

Developing a CALD Consumer Reference Group 1

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One service, many voices: enhancing consumer participation in a primary health service for multicultural women

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Abstract:

Background: Consumer participation in primary health care is important in providing quality consumer-focussed care but challenging when working with disadvantaged groups of diverse cultural and linguistic backgrounds. Womens Health Services (WHS) works with women from over sixty different nationalities, including many newly arrived migrants and refugees. New arrivals access a wide range of WHS programs including medical services, counselling, information, community talks and workshops, referral, and outreach, but few ethnic women attended the alcohol and other drug (AOD) services offered by the organisation.

Aim: To establish an active consumer reference group to assist understanding and reducing the barriers to AOD services for a heterogeneous disadvantaged group that includes individuals from different cultural, language and educational backgrounds.

Results: Leaning heavily on experiences from the mental health field, WHS overcame many practical and philosophical considerations which included: agreeing upon the purpose of the group and how it would operate within the structure of the organisation; the level of English language required by participants for the group to function; issues of resourcing the group; and ensuring an appropriate, workable demographic mix in terms of age, language, and migration experiences.

Conclusion: The process and the outcome of establishing a Consumer Reference Group (CRG) in a primary health care setting has been valuable for consumers and health service providers within the organisation.

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Consumer Participation in Primary Health Care

In 1978, the Declaration of Alma-Ata by the World Health Organisation set out a challenge for governments around the world to reduce health inequalities through improved primary health care.¹ Since the 1970's consumer participation has been cited as a key to successful primary health care programs by enabling service users to help set health care priorities and resource allocation². A "consumer" describes anyone who is accessing or has accessed a particular health service or program or who may use a particular health service or program in the future³. Consumer participation can happen individually or collectively, for example by a group or a community as a whole. Ideally, consumers assess their own health needs and problems, plan and implement solutions, create and maintain organisations or processes, evaluate their efforts and bring about any necessary changes to achieve their goals on an ongoing basis^{4,5}. In the tradition of Alma-Ata, consumer participation opens dialogue between health service providers and consumers to improve systems and services and is an important component of clinical governance⁶.

Advocates of consumer participation are not just ideologically driven but cite practical evidence in support of consumer involvement. International evidence has shown that when local people are involved in health projects and services there is a greater likelihood of success⁴, with improvements in psychosocial wellbeing, knowledge, mastery, coping and control⁷. As involvement increases, benefits to individuals and communities from the participatory processes also increase. As new values and perceptions are incorporated from consumers into the design and evaluation of a project or service, there is an expansion of access, greater responsiveness to needs, and programs and policies become more appropriate⁸. Other benefits include opportunities to learn more about health and the health system, more

equitable relationships between clients and service providers, greater diffusion of health knowledge in the community, greater use of local expertise, a sense of contribution, a feeling of some power or place in the system, and in some cases better future employment prospects for individuals^{5,8,9}. Governments, organisations and funding bodies also see consumer participation as a cost-effective way to amplify limited monetary and human resources⁵.

Despite the strong rationale for consumer participation, consumer involvement in all aspects of health services and programs including planning, implementation and evaluation is relatively rare⁴. Consumers' participation varies enormously, from passive, often tokenistic involvement where an organisation makes plans and announces them, to "community control" where consumers have control of the health organisation^{5,10}. Making consumer participation integral to health care planning, delivery and evaluation is challenging for service providers, particularly when working with culturally and linguistically diverse (CaLD) groups. While new migrants are usually healthier than the host population due to policies which exclude people with pre-existing conditions and illnesses¹¹, these health advantages often deteriorate over time¹². Understanding the complexities of a new health care system, distrust of government services, lack of awareness of services, poor understanding of how to access regular health care, and a lack of cultural awareness amongst health care providers can compound the impact of economic and social disadvantage migrants' and refugees' experience¹³. These factors contribute to a greater burden of illness amongst migrant refugee groups and to health inequalities¹¹. Participatory approaches could help overcome these obstacles, yet working with diverse multicultural groups, particularly those who are disadvantaged, presents additional challenges to consumer participation.

