

Community participation in primary care: what does it mean 'in practice'?

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ABSTRACT

INTRODUCTION: The New Zealand 2001 Primary Health Care Strategy requires primary health organisations (PHOs) to involve communities in their governance and be responsive to communities' needs. It is less clear what the implications of this policy are for general practices. This paper presents key findings from a national study undertaken in the wake of the 2001 primary care reforms on the purpose and process of involving communities in primary health care.

METHODS: A three-part qualitative process was employed. Initially, key informant interviews were undertaken with a diverse range of primary care policy makers, funders, practitioners and community stakeholders (n=42). A draft framework for involving communities in primary care was developed, and formed the basis of a consultation phase (n=26). The framework was further developed and then piloted in four PHOs around New Zealand.

FINDINGS: Views on community participation varied among different stakeholder groups in the sector. Most described it as a complex process of relationship-building over time, and one that is quite distinct from consumer feedback processes in general practice. For community representatives, it was a process of trust-building and information-sharing between communities and health professionals. These relationships enabled people to feel comfortable seeking care, and professionals to mould services to people's needs.

CONCLUSION: This research highlights that community is much more than a setting of care. As citizens, members of disadvantaged communities are partners with general practices and PHOs, working with them to improve health equity by ensuring that services are responsive to their needs.

KEYWORDS: Community participation; participation; primary health care; primary healthcare; health equity

Introduction

The primary care sector in New Zealand (NZ) has undergone significant changes in funding, structure and accountabilities since 2001, when the Primary Health Care Strategy (PHCS)¹ was first implemented. Between 2002 and 2005, over \$400 million of new funding was injected into the sector. During that time, Primary Health Organisations (PHOs) were formed, bringing together general practices and third sector primary care organisations (not-for-profit, community-governed). A PHO is responsible for delivering primary health care and health promotion to an enrolled population, and is funded through Dis-

trict Health Boards (DHBs) on a capitation basis, using a nationally approved population funding formula.¹ PHOs are required to involve consumers, iwi and communities in PHO governance. In the words of the PHCS:

“Primary Health Organisations will be expected to involve their communities in their governing processes. They must also be able to show that they are responsive to communities' priorities and needs.”¹

Requirements for PHOs, developed by the Ministry of Health (MoH), included only a minimal elaboration on the intention of this policy.²

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While a draft version of these requirements had contained guidelines on implementing ‘meaningful’ community involvement in PHO governance,³ the final version contained little detail.

Recent health policy has encouraged the merging of PHOs into much larger entities, with little consideration of community responsiveness, in the moves to establish Integrated Family Health Centres (IFHCs). In this policy context, ‘community’ is described as a setting for care, not as citizens to whom publicly funded health services are accountable.^{4,5}

In NZ and beyond, there is research and policy debate about the purpose of community involvement in health services. The PHCS has the reduction of health inequalities as a key goal, and reflects a strong recognition of the importance of primary care in achieving that goal.¹ There has been consistent evidence of inadequate access to primary care for groups with high health needs in NZ, such as Maori,^{6,7} Pacific,^{8,9} new migrant^{10,11} and low income¹² peoples.

In 2000, a key National Health Committee report recommended that significant resourcing should be put into the primary care sector, in order to reduce health inequalities and improve the effectiveness of health care expenditure.¹³ The recommendations drew on the research of Starfield and colleagues,¹⁴ which identified the following:

- That countries with stronger primary care systems tend to have better health outcomes than those with weak or absent primary care; and
- That when primary health care is strong, its benefits are greatest in areas of low income.

Along with the purpose of participation being debated, the interpretation of ‘community’ has also been contentious. Research has highlighted that health workers tend to define ‘community’ in a multitude of ways, imposing their own definitions on people.¹⁵ That tendency holds true for primary care. GPs and nurses in urban UK general practices with a scattered practice population have been found to value community less than those with a compact practice area,¹⁶ and GPs were more likely to define community as the practice population, while practice nurses

WHAT GAP THIS FILLS

What we already know: Community involvement in governance has been a policy requirement of Primary Health Organisations in New Zealand since 2001, yet there has been a lack of clarity about the purpose and process of such involvement. Few studies on community participation in health have examined the concept in light of current primary care policy and practice.

