Assessing and developing community participation in primary health care in Aotearoa New Zealand: a national study

Pat Neuwelt, Peter Crampton, Sue Crengle, Kevin Dew, Anthony Dowell, Robin Kearns, David Thomas

Abstract

Aims. This study aimed to develop and test a framework and tool for assessing and developing community participation in Primary Health Organisations (PHOs) in New Zealand.

Methods. A qualitative study completed in three phases: semi-structured interviews with 42 key stakeholders in the primary care sector; development of and consultation on a draft toolkit, which included a PHO review process; and piloting the toolkit in four different types of PHOs.

Results. A toolkit entitled *Community Participation: A Resource Kit and Self-Assessment Tool for PHOs* (CP Toolkit for PHOs) was developed, which contains a set of resources for organisational self-review and a framework for community participation under the six headings: Organisational Structure, Maori Responsiveness, Governance and Management Processes, Use of Resources, Links to the Wider Community, and Consultation & Decision-Making. The pilot PHO sites found the CP Toolkit, and the review process contained within it, to be very relevant to the implementation of the Primary Health Care Strategy at a PHO level.

Conclusions. The Community Participation Toolkit for PHOs complements existing quality tools available for clinical general practice and nursing, and supports the further development of primary health care in New Zealand.

Consumer and community involvement in the planning and delivery of health care is core to the original concept of primary health care, as defined in the Alma Ata Declaration.¹ Primary health care is essential health care based on practical, scientifically sound and acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination.

The Declaration was the response of the World Health Organization, and its international delegates, to the failure of hospital-centred health care to provide for the basic health care needs of the rural poor in developing countries. It recognised the success of early grassroots primary health care initiatives in South Africa and other developing nations.²,³ These initiatives had demonstrated the positive impacts on access, appropriateness, and affordability of involving people in planning their own local health services.²–⁴
Many rationales underlie the involvement of consumers and communities in the planning and delivery of health care—although in health policy, these rationales are often implicit. Arguments for participation include the legitimation of policy, the improvement of service appropriateness, the redistribution of resources, and the reduction of inequalities in health.\(^5\) A fundamental justification in New Zealand is found in the Treaty of Waitangi, which defined political participation as a right of the Treaty partners, Maori as tangata whenua, and the Crown.\(^6\) There is evidence that community participation in health organisations is ineffectual, unless the organisation has individuals within it who are committed to learning and open to change.\(^7\)

There are few rigorous studies that have measured the effects of community participation in terms of health outcomes; however there is evidence of service improvement. A systematic review of the evidence related to involving patients in the planning and development of health care concluded that involving patients contributes to changes in service delivery in several ways across a range of settings.\(^8\) Changes include an improvement of patient information sources and access to services (such as simplified appointment procedures, extended opening times, and improved physical access for people with disabilities) as well as the development of new services (such as advocacy, employment initiatives, and crisis services).

Third-sector (non-government and non-profit) primary care organisations in New Zealand and USA are more likely than private general practices to have community involvement in their governance.\(^9\) Research into third-sector services provides indirect evidence concerning the effects of community involvement.

In New Zealand, community-governed third-sector primary care organisations have been found to serve largely non-European and low-income populations,\(^10\) to have comparatively low user-charges, and to employ large numbers of Maori and Pacific staff.\(^11\) Similarly, the achievements of community-governed third-sector community health centres (CHCs) in the USA in improving access to care for vulnerable populations, providing high-quality primary care, improving health outcomes, and reducing health inequalities have been well documented.\(^12\)

Until recently, consumer and community participation in primary care organisations had been a reality for only a small proportion of providers in New Zealand.\(^13\) It became an explicit part of government policy with the advent of New Zealand’s Primary Health Care Strategy\(^14\) and the emergence of Primary Health Organisations (PHOs) in 2002, as demonstrated in the following statements:

