Community Participation:
Collective and individual participation in public health and primary health care policy and service delivery

Background Paper

This paper provides background information to the PHAA Community Participation Policy Position Statement (2019), providing evidence and justification for the public health policy position adopted by Public Health Association of Australia and for use by other organisations, including governments and the general public.

Summary

Health and health care concern everyone and impact broadly on peoples’ lives. It is therefore a democratic right that individuals should be able to participate in decisions about their own health and health care, and that communities and citizens participate in decisions about health research, policy development and services. The Alma Ata declaration\(^1\) and the Ottawa Charter\(^2\) feature individual and collective participation as a key principle of public health services. More recently, the concept of ‘person-centred care’ has become broadly articulated.

Community engagement is generally effective in improving health behaviours, health outcomes, participant self-efficacy and perceived social support. For health services, participation may lead to increased quality, relevance and effectiveness. Barriers to participation centre on power, representation and resources/support. Current charters on health rights are individually focussed and are predominately about making complaints.

This background paper highlights the need for the following policy priorities:

- Political leadership. As the major policy makers and health service funders, governments have the responsibility and capacity to direct community consultation and participation as core values
- Health literacy and empowerment for individuals and communities is crucial in gaining informed participation in health service decision-making
- Driving cultural and organisational change through funding models and criteria, quality and standards, management understanding, leadership and support that mandate a participatory approach
- Education and professional development all medical and health professionals should include assessed topics on respect for, and empowerment of, patients, clients and local communities.
Public health issue

Health and health care concern everyone and impact broadly on peoples’ lives. It is therefore a democratic right that individuals should be able to participate in decisions about their own health and health care, and that communities and citizens participate in decisions about health research, policy development and services. People have the right and duty to participate individually and collectively in the planning and implementation of their health care in a collaborative way.¹

Community participation is a principle of comprehensive primary health care (PHC) in the Alma Ata Declaration² and a crucial feature of health promotion in the Ottawa Charter.² Participation as described in the Alma Ata covers a spectrum of ideas, including universal health care coverage, individual participation in clinical decision making, the mobilisation of community resources in the delivery of health care, and collective participation in the planning and implementation of health services.³

More recently, the concept of ‘person-centred care’ has become broadly articulated within health service planning and development. The World Health Organization (WHO) framework on integrated people-centred health services states that ‘Integrated people-centred health services means putting the comprehensive needs of people and communities, not only diseases, at the centre of health systems, and empowering people to have a more active role in their own health’.⁴

Health promotion, a key component of public health and primary health care, is the process of enabling people to increase control over and to improve their health. This empowerment process has been defined as ‘a social action process that promotes participation of people, organisations, and communities towards the goals of increased individual and community control, political efficacy, improved quality of community life, and social justice”.⁵

Increasing participation at individual and collective levels is therefore a key issue for public health advocacy.

Background and priority

As noted above the Alma Ata declaration and the Ottawa Charter feature individual and collective participation as a key principle of public health. In Australia, the 1973 Community Health Program established participation an important element of public health practice.⁶

Terminology

Discussing participation can be problematic in that it is a process that goes under a huge variety of terms, sometimes reflecting the level or type of participation, but often used interchangeably. This presents a challenge to participatory approaches to research, policy development and service planning. Terms used in the participation literature include:

<table>
<thead>
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<th>Individual</th>
<th>Individual or collective</th>
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<tr>
<td>self-management</td>
<td>participation</td>
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<tr>
<td>patient-centred</td>
<td>consultation</td>
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<td>person-centred</td>
<td>empowerment</td>
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<td>patient-driven</td>
<td>involvement</td>
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<td>self-care</td>
<td>engagement</td>
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¹ Alma Ata Declaration
² Ottawa Charter
³ Alma Ata Declaration
⁴ World Health Organization (WHO) framework on integrated people-centred health services
⁵ World Health Organization (WHO) framework on integrated people-centred health services
⁶ 1973 Community Health Program
In this paper we use the terms ‘individual participation’ or ‘collective participation’ unless referring to a more explicit mode of engagement.