What this study adds: This study addresses the gap between policy and implementation, and translates the policy of community participation into practice for primary care practitioners. It identifies how and why community participation in primary care has the potential to improve health outcomes for disadvantaged members of society.

saw it in terms of either locality or shared interest groups.

Research on public involvement in the governance of UK primary care groups (PCG) and trusts (PCT), a policy requirement from 2000, identified a number of trends. First, community members rated their influence in board decision-making as limited and GPs’ influence as high.¹⁷ Second, although the community voice was weak in decision making, there was evidence of progress made in bringing this voice into the primary care domain.¹⁸ Third, the real impact of patient and public involvement was found to depend on what weight the PCG or PCT chose to place on the view of patients and local citizens in relation to professional judgment, and operational constraints.¹⁹ From the UK experience, researchers have argued that there is an important distinction to be made between the primary care involvement of citizens (or communities) and that of consumers.

“If the participant is cast as consumer their involvement at a strategic level may be unnecessary, as their prime contribution will lie in their experience of service delivery. The notion of citizen however introduces an extra dimension. The citizen can be seen as importantly contributing to the legitimacy of policy making.”²⁰

At the general practice level, practices oriented to having a narrow medical role and being primarily a business were found to be less likely to value public involvement than those oriented towards teamwork and a broader social role.²¹ The need

for education and training to empower citizens to participate in PCTs has been identified, and also for a recognition of the power struggles inherent when there is a shift in the influence held by physicians, managers and citizens.²⁰

The notion of communities being active players in health care planning and implementation originated in the primary health care movement, the principles of which are enshrined in the 1978 Alma-Ata Declaration on Primary Health Care²² and reiterated in a recent World Health Report.²³ Community participation in health has been defined as:

“a social process whereby specific groups with shared needs living in a defined geographic area actively pursue identification of their needs, take decisions and establish mechanisms to meet these needs. In the context of PHC [primary health care], this process is one which focuses on the ability of these groups to improve their health and health care and by exercising effective decisions to force the shift in resources with a view to achieving equity.”²⁴

Similarly, others have argued that the point of having policies encouraging participation in health is to ensure that marginalised groups have equal access to services.²⁵ As the ‘inverse care law’²⁶ highlighted, those in a place of relative advantage in society tend to have their health (care) needs adequately met, whereas the needs of those with less ‘agency’ can be overlooked.

In NZ, the reduction of inequalities in health is an implicit goal of community involvement in the governance of District Health Boards (DHBs)²⁷ and PHOs.²⁸ The practice of involving communities in the governance of local primary care services has previously been limited to the third (non-government, non-profit) sector. However, the Government’s current Health Quality and Safety Commission has identified consumer participation as an aspect of quality in health services.²⁹ Consumer and community involvement is an important aspect of continuous quality improvement for practices, if gains are to be made for those groups with highest health needs.

This study is an investigation of the understanding and practice of community participation in

primary care at the time of the early implementation of the PHCS between 2002 and 2004. The research question is: “What structures and processes can be put in place to foster and enhance community participation in primary health care in Aotearoa New Zealand?” This paper presents the key findings on the purpose and process of involving communities in primary health care.

Methods

The basic qualitative methodology employed in this research was a ‘Straussian’ form of grounded theory.³⁰ In this methodology the researcher brings his/her own past experience as well as some knowledge of the literature into the research at the outset, and data are analysed using deductive processes for developing theory, building on preconceived ideas.^{30,31} Although a general inductive approach was taken to data analysis,³² data were also analysed using deductive processes in light of the literature and of my past experience as a GP working with disadvantaged communities.

