Perceptions of community participation and health gain in a community project for the South Asian population: a qualitative study

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Abstract

Background The new public health rejects old individualist attempts at improving health and embraces community-based approaches in reducing health inequalities. Primary Care Trusts in England face the challenge of converting community participation in health into reality. This study explores differences in perception of participation between lay and professional stakeholders of a community health project for a South Asian population in Greater Manchester.

Methods In-depth interviews and focus groups were used to explore the views of professional and lay stakeholders. All data were audio-taped, transcribed and analysed for emerging themes using a qualitative framework.

Results Professionals talked of working in partnership with the community but lay stakeholders did not feel that they had control over the project. There were problems in engaging the community and local health professionals in the project. Lack of cultural awareness hampered participation in the project. There was agreement that the project improved the self-confidence of participants and created a more informed population. However, there was little support for claims of improvements in social cohesion and changes in lifestyle directly as a result of the project.

Conclusion Converting the rhetoric of community participation in health into reality is a greater challenge than was envisaged by policy makers. Marginalized communities may not be willing participants and issues of language and cultural sensitivity are important. Project outcomes need to be agreed to ensure projects are evaluated appropriately. Projects with South Asian communities should not be seen to be dealing with all ‘ethnic health’ issues without addressing changes in statutory organizations and other wider social determinants of health.

Keywords: community participation, health gain, South Asian

Introduction

The concept of community participation in health first appeared over three decades ago in the developing world as part of movement for social justice. It was envisaged that basic health needs could be met more appropriately and efficiently by the greater involvement of people themselves. Community empowerment is considered central to the process of participation, enabling people to have a greater say and more control over their own lives and local health care decisions. In working with marginalized communities, community participation could reduce health inequalities and improve equity. In 1991, the World Health Organization summarized the benefits of participation:

(1) coverage – involves more people than non-participatory projects;
(2) efficiency – promotes better co-ordination of resources;
(3) effectiveness – goals and strategies are more relevant as a result of participation;
(4) equity – promotes notion of providing for those in greatest need;
(5) self-reliance – increases people’s control over their own lives.

Primary Care Trusts (PCTs) in England are challenged with converting the rhetoric of community participation in health into reality, yet the precise nature of participation remains elusive and little is known on the actual benefits of participation. As PCTs move from policy to implementation, local understanding of the concepts of participation and its associated health gain need to be explored in situ in order to ensure that rhetoric can translate into reality.

The Asian Health Development Project (AHDP) was set up in a small town in Greater Manchester to access and respond to health needs of the local South Asian community. A community participation approach was used to achieve ‘potential health gain’. A number of initiatives were used to engage the community, including training programmes on health and health services, a diabetes awareness project with cookery classes, first aid courses and exercise classes. Many professionals...
from the PCT, Hospital Trust and the local authority were involved in these initiatives.

This paper presents the findings of a study that explored the perceptions of participation and its associated health gain amongst lay and professional stakeholders of the AHDP.

Methods

Semi-structured interviews were conducted with 13 professional stakeholders who had been involved in the project (project workers, managers, nurses, dieticians), exploring their perceptions of participation and health gain in the project. A non-probabilistic maximum variation sampling strategy was used to provide multiple perspectives. Interviews were conducted by G.B. and lasted between 60 and 90 min. Questions were adapted to each interview but concentrated on the nature and extent of participation by the local community and the health benefits the community had gained as a result of the project.

Three focus groups were conducted with each of the subgroups of the local South Asian community (Indian, n = 5; Pakistani, n = 5; and Bangladeshi, n = 4) exploring perceptions of participation and health gain in the project. All the participants were female (reflecting the gender of the majority of the participants of the project) and ranged in age from 25 to 46 years. The average length of focus groups was 90 min. To validate emerging themes from the focus groups, four in-depth interviews were conducted with lay informants using an opportunistic sampling strategy.

All interviews and focus groups were audio-taped and transcribed verbatim. Analysis was carried out using a content analysis for emerging themes based on Denzin’s Interpretive Interactionism framework. Emerging themes were grouped into categories and are reported below.

Results

Perceptions of participation: partner or problem?

Lay participants felt they had no control over the project or its resources and considered themselves as recipients of the project’s work rather than active shapers or partners in the process. In contrast, professionals frequently described the project as a partnership, but made little reference to distribution of power in the project.

Barriers to participation: engaging the community

Lay participants recognized that many people did not want to, nor had the time to participate in the project. The project was not considered a priority compared with the other problems families had to deal with. Professionals spoke of the difficulty they had in getting people to attend events associated with the project. The project failed to engage the most deprived Bangladeshi section of the community and was seen by some as widening inequity in the local South Asian population.

Barriers to participation: engaging health professionals

Engaging health professionals was seen as equally problematic. Professionals admitted the project had been unsuccessful in involving local GPs over its 5-year duration. There was fear and uncertainty amongst professionals about methods that challenged traditional ways of working.

Barriers to participation: language and cultural awareness

Some professionals expressed reservations that community participation was not possible without good interpreting services. Others viewed participation as an empowering process (not simply about getting health messages through) that could overcome language and cultural barriers. Lay informants agreed that non-English speakers were less likely to participate in community projects.

According to Professional D: ‘Language is not a barrier to people participating . . . with mother tongue support, people are glad their language is spoken and therefore think information is accessible and are therefore able to participate.’

