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The Case for Community Participation in Primary Care:
The potential to improve health equity

Beyond General Practice: Researching Health and Wellbeing in the Community: RNZCGP Conference Research Day

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The Case for Community Participation in Primary Care: The potential to improve health equity

OR

‘What I learned from my PhD’

Research Q:
What structures and processes can be put in place to foster and enhance community participation in primary health care in Aotearoa New Zealand? (2002-2007)
Acknowledgements

- Department of Public Health, University of Otago, Wellington
- Health Research Council of New Zealand: project grant
- Thanks to Prof Tony Dowell and the organisers of this primary care research day.
Positioning Myself as Researcher

- GP in economically deprived communities in Canada and New Zealand, with exposure to social, economic and cultural poverty

- Learned the importance of working collaboratively with colleagues from other sectors and with communities themselves, through engagement with community leaders, in order to improve the determinants of people’s health.

- From a nation where there were no user chargers in health care to one where cost was a barrier to accessing services for many

- Frustration at being ‘the ambulance at the bottom of the cliff’, rather than the fence at the top – went into public health.
Communities and clinicians: ? Differing paradigms

Unfortunately, Grandpa has lost bowel control so we're allowing him to die with dignity.
Key points: The case for community participation in primary care

1. Participation is the right of every citizen in a democratic society; participation in the planning of community-based health care services is no exception;

2. Health inequities and inequitable access to primary care have been well documented for tangata whenua, as well as for other disadvantaged communities in NZ;

3. The participation of patients/consumers is important but not enough to ensure that the voices of tangata whenua and other vulnerable communities are heard;

4. When vulnerable communities participate in primary health care both improvement in access to health care and reduction in health inequalities are likely to occur.
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.
Primary health care [must be] made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain... It is the first level of contact for individuals, the family and community with the national health system bringing health care as close as possible to where people live and work... Primary health care requires and promotes maximum community and individual self-reliance and participation in the planning, organization, operation and control of primary health care... [and] develops the ability of communities to participate
The political language now...

PHOs should be a partnership between community and clinicians. Strong clinician engagement is fundamental to achieving quality service.

Health providers need to work more in partnership with social and community organisations to promote well-being.

A faster and more convenient health system would see more work done in community settings such as Integrated Family Health Centres.

*(Better, sooner, more convenient* Hon T Ryall, Nov07)*
Primary health care: a meeting ground of primary care and public health
PHC as an approach: key principles

Primary health care incorporates not only the first level of contact with the health system, but also care based on the following:

- a concern for equitable access to health services;
- the involvement of individuals and communities in developing strategies to improve their health;
- a concern for addressing the social and environmental determinants of people’s ill-health.

Alma-Ata Declaration on Primary Health Care (WHO & UNICEF, 1978)
What is a ‘community’ for primary care?
Defining community: the complexity

Communities operate in multiple ways and you often need to be thoughtful in thinking about the types of communities you have got there, some of which will be interest based, some of which will be geographic, some of which will overlap. Some of them will be ethnic, some of them will be socio-economic and it’s about getting the key ones that people identify with and that give you insights into what people’s needs are...

(research participant, Ministry of Health)
Defining ‘Community’

- In health, the meaning of ‘community’ tends to be widely disputed (Jewkes & Murcott, 1996). Communities need to self-define, if engagement is going to be meaningful.

- Defined on the basis of shared identity, values, needs:
  - Needs-based communities and organisations
    - By age (e.g. Aged Concern, youth organisations)
    - By illness (Diabetes Association)
    - By disability (IDEA Services)....etc
  - Identity-based communities and organisations
    - By ethnic group
    - By religious identification
    - By sexual orientation...etc.

- Health services must identify key communities of interest, and invite them to choose their most appropriate representatives for engagement.
Consumers or Community?

Communities are NOT simply groupings of consumers.

There seems to be confusion between ‘consumer’ and ‘community’. The priority must be on the community. Naturally, there should be regular surveying and dialogue with the actual patients who make up the register of the PHO. But that is different to discussion with the community—this discussion will be driven by the community, on their venues, following their protocols, and led by their agenda.

A Consumer-Community Continuum

Sources: (Draper 1997; Consumer Focus Collaboration 2000)

INDIVIDUAL

- Individuals who are receiving or have received health care services
- Carers and/or family members who support individuals who receive health care
- Groups of consumers (who may share a common experience or chronic illness)
- Consumer organisations including advocacy, self-help and consumer network organisations
- Potential consumers, such as those with unmet needs or from population groups with particular needs or access issues
- Members of the community including future users and the wider community that benefits from health care services
- Taxpayers and citizens who ultimately pay for services

COMMUNITY
Who participates, (and in what)?
Two Approaches to Participation in the Literature

- Participatory democracy: people as citizens have a duty and a right to participate in decisions which affect them (basis of Alma Ata Declaration).

