

# Service providers' views of community participation at six Australian primary health care services: Scope for empowerment and challenges to implementation

Toby Freeman<sup>1</sup>, Frances E Baum<sup>1,2</sup>, Gwyneth M Jolley<sup>1</sup>, Angela Lawless<sup>1</sup>, Tahnia Edwards<sup>1</sup>, Sara Javanparast<sup>1</sup>, Anna Ziersch<sup>2</sup>

1 South Australian Community Health Research Unit, Flinders University

2 Southgate Institute for Health, Society and Equity, Flinders University

Short title: Community participation in Australian primary health care services

Corresponding author: Dr Toby Freeman

SA Community Health Research Unit, Flinders University

GPO Box 2100

Adelaide SA 5001 AUSTRALIA

toby.freeman@flinders.edu.au

Phone: + 61 8 7221 8468

Fax: + 61 8 7221 8424

# Abstract

Community participation is a key principle of comprehensive primary health care (PHC). There is little literature on how community participation is implemented at Australian PHC services. As part of a wider study conducted in partnership with five South Australian PHC services, and one Aboriginal community controlled health service in the Northern Territory, 68 staff, manager, regional health executives and departmental funders were interviewed about community participation, perceived benefits, and factors that influenced implementation. Additional data was collected through analysis of policy documents, service reports on activity, and a web-based survey completed by 130 staff. A variety of community participation strategies was reported, ranging from consultation and participation as a means to improve service quality and acceptability, through to substantive and structural participation strategies with an emphasis on empowerment. The Aboriginal community controlled health service in our study reported the most comprehensive community participation. Respondents from all were positive about the benefits of participation, but reported that efforts to involve service users had to compete with a centrally directed model of care emphasising individual treatment services, particularly at state-managed services. More empowering substantive and structural participation strategies were less common than consultation or participation used to achieve prescribed goals. The most commonly reported barriers to community participation were budget and lack of flexibility in service delivery. The current central control of the state-managed services needs to be replaced with more local management decision making if empowering community participation is to be strengthened and embedded more effectively in the culture of services.

**Keywords**: community participation, community involvement, empowerment, primary health care

## Background

Community participation is a principle of comprehensive primary health care (PHC) in the Alma Ata Declaration (World Health Organization, 1978) and a crucial feature of health promotion in the Ottawa Charter (World Health Organization, 1986). Participation as described in the Alma Ata covers a spectrum of ideas, including individual participation in clinical decision making, the mobilisation of community resources in the delivery of healthcare, and collective participation in the planning and implementation of health services. Given this broad range of actions, health services implement community participation in very different ways (Rifkin, 2009; Rifkin, *et al.*, 2000). This conceptual ambiguity and variety of implementations is one of the barriers to the establishment of an evidence base for community participation (Rifkin, 2009; Zakus & Lysack, 1998).

In our study of six PHC services in Australia, we examined service staff perspectives on how community participation is currently implemented, and the extent to which it is empowering. The six case study sites were comprised of four multi-disciplinary services funded and managed by state government, an Aboriginal community controlled health service, and a specialist sexual health non-government organisation.

### Australian history and context

The Australian community health sector was established by the 1973 Federal Community Health Program (National Hospital and Health Services Commission, 1973). Community involvement in the development of programs was a key principle of the Federal Community Health Policy and community health services historically had community boards of management (Laris, 1995). These boards were abolished in South Australia in 2004 and the metropolitan services were organised into three regions each with their own board. In 2006, the new board structures were dismantled and power moved instead to the central health department (Government of South Australia, 2003). A review of the history of community participation in community health in Australia (Butler, 2002) found that while there was strong policy support for participation, implementation had been highly variable across jurisdictions, and found regionalisation of community health services to be a significant barrier to community participation, as well as a focus on cost containment, and the complexity and diversity of the primary health care sector.

The Aboriginal community controlled sector pioneered comprehensive PHC in Australia in the 1970s (Foley, 1982). There are 152 Aboriginal community controlled health services across Australia (NACCHO, 2011) serving between a third to a half of the Aboriginal population (Dwyer, *et al.*, 2011). Aboriginal community controlled health services "are initiated, planned and governed by boards elected from the local Aboriginal community" (NACCHO, 2011, p.1), though some organisations started as government services with control then transferred to the community (South Australian Department of Health, 2010).

# **Continuum of community participation**

Since the Alma Ata, the World Health Organisation has further developed the concept of community participation (Kahssay & Oakley, 1999; Oakley, 1989). Oakley (1989) argued that there is a continuum of community participation, ranging from participation as a means, where community input is used to improve service quality, and the parameters controlled by the health service, through to substantive and structural participation which provide community participants with more control and scope to effect changes. Baum (2008) modified Oakley's continuum to reflect contemporary typologies of participation (presented in Table 1).

# [Insert Table 1 about here]

Consideration of the different gradations of empowerment evident in these typologies is critical. Empowerment is widely regarded as central to the achievement of good health and wellbeing (Commission on Social Determinants of Health, 2008; Sen, 1999). Like participation, there is a multiplicity of meanings of 'empowerment.' Rifkin (2003) argues that the key principles are that empowerment addresses issues of power and control, that it seeks to increase capacity and confidence, and that participation is necessary but not sufficient. Laverack and Labonte (2008) present empowerment as a continuum, ranging from individual (personal action) through to collective social and political action, and see participation as an opportunity for collective empowerment that benefits the program and participants' sense of empowerment. In Australia, this goal of collective empowerment is most evident in the Aboriginal community controlled sector, with its focus on self-determination (Eckermann, et al., 2010). A continuum of empowerment can also be seen in Arnstein's ladder of citizen participation, ranging from nonparticipation, through to tokenistic consultation and placation, and at the top of the ladder, delegated citizen power and citizen control (Arnstein, 1969). Butler's history of community involvement in Australian PHC paints a picture of a retreat from more empowering, collective structural participation and concepts of citizen power, to a more neo-classical economic approach to consumer consultation where the individual is 'sovereign', an approach that would be classified lower down the empowerment continuum or ladder (Butler, 2002). In this study we examine the extent to which Australian PHC community participation practice is empowering.