The research was undertaken in three phases, each with its own aim, method and sample. Ethics approval was sought through the multicentre ethics process, and granted in January 2003 by the Wellington Ethics Committee (reference WGT/02/11/111). A sampling matrix was developed on the assumption that there would be diverse views based on individuals’ roles in the primary care sector (some had multiple), their workplace or organisation, their geographic location and their major ethnic group (Maori, Pacific or other). In Phase One a snowball-sampling technique was used, beginning with people known to me, followed by purposeful heterogeneity sampling³⁴ in keeping with the sampling matrix.

In the initial phase, key informant interviews were undertaken with 42 primary care NZ stakeholders (policy makers, funders, practitioners and community stakeholders). A draft framework on community participation for primary care was developed, and formed the basis of subsequent research stages. Second, the framework was sent to 78 stakeholders to seek feedback, of which 32 written responses were received. Half were from new participants. The framework was modified in

light of responses. Third, it was piloted by visiting four PHO sites, through an organisational review process. The pilot process led to the final revision of a 'toolkit' on community participation for PHOs.³³

The Part One sample, of whom half were Maori, included MoH and DHB officials; leaders of national GP organisations; GPs, managers and community representatives from third sector organisations and other community and public health leaders. Participants were located in cities, provincial towns and rural areas, mostly in the North Island. Half of the Part Two sample were Part One participants, and half were participants from similar stakeholder groups as in Part One, but inclusive of Pacific and primary care nursing stakeholders and PHO board members. The Part Three sample consisted of GPs, nurses, practice and PHO managers, and iwi/community representatives on four PHO boards in the North Island.³⁵

In Parts One and Three, data were collected by individual and group semi-structured face-to-face interviews, and audio taped with participants' consent. Transcripts were analysed using N6 qualitative analysis software³⁶ to assist with data management and coding. A general inductive approach to data analysis was used, involving a constant comparative method of reviewing transcripts for similarities and differences, to identify themes.³⁷ From the themes, a framework or theory of community participation for primary care was developed, consistent with grounded theory methodology. Full details of the methods have been published previously.³⁸

Findings

A wide range of views on the purposes of, and processes for, community engagement in primary care was offered by participants, yet some struggled to offer any view on the topic. Notably, participants from DHBs or the MoH appeared not to have well-formed ideas on this issue, despite their responsibility for implementing the PHCS. The views of leaders of general practice organisations were distinct from those of many GPs, nurses, managers, and community representatives.

GP leaders tended to define 'community' as patients enrolled in a practice, and saw community participation as equivalent to the quality improvement process of consumer feedback, such as through the use of intermittent patient satisfaction questionnaires. Many participants, including physicians, had a broader set of purposes and processes for involving communities. Learning the needs of the populations served, and learning from communities about the broader issues that affect their health were two key purposes identified. For these participants, community engagement was described as a process of two-way information sharing between communities and health professionals, which created relationships of trust over time. These relationships enabled people to feel comfortable seeking care, and professionals to mould services to peoples' needs.

Community versus consumer

Inherent in the differing views about the scope of community engagement was a different understanding of the notion of 'community' as distinct from 'consumer' in the primary care context. It was evident early in the research that participants held varied understandings of the term 'community'. Leaders of GP organisations tended to view a PHO or general practice register as a de facto community, while other participants saw it differently.

Participants described community as having spatial dimensions, yet as much more than geography. They suggested that community equates much more easily to locality in the rural context where more people identify themselves as members of the locality and these localities are perceived to be reasonably homogeneous. In an urban setting communities were seen to be more heterogeneous, and not confined easily to a geographic area. For example, some argued that communities served by PHOs might be ethnically-based or based around community organisations, such as schools. Further, third sector participants argued that community must be inclusive of those who do not present at practices, if equity is of concern.

