associated with participants' comments, which also included participant feedback on the draft report and involvement in the development of recommendations. All participants were given feedback on the outcomes of the focus group interviews. Copies of the draft report were sent to all focus group participants with an invitation to provide any comments and feedback prior to it being finalised. They were asked to read the draft report and comment on areas where it was felt their focus group's views were not represented to their satisfaction, and give their overall opinion of the strengths and weaknesses of the report. In addition, participants from metropolitan Adelaide and

nearby towns were invited to attend a feedback session to provide verbal comments and assist in the development of recommendations.

Results

The following results section contains an overview of the participants involved in the study, and describes the findings under the headings of “general concerns” and then more “specific concerns” associated with different types of roles that they may be required to take on; for example, concerns about working on a committee; consultation with other consumers; representing a particular group’s views on a committee and reporting back to that group; and advocating for a consumer perspective.

Who was involved?

In total, 48 participants were involved in the focus group interviews—35 women and 13 men. The number of participants in each group ranged between three and 10, with an average of six per group. Participants were drawn from a broad base to include individual consumers of health care services in metropolitan Adelaide and regional South Australia, as well as members of community groups. Some participants represented specific groups (e.g., disability, mental health, men’s health, refugee women, and youth). We did not collect data on their age, their experience of committee work, or any previous preparation they may have had to be a consumer representative.

General concerns

General concerns in seven key areas emerged from the analysis of the data and could relate to any committee role a consumer representative takes on. The following areas are not listed in any order of priority, nor has any weighting been given to the frequency with which they were raised in the focus group interviews. The seven key areas identified were:

- Inaction or no outcomes achieved
- Dealing with conflict
- Intimidation, discrimination, rejection or humiliation
- Feeling uncertain about how to undertake the role and their capacity to fulfil expectations

- Resource issues
- Feeling obliged to participate
- Inclusiveness and equity.

Inaction or no outcomes achieved

Comments that participants made connected to the theme of “inaction or no outcomes achieved” included concerns that “participation will be waste of time when we have made a considerable personal investment”; “no real outcomes for the community”; “not knowing what processes or strategies to ensure action is taken to address concerns or needs”. These views imply that the participants would like their involvement to lead to action or some useful outcome, and that they are concerned their time will be wasted and nothing will come from their involvement.

Dealing with conflict

Participants’ responses suggested that conflict was inherent in the role of being a consumer representative and concern was expressed about how they could manage that conflict in a positive way. Comments that related to the theme of dealing with conflict included: “getting caught in the middle if consumers want one thing and an organisation wants something different”; “points of view not supported by other consumers, which is other consumers on the committee or in their constituency or broader community”.

Intimidation, discrimination, rejection or humiliation

For some participants there was concern about “being criticised, ridiculed, rejected or humiliated if others did not agree with their position”. It illustrates their concern about feeling vulnerable and having unequal power when being part of the “world of professionals” who have expert knowledge and often use alienating language, or conduct meetings in a way that does not use respectful processes.

Feeling uncertain about how to undertake the role and their capacity to fulfil expectations

Participants discussed concerns about their ability to undertake the role of consumer representative and fulfil other people’s expectations of them. The

issues raised that related to this theme were about their confidence, the demands of the role, having appropriate support (technological and guidable), and knowing who their constituency was, and how they would consult with them.

Fear of not contributing enough because they were “too nervous or embarrassed to speak up” was a key concern, as was “being too sensitive and feeling defensive and hurt when conflict occurred rather than staying focused on the key issues and not taking things personally”.

Participants indicated they would take the role of consumer representative very seriously and were “worried about the level of responsibility that came with the role” and whether they could cope with that responsibility. Others were worried about “how much time and energy will be demanded from them”. There was a realisation that they would need to draw on the experience and knowledge of others and they were concerned about “not knowing where to find people who could provide guidance and support” to them.

Resource issues

Lack of financial, technological and material supports to fulfil their role was a concern, especially for regional consumers or for those consumers who lived in the outer suburbs, for whom travel costs may be greater. For regional consumers there was the additional concern about increased communication costs. For some who received a pension or other benefits, there was concern about the impact of extra travel and communication on their limited income. They were also concerned that any payment received for undertaking their role as a consumer representative might affect pensions or other benefits, which, for some, would act as a disincentive to becoming involved.

