CONSUMER PARTICIPATION IN DIVISIONS

Purpose of this document

This document aims to assist Divisions in accessing and using consumer input in the development and implementation of Divisions' strategic and business plans in 2002 and beyond. It has been developed by a Working Group of the Divisions Standing Committee (DSC) of the General Practice Partnership Advisory Council (GPPAC) to promote an identified strategic priority in the Divisions of General Practice Program.

This document does not address the relationship between individual general practitioners and consumers as their patients, nor the issue of participation in general practices, but instead focuses upon the role and value of consumer participation in Divisions. It seeks to address a number of frequently asked questions from Divisions about consumers and their participation and to serve as a guide to further resources available to assist Divisions for these purposes.

What is a "consumer"?

The resource guide "Improving health services through consumer participation" (Consumer Focus Collaboration, 2000) notes that the term "**consumer**" refers to people who either directly or indirectly make use of health services. It covers the Australian population at different levels of aggregation: from the individual who is receiving or has received a health service, to their family and carers, to consumer organisation and representation, and ultimately to communities and citizens.

Identifying the consumers' perspective assists the focus on what outputs and outcomes are achieved by health services, including Divisions of General Practice. It provides a service user's view, which may differ from those whose primary role in the system is professional or organisational.

While it is obvious that all health care providers are also at various times consumers, a distinction should be made between their respective roles for the purposes of consumer participation strategies. A General Practitioner, Division staff member or local area health service representative each carry specific responsibilities and accountability when performing their role, and bring those perspectives to the service in which they work. To also perform a role representing the consumers within the same service is potentially a conflict of interest, as well as presenting difficulties of validity and reliability.

The Consumers' Health Forum defines a **consumer representative** as a person who voices the consumer perspective and takes part in decision making processes on behalf of consumers. To address the issues of representativeness and quality of input, this person is usually nominated by, and accountable to, an organisation of consumers (CHF, 1999). Consumer representatives have counterparts in other product and service sectors, such as finance, telecommunications, manufacturing, environment and the law, working on behalf of consumers and the community.

Health consumer organisations exist at local, state and national levels and provide a supporting structure for consumer representatives and advocates, as well as having a role in influencing government and service health policy in an organised manner. Consumer organisations may provide expertise and resources on general health issues, focus on specific agendas such as rural or public health, particular populations such as women, older or indigenous people or on specific health conditions such as diabetes. Many are incorporated under State or Territory legislation as non-profit organisations with formal rules and processes set out in a constitution. Others may be informal groupings such as peer support groups or coalitions around particular issues.

Carers are those people whose lives are affected by assuming a caring role to a consumer. In this role they bring another perspective to that of consumers, and for that reason it is expected that many Divisions may on occasion need to seek input from carers, in addition to that from consumer representatives. Similar considerations of representativeness and accountability apply to carer representatives.

Community representative is a term often used to describe someone representing the general views of "lay" people within a community, not necessarily those of particular health consumers. A community representative may be chosen because they are an eminent or respected community member, or have a background or occupation in social or welfare services, eg from a school, religious office, police, or a non-government service provider. Considerations of representativeness and accountability mean it is not always appropriate to assume that community representatives can speak from the perspective of a health consumer.

What value is consumer participation to Divisions of General Practice?

The Consumer Focus Collaboration (2001) guide "Improving health services through consumer participation" recommends four reasons that health care organisations should have a strong consumer focus and be involved in enhancing and responding to consumer participation:

- Participation is an ethical and democratic right of consumers as citizens;
- Participation makes services more responsive to the needs of consumers;
- Participation improves health outcomes; and
- Participation improves service quality and safety and helps gain service accreditation.

In a United Kingdom report, Oliver & Buchanan (1997) note that clinical researchers and health professionals valued consumers as partners "for their knowledge of local circumstances, perceptions about health related behaviour, observations about health services, explanations of lay values and priorities, skills in representing their peers, or their fresh insights and strong motivation (National Information Service, 2000).