- **PHOs must demonstrate that their communities, iwi, and consumers are involved in their governing processes and that the PHO is responsive to its community.\(^15\)**
- **The DHB must be satisfied that community participation in PHO governance is genuine and gives the communities a meaningful voice. In addition, DHBs will require PHOs to show how they respond to their communities.\(^16\)**

The implementation of this aspect of the Primary Health Care Strategy has proved challenging not only for many PHOs but also for District Health Boards (DHBs), charged with PHO contracting. While many third-sector primary care organisations have experience at successfully implementing community governance models, community involvement is largely foreign to the for-profit model of general practice, which has been mainstream in New Zealand.
In an environment of privately owned general practice, it is not easy for primary care providers, or even contractors, to adopt a culture that acknowledges the contributions of consumers and communities to health service planning and delivery. From both theoretical and practical perspectives, community involvement in governance challenges the ownership boundaries inherent in a business model.  

Despite clear government policy aimed at introducing community participation in the governance of PHOs, there has been a notable absence of frameworks and tools to aid PHOs in engaging with the communities they serve. This project aimed to develop a framework for assessing and developing community participation in PHOs, and to produce a toolkit for PHOs which would be a practical resource for primary care providers.

**Methods**

The research project was undertaken using qualitative methodology. Sampling was purposive, with the aim of collecting a diverse sample of key stakeholders from different levels of the primary care sector throughout New Zealand. Initially a snowballing technique was used, beginning with people known to the researcher (PN), followed by heterogeneity sampling for assumed diversity of views. The three key factors sampled for were role in the sector, ethnicity and geography.

In Part 1, participants were asked their views on, and experience of, community involvement in primary care organisations and how one might assess it. In Part 2 and Part 3, the role of participants was principally to offer feedback on the draft toolkit for PHOs.

Data collection was by in-depth semi-structured individual and group interviews; however a written feedback form was used in Part 2 for the toolkit consultation. Nearly all participants were interviewed face-to-face, with a few by telephone. All interviews were audiotaped (with the consent of participants) and subsequently transcribed. All Part 1 participants were sent their own transcripts for correction or comment.

Transcripts of the audiotapes were analysed with the help of NUD*IST qualitative analysis software (N6 version) to manage and code the data. Data analysis involved using a constant comparative method, in which transcripts are repeatedly reviewed to find emergent themes, consistent with a general inductive approach. The framework for the community participation toolkit (made up of a series of process indicators) was developed from these themes.

The research was organised around three parts, each with its own method and sample. These three parts are described below.

**Part 1—Interviewing key stakeholders in the primary care sector:**

- Completion of individual interviews (N=26) and focus groups (N=3) with key stakeholders in the primary care sector (Table 1).

- Development of a draft toolkit for assessing community participation in primary health care organisations, based on the literature and interview data.

**Table 1. Part 1 participants by role, ethnicity, and geography (N=42)**

<table>
<thead>
<tr>
<th>Role in the sector</th>
<th>Ministry of Health, district health boards, general practice, primary care provider organisations, primary health organisations, doctors' organisations (IPAC, Royal NZ College of GPs, one IPA), third-sector organisations, other opinion leaders (such as community activists, health sector consultants, and board members of third sector organisations)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ethnicity</td>
<td>Maori (20), Pacific (1), Non-Maori, non-Pacific (21)</td>
</tr>
<tr>
<td>Geography</td>
<td>Urban metropolitan (18), urban provincial (7), rural (17); North Island (41), South Island (1)</td>
</tr>
</tbody>
</table>

Part 2—Consultation on the draft toolkit:
The aim of Part 2 was to consult on the toolkit with Part 1 participants, and with an even broader group of key stakeholders in the sector. Invitations were sent by email to representatives of key stakeholder groups which had not yet participated in the research. In particular, the medical directors of eight Independent Practitioners Associations (IPAs) were contacted, and all but two of those organisations agreed to participate. Several primary care nursing leaders were also contacted, along with DHB employees working with PHOs.