For some participants who did not have access to computers or were not confident with computers, there was concern about the possible lack of technological support for them to fulfil their role as a consumer representative.

Feeling obliged to participate

Participants voiced the concern about “not being able to say no to requests to be involved, even though they might already be over-committed”. This feeling of obligation to participate was strong, as many felt committed to make a difference for other consumers. However, there was concern that this may come at a personal cost.

Inclusiveness and equity

When an organisation sought to involve consumers, the participants raised concerns that it may only seek to select people to fit its own agendas and interests rather than those of the community. There was also a concern raised that organisations may “seek only to involve majority groups, rather than also including minority groups”. Issues of inclusiveness and equity were of concern to participants who were very cautious about being expected to speak on behalf of “all types” of consumers.

Concerns associated with specific roles

The scenarios used in the focus group interviews explored four different types of roles that consumer representatives may be faced with when participating in the health system or health services. These roles were:

- Working on a committee
- Consulting other consumers
- Representing a particular group’s view on a committee and reporting back to that group
- Advocating for a consumer perspective.

This section provides more specific concerns associated with these particular roles. The information in this section needs to be considered in addition to the general concerns identified previously.

Working on a committee

Seven key themes emerged in relation to working as a consumer representative on a committee. These were concerns about accountability, role value, scope of the committee, isolation, meeting procedures, effectiveness in role and imbalance of power.

Within the theme of accountability, participants were concerned about issues of litigation and to whom they would be accountable when working on a committee. Role value was a theme that emerged from concerns expressed such as: the perceived value and credibility of consumers participating in organisational settings; if consumers were genuinely wanted and valued on committees, or whether it was tokenism to fulfil requirements; and concerns about not involving consumers in the early stages of planning and when decisions

about the identity and function of a committee group are made. Another theme that emerged was the concern about the breadth of issues and the scope of the role they will need to contend with on various committees. Isolation was another theme that was identified. This related to concerns about the isolation felt by not having a constituency to refer to or some sort of support base, and feeling isolated and insignificant. One issue that caused great concern was consumers not knowing other committee members and being left to sit on the margins whilst other people knew each other well, as they interacted with each other on a regular basis.

Concerns were raised about aspects of meeting procedures. One concern related to knowing how to tap into knowledge about how committees worked so that consumers could pursue their brief as thoroughly as possible. Another concern in the area of meeting procedures was about a lack of understanding of boundaries or regulations placed on meeting procedures, particularly in the area of confidentiality. There were many issues that arose under the theme of effectiveness in role. Issues raised were:

- Not knowing how to articulate needs or concerns
- Dealing with responses by others on the committee if their opinion differs from professional view
- Personal skills including the ability to comprehend, grasp issues, articulate concerns or opinions, handle conflict and rejection, and remain focused
- Not understanding what people are talking about in meetings, especially if jargon or specialist language is used
- Experiencing information overload
- Feeling fearful of asking questions if not understanding issues
- Not being able to articulate points of views adequately, especially in group settings
- Not contributing enough because too nervous or embarrassed to speak up.

Imbalance of power was the final theme raised about concerns of working on a committee. This theme covers issues such as participants being concerned about feeling overpowered by

professionals and not being able to contest issues for the benefit of consumers, and information being withheld from them for various reasons. Another issue related to being discriminated against for representing a particular group of consumers; for example, mental health consumers.

Consultation with other consumers

Participants identified specific concerns they had about being required to consult with other consumers. Two key themes that emerged were about identifying a constituency and how to consult and provide feedback. With regard to identifying a constituency, the issues of not knowing where to find people to help them form stronger ties with consumers in the community, and not knowing with whom to consult to develop a legitimate brief about consumer issues and needs, were a real concern. Also the issue of how to consult and provide feedback was a concern, especially with regard to knowing how to conduct community consultation effectively and how to feed information back to their constituency (if they had one).

Concerns about representing other consumers' views

Two key themes of specific concern that emerged were about their competence to represent other consumers' views, and issues about separating their own views from their constituency. Lacking confidence and doubting their ability to take on an official role competently was a significant concern, as was fear about letting down the group/constituency by not fulfilling the role adequately.