# **Challenges in community participation**

There is a sizable literature on challenges faced by community participation efforts in health services, particularly the more demanding substantive or structural efforts . Challenges highlighted in the literature reflect concerns about 1) power, 2) supports and resources, and 3) representation.

*1. Power.* Community participation can be perceived as a threat to entrenched practitioner and management power, which may lead to efforts to block or limit community

participation opportunities (Church, *et al.*, 2002; Kahssay & Oakley, 1999; Zakus & Lysack, 1998). In particular, the dominance of biomedical power is often noted as suppressing comprehensive PHC efforts (resulting in a selective, disease-focused approach to PHC), including community or collective approaches to health promotion and empowerment (Baum, 2008; Baum & Sanders, 2011; Butler, 2002; Lavarack & Labonte, 2008). Conversely, authors are often sceptical of whether any transfer of power to the community occurs (Church, *et al.*, 2002). Linked to this concern is the need for health services to have the authority, autonomy, and resources to be able to act on community input – i.e., a need for some level of decentralisation within the health system (Butler, 2002; Kahssay & Oakley, 1999).

2. Supports and resources. Community participation requires capacity building and support for community members (Zakus & Lysack, 1998), which requires health services to commit resources and time to support participation (Boyce, 2002; Kahssay & Oakley, 1999; Tobin, *et al.*, 2002). Additionally, effort and time is needed to provide clarity on roles and expectations of community participants (Nathan, *et al.*, 2011; Zakus & Lysack, 1998) and also to train and support workers so that the participation is effectively supported and its outcomes influence the service (Tesoriero & Ife, 2010).

*3. Representation.* Communities are not homogenous, harmonious entities that can easily be represented (Rifkin, 2003; Wayland & Crowder, 2002). Hence, selecting who participates and has the job of representing a community is a significant consideration (Church, *et al.*, 2002; Jewkes & Murcott, 1998; Learmonth, *et al.*, 2009; Zakus & Lysack, 1998). Critical questions are: who is represented in initiatives, and which elements of the community are not represented? Often the least powerful in a community are the least likely to participate (Boyce, 2002; Church, *et al.*, 2002; Jewkes & Murcott, 1998; Nathan, *et al.*, 2011). Without adequate investment in building the capacity of community participants, those already possessing the resources to participate are likely to come from the more well-

resourced and powerful section of the community (Church, *et al.*, 2002; Tobin, *et al.*, 2002). Concerns are also voiced that community participants may pursue their own agendas rather than reflect the views of their community (Learmonth, *et al.*, 2009). Community members may not want to be part of community participation initiatives (Botes & van Rensburg, 2000) or they may not see benefits in participating when they are well or not dissatisfied with the service (Church, *et al.*, 2002). Without community input however, there is much greater danger that professional voices alone will dominate the agenda (Learmonth, *et al.*, 2009).

The current study draws on Australian PHC staff perspectives on community participation. The questions we sought to answer were:

- 1. Are Australian policies supportive of community participation in PHC?
- 2. What forms of community participation exist in the case study PHC services, and to what extent do they have scope to be empowering?
- 3. How do PHC staff conceive the value and benefits of community participation in the operation of their services?
- 4. What challenges do PHC services face in implementing community participation, and what factors influence what forms of community participation are achieved?

# Methods

#### **Case study sites**

Data collection was part of a larger project to evaluate the effectiveness of comprehensive PHC. This paper reports data relating to community participation at the six participating services. The services all had a pre-existing relationship with the researchers, and were selected to maximise diversity. The services ranged from longstanding examples of PHC to newly emerging models. Central Australian Aboriginal Congress, an Aboriginal community controlled organisation, and SHine SA, a sexual health NGO both requested to be identified in publications. The four state government services are anonymised as Services A, B, C, and D (an Aboriginal health team). The characteristics of the sites are summarised in Table 2.

#### [Insert Table 2 about here]

Congress and SHine SA incorporated community participation in their governance through membership on boards. The four state government managed sites did not have such formal community participation structures.

# Procedures

Community participation was examined through 1) analysis of policy documents, 2) six monthly reports from services on their activities, 3) interviews with service staff, and 4) a web-based survey of service staff. Data are not provided here on community members' experiences of participation, as this was beyond the scope of the study, although we acknowledge the importance of research capturing community members' perspectives. Between the service staff interviews and the web-based survey, Service B withdrew from the study due to high staff workloads and significant organisational change. Such turnover was expected, given the project spanned five years at a time of considerable change and reorganisation. Data from Service B were collected and are reported for policies, service reports, and interviews with staff, but not the web-based survey of staff. A seventh PHC service, a state government funded and managed service, began participating in the study to replace Service B in April 2012. Their results are not included.

1. *Examination of policies*. To examine the policy context of the PHC services, relevant policy documents at the national, state, and regional or organisation level were examined for references to community participation. A manual search of government websites was conducted for policies, and supplemented by requests to federal, state, regional and service representatives to supply any policies relevant to community participation. One national, one state, four regional, and two PHC service documents were identified.

2. *Service reports*. Services produced six monthly reports on a negotiated set of 19 questions which included staffing, discipline mix, funding, policies, programs and services, and efforts to seek input from clients or the community. This paper draws on community participation activity reported for the periods June- December 2009 and Jan – June 2010.

3. *Interviews with service staff.* Semi-structured interviews were conducted by the research team with key PHC personnel (N = 68) in 2009-2010. At each site, seven to fifteen semi-structured interviews were conducted depending on the size of the service, inclusive of managers and team leaders, community members of governing boards/councils, practitioners, and administration staff. Specific disciplines were requested from each site such that the total mix of disciplines reflected the spread of disciplines employed at the six sites and included dietitians, occupational therapists, speech pathologists, psychologists, social workers, Aboriginal Health Workers, medical officers, lifestyle advisors, nurses, counsellors, and project officers. In addition, six regional health executives and two South Australian health department (SA Health) representatives were interviewed.

Interview questions were developed by the research team and piloted on three practitioners and one manager. The interview included questions on current practices of community participation, and its contribution to service goals and outcomes. Example questions included: "Can you tell us how the operating principle of community participation/empowerment plays out in your work?" and "Can you give an example of how community participation has worked?"