Divisions and general practice also gain value from working with consumers, through:

- Giving general practice a stronger voice in the community assisting it to be more effective in bringing about change;
- Fostering the central place of general practice in the primary health care system and assisting consumers in their choice of health care provider and health care strategies;
- Improving quality improvement through end-user input on policy and program development; and
- Ensuring a culturally relevant context for program development, and assisting access to hard-to-reach communities.

Divisions should consider best practice models for consumer participation in Australian general practice. The National Information Service (NIS) 1999/2000 Annual Survey "Distinct Divisions", shows consumer participation occurring in governance, program advice, planning and implementation across many Divisions. Involvement extends from consumers participating in Division decision making bodies and advisory groups, to Divisions providing education and information for consumer support groups and communities. The breadth of topics addressed include:

- demographic needs (eg aged care, young people);
- health conditions (eg mental health, diabetes);
- treatment strategies (eg immunisation, allied health);
- service models (eg hospital-community processes); and
- workforce issues (eg recruitment, after hours).

How can Divisions of General Practice access consumers?

"Working with consumers – a Guide for Divisions of General Practice" (Consumers' Health Forum, 1996) offers a number of practical strategies for Divisions, including a section on where to 'find' consumers.
Strategies commonly used by Divisions include:

- **Engaging consumer representatives**

Once the 'type' of consumer (ie general or specific consumer representative, carer or community representative) and level of consumer engagement required is known, Divisions may be able to access an appropriate representative through contacting consumer organisations at local or state level, through local government or health service networks or by advertising.

- **Establishing a Consumer Reference Group (CRG)**

A Division may receive greater benefit from having access to a number of consumers across a range of issues who work together (or at times individually) for the Division, with the consumer representatives benefiting from peer support. "Working with Consumers" gives further details on how to establish a CRG.

- **Accessing input as needed from an appropriate external consumer organisation**

Where consumer input is needed on a specific issue and the Division's consumer representative/s may not have specific expertise in that area, Divisions may choose to contact specialist consumer bodies or organisations for input. This may include utilising consumer input from other health organisations, for example from the State Based Organisation (SBO), or the Area Health Service board.

What levels of participation can Divisions expect from consumers?

There are a number of options for Divisions seeking to utilise or improve consumer participation. The Consumer Focus Collaboration (2001) guide "Improving health services through consumer participation" describes 43 strategies and techniques that can be used for consumer participation, together with their strengths and weaknesses.

It is generally recommended that consumer participation be developed in a planned way, with consideration of appropriate strategies for the organisation and the consumers with whom they wish to work. The level of participation is often described on a continuum from low to high, with consequences for process and outcomes, as outlined in the "ladder of participation" below, at Table 1:

Degree	Participants' action	Illustrative Mode
High	Have control	Organisation asks community to identify the problem and to make all the key decisions on goals and means. Willing to help community at each step to accomplish goals.
	Have delegated	Organisation identifies and presents a problem to the community, defines the limits and asks community to make a series of decisions, which can be embodied in a plan it can accept.
	Plan jointly	Organisation presents tentative plan subject to change and open to change from those affected. Expects to change plan at least slightly and perhaps more subsequently.
	Advise	Organisation presents a plan and invites questions. Prepared to modify plan only if absolutely necessary.
	Are consulted	Organisation tries to promote a plan. Seeks to develop support to facilitate acceptance or give sufficient sanction to plan so administrative compliance can be expected.
Low	Receive information	Organisation makes a plan and announces it. Community is convened for information purposes. Compliance is expected.
	None	Community not involved.

Table 1: Ladder of Participation (Brager & Specht, 1973, cited in the Consumer Focus Collaboration, 2000)

Divisions can incorporate consumer input at multiple levels of business:

At the organisation level through:

- participation in community needs assessment processes;
- participation in strategic and business planning processes; and
- decision-making at Board and executive level.