"[our community is] those who also don't walk through our door, so we are very aware that there are many—perhaps some parts of the community that don't use us or have had reasons for feeling

that... their needs may not be met.” (Manager, large health NGO)

A representative from Health Care Aotearoa,³⁹ a national network of third sector primary health care organisations, made a clear distinction between consumers and communities:

“I think that there are consumer issues which will be very particular and they will relate to things like standard of care issues to do with the actual premises, waiting times...ability to make appointments... a disease profile of the practice...that would help drive the service... I see that as being different to them saying ‘The community these people live in, what are the issues that the community faces and how can we, as a service, be more responsive to those issues?’ That will not be consumer driven per se, but will be driven by leaders and key players in that community.”

Community, then, must be understood as much more than a patient register, which simply identifies the enrolled population.

The purpose of community participation

Those participants from the MoH, and those with experience in third sector primary care organisations, saw community participation as a means of improving access to primary care services for disadvantaged people or populations. They described the importance of community engagement to learn about unmet need, in order to address it.

“So, okay, if you challenge with ‘Have you actually just asked the doctors what they thought was a good idea...how have you engaged your community so you can say that you are responsive to them?’” (MoH clinical leader)

Community participation was seen to be an important means of gaining knowledge from communities about the broader issues affecting their health.

“There is no doubt that communities who have not had the opportunity to contribute in this way may well... feel, ‘Oh, we don’t have the confidence to contribute, because we don’t know anything about health services.’ It’s quite true, but that doesn’t

mean to say that there aren’t other issues that affect health that the communities can’t contribute to.” (Pacific GP)

As implied in this statement, many participants felt strongly that the inclusion of community voices can (and should) challenge health services to consider the determinants of health and illness, such as people’s access to employment and affordable housing.

The process of community participation

Community participation in governance was recognised by participants to be a requirement for PHOs, but there were different views on how it should occur. Many participants did not consider that patient satisfaction surveys or formal meetings were adequate in involving communities, and argued for community involvement beginning with the clinical encounter in general practice.

The head of a GP organisation stated that GPs usually engage with community views indirectly, through patient feedback questionnaires, or informally, through feedback in the community. She felt that formalising community involvement could be detrimental to general practice by allowing communities too much influence.

“I mean in practices we often rely on either surveys or just general feedback for getting community input... that probably varies from practice to practice and community to community... I wouldn’t like to see a lot of rigidity... in terms of ‘you must do this, or you must do that, or you need X, Y or Z consumer input because that actually may just kind of derail the whole usefulness of the process.”

In contrast, others were critical of this view of community engagement.

“The [GP] practices... feel that they are attuned to what’s going on among their service users, but they tend to do it through those formal complaints feedback procedures... so they are not out there in the community talking enough. They are static, you know, bricks and mortar.” (CEO, provincial PHO)

This manager argued that the delivery of community-based programmes, such as those offered to

Maori elders in her PHO, is one important means for engaging with communities. Taking services out to disadvantaged communities was argued to be a more valuable means of engaging with communities than calling hui or community meetings.

“People get hui-ed out, they have other things that they need to attend to... ‘Today I have to be at WINZ. I have got to be at IRD or the kids have got to be immunised.’ And they will prioritise those, and the health will probably be at the bottom, because WINZ means money.” (Urban kaiawhina / community health worker)

Participants distinguished community participation from consultation. Consultation processes were seen as formal, by one participant, and as not influencing ultimate decision making.

“...so that they are not just a consultation that listens to people and then goes off and does whatever a powerful group has to say.” (Community representative)

Meaningful community participation, on the other hand, was seen as beginning with less formal, more transparent, two-way communication leading to positive change for communities.

Many argued that engagement must begin at the general practice visit, during the encounter with the practice receptionist, nurse or the GP.

“Some branches of the PHO haven’t got very good customer service skills, and so you immediately get put off at the fence, at the gate, asking the receptionist for your appointment... There needs to be some cultural awareness...” (Iwi representative, PHO board)

One participant suggested that for GPs and practice teams to focus on building relationships with patients is a more valuable use of their time, in the long term, than providing patients with ‘lifestyle advice’.