A team approach was taken to thematic analysis with the aid of NVivo software. Preliminary analysis of the data revealed a 'meaningful range' of emerging common themes as well as some divergent views (Mason, 2002). Codes were developed, and themes discussed and revised during regular team meetings ensuring rigour through constant monitoring of analysis and interpretation (Morse, *et al.*, 2002). TF lead the analysis of data specific to community participation. Community participation strategies were classified according to Baum's (Baum, 2008) typologies, and this was double-coded to enhance rigour (TF and GJ coded the strategies separately according to the classifications presented. Where codes differed, they were discussed until consensus was achieved). Findings were fed back to participants at staff meetings and to investigators and stakeholders at project meetings, and interpretations discussed.

4. Web-based survey of service staff. To follow up on issues raised in the interviews with service staff, a web-based survey was conducted between October 2012 and February 2013. Managers at each service invited all practitioner and team leader/management staff to participate via email, and were invited to complete the survey themselves. Each manager sent two reminder emails to staff over the period the survey was open. Staff were also provided with a hard copy of the survey with a reply paid envelope in case they preferred to complete the survey in hard copy. There were a total of 130 responses (response rate 54%) from Services A (n = 5, response rate 38%), C (n = 20, response rate 65%), D (n = 10, response rate 77%), Congress (n = 59, response rate 45%), and SHine SA (n = 35, response rate 66%).

The survey questionnaire was developed drawing on the review of literature and the findings from the service staff interviews and included questions on attitudes and perceived utility and importance of community participation. The questionnaire was piloted on three staff from a PHC service that was not participating in the broader study. Overall percentages were reported for each response category. Since low staff numbers at the small government services prohibited analysis according to service, the four government services were grouped together and compared to Congress and SHine SA using ANOVAs for continuous data on staff attitudes, and chi square tests for categorical data on barriers to community participation.

Ethics approval for the service reports and interviews was received from the Flinders University Social and Behavioural Research Ethics Committee and the Aboriginal Health Research Ethics Committee, South Australia. Ethics approval for the survey was received from the Southern Adelaide Clinical, SA Health, and Aboriginal Health Research Ethics Committees.

#### **Results**

#### How policies defined PHC's role in relation to community participation

The policy environment in relation to community participation was assessed through the analysis of relevant PHC policies. In the national policy document, the Primary Health Care Reform in Australia report, participation is included as one of the rights of patients in the Australian Charter for Healthcare Rights (Australian Government Department of Health and Ageing, 2009). However, this charter defines participation as being included in clinical decision-making, with no references to more collective involvement in activities like planning, prioritising or managing services (Australian Commission on Safety and Quality in Healthcare, 2008). The state-based South Australian Health Consumer and Community Participation Policy Directive 2009-2011 is broader in scope, referencing "individual's participation in decisions concerning their own health care, as well as consumer and community participation in decisions related to health service quality improvement, equity and management" (SA Health, 2009, p. 1). The policy guidelines also include explicit reference to empowering consumers and the community.

At the time of the interviews, the state managed services sat within two regions: Central Northern and Southern. Neither of these regions included references to participation in their strategic plans (Central Northern Adelaide Health Service, 2008; Southern Adelaide Health Service, 2009). However, both had comprehensive community participation frameworks developed in 2005 that aimed to embed community participation in the operation of services (Central Northern Adelaide Health Service, 2005; Southern Adelaide Health Service, 2005). These frameworks cited benefits of participation for services and the community, and covered individual participation in health decisions through to structured community participation in the planning and delivery of services.

Congress and SHine SA's strategic documents indicate a commitment to community participation. Community control and self-determination are central to Congress's philosophy, with the goals of the board including "to assist communities who wish to establish their own community controlled health service," (Central Australian Aboriginal Congress, 2011, p. 28) "to remain a community controlled organisation," and "to maintain self-determination" (Central Australian Aboriginal Congress, 2011, p. 28) "to remain a community controlled organisation," and "to maintain self-determination" (Central Australian Aboriginal Congress, 2011, p. 30). SHine SA's Strategic Directions 2010-2013 include the aims to "build the capacity of individuals and communities to advocate for their own sexual health and wellbeing" (SHine SA, 2009, p. 2) and to provide "opportunities for participation by our communities of interest" (SHine SA, 2009, p. 3).

# **Current forms of community participation**

Data on forms of community participation were taken from the interviews with service staff and the service reports. Community participation took on a wide range of forms in the case study services. Analysis and presentation of these forms are framed by classification according to Baum's (Baum, 2008) typologies (see Table 3).

# [Insert Table 3 about here]

All services implemented consultation strategies such as evaluation and client satisfaction surveys aiming to gather information about the acceptability of current services. Services typically conducted pen and paper evaluation questionnaires after a group program to receive feedback for subsequent groups, had complaint procedures, and conducted less frequent (typically annual or biennial) broader satisfaction surveys of users, sometimes as an element of practice accreditation.

All services also employed participation strategies for specific means – committees and consultation directed at improving the quality and acceptability of programs and services. These strategies did not necessarily have an empowerment agenda. A common example was seeking input into the design of new group programs, such as for a self-confidence group at Service A, a diabetes service at Service B, and a peri-natal depression group at Service C. The practitioner running this last group reported how they "*sent out invitations to a range of people who have experienced postnatal depression, through networks, for people to take part in that focus group, to feed into it what they thought would be helpful, what was helpful, where the gaps were, that sort of thing.*"

Substantive participation strategies with clearer links to empowerment were found at five of the six sites. The exception was Service C, where opportunities to enact such community participation were reported to be rare. Congress reported how they built community capacity through engaging community members in leadership roles and supporting community members to attend forums:

"We have some very big goals in terms of Aboriginal leadership, and participation, and we work on a strengths base. We often do activities that engage people in leadership roles ... we often do find the resources to take groups of people to national forums, and to white forums so that their voice is heard directly." Practitioner, Congress.

Service A engaged peer educators and trained community members to contribute to the running of group programs and community development initiatives, which they saw as empowering the community volunteers and also having benefits for the service. Similarly, SHine SA saw benefits for the service in their Youth Action Teams (groups of young people convened and reimbursed by SHine SA to contribute to health promotion activities, design of resources, and governance), and also saw the teams as empowering young people:

"We've had young people who we've actually supported to go overseas to youth conferences ... It just builds their self-esteem, being involved and learning does actually change young people's self-esteem and I think it changes their motivation and their behaviour." Manager, SHine SA.