A feedback form was developed, which invited participants to rate the degree to which they agreed with a series of statements about the toolkit’s form, content and potential usefulness to general practice and to PHOs.

Seventy-eight copies of the draft toolkit were mailed with feedback forms to the Part 1 participants and the other stakeholders who had responded positively to the invitation. The consultation period was extended from 1 to 3 months, due to the limited number of early responses. A total of 32 written responses were received from the sector over the 3-month period. Half of the respondents were Part 1 participants. None of the IPAs returned feedback forms, but feedback was received from five primary care nursing leaders, from seven PHOs, and from six different DHBs. Despite the limited response from GP organisations, there was a large amount of useful feedback received from a wide variety of stakeholders, including three GP leaders.

Part 3—Piloting the CP Toolkit in Primary Health Organisations

Part 3 consisted of the following activities:

- Informal invitation to several PHOs to participate in the pilot process.
- Selection of a sample of five PHOs, diverse by size, type and location.
- Negotiation of a realistic pilot process with the interested PHOs.
- Production of an information package and sending out of formal invitations to five PHO boards.
- One or two day visit to pilot sites to facilitate the organisational review process with each PHO.

From a research perspective, it was important to have a diverse group of PHOs involved in piloting the toolkit; diverse by location, size, and history/type. Of the eight PHOs which expressed an interest in participating, five were formally approached. These five included two rural PHOs (one in the North Island and one in the South Island), two urban PHOs (one moderately large, one small) and one very small PHO located in a small town. Two of the PHOs served a high proportion of Maori and one served many Maori and Pacific peoples. Three of the PHOs were funded on the Access formula, one on the Interim, and one on Interim with Access practices. Two of the PHOs grew out of community-based organisations, while the other three grew out of partnerships between IPAs and community providers. Despite initial consent by its board, the South Island PHO subsequently withdrew from the research before the pilot site visit, leaving four PHOs in the pilot phase.

The researcher negotiated with the PHO contact people (usually managers) to arrange meetings with key individuals to trial the toolkit’s review process. For the purposes of the pilot process, the full review was adapted by combining the self-review and external reviews. Different groups within each PHO tested different sections of the toolkit. In three PHOs, all six sections of the CP Toolkit were tested. Meetings were held with PHO boards, iwi representatives, community representatives, PHO management staff, and other groups (such as clinical advisory groups).

All meetings were audiotaped and transcribed, and data analysed. In one PHO, the researcher was only able to facilitate a limited review process with one staff and one board member, due to staff time constraints at the time of the visit.

Subsequent to the pilot site visits, each PHO manager responded to an email questionnaire which sought feedback on the usefulness to their PHO of the CP Toolkit for PHOs. Data gathered during the pilot process contributed to the final editing of the toolkit.
Results

Part 1—The primary output of this study has been the Community Participation Toolkit for PHOs, which will be published in 2005. For the scope of this paper, it is not feasible to do more than give an overview of the toolkit contents.

The toolkit consists of a set of resources on community participation in primary health care, including defining communities, engaging with Maori communities, and a ladder of participation. It also includes a review process, involving process indicators, that a PHO can use as part of its strategic planning or continuous quality improvement processes. Finally, the toolkit contains a list of references for further exploration of the topic.

Part 2—The feedback from the consultation was mostly very positive and a large majority of respondents could see the relevance and importance of the toolkit for PHOs. A summary of the rating of individual items on the feedback form is shown in Table 2.