Background to the Current Project

Womens Health Services (WHS) in Perth Western Australia (WA) provides multidisciplinary primary health care including clinical services, counselling, information, community workshops, referral and outreach to women in WA. An alcohol and other drug (AOD) service was established within WHS in 1989 to provide gender-specific counselling, information and education services to women experiencing problems as a result of their own or someone else's alcohol or drug use. However, despite working with women from over sixty different nationalities, few ethnic women attended the AOD services offered by WHS. Staff attributed this service delivery not matching women's needs rather than lack of need and were aware that effective consumer participation methods might facilitate uptake.

To understand the issues better, WHS proposed a needs assessment to examine barriers that prevented newly-arrived women from accessing AOD services and explore the types of services women wanted. An important consideration was the establishment of a consumer reference group for input, assistance with cultural sensitivity, advice around recruitment, and to ensure shared communication between the researchers and relevant community members.

While many guidelines exist for increasing consumer involvement in research and community-based health service delivery, most groups are established around a single issue or to empower a single, identified marginalised group. Although consumer reference groups and consultative processes with ethnic communities are established practice in the mental health area¹⁵, little use of them has occurred around alcohol and other drugs (AOD). Thus, there was little guidance available around the establishment of a consumer reference group with individuals from diverse cultural, language and educational backgrounds in relation to alcohol and other drug issues³. The dearth of

material was particularly surprising given the prevalence of AOD issues and the fact that many primary health services around the world are situated in communities whose members come from multiple language and cultural groups. Although the models used by the mental health sector providing a starting point of how to include CaLD consumers in participatory processes, many practical and philosophical considerations were encountered in establishing an AOD consumer reference group (CRG). This article describes the decision-making and practical steps of a primary care organisation in achieving consumer participation of culturally heterogeneous client groups into primary health program planning and services.

Practical Considerations in Developing a Reference Group

Although WHS had often used relatively passive forms of consumer participation, a more dynamic approach to engaging consumers was considered necessary to understanding and reducing the barriers to AOD service access. Other projects with ethnic communities have found a CRG useful as a forum for discussion, debate, decision making and action¹⁶. An active consumer reference group that met regularly with staff facilitators could overcome some of the barriers described with other participation models and be more useful than one-off consumer consultation^{4,17}.

Defining the Purpose

A critical factor in successful consumer participation in health is the extent to which an agency is ready or prepared for consumer participation¹⁰. This readiness includes management and staff commitment, having processes and structures that facilitate consumer participation, and clear aims and objectives for consumer participation¹⁰. For this reason, agreeing upon the purpose of the CRG and how it would function within the organisational structure of WHS was critical. Discussions with the program

managers and the Chief Executive Officer of WHS ensured that, once established, the proposed group would operate within the structure of the organisation and its decision-making processes and not be a tokenistic gesture operating outside of the health service's planning, implementation, resource allocation and evaluation systems.

The purpose of the group initially agreed by staff was to assist Womens Health Services to plan education and prevention programs, improve service access, and improve AOD information for migrant and refugee women and their families. A general statement about the purpose of the group helped with the initial advertising and recruitment of women to participate. The description was intentionally left broad to allow participants to determine a more exact direction, a strategy reported as useful in other projects involving community participation with ethnic communities¹⁶. Indeed, the description of purpose was later revised by group members to enable greater clarity of purpose using words and terms they were familiar with.

Consumers as Representatives

Through internal discussion, staff decided that women would be invited to participate based upon their capability and interest rather than as appointed representatives of an association or ethnic group. The word "representative" implies that there is a constituency that the consumer is accountable to, reports back to, and liaises with¹⁸. WHS was not so much interested in representatives, but rather in gaining a consumer perspective in planning, implementing and evaluating services and programs. Given the numerous nationalities with which WHS works, there were difficulties associated with choosing or managing "representatives". Moreover, communities are heterogeneous not only demographically but in terms of people's interests and

concerns⁵. This can create real problems for selecting representation and accountability of individuals: who is a legitimate representative? It is difficult for one person to represent a community that, although having a common first language, is diverse in other respects such as of age, gender, migration experiences, length of residency in Australia and interest in the issues needing to be addressed. Any one ethnic or language-based group may have several community associations and yet people of the same ethnicity or language group may not participate in any community association. Although not “representatives”, CRG members were encouraged to discuss issues raised in the group with other women in their community, work or place of study.

A potential pitfall for consumers participating in health planning is that they may be criticised for appearing to be too closely allied with health service providers⁵.