Congress' commitment to employing Aboriginal staff where possible, particularly local community members, can be seen as a form of substantive participation designed to empower and build the capacity of the local Aboriginal population, by providing employment and developing a local health workforce. A Congress manager described how the local Aboriginal staff members meet as a "*peer support group*" and then "*come as a bigger group then we meet and we talk about cultural issues and obviously the client base*." Service D's solely Aboriginal staff is a similar form of empowerment, and the team has recently established an accredited training centre to support Aboriginal people to train as health professionals.

The one example of structural participation was Congress' board. At the time of the research the board comprised nominees elected by the community and two members appointed by the Alice Springs native title holder group. Congress itself was established as a result of community meetings concerning a range of issues having an impact on Aboriginal people in Central Australia. It was initially set up in 1973 as an Aboriginal advocacy organisation, which provide a PHC service from 1975 (Bartlett & Boffa, 2001). Community control was argued to empower the community, providing a sense of "*confidence that community has*" (Practitioner, Congress) – in particular, respondents nominated the community's confidence to use the health service and to provide feedback and assert their rights.

# **Staff perceptions of benefits**

As well as empowerment of participants, respondents in the service staff interviews cited a number of benefits of participation for the services: increased accessibility, a source of cultural knowledge, and the scope to be innovative and responsive.

*Increased accessibility*. Participation was cited as improving utilisation through several avenues: ascertaining receptiveness to a proposed program, taking community feedback into consideration to design a more accessible and appealing program, raising awareness of the program through consultation, and encouraging a sense of ownership.

Source of cultural knowledge. For SHine SA and Congress particularly, community participation was a source of cultural knowledge. At Congress, the women's health branch had "an established cultural advisory council ... made up of eleven traditional grandmothers" (Manager, Congress) who were "a very invaluable source of cultural knowledge." At SHine SA, the Youth Action Teams serve to ensure that events and materials such as pamphlets and posters appealed to young people.

*Freedom to be innovative*. Congress and SHine SA articulated how their boards supported implementation of a more progressive vision:

"The first thing is it provides the independent institutional framework where a progressive vision for health and the social model of health can actually be implemented, it's not government controlled." Practitioner, Congress.

"[The Council and the organisation] *could see the evidence, and could see the need* for change, and could see that the organisation that was set up in 1970 lived now in a totally different social political economic context to what it had in 1970." Manager, SHine SA.

This freedom can be attributed to being non-government organisations (albeit with the overwhelming proportion of their funding coming directly from government) as well as the

community participation structures each had. This freedom is also clearly contingent on community participants sharing the same values and vision.

Two questions gauging attitudes towards community participation were included in the web-based survey of staff. Responses are presented in Table 4. Service staff generally indicated highly positive attitudes towards community participation, perceiving it to be important and to have the capacity to improve quality of care. Attitudes to community participation did not significantly differ between Congress, SHine SA, and the government services, Q1 F(2, 133)=1.371, p=.26, Q2 F(2,111)=0.179, p=.836.

[Insert Table 4 about here]

# Challenges in the implementation of community participation, and factors affecting what forms of community participation were achievable

The factors reported by interviewees are grouped under the following issues 1) power, 2) supports and resources, and 3) representation.

1. Power

The two key power-related themes evident in responses were a tension between participation and clinical evidence-based practice, and a tension between central decision making and local participation.

*Tension with evidence-based practice*. This tension emerged from a number of different perspectives. Some saw the clinical evidence-based movement as a threat to community participation:

"There's a lot more emphasis now on accreditation, frameworks and along with what is seen as best practice and evidence based. And all of that can be code against community control. Because communities don't operate in terms of evidence. It's structured in the way that medicine just needs to be practiced ... And again sometimes you do hear people say 'What does [the Board] know, they're not clinicians.' So there is this tension from time to time between professionals who think they should be running everything, and the mechanisms of community control and Aboriginal control." Manager, Congress.

For some practitioners in some circumstances, evidence and clinical judgement was preferenced over community participation, for example:

"The groups that we would tend to run typically would be things that would be informed by the evidence and clinical judgement ... I guess there will be times when there would be community consultation ... [but mostly] we use clinical judgement to make a decision about what sorts of services we tend to offer." Practitioner, Service C.

One practitioner saw benefits in services being informed by both:

"This thing about community knowledge and evidence is potentially a tension point but there's also a dynamism there between bringing both to the table and making sure that both are at the table and it's not all one or the other." Practitioner, Congress.

*Tension with central control.* The move to more central control of the state-managed services was reported to have substantially reduced the space for community participation. Community participation policy statements tended to be viewed cynically. Workers saw little point in "getting feedback and then not being able to act on it" (Practitioner, Service B) because of a lack of autonomy to respond to expressed needs:

"There was a draft [community participation] policy that was floating around not too long ago, and people kind of laughed at it a bit ... It's just a bit of a joke because most of the work we do comes from above." Practitioner, Service A.

Congress reported vertical, siloed funding sources as a barrier to being responsive to community requests for comprehensive service provision, observing that "*funding bodies tend to get nervous if they can't see their program get up in a siloed way*." (Practitioner, Congress.)

2. Supports and resources

The three major concerns concerning supports and resources were: competing priorities; a movement towards more clinical, individual services, particularly at the state-managed services; and the need to build capacity of community members.

*Competing priorities.* Staff reported being under stress, with high workloads and long waiting lists. In this climate, community participation was not always seen as a priority, as the two participants reflect here:

"... we've got so much demand and such a waiting list that we're not available to all, so there's not strong emphasis on participation and empowerment in that way." Practitioner, Service C.

"I think it's seen as it's in our accreditation so we all have to do it, and it's an important thing to do, and we'll get to it, but it's not one of our first 10 priorities." Regional Health Executive.

Similarly, short time frames could squeeze out community participation efforts:

"Suddenly you've got two weeks to get something done so you haven't got time to get someone in." Practitioner, Service A.