- Consumerism: identifies ‘customer preference’ to enhance market competitiveness (basis of marketing health care).

NB: The ‘Horn Report’ refers to ‘patients and consumers’ only. Community is simply a setting. *(Meeting the Challenge, Ministerial Review Group, July 2009)*
If improvement in health equity is a goal, then the distinction between the involvement of *community* and *consumers* is important.
“Universally accessible through their full participation” (Alma-Ata Declaration, 1978)

Participation leads to improved access to PHC:
- PHC offered ‘local’ to where people live/work
- Affordable PHC services
- Culturally appropriate PHC services
- More comprehensive PHC services
- PHC services where people feel ‘at home’.
“The people have the right and duty to participate individually and collectively in the planning and implementation of their health care.”

(Alma-Ata Declaration 1978 Section IV)

NOTE:
- individual participation as consumers/patients
- collective participation as citizens/communities
Differing Value Sets: Consumers and Communities

- Consumers or patients:
  Emphasis on his or her own needs, or that of immediate family. Often, though not always, single issue focus.

- Citizens or members of communities:
  
  *The citizen expects equity, fairness, value for money and effectiveness in the allocation of public resources...*

Citizens’ values are more likely than patients’ values to embrace interest in others in the society. Equity, for example, may be of little concern to the patient; it is more likely to figure in the mindset of the citizen.

The UK experience:
public involvement in primary care = consumerism

- UK experience in Primary Care Trusts suggests that where the agenda for public or community involvement is simply consumer responsiveness, the reduction of inequalities is unlikely to be an outcome.

- Some analysts of public involvement in Primary Care Trusts have argued that a community development approach – which, by its nature, is based on citizenship rather than consumerism – is the most appropriate in meeting the needs of marginalised groups.


Consumer and Community Participation

- Tension between consumer values and community values will lead to different outcomes from community participation in primary health care organisations.
- Consumers must have a voice, particularly given the ‘business of general practice’.
- Communities must also have a voice, if the goal is the improvement of health equity.
- The goal underlying community participation, then, will determine how ‘community’ is defined.
If the goal is continuous quality improvement with no explicit focus on equity

OUTCOME: 1. Does not improve equity and often increases inequity. 2. Excludes non-users, which leaves those most vulnerable with no voice in health care planning.
If the goal is to improve health equity

- Participatory model: empowering process of CP
- PHO ‘community’: defined & prioritised by NEED
- Policy agenda: reducing health inequalities
Participant Voices
Risks for disadvantaged communities of participation being simply rhetoric

My anxiety around that [community participation]...is that those most at risk... tend to be those who are most disempowered and least likely to turn up for a forum or a fono or hui...It will be street kids, sex workers, people with mental health issues, young people [who don’t turn up].

(Third sector health NGO manager)
The need for PHC be responsive to people’s issues and address the social determinants of health

So health care for low income people and marginalised people is often about very basic stuff like housing, adequate information about nutrition, adequate income, adequate opportunities for education. All of those social determinants impact on their health, and as a health organisation—as distinct from a sickness one—we need to find out from them what the issues are. Otherwise we simply remain as the local doctor who treats the disease.

(Third sector practice manager)
The need for PHC to ‘give voice’ to people who are ‘voiceless’

The fact is, in these poor communities a whole lot of these [GP] services are run by entrepreneurs. This is a community that don’t complain, that shop around...It wasn’t until we set up...and started changing people’s expectations that people are starting to lift their game. It’s a really important mechanism for giving voice to a community that doesn’t have a voice.

(Pacific GP)
Other Research Findings

- Smaller PHOs, which had developed from NGOs, were more likely to have community representatives actively engaged at governance level than larger PHOs.

- Large PHOs, which had grown out of GP organisations, had individual ‘consumer’ not ‘community’ representatives.

- Many community representatives were struggling to ‘find a voice’ in the PHO.

NB: These findings consistent with Barnett, Smith and Cumming, *The Roles and Functions of PHOs*, July/09.
The involvement of vulnerable or disadvantaged communities

The involvement of vulnerable communities can improve health equity through:

- improved access to appropriate and affordable health care
- improved access to the determinants of health (employment, housing, etcetera)
- individual and community empowerment through the process of meaningful engagement in a local organisation.
‘Better, sooner, more convenient’

TO CONCLUDE:

It is critical that ‘better’ includes more equitable, otherwise ‘better, sooner, more convenient’ is likely to be effective at reducing costs to the sector while transferring costs disproportionately to disadvantaged communities and driving up socioeconomic and health inequalities.

‘Better’ must incorporate meaningful community participation, and not only the voices of individual (i.e. advantaged) consumers.