**Types of participation**

Different terminology may reflect different degrees or perspectives of participation. A number of commentators have constructed hierarchies or typologies in order to tease out these differences.

Arnstein’s (1969) ladder is one of the first to describe and analyse different levels of participation in terms of power distribution.\(^7\)

<table>
<thead>
<tr>
<th>Citizen power</th>
<th>Citizen control</th>
<th>Delegated power</th>
<th>Partnership</th>
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<tr>
<td></td>
<td>Citizens direct planning, policy making and managing a programme with no intermediaries to the source of funds.</td>
<td>Citizens holding the majority of seats on committees with delegated powers to make decisions. Public has the power to assure accountability of the program</td>
<td>Power is redistributed through negotiation between citizens and power holders. Planning and decision-making responsibilities are shared</td>
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<tr>
<td>Tokenism</td>
<td>Placation</td>
<td>Consultation</td>
<td>Informing</td>
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<td>Non-participation</td>
<td>Therapy</td>
<td>Manipulation</td>
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Oakley (1989) argued that community participation can be seen as a mean or as an end.\(^8\) In participation as means, community input is used to improve service quality, and the parameters are controlled by the health service. The focus is on a short-term exercise with a defined goal and tasks. Participation as an end is dynamic and unpredictable, providing community participants with more control and scope to effect changes.

Baum (2008) modified Oakley’s depiction to reflect contemporary typologies of participation:\(^6\)

- Structural participation: participation as an engaged and developmental process, community control predominates, ongoing, potentially empowering
- Substantive participation: community actively involved in determining priorities and implementation, but external control remains, may lead to shift in power over time
- Participation as a means: using participation to achieve a defined end, for example, increasing attendance and compliance within a program, no shift in power, driven by organisation
Consultation: asking for people’s opinions and reactions to policy plans, for example, feedback surveys, limited one-off and controlled by organisation.

In all these typologies the main focus is on the purpose of the participation and the degree of power and control redistribution.

**Participatory Action Research**

Participatory Action Research (PAR) is a specific case where participatory approaches are applied to research. PAR differs from other research by seeking to understand and improve the world through action. Researchers and participants undertake collective, self-reflective inquiry in order to understand and improve upon the practices in which they participate and the situations in which they find themselves. PAR aims to address the power differences between the researcher and the researched. The researched cease to be objects and become partners in the research process. This has similarities to structural participation where power differences between lay people and those in control are minimised.

**Benefits of participation**

A 2013 systematic review of community engagement found that interventions are generally effective in improving health behaviours, health outcomes, participant self-efficacy and perceived social support for disadvantaged groups. Benefits may flow across the system, service or organisation and the participants. There also appear to be gains to human and social capital.

For health services, participation may lead to increased quality, relevance and effectiveness. For example, Oakley (1991) describes some organisational benefits of participation:

- **Efficiency:** people are more likely to be convinced of the benefits of an initiative they have helped to develop, may reduce time needed by paid professionals
- **Effectiveness:** people have a voice and contribute local knowledge and skills
- **Sustainability:** external initiatives frequently fail to be sustained, where local people are the main dynamic chance of sustainability increases.

For the participants, benefits may include helping to overcome powerlessness by increasing self-esteem, control and empowerment. Oakley (1991) suggests participation increases self-reliance, leading to community development, reducing dependency, increasing sense of control and helping to create social capital. Other benefits for participants may include skills acquisition, future employment and improved perceived social support.

In terms of participation in health policy, engaging consumers and communities in policy development and advocacy work means that the opinions and perspectives of the public can play a valuable role in developing high-quality, evidence-informed policy. The legitimacy and sustainability of primary health care policy decisions depends on how well it reflects the underlying values and views of the community.