*Focus on clinical work*. In the state-managed services, a greater concentration on clinical work, typically with a chronic disease focus, was reported. This was seen to change the parameters of what community participation was achievable, curtailing opportunities for engagement with the wider community in favour of consultation focusing largely on individual clients:

"When I think about it, it's a lot about 'community empowerment' or 'community participation' - I think 'client participation' or 'client empowerment.' Because it's really the people I have direct contact with or provide services to are already listed and so they're clients. Because I'm not out there doing that health promotion and that community work." Practitioner, Service C. *Capacity building for community members.* A concern with capacity building and support for community members was highlighted by a Council member at SHine SA:

"It takes a great deal of training and support for a young person to even have a voice and feel comfortable to have a voice on the Board, let alone understand the complexities of the governance role and all of the other things they have to deal with. So a young person coming in to discuss young people's issues on a board still has to deal with the finances and the staffing issues."

The Council member nominated this as one of the reasons why SHine SA had chosen to have professionals for council representatives who would then take on a community of interest as their portfolio area, rather than have lay representatives from those communities of interest.

# 3. Representation

Only a few concerns about representation were expressed. Congress and Service D both reporting difficulties with negative individuals dominating participation forums, and another manager recounted an example of a community representative pursuing their own agenda:

"You sometimes get semi-professional community reps who don't really represent anyone other than themselves ... I know that to be a case of a project I've worked in recently, and the lady who is a community rep, she's participating to lead the direction of a new project because she's got a thing about sleep apnoea, and that's her agenda." Manager, Service C.

Participation in the state-managed services was reported to focus largely on existing clients – efforts to listen to community views typically entailed consulting clients who already used the service, for example through client surveys, rather than groups or individuals out in the community. No interviewees reported difficulties with finding community members who wanted to participate, and in one case with Community Foodies, community members' desire to participate outstripped the service's capacity. Staff at the two Aboriginal services in particular characterised their communities as "*thoughtful*" and "*engaged*". For Congress, this was a reflection of how Aboriginal community controlled services developed from the desire of Aboriginal and Torres Strait Islander peoples to have control over their health care. However, workers were well aware of who wasn't participating – the non-users of the service were not necessarily 'invisible.' For example, this practitioner was able to reflect critically on who the service wasn't engaging:

"There would certainly be areas that we could consult. Maybe dads is one area. We've started thinking about the fathers in the community, that often it's mums that we tend to work with, so hearing more from dads about what would be helpful ... newly arrived families or ATSI [Aboriginal and Torres Strait Islander] families." Practitioner, Service C.

A section on barriers to community participation was included in the web-based survey of staff (see Table 5). Consistent with the qualitative data from the interviews, the most commonly reported barriers to engaging in more community participation were budget constraints, and a lack of flexibility to respond to community wants and needs. Only nomination of budget constraints as a barrier varied significantly between Congress (39.6%), SHine SA (65.7%), and government services (61.3%),  $\chi^2(2, N=119) = 6.93$ , p = .031, though all of the standardised residuals were below 1.96, indicating no post hoc comparisons were significant.

# [Insert Table 5 about here]

#### Discussion

This research highlights the variety of ways community participation is being thought about and acted upon in Australian PHC services, ranging from consultation strategies such as satisfaction surveys through to community boards of management in Aboriginal Community Controlled Health Organisations. The strengths we found were service staff's positive attitudes towards the importance and utility of community participation, and the number and range of different strategies employed, including substantive strategies with clear empowerment goals and the structural participation evident at Congress. The Aboriginal Community Controlled sector has long been a leader of comprehensive PHC in Australia, and it is unsurprising that the community controlled service here exhibited the most structural participation. This concurs with the most recent review of community participation in PHC in Australia (Butler, 2002). Butler (2002) suggests that community participation has flourished more in Aboriginal health because of a greater willingness to allow for less mainstream solutions to Aboriginal health disparities, the compatibility of community control with the notion of self-determination, and a greater ability to define Aboriginal and Torres Strait Islander "communities."

The variety of approaches to community participation highlights the difficulty of building the evidence base for the health and other benefits of community participation, and the impossibility and undesirability of establishing a "replicable strategy" (Rifkin, 2009, p. 34; Zakus & Lysack, 1998) for participation. Instead, deeper understanding of commonalities and differences in participation strategies through the use of typologies such as those presented by Baum (2008) are a valuable tool which can aid classification, discussion, and synthesis of findings for different forms of community participation. The clarion call of realist evaluation, to examine what works, for whom, and in what circumstances is crucial in elucidating the mechanisms at work in the process of community participation, and the contextual factors that allow those mechanisms to work (Pawson & Tilley, 1997).

The main shortcomings we found were a pragmatic approach to participation that largely only included existing users of the service, and a weaker emphasis on substantive and structural participation strategies that typically have greater scope for empowerment. These shortcomings were particularly evident at the state managed services, and reflected a range of political and resource issues including incompatibility of such participation with a model of central control that allows little local flexibility.

While valuable in terms of improving service acceptability, the sole focus on existing clients raises a concern about what avenues exist to reach those who do not use the service. Workers were well aware that there were groups in the community who were underutilising their service, but lacked opportunities, largely due to lack of management support and resources, to include these groups in participation efforts. Yet without such participation, health service delivery is unlikely to make changes which would encourage utilisation by underserved groups who are likely to have high needs for PHC services.

The greater reliance on consultation or participation as a means rather than substantive or structural participation indicates the main goal of current participation efforts is improvement of service quality and acceptability, rather than empowerment. For such strategies, the terms of reference and final decision-making rested with the health services. Although five services also had examples of empowerment-focused substantive or structural participation, these tended to be less broadly inclusive strategies, where not all community members could participate (such as peer education programs targeting specific issues or populations). This moderate emphasis on less empowering strategies is consistent with the trajectory Butler (2002) describes in the history of community health in Australia, and suggests that only some progress is being made against the original conceptualisation of participation as being able to provide more control to the community, and include community voices in health service planning and decision making. This is consistent with Baum and Sanders' (2011) suggestion that the more political, progressive elements of PHC have not been fully implemented, and this is the case despite the SA State community participation policy and regional frameworks stating as an aim embedding participation in service practice, including collective participation in planning and delivery of services. One exception was Congress, for whom participation was strongly enmeshed with their advocacy efforts and commitment to self-determination.

