Consumer and Citizen Participation in Health Care: Where are the Principles for Ethical Conduct?

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Many health services strive to actively involve consumers and citizens in improving service provision and the safety and quality of health care. However, some health professionals and consumer and citizen participants have raised concerns about ethical issues that have emerged as a consequence of how some of these participation processes are implemented. Issues raised by both health professionals and consumer and citizen participants relate primarily to tokenism and social control practices. It is of paramount importance that the health sector develops ethical principles to underpin ethical conduct for consumer and citizen participation, and define accountability mechanisms to support ethical conduct. This not only protects consumer and citizen participants, but also health professionals.

Increasing Recognition of the Importance of Consumer and Citizen Participation

Effective consumer and citizen participation is seen as an integral component of ensuring improvements in service delivery and the safety and quality of health care, and for reducing the risk of adverse events (Australian Council for Safety and Quality in Health Care 2003; The Australian Council on Healthcare Standards 2002). In recent years increased recognition and acceptance of the value of involving consumers and citizens in decision making to help shape health systems has been evident. Such participation helps 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 (Victorian Government Department of Human Services 2005; Government of South Australia 2003; Johnson 2001; Commonwealth of Australia 1993).

Emerging Ethical Concerns

Health services use a diverse range of methods of participation including formal committee and working group structures, and more ad hoc consultation and feedback mechanisms. Inherent in most participation methods are the dilemmas of whether consumers and citizens are active or passive participants; and the potential power imbalance between health professionals who typically control the agenda and consumers and citizens who can struggle to have their voices heard.

Several commentators have identified that a pretext of consumer and citizen participation can struggle to have their voices heard. This in turn may lead to greater mistrust or dissatisfaction with the service. Practices may create an unrealistic expectation of the service. Deliberate, or has occurred out of ignorance, does not change the fact that these are unethical practices. In addition, such practices may create an unrealistic expectation of the service.

Tokenism occurs when the power-holders seek input from consumers and citizens but the method of participation means that consumers and citizens lack the power to ensure that their views are heeded by the power holders. With tokenism there is no follow through and no assurance of changing the status quo (Arntstein 1969). Whether this outcome of participation is deliberate, or has occurred out of ignorance, does not change the fact that these are unethical practices. In addition, such practices may create an unrealistic expectation of the service. This in turn may lead to greater mistrust or dissatisfaction with the service by consumers.
Ethical Conduct of Health Research

Traditionally the concept of "ethical conduct" has only applied to research conducted by health professionals, with the aim of protecting the welfare and rights of research participants. The principles of ethical conduct for research include: integrity, respect for persons, beneficence and justice; research merit and safety; and ethical review and conduct of research (National Health and Medical Research Council 1999). More recently guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research have been developed and include the values of spirit and integrity, reciprocity, respect, equality, survival and protection, and responsibility (National Health and Medical Research Council 2003). The National Health and Medical Research Council (2002, p. v) has adopted a Statement on Consumer and Community Participation in Health and Medical Research which recommends that:

- consumers be given the opportunity to participate in decisions about what types of research should have priority;
- consumers who take part in research be told about the outcomes of that research; and
- researchers involve the community in the research process by disseminating information about the role, benefits and results of research, consequences of new areas of research and ethical issues.

Stringent systems and processes are set up within the health sector to ensure ethical principles are applied to most research. Some health services have linked aspects of consumer and citizen participation management to the research ethics processes in their organisations to ensure ethical management (Women’s and Children’s Hospital 2006). While this practice addresses issues related to the ethical management of consumer participation strategies that are congruent with the research ethical principles, it does not address broader ethical issues of participatory practices which should ideally be in place to reduce the occurrence of tokenism and manipulation (or social control).

Conclusion

There is an urgent need for health consumer organisations, health services, health departments, and leading quality health organisations such as the Australian Commission on Safety and Quality in Healthcare, Australian Patient Safety Foundation, and The Australian Council of Health Care Standards to work together to develop guiding principles for ethical conduct for consumer and citizen participation in health services. There is a further need to develop recommendations and clear processes for implementation based on these principles, to ensure health services are accountable for implementing these ethical principles so that they become an integrated and sustainable part of how services work with consumers and communities.

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