Working with AOD service providers could be highly problematic for CRG members as drug use in many ethnic communities is highly stigmatised. Reference group members might be criticised within their communities for talking about AOD use issues and experiences within their community, for “inventing problems” and aligning themselves with “interfering service providers” instead of leaving drug use issues to families to deal with as a private matter. Concerns were expressed that CRG members could be shunned by other community members; merely being part of an AOD reference group could lead others in that community to assume the person had a current AOD problem, an unsavoury lifestyle or was morally corrupt in some way. Fortunately, none of these concerns have been borne out to date.

Interpreters and Translations

The cost of employing interpreters and potential difficulties with requiring multiple translations led to a decision that all meetings would be held in English and that the

minutes would be distributed in English. Therefore, women interested in joining the reference group needed reasonable English language listening, speaking and literacy skills although not necessarily be fluent in English. A good command of English was important for participants to communicate their ideas and opinions and so staff could communicate information about the agency and its programs to women in the group. As Brownlea⁹ noted, participants need to be able to communicate insights and concerns to others so that others can understand what the issues and options are and where the constraints lie. Having English as a common language for the group obviously precluded some women, but not using interpreters meant the group was financially viable and more sustainable for a not-for-profit organisation over the long term, increasing the likelihood that the reference group would become an enduring part of the organisation.

Resourcing the Reference Group

In many circumstances, the only people able to contribute are those with the time, money and other resources to participate^{5,9}. Without taking potential participants' resources into account, only relatively privileged segments of society can be involved, effectively excluding people from lower incomes, often the same individuals who most require health services and programs⁵. Disadvantage is not dichotomous but exists on a continuum¹⁷. In recruiting volunteers for the CRG, WHS needed to recognise the social disadvantages that many potential participants would have to deal with, including low income, lack of transport, unemployment or underemployment, having English as a second language, and the demands of responsibility for care of children. Women would need to juggle to fit the reference group around work, study and/or family responsibilities.

A key to successful involvement was that participants experienced few out-of-pocket costs, as even small costs may be excessive for those on low incomes¹⁵. As much as possible in planning the CRG, potential barriers to participation were addressed. Strategies included flexible meeting times, offering child care, providing healthy snacks at meetings for women coming straight from English classes or work, and offering transport if a meeting was held away from WHS (which is well serviced by public transport).

Two staff members acted as liaison and contact people for the CRG so that if one staff person was sick or away, meetings could still be held. These staff were allowed time within their schedules to prepare for and attend the CRG meetings but were also allocated time to be 'available', to listen to personal problems and issues that arose as barriers for CRG participants regardless of whether the issues could be resolved. The experience of other consumer participation projects with CaLD consumers is that the facilitator(s) can become seen less like a worker and more like a colleague or friend¹⁵. The allocation of a facilitator(s) has been seen to demonstrate the service or agency's commitment to involving consumers and/or carers in the planning, delivery and evaluation of the service¹⁵.

Staff Roles in the Reference Group

Being involved in the CRG meant that some staff took on a facilitation role by providing necessary information, resources and administrative support for the group. This required these staff to step away from the traditional health professional role of defining needs and solutions to a less traditional role of assisting community women in developing a belief in them selves, that their viewpoints and contributions were worthwhile¹⁹, and that they could influence health issues, programs and services²³.

Staff realised that they themselves needed to be open to reflecting on and possibly changing their own opinions and practices as a result of their involvement with the CRG. Effective consumer participation requires that both consumers and health service providers accept that the others' contributions and viewpoints are equally valuable, and experience in the mental health field is that changes occur both in consumers and staff¹⁹.

Philosophical Considerations

A number of philosophical concerns were considered around the establishment of the CRG, particularly that it should not be the only way ethnic women could become involved in influencing health service planning, delivery and evaluation at WHS. Staff were aware that concepts of consumer participation are primarily 'Western', based on notions of self-reliance, equality, and individualism as well as a Western biomedical model of health²⁰. These values and understandings are not universally shared by women from different cultural backgrounds, and asking women to participate in the CRG could be regarded as yet another example of Western ethnocentrism⁴. Not all cultures desire participatory approaches to health decision making⁹ or place a high value on participating in health services, especially if in the past they have only been consulted in a tokenistic way⁵. Cultural factors also influence the ways that individuals and communities participate in health services and programs⁴. Thus, for some women the idea of participating in a formal reference group may be too different to their notion of how clients and service providers should interact based upon their experience of the health system and consumer participation in their own countries. Care was needed to ensure that more collectivist cultural viewpoints were not excluded from being represented. Staff also recognised that women in the midst of a personal crisis needed other, less structured ways to

participate. For these reasons, the establishment of the CaLD CRG was seen as an additional way for women to participate in improving service delivery at WHS, not the only way they could have influence. Consultation and participating needs to occur in a variety of ways even for the “same” community, as there is a considerable diversity within any given community¹⁶.