Respondents perceived a range of benefits of participation, believing it could empower and provide a sense of ownership for community members, and improve the quality, utilisation and acceptability of services. Research supports these potential benefits: there is evidence linking participation with service efficiency and impact, and more limited evidence supporting the effect of participation on empowerment, health and wellbeing outcomes (Hossain, et al., 2004; Mansuri & Rao, 2013; Rosato, et al., 2008; Wallerstein, 2006). These findings complement broader research indicating the link between power and control, and health and wellbeing (Commission on Social Determinants of Health, 2008; Marmot & Wilkinson, 1999; Sen, 1999). The lack of difference in staff attitudes towards community participation across sites may be due to the strong shared history of community health in South Australia (Baum, 1995), and the emphasis of the community controlled sector on community participation for Congress. Participation through governing boards was seen by Congress and SHine SA respondents as having important benefits in terms of empowering the community and providing an opportunity for the service to be innovative and responsive. However, given the benefits cited for other forms of participation, we would echo Gauld's (2010) and Butler's (2002) call that participation in governance ought to be complemented by other forms of participation. This can be seen in the two non-government services, where a range of more specific consultation and participation strategies complemented the community board or governing council.

There was substantial support for community participation in state policy and regional frameworks, and staff attitudes towards community participation were very positive. However, we found little empowering community participation, especially in the state managed services,. The barriers limiting community participation in Australian PHC reported in the interviews and survey tended to focus on services' operating environment, such as budget limitations, centralised control with imposed rather than locally developed programs and less flexibility to respond to local needs, and an emphasis on the provision of individual, clinical care. This suggests a conflict between two policy foci – on one hand, an evident push towards more individual focused, centrally developed programs, often targeting chronic disease, and on the other, policies seeking to support community participation in decision making. The experiences of the staff at the state managed services indicate that the former direction is largely taking precedence, and this conflict may be one the greatest current impediments to community participation in PHC in Australia. It is likely that strengthening community participation in PHC can be supported by balancing the focus on individual treatment with more attention to population-wide strategies that aim to increase empowerment. Likewise the trend towards centralised control reported by respondents is not conducive to local program development nor supportive of health workers in conducting meaningful participatory strategies. Prior to 2004, the state managed services had community boards of management (Laris, 1995), and this local management was reported as more congenial to participation efforts (Butler, 2002; Laris, 1995). The examples from SHine SA and Congress here reinforce the importance of such boards in fostering a culture of community participation.

Tension was found between the principles of community participation and evidencebased practice. While there is literature on the potential for conflict between practitioner interests and agendas and those of community members (Nathan, *et al.*, 2011; Rifkin, 2009), there is little that provides guidance in terms of the 'evidence-based' health care movement and the extent to which that may compete or conflict with community participation. Some PHC services reported struggling to navigate this tension, and this may be one area where research could better support and guide PHC services. Realist evaluation may prove useful frameworks as they examine, interventions in their context (Pawson & Tilley, 1997). Thus context is part of the 'evidence', and community participation is one important means of gaining information on the local context.

# Limitations of the study

These findings are based on six case study services, and hence provide an in depth examination of community participation at the expense of being able to provide breadth in terms of the number of services surveyed. There was also little scope to examine the broader health system beyond the policy review and regional executive and central health department interviews. A comprehensive systems analysis of the impediments to community participation may help to further elucidate the current constraints on the achievement of participation, particularly in the state-managed sector where the organisational environment was reported as being more constraining.

With the exception of two interviews with board members, this study did not include community members' experiences of participation, and the extent to which community members found participating empowering, and what the costs, challenges, and benefits were for them is not explored here. Such questions are critical to evaluations of community participation initiatives.

Finally, the sample size for the web-based survey of staff was low (N=130), due to the low number of staff at some services (ranging from 13 to 130 staff eligible to complete the survey) and a response rate of 54%. This has reduced our power to find differences between services. The response rate of 54% raises the question of who didn't participate in the survey, and we would hypothesise that those most committed to comprehensive primary health care, including to the principle of community participation, may have been more motivated to

participate, and hence the sample could be seen as a 'best case' sample of those with the most positive attitudes.

#### Conclusion

Our mapping of current community participation practices in six Australian PHC services highlights important strengths, such as the wide range of participation strategies used, and the inclusion of some substantive and structural participation strategies with explicit empowerment agendas. Staff in this study argued that greater community participation can lead to more empowerment of individuals and the community, and greater accessibility and service acceptability for more disadvantaged and marginalised groups. If this was achieved, strengthening community participation may provide opportunities to support people's control over their health and reduce some of the disparity in the health of disadvantaged groups in Australia. However, the findings suggest that for community participation in Australian PHC to be strengthened further, the current emphasis on provision of individual services, particularly targeting chronic conditions at the expense of population-wide health promotion, and on central rather than local decision making need to be redressed.

# Acknowledgements

This research was funded by an NHMRC project grant (535041). FB is funded by an ARC Federation Fellowship. AZ is funded by an ARC Future Fellowship. We would like to acknowledge the staff of each participating service and thank them for their time and trust in allowing us to conduct research in partnership with them.

# References

- Arnstein, S. R. (1969). Ladder of citizen participation. *Journal of the American Institute of Planners*, 35, 216-223.
- Australian Commission on Safety and Quality in Healthcare. (2008). Australian charter of healthcare rights. Sydney, NSW: Australian Commission on Safety and Quality in Healthcare.
- Australian Government Department of Health and Ageing. (2009). Primary Health Care reform in Australia. Canberra: Commonwealth of Australia.
- Bartlett, B., & Boffa, J. (2001). Aboriginal community controlled Comprehensive Primary Health Care: The Central Australian Aboriginal Congress. *Australian Journal of Primary Health*, 7, 74-82. doi: doi:10.1071/PY01050
- Baum, F. (2008). The New Public Health (3rd ed.). Melbourne: Oxford University Press.
- Baum, F. (Ed.). (1995). *Health for All: The South Australian Experience*. Adelaide, SA: Wakefield Press.
- Baum, F., & Sanders, D. M. (2011). Ottawa 25 years on: a more radical agenda for health equity is still required. *Health Promotion International*, 26 Suppl 2, ii253-257. doi: 10.1093/heapro/dar078
- Botes, L., & van Rensburg, D. (2000). Community participation in development: nine plagues and twelve commandments. *Community Development Journal*, 35(1), 41-58. doi: 10.1093/cdj/35.1.41
- Boyce, W. F. (2002). Influence of health promotion bureaucracy on community participation:
  a Canadian case study. *Health Promotion International*, *17*(1), 61-68. doi:
  10.1093/heapro/17.1.61