Also, engaging consumers and communities in policy work may lead to an increased level of public trust and confidence in the health care system.
Barriers to participation

Barriers to participation centre on three main issues: power, representation and resources/support:

Power

Since high level community participation involves a shift in power and control it can be perceived as a threat to entrenched power such as that assigned to health professionals working under the medical model. Participation as a means maintains power within the hands of the professional, whereas a more developmental approach involves professionals working in partnership with lay people. Working under this model means professionals need to give up their traditional authority and recognise the value of lay knowledge.14

Strategies to achieve active community participation in the development of health policy, health services and individual care need to recognise the often disempowered nature of people’s relationships with health care providers in a health system that is highly complex and confusing for people. This requires support for building the capacity of persons to be actively involved in making decisions about their own health and health care.15

Representation

Communities are not homogenous, harmonious entities that can easily be represented.16, 17 Hence, selecting who participates and has the job of representing a community is a significant consideration.18, 19 Critical questions include: who is represented, and which elements of the community are not represented? Often the least powerful in a community are the least likely to participate.

Rather than expecting one person to represent a whole community, individuals can represent a constituency formed by their own networks and links within the community.6

Support and resources

Capacity building and support for community members is crucial. Poor health literacy is a critical barrier to engagement and has a large impact on people’s capacity to access, understand, appraise and apply information concerning health and wellbeing. Only about 40% of adults have the level of individual health literacy they need to be able to make well-informed decisions and take action about their health.20

Training and support should be available to assist community members to understand the system or service bureaucracy and to contribute meaningfully. Reimbursement for meetings and meeting preparation times indicates that lay people’s time is valuable and appreciated.

Health literacy is not only about the capacity of individuals but also the organisational environment. This includes the systems, processes, people, information and practices that make up the health and health care industries and sector.21 The health system and health services need to develop an organisational culture that welcomes and supports participation. Adequate resources and support are needed to undertake participatory activities. Health practitioners and policy makers may need training in using a participatory approach as this is seldom included in professional education.6, 22
Current situation

According to a recent report by the Consumers Health Forum of Australia, policy makers and service developers are placing increased value on lived consumer experience. Demand for consumer representatives on committees and forums is growing and terms such as ‘consumer centred care’ and similar are widely used in policy and planning documents. Health service accreditation standards increasingly have criteria around patient engagement as do research funding programs. However, the extent to which this translates into effective practice varies. For example, consumer and community representation is required for Primary Health Networks and Local Hospital (Health) Networks but the way this is implemented across jurisdictions is inconsistent.

The Australian Charter of Healthcare Rights
The Australian Charter of Healthcare Rights describes the rights of patients and other people using the Australian health system. The Charter states that “A genuine partnership between patients, consumers and providers is important so that everyone achieves the best possible outcomes.” One right is directly relevant to participation: “Participation: I have a right to be included in decisions and choices about my care”. The guide for patients explains participation thus: “You are encouraged to participate in decisions about your care. Ask questions if you are unsure about what is happening to you. Involve your family or carer if this makes you more comfortable and sure”. Clearly the Charter is focussed on individual rather than collective participation and seems to suggest patients need to be active in asking for information about their care rather than expecting it as a right. Advice to health care providers is in the same vein suggesting that the patient or consumer and/or carers should be engaged in discussions about treatment options. While States and Territories have their own health rights commissions these are also individually focussed and are predominately about making complaints.

Patient stories
It has been noted that, in contrast to more commonly gathered forms of evidence about health service and system performance (such as statistical measures of clinical safety and effectiveness, and surveys of patient experience), a more comprehensive picture and in-depth understanding of service user experiences can be obtained by supplementing this information with qualitative data. This allows organisations to better and more fully understand patients’ concerns and generate appropriate action plans to improve user experiences. People’s stories about their health experiences can provide detailed information about ‘whole of life’ and ‘whole of system’ experiences of health and health care. For example, consumer narratives can highlight what matters most to people about the health care they receive (or are not able to access); their experiences of continuity (or discontinuity) in care; the relationship that exists between the health services they receive and their health outcomes; and the importance of policies, services and experiences that sit outside of the health system, but which powerfully shape health status and outcomes. Stories allow people to provide their perspectives on what changes would improve their own, and others’, health experiences and outcomes.