One Year Later

Staff took over three months to do the preliminary work for the reference group before the group had its first meeting. The time spent looking at different models, deciding how the group would fit into the management structure of WHS and be resourced proved to be invaluable once the group commenced meeting regularly. After a year of operation, evaluation of the group and its role was undertaken to gain feedback on the experiences of women and recommend changes to the group and/or its practices if needed. Women were interviewed individually by an external evaluator to allow group members to freely express themselves without WHS staff being present. Individual interviews allowed more personal information to be obtained about what each woman had gained from the group and how they felt the group was progressing.

Strengths of the Consumer Reference Group

A number of factors were identified as contributing to the success of the CRG. Having an appropriate time for meeting was important as many CRG members were studying English, requalifying, or pursuing tertiary studies. Members welcomed being involved in decision-making processes of planning, implementation and evaluation of the group’s activities. Involvement also provided members with information regarding

health issues, the West Australian health system and how WHS worked within this health system.

The evaluation identified positive features of the CRG during its first year of operation. The group was diverse in cultural backgrounds, life experiences, age and length of residency in Australia. The patience and understanding of the main facilitator of the group was noted as creating a safe environment for sharing of ideas and viewpoints. Participation provided opportunities for members to meet other CaLD women and build their social networks. Women with stronger English language fluency were sensitive and patient with women with poorer English, often taking it upon themselves to ask other members their opinions and drawing them into discussions.

Throughout the year, CRG members had guest speakers attend their meetings as well as visiting other AOD agencies with which WHS worked. Through these activities, most women stated they had increased their knowledge about AOD issues and the different services available. These provided opportunities for the women to share with various service providers their views on AOD issues and services.

Barriers and Challenges

A number of barriers and challenges were reported. Some women felt their English was poor and were uncomfortable asking questions and sharing their ideas during the group. The English language fluency within the group varied, some having English as their primary language while others were still studying English. When visiting other agencies or when guest speakers attended the CRG, it was important to let speakers know that English was the second language for the majority of group members and that speaking slowly and clearly would assist women's understanding of the

information and topic. An information sheet with tips given to guest speakers prior to their meeting with the CRG had tried to address this.

Future Directions and Unanticipated Outcomes

The evaluation identified that CRG members wanted to do more practical, action orientated work, such as going out into the community to share information or talk to people about AOD issues, an action which will be taken up in the next year of operation of the CRG. Members also requested the development of strategies so that they could disseminate the information they had gained to other CaLD women in the community.

There were a number of unanticipated outcomes of the CRG. Women commented favourably that the group was a place where they could come to interact and communicate with other people from different cultures. Women did not see the reference group as just a place to come to discuss AOD issues. Some CRG members undertook further volunteer work with WHS, gained employment in AOD-related areas, or returned to tertiary studies often citing their experiences in the CRG as contributing to their self-confidence to undertake these activities.

Conclusion

Many primary care services that cater to vulnerable populations could benefit from consumer input. In an increasingly globalised world with movement of populations across borders and continents, the strategies and lessons within WHS of seeking input from a diverse range of CALD women could be useful to others. Although still developmental, the value and utility of the CRG to both the participants and to WHS is already clear, vindicating the approach and auguring well for its sustainability as one of many consumer participation strategies within Womens Health Services.