- Butler, A. (2002). Consumer participation in Australian primary care: A literature review.Melbourne, Vic: National Resource Centre for Consumer Participation in Health, La Trobe University.
- Central Australian Aboriginal Congress. (2011). 2010/2011 Business Plan. Alice Springs, NT: Central Australian Aboriginal Congress.
- Central Northern Adelaide Health Service. (2005). Community and consumer participation framework. Adelaide, SA: Central Northern Adelaide Health Service.
- Central Northern Adelaide Health Service. (2008). Strategic intent 2009-2011. Adelaide: Central Northern Adelaide Health Service.
- Church, J., Saunders, D., Wanke, M., & Pong, R. (2002). Citizen participation in health decision-making: Past experience and future prospects. *Journal of Public Health Policy*, 23(1), 12-32. doi: 10.2307/3343116
- Commission on Social Determinants of Health. (2008). Closing the gap in a generation: Health equity through action on the social determinants of health. Geneva: World Health Organization.
- Dwyer, J. M., Lavoie, J., O'Donnell, K., Marlina, U., & Sullivan, P. (2011). Contracting for Indigenous Health Care: Towards Mutual Accountability. *Australian Journal of Public Administration*, 70(1), 34-46. doi: 10.1111/j.1467-8500.2011.00715.x
- Eckermann, A., Dowd, T., Chong, E., Nixon, L., Gray, R., & Johnson, S. (2010). *Binan* goonj: Bridging cultures in Aboriginal health (3rd ed.). Chatswood, NSW: Elsevier.
- Foley, G. (1982). Aboriginal Community Controlled Health Services: A short history. *Aboriginal Health Project Information Bulletin*, 2, 13-15.
- Gauld, R. (2010). Are elected health boards an effective mechanism for public participation in health service governance? *Health Expectations*, 13, 369-378. doi: 10.1111/j.1369-7625.2010.00605.x

- Government of South Australia. (2003). Better choices better health: Final report of the South Australian generational health review. Adelaide: Government of South Australia.
- Hossain, S. M. M., Bhuiya, A., Khan, A. R., & Uhaa, I. (2004). Community development and its impact on health: South Asian experience. *BMJ*, *328*(7443), 830-833. doi: 10.1136/bmj.328.7443.830
- Jewkes, R., & Murcott, A. (1998). Community representatives: Representing the "community"? Social Science and Medicine, 46, 843-858. doi: 10.1016/S0277-9536(97)00209-8
- Kahssay, H. M., & Oakley, P. (Eds.). (1999). *Community involvement in health development: A review of the concept and practice*. Geneva: World Health Organization.
- Laris, P. (1995). Boards of directors of community health services. In F. Baum (Ed.), *Health for all: The South Australian experience*. Kent Town, SA: Wakefield Press.
- Lavarack, G., & Labonte, R. (2008). *Health promotion in action: From local to global empowerment*. London: Palgrave Macmillan.
- Learmonth, M., Martin, G. P., & Warwick, P. (2009). Ordinary and effective: the Catch-22 in managing the public voice in health care? *Health Expectations*, 12(1), 106-115. doi: 10.1111/j.1369-7625.2008.00529.x
- Mansuri, G., & Rao, V. (2013). Localizing development: Does participation work? Washington, D.C.: The World Bank.
- Marmot, M., & Wilkinson, R. (1999). *Social determinants of health*. Oxford: Oxford University Press.
- Mason, J. (2002). Qualitative researching. London: Sage.
- Morse, J. N., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods, 1*, Article 2.

- NACCHO. (2011). NACCHO: An overview 2011. Canberra, ACT: National Aboriginal Community Controlled Health Organisation.
- Nathan, S., Johnston, L., & Braithwaite, J. (2011). The role of community representatives on health service committees: staff expectations vs. reality. *Health Expectations*, 14(3), 272-284. doi: 10.1111/j.1369-7625.2010.00628.x
- National Hospital and Health Services Commission. (1973). A Community Health Program for Australia. Canberra: AGPS.
- Oakley, P. (1989). Community involvement in health development: An examination of the critical issues. Geneva: World Health Organization.

Pawson, R., & Tilley, N. (1997). Realistic Evaluation. London: Sage.

- Rifkin, S. B. (2003). A framework linking community empowerment and health equity: It's a matter of CHOICE. *Journal of Health, Population, and Nutrition, 21*, 168-180.
- Rifkin, S. B. (2009). Lessons from community participation in health programmes: a review of the post Alma-Ata experience. *International Health*, *1*(1), 31-36. doi: 10.1016/j.inhe.2009.02.001
- Rifkin, S. B., Lewando-Hundt, G., & Draper, A. K. (2000). Participatory approaches in health promotion and health planning: A literature review. London, UK: Health Development Agency.
- Rosato, M., Laverack, G., Grabman, L. H., Tripathy, P., Nair, N., Mwansambo, C., et al. (2008). Community participation: lessons for maternal, newborn, and child health. *The Lancet*, *372*(9642), 962-971. doi: http://dx.doi.org/10.1016/S0140-6736(08)61406-3
- SA Health. (2009). Consumer and Community Participation Policy Directive. Adelaide, SA: SA Health.
- Sen, A. (1999). Development as freedom. New York: Knopf.

SHine SA. (2009). Strategic directions 2010-2013. Adelaide: SHine SA.