Table 2. Part 2 feedback form responses (N=26)

<table>
<thead>
<tr>
<th>Question</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>User-friendly?</td>
<td>13 (50%)</td>
<td>8 (31%)</td>
<td>5 (19%)</td>
</tr>
<tr>
<td>Manageable size?</td>
<td>12 (46%)</td>
<td>8 (31%)</td>
<td>6 (23%)</td>
</tr>
<tr>
<td>Clear language?</td>
<td>23 (92%)</td>
<td>1 (4%)</td>
<td>1 (4%)</td>
</tr>
<tr>
<td>Inclusive of relevant communities?</td>
<td>7 (29%)</td>
<td>11 (46%)</td>
<td>6 (25%)</td>
</tr>
<tr>
<td>Appropriate name?</td>
<td>9 (35%)</td>
<td>9 (35%)</td>
<td>8 (30%)</td>
</tr>
<tr>
<td>Important dimensions of CP?</td>
<td>20 (80%)</td>
<td>0 (0%)</td>
<td>5 (20%)</td>
</tr>
<tr>
<td>Appropriate for kaupapa Maori organisations?*</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Appropriate for Pacific organisations?*</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Appropriate for general practice?*</td>
<td>3 (30%)</td>
<td>2 (20%)</td>
<td>5 (50%)</td>
</tr>
<tr>
<td>Appropriate for other primary care organisations?*</td>
<td>4</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Use a modified version?</td>
<td>2</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Relevant to PHOs more than individual providers***</td>
<td>14 (64%)</td>
<td>1 (4%)</td>
<td>7 (32%)</td>
</tr>
<tr>
<td>Relevant to individual providers more than PHOs***</td>
<td>2 (10%)</td>
<td>1 (5%)</td>
<td>17 (85%)</td>
</tr>
<tr>
<td>Relevant to both PHOs and providers***</td>
<td>10 (50%)</td>
<td>5 (25%)</td>
<td>5 (25%)</td>
</tr>
</tbody>
</table>

*Those items which only selected participants were asked to complete, and therefore the number of responses is low; **Confusion over questions 13–15 (which were interrelated) meant that the written feedback was given more weight than the ratings for these items.

There was concern expressed by some that PHOs were in need of a set of resources, but perhaps were not ready to seriously engage in the review process outlined in the CP Toolkit for PHOs. Many stated a view that the toolkit was relevant to general practice as well as PHOs, while others stated that it had no relevance to general practice. Many respondents offered suggestions for decreasing the size of the toolkit and making it more user-friendly for PHOs. As a result of the feedback, many changes were made to the toolkit before the second draft was completed for the pilot process.

Part 3—The three pilot PHOs that completed the full adapted review process expressed satisfaction with the process. They felt that the discussion of items in the toolkit’s workbook gave them the opportunity to reflect on what their PHO had achieved, to discuss future goals, and to further develop relationships within the PHO.
during the process. There was evidence of particular benefit for iwi and community representatives on boards and community advisory committees. They felt that they learned new information about their local PHO through the review process, and gained confidence in their role in the organisation. The fourth pilot PHO expressed regret that they were unable to complete the review due to time limitations, as they felt it would have been beneficial to their organisation.

Following the pilot site visits, the PHO managers’ feedback on the toolkit and its review process was very positive, with suggestions that they would use the toolkit in a number of ways, such as for strategic planning, board training, or as performance indicators for PHO management.

Despite the difference in the provider make-up of the four pilot PHOs, in each PHO there was evidence of a genuine commitment to engaging with communities, and each was taking a unique approach to it. In three of the four PHOs, the PHO manager demonstrated strong leadership for community participation. Health promotion coordinators and some board members were also notable advocates. In the fourth PHO, the leadership for community engagement came from a practice manager and a board member. Much of the leadership for community participation in the pilot PHOs came from people with nursing backgrounds.

In this study, there appeared to be some relationship between the level of buy-in that providers had in the PHO and the size of the PHO. In the larger organisations, the PHO was perceived by providers to be external and separate to them. This observation held true not only for GP providers but also community health providers, and in both rural and urban locations. The smaller PHOs demonstrated a stronger identity, regardless of their provider make-up.