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References

1. WHO & UNICEF. Final report of the international conference on Primary Health Care (Alma Ata Declaration) [online] 1978. [cited 2008 September 20] Available from http://www.euro.who.int/AboutWHO/Policy/20010827_1
2. Walt G, Rifkin S.. The political context of primary health care. In Streefland P and J. Chabot J, editors. *Implementing Primary Health Care*. Amsterdam: Royal Tropical Institute, 1990. p 13-20.
3. Health Outcomes International. *Consumer and Carer Involvement in Comorbidity Treatment Planning Project, Literature Review*. ACT: Australian Government Department of Health and Ageing; 2005.
4. Stone L. Cultural influences in community participation in health. *Social Science and Medicine* 1992; 35 (4): 409-17.
5. Zakus J D, Lysack C. Revisiting community participation. *Health Policy and Planning*. 1998; 13(1): 1-12.
6. Central Northern Adelaide Health Service. Clinical governance framework 2006. Adelaide: Central Northern Adelaide Health Service; 2006.
7. Kyrouz E, Humphreys K, Loomis C. A review of research on the effectiveness of self-help mutual aid groups. In: White BJ, Madara EJ, editors. *The Self-Help Sourcebook: Your Guide to Community and Online Support Groups*. 7th ed. Cedar Knolls: American Self-Help Group Clearinghouse.2002. p. 71-85.
8. Smith BC. Participation without power: subterfuge or development? *Community Development Journal*. 1998; 33 (3):197-204.
9. Brownlea A. Participation: myths, realities and prognosis. *Social Science and Medicine*. 1987; 25(6): 605-14.
10. Dawson MT. The role of consumer participation in Victorian Primary Care Partnerships. *Australian Journal of Primary Health*. 2004; 10 (2):134 –143.
11. Kelaher M, Williams G, Manderson L. Towards evidence-based health promotion and service provision for new migrants to Australia. *Ethnicity and Health*. 1999; 4 (4): 305-13.
12. Adily A, Ward J. Improving health among culturally diverse subgroups: an exploration of trade-offs and viewpoints among a regional population health workforce. *Health Promotion Journal of Australia*. 2005; 16(3): 207-12.

13. Davidson N, Skill S, Burgner D, Kelly, Raman S, Silove D, Steel Z Vora R and Smith M. An issue of access: delivering equitable health care for newly arrived refugee children in Australia. *Journal of Paediatrics and Child Health*. 2004; 40; 569-75
14. Consumer Focus Collaboration. (2001). *The evidence supporting consumer participation in health* [online] 2001. [cited 2007 February 1] Available from www.participateinhealth.org.au/clearinghouse/Docs/evidence.pdf
15. Sozomenou A, Mitchell P, Fitzgerald M, Malk A, Silove D. *Mental health consumer participation in a culturally diverse society* (2nd Edition). Sydney, NSW : Australian Transcultural Mental Health Network; 2000.
16. Karantzas-Savva E, Kirwan A. Ethnic community stakeholders as partners in primary and secondary diabetes prevention. *Australian Journal of Primary Health*. 2004; 10 (3): 61–6.
17. Nathan S. Consumer participation: the challenges to achieving influence and equity. *Australian Journal of Primary Health*. 2004; 10 (3): 15-20.
18. National Resource Centre for Consumer Participation in Health. *Information series: consumer participation on committee*. [online] 2004. [cited 2006 April 17] Available from www.participateinhealth.org.au/clearinghouse/docs/infoseriescommittees.pdf
19. Browne G, Courtney M. “Are we there yet?” consumer participation in mental health services. *Australian Journal of Primary Health*. 2006; 12 (1): 8 – 13.
20. Bevan K. Reflections on one year of consumer participation at the Transcultural Mental Health Centre. In: Ferguson B, Barnes D editors. *Perspectives on transcultural mental health*. Parramatta BS, NSW: Transcultural Mental Health Centre; 1997.p 22-31.

How this fits in with quality in primary care

What do we know?

International evidence has shown that when local people are involved in health projects and services there is an expansion of access, greater responsiveness to needs and that programs and policies become more appropriate. However, making consumer participation integral to health care planning, delivery and evaluation is challenging, particularly when working with culturally and linguistically diverse (CaLD) groups who have a range of educational backgrounds and English language skills. Under-utilisation of an alcohol and other drug service based within a primary care service provided the catalyst for consideration of how consumer participation around the often stigmatised issue of alcohol and other drugs could be addressed to increase service usage.

What does this paper add?

This article describes the decision-making and practical steps of a primary care organisation in achieving consumer participation of culturally heterogeneous client groups into primary health program planning and services. It discusses how the organisation resolved the many factors to be considered. These include: defining the purpose of the group and its role in the organisation; membership and whether participants are “representatives”; how to ensure inclusivity for those with children, on low incomes or engaged in work or study; language issues including whether translators are used; resourcing the group; and the relationship of staff to consumer reference group. The description of how these issues were negotiated will provide practical assistance for other primary care services interested in increasing consumer participation in service planning, implementation and evaluation.