Collective participation
As noted above, Australian health rights legislation is individually focussed. The right to collective participation and action relating to health policy and health service provision is mostly limited to invitations to community groups to make submissions and at the ballot box. The Consumers Health Forum does provide consumer representation on national strategic committees and most States and Territories have a ‘health consumer alliance’ or similar organisation.
However, funding can be precarious, and the focus tends to be on hospital care. Some have written community engagement frameworks and guidelines, but it is unclear to what extent these are taken up by governments and services. Overall, there is a lack of opportunity for day-to-day community input into health policy and service provision.

**Aboriginal community-controlled health services**

Aboriginal community-controlled health services provide a model for primary health care where power is explicitly vested in local communities. Aboriginal community-controlled health services provide comprehensive primary health care, through community governance, and the funding of the service through block grants enabling untied funds to provide diverse services to meet community needs based on the leadership of the board. This ensures access to health promotion, allied health, dental and other services and determined by the local community.

Such models should be considered as a way to increase the level of local community participation and have the potential to improve the health of individual people and the community as a whole. Other community-based health services and women’s health services also provide examples of successful models for achieving community participation and commitment.

**Participation by vulnerable populations**

Being an active and empowered participant in one’s own health care or in collective action requires resources, skills and capacity. The CHF and other state-based organisations provide some training and support for consumer representatives. For some population groups, structural and cultural issues can make participation more difficult. For example, the traditional male dominated, western approach to medicine and health care presents barriers to Indigenous Australians, many migrants, older people and women. Individuals and communities living in poverty or with mental illness will seldom have the resources to be engaged in community action while struggling with everyday life. This means that representation of these vulnerable groups can be problematic and special efforts will be needed to gain a broad range of perspectives.

**Using participatory data**

Most of the literature on participation focuses on its use in improving the quality of health care. Despite data on patient experience being increasingly collected worldwide, there are still questions regarding how it is used to improve health care quality. It has been argued that health care organisations focus on collecting data rather than using the information to improve service quality. Further, little effort has gone into how to understand and use patient experience data to increase the responsiveness of a health care organisation to the needs of its clients. While the literature identifies the value of consumer narratives, it remains relatively uncommon for health services and health policy agencies to gather and use this information in a systematic manner.
Policy options

This background paper highlights the need for the following policy priorities:

**Political leadership**

Federal and State and Territory governments have an important role in setting the standard for genuine community engagement. As the major policy makers and health service funders, governments have the responsibility and capacity to direct community consultation, engagement and participation as core values.

**Increasing health literacy and empowerment**

Increasing health literacy for individuals and communities is crucial in gaining informed participation in health service decision-making. Health and wellbeing are complex issues, under the jurisdiction of different levels of government, with public and private service providers and often surrounded by technical terminology and professional jargon. When people are sick, or in need of a service, they are likely to be at their most vulnerable.

**Driving cultural and organisational change**

Mechanisms for driving change include:

- funding criteria for services and research that mandate a participatory approach including adequate time frames and support for community consultation
- quality and standards criteria that include KPIs for engagement and participation at all stages of planning, implementation and evaluation
- management understanding, leadership and support for development of a participatory approach

Aboriginal community-controlled health services provide a successful model for community participation and this approach could be used more broadly.

**Education and professional development**

Education of all medical and health professionals should include assessed topics on respect for, and empowerment of, patients, clients and local communities. The value of lay knowledge and patient stories needs to be recognised. Ongoing professional development should also further upskill health professionals in using participatory approaches.

**Recommended action**

The Public Health Association of Australia strongly advocates with governments, policy makers, health care providers, universities, other organisations and the general public for the implementation of these policy priorities.

Governments, policy makers, health care providers, universities and other organisations take urgent steps to increase the extent and effectiveness of individual and collective participation in line with these policy priorities.

ADOPTED September 2019
References


