

Consumer, Carer and Community Participation in Service Planning

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Section 2.4 of the *Integrated Service Planning: Interim Guidelines* for Primary Care Partnerships (PCP) identified that information for developing plans should come from a number of sources, including from community and stakeholder participation. Stakeholders may include communities, consumers, carers, service providers and peak organisations. Each of these groups will have a particular type of expertise and knowledge to bring to the development of the service plan. Consultation with one group of stakeholders (for example service providers) does not replace the requirement for consultation with another group of stakeholders (for example, consumers) as they will have different interests in the development of health services.

This Information Resource addresses the issue of consumer, carer and community participation in service planning.

In this Information Resource, consumers are defined as people who are current or potential users of health services and carers are families and friends providing unpaid care to consumers. Communities are defined as groups of citizens who have interests in the development of an accessible, effective and efficient health services that best meet their needs.

Why involve consumers, carers and communities in service planning?

Consumer and community participation in service planning is critical if PCP services are to meet community and consumer needs, and in particular to work towards developing the kinds of local services that support improvements in health outcomes by developing social models of health.

Involving consumers and communities in developing service plans will enable PCPs to obtain additional information to that available from quantitative data sets, enable services to gain an in-depth understanding of issues for different consumer groups and provide an opportunity for services to collaborate with communities to identify problems, prioritise issues and develop innovative and appropriate strategies for addressing health and well being needs (South Australian Community Health Research Unit, no date).

Information provided by consumers and communities can also assist in overcoming some of the limitations of quantitative population data, particularly when:

- Data is ambiguous or unclear;
- Problems and issues may be complex and difficult to explore using only quantitative data;
- The information required may not be easily obtained from existing data sets and/or may not be easy to quantify. For example, data may assist in identification of populations with specific needs, but may not assist in developing a practical understanding of the real issues facing those groups, or in developing appropriate strategies to address those issues; and
- Data does not provide information about which issues are most important to the community.

In particular, identifying and consulting/involving those consumers who have limited access to services is a critical part of informing the development of service approaches that enhance access and appropriateness of services to all community members.

Steps to involving consumers, carers and communities in service planning

There are many ways that PCPs can involve consumers in service planning. Some useful ideas are outlined in the following section.

1. Identify how the PCP will utilise consumer and community input

Prior to engaging consumers and communities in service planning, it is important that PCPs make a commitment to ensuring that this information will be valued and utilised in the service planning process. This does not mean that consumer, carer and community views are the only voices that should be listened to, but that their views and perspectives should be part of the debate and dialogue around setting priorities and deciding on action. PCPs who do not develop mechanisms for making sure consumer, carer and community views are actively included, may end up collecting information from these groups which they do not use. This can result in cynicism amongst consumers, carers and communities about the commitment of the PCP to listening to them and to developing appropriate responses.

2. Identify existing information from consumer and community consultation

Some of the services within the PCP may have already developed good links with a range of diverse consumers and community groups and consulted with them about their health and well being issues. It is valuable to identify these links and this existing information and build on it, rather than seeking the same information from the same people.

3. Identify how to engage consumers and communities

Having developed a community profile through utilising existing data sets, PCPs should develop strategies for engaging with a range of consumers and community groups within their catchment. There are two critical issues that will influence the methods chosen for doing this. The first is the purpose for involving consumers and communities and the second is the range of groups who should be engaged.

3.1 The purpose for engaging consumers and community groups

There are a range of levels to which consumers and communities can be involved in service planning. One way of characterising these is along a continuum. The level to which services want to engage consumers and communities will determine the method used for that engagement. For example, if services are simply seeking information from consumers, then focus groups, community forums and public meetings are some appropriate strategies. If services want to involve consumers in decision making, more active participatory mechanisms are required. These can include involving consumers in working groups from the beginning of the process and running workshops where all stakeholders contribute to resolving issues and developing strategies. Services might use a combination of information collection and active participation strategies.

Level of participation	Role of consumers, carers and communities	Examples of participatory activities ²
Community control Delegated power	Communities control and run health services. Services ask consumers, carers and communities to make decisions about particular aspects of service planning.	Consumers, carers and communities are provided with resources to develop strategies and programs to address specific issues. ³
Partnership	Consumers, carers and communities are asked to participate as partners in service planning decision making. For this activity to occur consumers, carers and communities should be provided with all the information provided to other stakeholders required to participate in decision making.	<ul style="list-style-type: none"> • Consumers, carers and communities are involved in all activities from the beginning. • Consumers, carers and community members participate in decision making service planning committees and advisory groups. • Consumers, carers and community members participate in workshops where all stakeholders come together to work through issues and participate in decision making.
Consultation	Consumers, carers and community members are involved in a consultation process where they provide information and comment on documents and strategies. Consumers, carers and community members may participate in decision making processes.	Combinations of information seeking/sharing activities (see below), plus consumers, carers and communities asked to comment on documents and strategies.
Information seeking/ sharing	Consumers, carers and communities are asked to provide services with information and/or services provide consumers, carers and communities with information. Services decide what to do with the information.	<ul style="list-style-type: none"> • Focus groups • Consumer advisory groups • Consumer representatives on committees • Development of links with consumer groups to share information. • Community forums
No input	Consumers are not engaged in service planning.	