“You know, when you talk to GPs and they say ‘I tell people to give up smoking and I tell people to eat less, and I tell people to walk more, but what can I do in 7.5 minutes?’ Well, there’s plenty you can do. You don’t have to do it in 7.5 minutes, but

you can make the connection and it will unfold and it unfolds.” (CEO, provincial PHO)

Community participants rated highly the importance of practitioners building relationships with patients based on trust, and which encourage the meaningful exchange of ideas and information. Such relationships were seen to be critical to developing wider community involvement in a practice or PHO. They were identified to be of particular importance for marginalised groups, and even a step towards their empowerment.

“First of all it’s about information and how you get that information across. If you have got pretty little books or pamphlets I can assure you, after working for WINZ for 12 years, it doesn’t work. ...It’s all about information, as far as I’m concerned, and ... ongoing contact.” (Urban Maori kaiawhina/community health worker)

At the level of PHOs, many community representatives on PHO boards described deferring to GP board members, taking the view that ‘the doctor knows best’. Two-way information sharing, whether with a patient or community representatives, was expressed as requiring trust in both directions.

“They know... when their involvement is genuine and when it is not, so I think we pay a great disservice to disadvantaged communities and high needs communities, I suppose, by not at least acknowledging that they’re intelligent people who can make decisions, given enough information.” (MoH official)

The gap between some general practices and disadvantaged communities was seen to be something that community representatives could bridge.

“Our community people see us here, who are on the board, as people first, community first... That makes it easier for the movement of information to and from us... And that’s good.” (Iwi representative, PHO board)

For community participants, engagement was largely about two-way information sharing, between themselves and their communities, and between themselves and the practices or PHO.

In summary, the process of involving communities in primary care was seen to be both a formal requirement of PHOs and an important informal aspect of primary care practice. The informal involvement was described as occurring through a series of steps, each building on the next as primary care team members build trust with patients, families and communities:

1. Treating patients and families with respect when they contact the practice.
2. Practice team (receptionist, nurse, GP) sharing information meaningfully with patients and families.
3. Two-way sharing of information, in which practice teams learn the real needs of families and communities.
4. Taking services (nursing, health promotion, even medical) into community settings, which allows team members to gain further insights about the needs of families and communities who may not routinely seek the services of general practice.
5. Attending formal and informal community gatherings, and engaging with community organisations, to engage in broad discussions at the community level.
6. Engaging in advocacy for and with patients, families and communities on issues that affect them, such as access to appropriate housing.

Community participation was considered to be relevant not only to PHO governance but something to be negotiated with communities through formal and informal invitations to engage. It was described as a complex process of relationship-building over time, and one that is quite distinct from consumer feedback processes in general practice.

The voices of two GP participants speak for themselves in highlighting challenges and benefits of working with communities.

“...they [the community] keep you honest, to a certain extent. You have to deal with people who... basically don't ‘kowtow’ to you with your position, as such, and they are prepared to say things that they have got concerns about... but I think the other side of the coin is that that then gives them an outlet for their quite legitimate frustrations and

concerns and it... allows you to interact with people on a level where you wouldn't do necessarily in a consultation... So you get, I think, a better understanding...” (Rural GP leader)

“If you're the expert, when things go wrong you have to completely wear that. When you're working in partnership with communities, people are very forgiving... I think you start to see health gains that you wouldn't see normally... intellectually, it's more satisfying to be working at that level instead of just with individual clinical problems.” (Urban third sector GP)

According to these GPs and others, closer engagement with communities can bring challenges, but also personal and professional satisfaction to GPs and primary care teams.

