

Community Participation in Primary Health Care

Policy Position Statement

Key messages:

Health and health care are of fundamental importance to people. It is therefore a democratic right that every person should be able to participate in decisions about their own health and health care services and the decision-making processes that determine health research and policy development.

The 1978 Alma Ata (now Almaty) Declaration highlighted community participation as a foundational approach to improving health for all. Community engagement can positively influence an individual's health outcomes and behaviours, self-efficacy and social support.

Community participation in healthcare decision making may be impeded by power inequities; a lack of representation; limited health literacy; and lack of community participation training for policymakers.

Historically, charters on health and healthcare rights have been service-orientated, individual focused, and centred on complaints. The ongoing development of comprehensive healthcare charters that have a person-centred focus, are supported.

Key policy positions:

Governments have the responsibility and capacity to embed community consultation and participatory approaches as core values in primary health care service delivery.

Strategies are needed to strengthen health literacy of individuals and the community. Informed decision making are foundational for health equity.

To firmly establish a community participatory approach in health care, cultural and organisational changes are required.

Enhance health professional respect for the power that resides in people and communities. Develop health professional understanding of community participation in primary health care decision-making.

Audience:

Consumer groups; Governments, policymakers and program managers; Aboriginal community-controlled health organisations; primary health care non-government organisations, including general practices; PHAA members; and the media.

Responsibility:

PHAA Primary Health Care Special Interest Group (PHC SIG)

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Community Participation in Primary Health Care

Policy position statement

This position statement should be read in conjunction with the background paper titled *Community Participation in Primary Health Care - Background Paper*.

PHAA affirms the following principles:

- 1. Health and health care are of fundamental importance to people and communities. It is therefore a democratic right that every person should be able to participate in decisions about their own health and health care, and that individuals and communities and are involved in the decision-making processes that determine health research, policy development, and services.
- 2. The Almaty Declaration¹ and the Ottawa Charter² feature individual and collective participation as key principles of public health. Participation covers a spectrum of ideas, including 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
- 3. Concepts of participation can be problematic, as it is a process comprising of variable definitions and understandings. A wide range of terminologies are used, often interchangeably, with some reflecting the level or type of community involvement in the participatory processes. This presents a challenge to understanding approaches to research, policy development, and service planning. A contemporary typology of participation includes:
 - Structural participation participation as an ongoing, engaged, and developmental process where community control predominates. The agency capacity of individuals and communities is developed though this type of participation.
 - ii. Substantive participation community actively involved in determining priorities and implementation, but external control remains; may lead to a shift in power over time.
 - iii. 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.
 - iv. *Consultation* asking for people's opinions and reactions to policy plans, for example, feedback surveys; often involving a limited, one-off approach, and controlled by the organisation.⁴
- 4. The use of co-design to construct, implement and evaluate primary health care activities, products, and services, fosters the person-centred approach to care. Spanning the range of the participatory typology, co-design involves an equal partnership between consumers, carers, health professionals, service staff and researchers, to generate new knowledge and ideas. Working with respect, trust and empathy, the approach is characterised by open communication. Using co-design, stakeholders share ownership and control of the change process, learn from each other, and build health systems together.⁵

PHAA notes the following evidence:

- 5. Community engagement interventions are effective in improving health behaviours, health outcomes, individual and community self-efficacy, and social support for disadvantaged groups.^{6,7}
- 6. Individual and community participation in the design and delivery of health services, may lead to increased quality, relevance, effectiveness, and sustainability.⁶
- 7. Promoting 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 a wide range of public and private service providers, and often communicated by using technical terminology and jargon. When people are sick, or in need of a service, they may be at their most vulnerable.
- 8. Increased self-reliance, skills acquisition, future employment and improvements in social support are benefits to the individual of community participation. For the wider community, participation may lead to community development and help to increase social capital. Engaging individuals and communities in health policy development and advocacy work, validates their role in contributing knowledge and understanding to the co-creation of high-quality, evidence-informed policy. This, in turn, increases the level of public trust and confidence in the health care system.
- 9. Aboriginal community-controlled health services provide a model for primary health care where power is explicitly vested in local communities. These health services provide comprehensive primary health care, through a community governance framework. Service funding through block grants allow the untied funds to provide a diverse range of services, specifically designed to meet the health needs of the local community. Further, Aboriginal community-controlled health organisations provide strong leadership in the delivery of culturally safe healthcare, providing guidance for other health services in their approach to care.
- 10. Barriers to community participation centre on four fundamental issues:
 - Power inequities working in a partnership model means health professionals and policymakers need to reassess their traditional authority and recognise the value of personcentred knowledge.¹¹
 - ii. Lack of representation and shared identity harmonious entities can more easily be represented, however communities are not homogenous. Hence, selecting who participates and has the job of representing a community is a significant consideration. Shared identity is closely linked to representation and involves how communities are defined and structured. Increasing rates of immigration, migration between rural/remote and urban areas, and people living in social isolation, are factors that may inhibit a community's shared understanding of their identity, hindering community participation in healthcare.
 - iii. Health literacy challenges poor health literacy impacts people's capacity to access, understand, appraise, and apply information concerning their 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.¹⁵ In addition, eHealth literacy is an emerging challenge, as the use of technology in health care continues to grow.
 - iv. *Insufficient training* without sufficient training in using participatory approaches to decision-making in health and healthcare, health practitioners and policymakers are unable

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to commit to the necessary process. Initial and ongoing training for health professionals and policymakers, as part of their professional education, is required.^{4, 16}

11. Implementation of strategies that align with this policy position statement would contribute towards UN Sustainable Development Goals 3 – Good Health and Wellbeing and 10 – Reducing Inequalities.

PHAA seeks the following actions:

- 12. Federal, State and Territory governments must set the standard for genuine community participation in health and health care service decision-making. Major policymakers and health service funders must support and mandate community consultation, engagement and participation as core values in primary health care organisations and play a leadership role in implementation.
- 13. Encourage the continued development of health care charters that promote a person-centred focus to the delivery of health services.
- 14. Advocate for further investment in community-based strategies to reduce social isolation.
- 15. Promoting a plain language health system, with reduced jargon and technical terminology.
- 16. Promote person centred systems and services, to enable easier navigation within and across health services, using technology that is fit-for-purpose.
- 17. Mechanisms for cultural and organisational change include:
 - i. funding models and criteria for services and research that mandate a participatory approach including adequate time frames and support for community consultation.
 - ii. quality and standards criteria that include key performance indicators (KPIs) for engagement and participation at all stages of planning, implementation, and evaluation.
 - iii. management understanding, leadership, and support in the development of a participatory approach.
 - iv. supporting the diverse needs of individuals, communities, decision makers and health care teams involved in the participatory approach; this includes strengthening the cultural, economic, and technological capacity of organisational systems and services.
 - v. adopting the Aboriginal Community-Controlled Health Service model more broadly.
- 18. Call for improvements in educating health professionals and policymakers on the value of personcentred knowledge, and recognising, acknowledging, and respecting people and community power.
- 19. PHAA will advocate for ongoing health professional development to upskill community participatory approaches.

PHAA resolves to:

20. Advocate with people and communities, governments, policymakers, health care providers, universities, and other primary health care organisations for the implementation of these policy priorities, to increase the extent and effectiveness of individual and collective participation in health and health care decision-making.

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