There was evidence in the pilot PHOs of tension between the business imperative of running a viable not-for-profit organisation and involving communities in governance and decision-making processes. There were two distinct issues described. Firstly, managers described a lack of adequate funding for PHOs to spend the time necessary to meaningfully engage with communities. Even those PHO managers who were clearly passionate about working more closely with the communities they served stated that PHO management funding in their contract was inadequate to cover the actual cost of community participation.

Secondly, some GPs expressed concern that community representatives on PHO boards could have the potential to make decisions that impacted negatively on their constituent practices. In the three pilot PHOs that had a private GP provider base, the GPs were strongly represented at board level.

**Discussion**

This research has led to the publication of the *Community Participation Toolkit for PHOs*, which has been preliminarily tested in a small set of PHOs. Consistent with the literature, this research offers further evidence that it is possible to define the processes which health organisations can set in place in attempting to ensure that community involvement benefits communities and health organisations alike. Detailed discussion of the toolkit is the subject of another paper.

While the toolkit is intended for use by PHOs, it may also be a useful resource for District Health Board (DHB) and Ministry of Health personnel responsible for
primary health care funding and planning. The toolkit relies on the commitment of a PHO, its staff, and its board to involving communities in decision-making. The existence of visionary leaders in PHO management and governance, who are committed to working with communities and to developing innovative primary health care services, is an essential ingredient to meaningful community engagement in PHOs. This finding is consistent with previous research. In particular, the UK research on Primary Care Groups demonstrated that leadership for public involvement and openness to organisational change were key factors in public involvement leading to positive change.

Even with the emergence of the ‘PHO model’, there is clear evidence that different types of PHO lead to different expressions of community engagement. As each PHO has a unique history of local relationships, there can be no ‘gold standard’ for engaging communities in PHOs. There is a particular challenge ahead for large PHOs in which both providers and communities may feel less engaged in the PHO. For them, the first task may be to develop the ‘internal PHO community’ to the point where providers share a vision for the PHO and are open to developing innovative health promotion and health services.

The cost of community participation is a challenge for PHOs, since engaging with communities can be a time-consuming process. Without a doubt, the business imperative of both PHOs and constituent provider organisations can act as a barrier to meaningful community engagement. Furthermore, there are ongoing tensions in the sector due to the issue of ownership boundaries in primary care still remaining unresolved from a policy perspective, as discussed elsewhere in the literature.

During the period of this research (2003–2005), there was a notable shift in the views of many key individuals in the primary care sector about the place of community involvement in the planning of primary health care at a local level. At the outset of the project, many participants were uncertain about the relevance of community involvement to primary health care. By the time of the pilot site visits, the leadership for community engagement in PHOs was coming not only from communities, but also from nurses and GPs.

This study had some limitations. Participants were limited in number for practical reasons. There are many advocates of consumer and community involvement who work outside the formal health sector, and their views were not incorporated into this study. There were some key stakeholder groups in the sector that the researcher had difficulty engaging in the study. The pilot process was limited by the timing of the research. Many PHOs were in the early stages of development and managers were coping with the new reporting requirements. This administrative load took precedence, for some, over participating in the research.

As a result, one pilot site pulled out and another did not complete the full review process. Clearly, the pilot process was not a comprehensive testing of the toolkit. To validate the observations made during this research, a much larger evaluation of the toolkit, involving many more PHOs in New Zealand, would need to be carried out. The CP Toolkit for PHOs has, however, been reviewed in-depth by three diverse PHOs, and was found to be a useful resource.

As the research employed qualitative methods, it is not possible to generalise the findings described here to all PHOs. Instead, the findings offer insights into some of
the issues facing PHOs with regard to their engagement with the communities they serve. By its very nature, each PHO is unique as there is no ‘one size fits all’ for primary health care services if they are responsive to their communities.

Engaging with communities is core to the development of innovative services and health promotion in primary health care. The *Community Participation Toolkit for PHOs* has been developed to complement existing quality tools available for clinical general practice and nursing, and is intended to support the ongoing development of primary health care in Aotearoa New Zealand.

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