Advocating for a consumer perspective

The final role explored with participants related to advocating for a consumer perspective. The key area that emerged related to their effectiveness in being able to advocate. Issues raised were related to concerns about letting down the group/constituency by not fulfilling the role adequately and not being able to articulate needs or concerns effectively.

Discussion

This study has highlighted some of the emerging challenges for the health system and health services, and consumer organisations, from a consumer representative perspective, to effectively and respectfully engage with consumers through

formal participatory processes such as committees and advisory groups.

What was noticeable in this study was the degree of awareness participants had about the complexity of the various roles that were being discussed, and what would be required of them as consumer representatives to effectively “perform” in these roles. Their awareness of the roles was coupled with their concerns about their ability and capacity to fulfil these roles adequately.

It was apparent, when critically reflecting on the concerns expressed in this study, that the provision of training and support to consumers to develop their individual competencies to be a consumer representative—whilst important and needed—is only one dimension of how to address the range of concerns identified by participants. It is important to recognise that by only focusing on developing the capacity of individual consumer representatives we make it their individual “problem” where they have to “learn to perform better”, whereas in reality the concerns highlight significant changes that need to occur in the way meetings are structured and consumers are supported within the health system and health services, and in the way consumer organisations facilitate and support the involvement of consumer representatives.

Conclusion

The consumer representative role is one way of gaining consumer views and perspectives within the health system and health services, but this approach to involving consumers in decision-making is not maximised if consumers cannot engage confidently, nor have their capacity to contribute supported and developed. This study has highlighted areas of concern, both general and specific, whereby health consumer representatives’ capacity and confidence can be developed, and hopefully make a difference to the effectiveness of the consumer representative role and the satisfaction of consumers working in these roles.

These areas can be broadly categorised into those related to the health system and health services, and those related to health consumer organisations. Areas that can be addressed by health systems and health services when developing structures and approaches to involving consumer representatives can include:

- Ensuring outcomes are achieved

- Reducing the risk of intimidation, discrimination, rejection or humiliation
- Reducing representatives’ uncertainty about how to undertake their role and fostering their capacity to fulfil expectations
- Ensuring adequate resources are available
- Ensuring inclusiveness and equity in participation
- Ensuring clarity around accountability (to whom they are accountable and address concerns about litigation)
- Ensuring role is valued
- Being realistic about the scope of the committee role
- Reducing isolation of representatives
- Having clear and respectful meeting procedures and ensuring they are followed
- Managing meeting procedures to reduce potential imbalance of power.

It is clear from this study that for consumer participation to be effective the health system and health services need to create systems and structures to ensure consumer representatives are appropriately supported in their various roles. They also need to consider the most strategic way that consumers can contribute to the organisation, as there are many ways for this to occur apart from formal forums such as committees or advisory groups.

Health consumer organisations need to strengthen their advocacy role for consumer representatives to ensure that the health system and health services take into account the abovementioned concerns when developing structures and approaches to involving consumer representatives.

Training and ongoing support should continually be available for consumer representatives. This needs to be a responsibility of both the health system and health services and consumer organisations, and coordinated to prevent duplication and/or gaps.

Areas of concern that can be addressed when developing training and support approaches and

managing consumer representative selection programs include:

- Understanding the consumer representative role
- Developing strategies for dealing with conflict
- Developing understanding about, and skills in, meeting procedures
- Being effective in fulfilling an advocacy role
- Developing strategies for identifying a constituency, understanding how to consult and provide feedback to that constituency, as well as learning how to separate their own views from that of the constituency

- Dealing adequately with consumers' feelings of obligation to participate, to prevent over-commitment or participating in areas where they do not feel confident to participate.

It is important to emphasise that the capacity building process for consumer representatives' participation in formal forums such as committees and advisory groups be seen as a joint partnership between the health system and health services, and health consumer organisations, rather than just the responsibility of the individual consumer representative. It is also important not to lose sight of one of the main purposes of consumer participation in the health system and health services; that is, that consumer participation is ultimately about improving health outcomes.

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