

## Reconceptualising community participation in primary health

Internationally, there is a push to involve communities and community members in all stages of healthcare design, delivery and evaluation. Proponents argue that, by involving community members, self-determining empowered communities will emerge and contribute to locally responsive healthcare delivery and improved health outcomes. Critics of the community participation agenda cite neoliberal underpinnings and argue that shifting the responsibility to ordinary people is an attempt to absolve the responsibilities of the State. In these debates, there is, of course, always a middle ground. It is clear that the idealised notion of actively engaged, well-behaved community members, passionate about shaping primary healthcare, is far from reality. When the public do become involved in driving healthcare, many within the health system are pushed into a very uncomfortable space.

When discussing and operationalising the notion of community participation, many fall back on the tokenistic consumer on an advisory board or the advisory board of community members who offer advice, but have little direct power in decision making. Well-meaning people seek ways to engage with the ‘hard to reach’. Few step back and question whether it is the health system and health professionals that are hard to reach.

On a recent trip to a Canadian conference it was intriguing to be introduced to a person who was described as ‘our patient’. The person’s name was not used and there was a lack of acknowledgement that everyone in the room would interact with the health system at some point. The description of the person as ‘the patient’ came from a well-meaning and genuine place, but it highlighted the struggle that we have to really understand how the public should be involved in primary healthcare design, delivery and evaluation; for what purpose and for what outcomes.

In this special issue many of the advantages, challenges, issues and quandaries in the community participation space are highlighted. Pagatpatan and Ward (2017) describe their realist synthesis approach to critical analysis of the concept of ‘effective’ public participation, and they examine the factors that make public participation effective. In this article, questions are asked about the techniques of public participation and whether people must only engage in methods developed and driven by those in the health system. The ability of those in positions of power to listen to the public is questioned. Farmer *et al.* (2017) emphasise the importance of differentiating between types of participation and identifying those accountable for outcomes.

Case studies of Primary Health Networks (PHN) and their engagement with consumers are presented in the papers by McClean and Trigger (2017) and Blignault *et al.* (2017). We pondered whether there are examples where Community Advisory Councils have directly affected PHN outcomes and whether decisions and actions were evaluated to see if primary health services were improved. These articles prompted us to have

a robust discussion about whether there is greater opportunity for Community and Clinical Advisory Councils to work together in co-design and co-production activity. The disparate operation of these groups prompts the question, are those in the health system really ready to participate?

Kelly *et al.*’s (2017) description of co-creation of patient journey mapping tools is an interesting example of people with different but complementary expertise working together. The need for different but complementary expertise is reinforced by the work of Guzys *et al.* (2017). In their study they challenge the emphasis on fiduciary responsibilities in boards and advisory committee’s and reinforce the fundamental importance of participation by directors or advisory committee members who have strong understanding of health and community needs and who use this knowledge in decision making.

Pagatpatan and Ward (2017) highlight that effective participation in policy making is characterised by political commitment, partnership synergy, inclusiveness and deliberativeness. There are examples of these factors in this special issue. A study by Bovill *et al.* (2017) on the design of a culturally responsive smoking intervention for Aboriginal mothers, provides new insights on these. Spurling *et al.* (2017) reinforces how investigator driven research may represent ‘an extension of colonial control’ and that much can be learned by asking people about their priorities. The theme of participation and research priority setting is picked up by Ball *et al.* (2017).

Hesson *et al.* (2017) argue that parents are rarely involved in the development of child and family services and stresses the importance of timely, integrated, continuous participatory mechanisms driven by consumers. In reading this article, we thought about the concept of defensive reasoning, where those working in primary health may engage in defensive behaviours when their work or views are challenged. There is a need to support those in the health system to accept and better respond to the views of those interested in or accessing primary care.

We have really enjoyed reading the papers in this special edition and it has challenged us to think in new and different ways. This issue made us wonder where we sit on the spectrum between zealous promotion of community participation, as almost a panacea to the woes of primary healthcare delivery, and the neoliberal cynicism that sees community participation as a transfer of responsibility to communities who are expected to have the capacity and willingness to participate, often with no funding and no support.

Perhaps we have a slightly utopian view, but when thinking about wicked challenges in primary health, we argue that siloed thinking that perpetuates the notion of groups of consumers and groups of primary health professionals working independently, or the tokenistic consumer in an advisory capacity, represents a missed opportunity for working together. Real gains will only be achieved when we push the agenda and reconceptualise

community participation as all members of the community and remove the siloed boundaries between those who work in the primary health system and those who experience it.

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## References

- Ball L, Barnes K, Leveritt M, Mitchell L, Williams LT, Ball D, Patterson E (2017) Developing research priorities in Australian primary health care: a focus on nutrition and physical activity. *Australian Journal of Primary Health* **23**, 554–559. doi:[10.1071/PY16068](https://doi.org/10.1071/PY16068)
- Blignault I, Aspinall D, Reay L, Hyman K (2017) Realisation of a joint consumer engagement strategy in the Nepean Blue Mountains region. *Australian Journal of Primary Health* **23**, 531–535. doi:[10.1071/PY16103](https://doi.org/10.1071/PY16103)
- Bovill M, Bar-Zeev Y, Gruppetta M, O'Mara P, Cowling B, Gould GS (2017) Collective and negotiated design for a clinical trial addressing smoking cessation supports for Aboriginal and Torres Strait Islander mothers in NSW, SA and Qld – developing a pilot study. *Australian Journal of Primary Health* **23**, 497–503. doi:[10.1071/PY16140](https://doi.org/10.1071/PY16140)
- Farmer J, Taylor J, Stewart E, Kenny A (2017) Citizen participation in health services co-production: a roadmap for navigating participation types and outcomes. *Australian Journal of Primary Health* **23**, 509–515. doi:[10.1071/PY16133](https://doi.org/10.1071/PY16133)
- Guzys D, Threlkeld G, Dickson-Swift V, Kenny A (2017) Rural and regional community health service boards: perceptions of community health – a Delphi study. *Australian Journal of Primary Health* **23**, 543–548. doi:[10.1071/PY16123](https://doi.org/10.1071/PY16123)
- Hesson A, Fowler C, Rossiter C, Schmied V (2017) 'Lost and confused': parent representative groups' perspectives on child and family health services in Australia. *Australian Journal of Primary Health* **23**, 560–566. doi:[10.1071/PY17072](https://doi.org/10.1071/PY17072)
- Kelly J, Dwyer J, Mackean T, O'Donnell K, Willis E (2017) Coproducing Aboriginal patient journey mapping tools for improved quality and coordination of care. *Australian Journal of Primary Health* **23**, 536–542. doi:[10.1071/PY16069](https://doi.org/10.1071/PY16069)
- McClellan J, Trigger K (2017) Not just tea and biscuits; the Gold Coast Primary Health Network process of designing, implementing and operating a Community Advisory Council. *Australian Journal of Primary Health* **23**, 504–508. doi:[10.1071/PY16157](https://doi.org/10.1071/PY16157)
- Pagatpatan CP, Ward PR (2017) Understanding the factors that make public participation effective in health policy and planning: a realist synthesis. *Australian Journal of Primary Health* **23**, 516–530. doi:[10.1071/PY16129](https://doi.org/10.1071/PY16129)
- Spurling GK, Bond CJ, Schluter PJ, Kirk CI, Askew DA (2017) 'I'm not sure it paints an honest picture of where my health's at' – identifying community health and research priorities based on health assessments within an Aboriginal and Torres Strait Islander community: a qualitative study. *Australian Journal of Primary Health* **23**, 549–553. doi:[10.1071/PY16131](https://doi.org/10.1071/PY16131)