Discussion

The requirement for PHOs to involve and be responsive to communities has been challenging for a sector that has such differing key stakeholders as consumers, communities, health service managers, GP-owners, DHB personnel and, increasingly, private investors. Yet, whatever the stakeholder group, there is a desire to provide quality primary care services to individuals, whanau and communities. This research has provided some evidence consistent with the UK experience of public participation in primary care cited earlier. For example, in keeping with Brown,^{1,6} GPs in this study tended to define community for primary care as their list of enrolled patients, whereas other participants did not. Further, third sector participants distinguished between the notion of ‘community’ and that of ‘consumers’—similar to the argument made based on UK experience.²⁰ Finally, voices from community representatives in this research suggest that the actual influence of community members on PHO board decision-making was limited at the time of the research, again consistent with the early experience of Primary Care Groups and Trusts in the UK.¹⁸

This research also highlights an alternative way of understanding community involvement for primary care that is more than having a community representative on a PHO board. Community engagement which would benefit communities,

rather than simply 'tick the policy requirement box', occurs over time through a series of small, but important steps carried out at the practice level by all team members.

Many participants described the purpose and process of community participation in quite simple terms; as the building of relationships of trust between health professionals and people with high health needs, in order for meaningful information sharing to occur in both directions. These findings do not imply that such steps never occur; rather, that they fail to occur consistently, and across practices, for people from disadvantaged population groups, as highlighted in NZ research on primary care access, cited previously. Further, this research identifies that the outcome of genuine information-sharing with patients, whanau and communities is that services are delivered differently, in order to better meet the needs of disadvantaged individuals and groups.

This research highlights that the encounter between primary care practitioner and patient or community requires cultural competence or, at a minimum, the ability of health professionals to translate health information in a way that encourages patient/community understanding. This aspect of community involvement links directly to the notion of health literacy, which is currently on the policy agenda in NZ.^{40,41}

Community participation is reminiscent of patient-centred clinical care,⁴² which recognises that, just as the physician holds expertise on Western medical knowledge, the patient (or community) holds expertise on his/her (its) own wellbeing. The encounter between them is of most benefit to each when there is a sharing of learning. Primary care practitioners can learn about appropriate service delivery from population groups who have traditionally missed out on receiving the best possible primary health care. In this way, community participation is directly linked to continuous quality improvement in primary care.

Research limitations and future research

The limitations in this research relate to its timing and sample. The PHCS was released in November 2001 and the formal research process

began in mid-2002. Impacts of the reforms were being felt at every level of the sector at that time. General practice organisations, and especially Independent Practitioner Associations (IPAs) were defensive, regularly speaking out in the media, challenging various aspects of the PHCS. The MoH, charged with the task of implementing the PHCS, was very interested in supporting the research given its potential to support the implementation process. The leaders of national GP organisations were also interested in engaging with the research, in part to ensure that the interests of GPs were represented in the work. In contrast, it was difficult to engage with DHB personnel and with the medical directors of IPAs.

Part One interview data were collected prior to the active involvement of participants in PHOs. During this early stage, the greatest level of support for the research came from the MoH and third sector primary care organisations, along with other NGOs and public health leaders. By Part Two, some PHOs were operational, and some new participants, from groups yet unrepresented (such as nurses), engaged in the research. The large IPAs agreed to participate in Part Two, yet failed to return the consultation documents. By Part Three, most PHOs were fully operational; thus, these data provided the clearest 'PHO perspective' on community participation. Although community involvement was not evident in the minds of mainstream primary care providers during Parts One and Two, that had changed by the time of the PHO pilot process. No doubt even richer data on the experience of engaging communities in PHO governance could be gathered now.

The next stage in extending the present research would be to assess the impact of increased levels of community participation in PHOs on services and on health outcomes, particularly for disadvantaged individuals and communities.

Conclusion

This research provides evidence to suggest why community participation in primary care must not disappear from policy and practice as larger, 'more efficient' centres of care are established throughout NZ. The voices of consumers and communities will be invaluable to ensure that In-

egrated Family Health Centres meet the needs of those people most disadvantaged in health terms. In its recent Health Equity Position Statement, the New Zealand Medical Association⁴³ “calls for doctors to work more innovatively and collaboratively to develop systems to reduce health inequities.” This research suggests that communities are important collaborators in that work.

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COMPETING INTERESTS

None declared.