- South Australian Department of Health. (2010). Aboriginal Health Care Plan 2010-2016. Adelaide: Statewide Service Strategy Division.
- Southern Adelaide Health Service. (2005). Community and consumer participation framework. Adelaide, SA: Southern Adelaide Health Service.
- Southern Adelaide Health Service. (2009). Strategic plan 2009-2012. Adelaide: Southern Adelaide Health Service.
- Tesoriero, F., & Ife, J. W. (2010). *Community development: Community-based alternatives in an age of globalisation* (4th ed.). Frenchs Forest, NSW: Pearson Education.
- Tobin, M., Chen, L., & Leathley, C. (2002). Consumer participation in mental health services: Who wants it and why? *Australian Health Review*, 25(91-100). doi: 10.1071/AH020091
- Wallerstein, N. (2006). What is the evidence on effectiveness of empowerment to improve health? Copenhagen: WHO Regional Office for Europe.
- Wayland, C., & Crowder, J. (2002). Disparate views of community in Primary Health Care: Understanding how perceptions influence success. *Medical Anthropology Quarterly*, 16, 230-247.
- World Health Organization. (1978). Declaration of Alma-Ata, International Conference on Primary Health Care, USSR, 6-12 September. Alma Ata: World Health Organization.
- World Health Organization. (1986). Ottawa Charter for Health Promotion. *Health Promotion*, *1*(4), i-v.
- Zakus, J. D. L., & Lysack, C. L. (1998). Revisiting community participation. *Health Policy* and Planning, 13, 1-12.

	Type of participation				
Feature	Consultation	Participation as a means	Substantive participation	Structural participation	
Form it takes	Asking for people's opinions and reactions to policy plans.	Using participation to achieve a defined end.	People are actively involved in determining priorities and implementation but initiative externally controlled.	Participation as an engaged and developmental process in which community control predominates.	
Who initiates	Organisations outside the community.	Organisations outside the community.	Initiated by outsiders but may lead to structural participation in time.	Control by the community – initiative may have come from the outside initially but control will have been handed over.	
Features	Limited, usually one-off activity controlled by organisation	Instrumental. Lasts for the life of the initiative. Driven by outsiders. No shift in power. May lead to more developmental participation but this is not initial aim. Scope of activities limited to agenda of those initiating exercise.	Engaged and developmental. Active involvement. Despite this control, still outside the community. Will usually involve a shift in power to the community. Scope initially determined by those introducing initiative but may change over time.	Engaged and developmental. On-going relationship. Driven by community. Potentially empowering to individuals, organisation and community. Scope of activities as broad as the community wishes.	
Examples	Consultation on policies by federal government. Feedback surveys on quality of services.	Community panels for priority setting in health services.	Self-help groups initiated by community health centre staff. Community heart health programs working with local agencies.	Aboriginal-controlled health services. Victorian District Health Councils. Resident action groups.	

Baum's (2008) typologies of community participation, adapted from Oakley's (1989) continuum.

Table 1

	Approximate # of staff (FTE)	Budget (p.a.)	Main source of funding	Governance	Examples of disciplines employed
Service A	16 (13.5)	\$1.2m	SA Health	State funded and managed	Social worker, nurse, speech pathologist, occupational therapist, dietitian, cultural worker, lifestyle advisor
Service B	26 (20)	\$1.1m	SA Health	State funded and managed	Medical officer, lifestyle advisor, PHC worker, podiatrist, nurse, speech pathologist
Service C	36 (22)	\$1.7m	SA Health	State funded and managed	Nurse, dietitian, speech pathologist, psychologist, occupational therapist, cultural worker, social worker
Service D	12 (10.8)	\$0.5m	SA Health	State funded and managed	Aboriginal health worker, PHC worker
Congress	320 (188)	\$20m	Dept. of Health & Ageing	Aboriginal community controlled Board	Medical officer, psychologist, social worker, youth worker, midwife, nurse, Aboriginal health worker, pharmacist
Shine SA	100 (55)	\$6.1m	SA Health + Dept. of Health & Ageing	Non-government organisation with governing Council	Medical officer, nurse, counsellor, workforce educator, community health worker, disability worker, Aboriginal educator, multicultural worker

Table 2Characteristics of the six case study PHC services

Table 3

Forms of community participation reported at each service, grouped according to Baum's (2008) typologies

Service	Consultation	Participation as a means	Substantive participation	Structural participation
Service A	Client surveys Evaluation of programs	Consultation around new programs	Community foodies Volunteer run walking	
			group	
			Peer education programs	
			Community members	
			involved in running	
a i p			groups	
Service B	Client surveys	Consultation around new	Community foodies Outreach service	
		programs	provision based on	
			requests from	
			organisations in	
			community eg children's	
			centres	
Service C	Consultation around new	Consultation around new		
	building	programs		
	Client surveys	Parent groups convened		
	Evaluation of programs	for particular issues		
	Attendance at community			
	forum run by local			
Service D	government Verbal feedback, informal	Input into	Employment of	
Service D	consultation with clients	Input into agenda/activities for	Aboriginal workers	
	Evaluation of programs	groups and camps	Auonginai workers	
Congress	Complaints system and	Consultation around new	Taking community	Board of Management
	help to make complaints	programs	members to forums	
	Suggestion box	Cultural advisory	Employment of	
	Client surveys	committees	Aboriginal workers	
	Evaluation of programs		Engage community	

SHine SA	Client surveys Consultation with communities of interest	Consumer advisory panels Close the Gap reference committee	members in leadership roles Council Youth Action Teams Social action, health education, advocacy in response to expressed needs or requests Peer education program	
----------	--	---	--	--

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
Participation of community in the planning, delivery and evaluation of primary health care is important to the quality improvement of primary health care services	48.3%	44.0%	6.9%	0.9%	0.0%
The planning and operation of primary health care services are professional functions which should not be influenced by pressures from the community	3.5%	7.9%	14.9%	47.4%	26.3%

Table 4 Attitudes towards community participation in primary health care: Results of the web-based staff survey (n = 116)

# Table 5

Barriers reported to community participation in the web-based survey of staff (N =

# 119)

Potential barriers	% selected as barrier
	to community
	participation
Budget constraints	52.9%
Lack of flexibility to respond to community wants and needs	42.0%
Lack of staff/management knowledge and skills on community participation	41.2%
High workload	38.7%
Lack of community representatives on service management committee/board	37.8%
Lack of supporting policies	29.4%
Poor collaboration with community organisations	26.1%