At the program level, consumer input can be incorporated through participation and collaboration in the planning, implementation and evaluation of a Division's programs. An example of a program area in which Divisions might gain useful consumer input would be in the development, implementation and evaluation of local programs addressing the new Medicare items for mental health, diabetes and asthma for general practitioners in the Division.

What do consumers need from Divisions of General Practice?

Divisions may wish to engage consumers at different levels for different purposes. Responding to a questionnaire involves different participation to being a member of a program advisory group or Board. A resource list at the end of this document provides references to guides for both Divisions and consumer representatives in the principles and processes for setting up and maintaining consumer participation. In all cases Divisions should avoid "tokenism" through engaging meaningful and active participation of consumers, valuing and acknowledging their role in Divisional planning and decision making.

Some common issues requiring consideration include:

- Orientation to the Division and its role in general practice;

- Clear understanding of the role of consumers in the Division by the consumers *and* the Division's staff and board, including expectations relating to the outcomes anticipated by the Division though the involvement of consumers. This may be aided through the development of a Divisional consumer participation policy, as undertaken by some Divisions already;

- Support for consumer participation from the Division's management and staff at all levels;

- Access to support from other consumers, eg the Division's Consumer Reference Group, other Divisions' consumer representatives or local/state/national consumer bodies;

- Access to resources including computers and/or workspace, training, mentoring; and

- Agreed remuneration for participation/input, and costs of involvement incurred eg costs of travel, childcare, respite care etc, where appropriate.

Resources for Divisions to increase consumer participation

There are many resources available for Divisions seeking further information on consumer participation from organisations such as:

- Consumers' Health Forum of Australia (website: http://www.chf.org.au);
- The National Centre for Consumer Participation in Health (NRCCPH) based in Victoria (website: http://www.nrccph.latrobe.edu.au);
- The Health Issues Centre (HIC) in Victoria (website: http://www.vicnet.net.au/~hissues);
- The South Australian Community Health Research Unit (SACRHU) (website: http://www.dhs.sa.gov.au/sachru); and
- The Commonwealth Department of Health and Aged Care (DHAC) (website: http://www.health.gov.au/acc/whoswho/orgs/consumer.htm).

The following publications provide comprehensive information for Divisions from recognised consumer bodies:

Improving health services through consumer participation – a resource guide for organisations. Consumer Focus Collaboration, Canberra, 2001:
A series of publications which provide practical tools to support consumers, health care providers and mangers with ideas and information about how to work together in partnerships. The series focuses on education and training, building consumer and provider capacity, and research into consumer involvement in health services (website: http://www.nrccph.latrobe.edu.au)

Working with consumers – a guide for Divisions of General Practice. The Consumers' Health Forum of Australia, Inc, Canberra, 1996:
A practical guide for Divisions on strategies for working effectively with consumers. Includes studies from Divisions. Some policy information is no longer current (website: http://www.chf.org.au)

References for this document

Bastian, H. (1994) 'The power of sharing knowledge: Consumer participation in the Cochrane collection'. http://www.cochraneconsumer.com/p /Involve.asp

Consumer Focus Collaboration (2000) 'Improving health services through consumer participation – a resource guide for organisations'. Commonwealth Department of Health and Aging, Canberra.

Consumer Focus Collaboration (2001) 'The evidence supporting consumer participation in health'. Commonwealth Department of Health and Aging, Canberra.

The Consumers' Health Forum of Australia, Inc (1996) 'Working with consumers – a guide for Divisions of General Practice', Canberra.

The Consumers' Health Forum of Australia, Inc (1999) Guidelines for Consumer Representatives (4th Edition), Canberra

Moynihan, A (2000) 'Consumer participation in the Divisions of General Practice in Queensland – a discussion paper', unpublished.

National Information Service (2000) 'Consumers and Non-Clinical Researchers in General Practice Research, Evaluation and Development', Adelaide.

National Information Service (2001) 'Distinct Divisions: Report on the 1999/2000 Annual Survey of Divisions of General Practice in Australia', Adelaide.