3.2 Engaging a range of consumer and community groups

All communities will include consumers from diverse groups. This diversity can be influenced by factors such as ethnicity, race, ability, class, socio-economic background, education, gender, sexuality, religion, geographical location, and health status or health condition. Consumers from some groups within each community will have differing access to services and different levels of involvement with services.

It is important that PCPs try to engage with consumers from a range of backgrounds when developing service plans. Developing strategies for working with different consumer and community groups may involve adapting existing strategies, or developing new ways of working. For example, if there are groups of consumers within communities who do not access services, it may be useful for service providers to go out to those communities and meet with community leaders to begin to develop a relationship with people from those groups. Services can then find out from communities how they would like to participate, the kinds of strategies that will be most appropriate for that group, how existing strategies may need to be changed (which can be as simple as holding separate focus groups for men and women, or going out to communities rather than expecting them to come to you), and whether new ways of doing things may need to be considered (for example, employing and training people from marginalised groups to facilitate the participation of their communities).

4. Provide the community with feedback

Whatever strategy is adopted for seeking consumer, carer and community participation in service planning, it is critical to keep communities informed about where you are up to with the process and what the outcomes are. Providing this feedback is one way that PCPs can be accountable to consumers and communities and it contributes to the development of trust and ongoing working relationships. This can be done through utilising the local media, convening meetings or reporting directly back to community groups and organisations.

Resources

1. Community organisations, groups and programs

There are many community based organisations which may be able to assist PCPs in linking with communities or may be able to provide community perspectives on some issues relevant to service planning. These include statewide organisations like the Victorian Aboriginal Community Controlled Health Organisation, Action for Disability in Ethnic Communities, the Centre for Culture Ethnicity and Health, the Ethnic Communities Council Victoria, Health Issues Centre, the Chronic Illness Alliance, the Council on the Ageing and Carers Association Victoria. There are also many regional and local organisations, such as Migrant Resource Centres, Ethnic Community Councils, Women's Health Services, Carer Respite Centres, consumer self help groups and local clubs and associations which may be able to provide assistance.

In addition, there are a number of systemic change projects operating across Victoria to improve the responsiveness of services to some of the more marginalised groups of consumers, people of Aboriginal and Torres Strait Islander descent, people from culturally and linguistically diverse backgrounds and people with mental health issues. These projects are being undertaken as part of the following programs:

- Ethnic Services Development Program (with a focus on aged care services)
- Program Development and Access Program (with a focus on HACC services)
- Ethnic Mental Health Consultancy Program (with a focus on mental health services)
- Koori Aged Care/HACC networks (resourcing Aboriginal aged care providers)
- Community Connections Program (with a focus on homelessness).

Primary Care Partnerships may wish to consider if there are ways they can foster collaboration with and between agencies undertaking these projects to ensure the interests of the different consumer groups are represented in their service plans. The following individuals can provide more information about these projects:

- Lois Browne, Home and Community Care, Department of Human Services, Phone: (03) 9616 9859
- Meyer Eidelson, Action for Disability in Ethnic Communities (ADEC), Phone: (03) 9383 5566

2. Tools and kits

Some useful tools for conducting community needs assessments are listed below. The first three references include planning principles and check-lists.

Planning Healthy Communities: A Guide to Doing Community Needs Assessment, (no date) South Australian Community Health Research Unit, available from the South Australian Community Health Research Unit, c/- Flinders Medical Centre, Bedford Park, South Australia, 5042. Phone 08 8204 5988, Fax 08 8374 0230.

Planning Healthy Communities (Rural Focus): A guide to doing needs assessment in rural communities, available from the South Australian Community Health Research Unit, c/- Flinders Medical Centre, Bedford Park, SA 5042, Telephone 08 8204 5988, fax 08 8374 0230.

Community Consultation and Participation: Resource Kit for Area Health Service Managers and Project Leaders, 1999, NSW Health, full text available on the internet at <http://www.health.nsw.gov.au/public-health/crcp/hib/publications/community.html>, or by contacting the Health Improvement Branch, Locked Mail Bag 961, North Sydney, NSW, 2059, phone 02 9391 9399, fax 02 9391 9707.

A Guide to Participation for Older Victorians's (1999), Department of Human Services, Victoria.

Consultation Guide for People with a Disability available in full text on the internet at: <http://www.facs.gov.au/disability/ood/congdein.htm>

Mental Health Consumer Participation in a Culturally Diverse Society (Sozomenou et al, 2000) available from the Transcultural Mental Health Network, Locked Bag 7118, Parramatta BC, NSW 2150, Phone 02 9840 3333, email: atmhn@wsahs.nsw.gov.au.

Endnotes

¹ Adapted from Arnstein, S, 1971, 'Eight rungs on the ladder of citizen participation', in: Cahn, S and Pasett, B (ed) *Citizen participation, effecting community change*, Praeger Publications, New York.

² Adapted from Silburn, K and Johnson, A, 1999, *Needs Assessment*, National Resource Centre for Consumer Participation in Health, Melbourne (full text at: <http://www.nrcph.latrobe.edu.au>)

³ An example of this type of strategy is discussed by Labonte, R, 1986, 'Social inequality and healthy public policy', *Health Promotion*, 1(3):341-351.