Lay informants were frustrated by the lack of cultural awareness and sensitivity in the project. Others felt that some health professionals held stereotypical views of Asian women and made assumptions about beliefs and behaviour.

Barriers to participation: time and resources

Professionals working to short deadlines and used to more immediate results felt frustrated at the slow pace of change in participation projects. Others recognized that slow, steady progress was the only way to ensure reliable and sustainable results and to avoid ‘quick fixes’ that were not relevant. There was consensus amongst health professionals that community participation was not a cheap option and considerable resources were required by projects to achieve their potential and demonstrate cost-effectiveness.

According to Professional I: ‘You have got to have recurrent funding. . . you are competing with a lot of other priorities, so you have got to have a clearer idea about what your outcomes are and be able to show them.’

Benefits of participation: a more informed population

There was agreement between lay and professional informants that the project had raised awareness on health issues and services and created a more informed population. Community members felt they had learned a lot and some had moved onto further training and employment opportunities.

Health impact of project: psychological benefits

Lay informants felt more confident through participating in the project. Confidence was perceived to have improved through gaining knowledge and skills and making new friends. Professional informants felt the project had raised the self-esteem of those who participated.
Health impact of the project: social cohesion

Professional informants believed participation in the project had enhanced the sense of social cohesion in the community. This was seen to have been achieved by greater engagement of the South Asian community in regeneration initiatives and neighbourhood forums. Lay informants had made new friends on the project, but did not feel the project had made any difference to the community at large or improved community cohesion in any way.

Health impact of the project: lifestyle changes

There was disagreement between lay and professional informants as to whether the project had resulted in any lifestyle changes amongst participants. Some professional informants
were optimistic about the project’s impact, whilst others recognized the project’s limitations in affecting the broader social determinants of health. Lay informants did not make the link between health knowledge gained and changes in lifestyle. Healthy living ideas from the project were difficult to put into practice and often met with resistance from other family members.

Health impact of the project: better use of health services
Some professional informants felt the local population were more appropriate users of services as a result of the project. However, the project was perceived to have had little influence over local service providers and the allocation of resources. ‘I wouldn’t say the project has got to the stage where you could show changes in the direction of resources or services, as a result of involvement of South Asian people’ (Professional K). The project was considered to have failed in its remit to influence local service providers.

Discussion
This study used qualitative methods to explore the views of lay and professional informants. It suggests that there are important differences in perceptions of participation and its associated health gain.

There are fundamental differences in the understanding of the term ‘partnership with the community’. Lay informants did not consider the AHDP as a partnership. The equal nature of partnerships with the community is contested in the literature with unrealistic expectations leading to disillusionment and frustration. The issue of power is considered central to the process of participation, but professionals tend not to have to account for the weight they attach to local views. The ‘I plan, you participate’ philosophy may lead to failure in local participation projects.

Engaging communities can be problematic and deprived communities may not be willing participants, particularly if the benefits of projects are not apparent and tangible. The Bangladeshi community, which is the most deprived in the area, participated the least in the project. Cultural insensitivity may hamper projects with the South Asian Community, but the heterogeneous needs of the South Asian community need to be acknowledged to ensure participation projects do not exacerbate inequalities. Campbell et al. warned that expressed ethnic allegiance does not mean people will have common needs and interests that will unite them in local health initiatives. Madan suggests that participating communities are ‘made, not born’ and the project needs to rethink its strategy for engaging all sections of the community.

Previous studies have shown professional uncertainty and inability to relinquish power can also hinder participation projects. Health care professionals who are taught little on empowering and emancipatory approaches may find it difficult to participate themselves and enable participation from the public. Training in participatory education for professionals may address lay concerns about communication issues and enhance participation by professionals.

Lay informants perceived health gain on an individual level in terms of knowledge gained and confidence achieved. Self-confidence and self-esteem are developed through the participation process and the project appears to have been successful in this area. However, there is no necessary link between knowledge gained and behaviour change. The project did not result in any socio-environmental changes, having relied more on an educational approach, rather than a community-development approach. Consequently, lay informants did not admit to any lifestyle changes.

There was disagreement as to whether empowerment at an individual level had transmitted to health gain at a community level. Strong social networks are thought to create healthier settings. There was little change within statutory organizations as a result of the project. Partnership models in some community initiatives may represent mediation of continued disadvantage, because they tend to be based on relationships of unequal power and allow statutory organizations to assume the notion of community is contested in the literature and studies show that implicit assumptions regarding sharing are often not held out in practice. The local South Asian community is culturally diverse and geographically scattered and professional notions of increased social cohesion require further exploration.

Appropriate and accessible health services impact on health gain, but the project was perceived to have had little influence on local services. There was little change within statutory organizations as a result of the project. Partnership models in some community initiatives may represent mediation of continued disadvantage, because they tend to be based on relationships of unequal power and allow statutory organizations to assume that projects will manage minority ethnic issues without any need for internal change themselves.

The weaknesses of this study included the limited access to the local population, which determined the opportunistic sampling strategy used for the focus groups. Although our results suggest that the views of the subsections of the community were consistent with one another, our small sample size may have limited access to a variety of opinions, reflecting the heterogeneous nature of the South Asian community. Key themes were identified and supported by the literature, which improves the generalizability of the results to other settings.

The allure of community participation has captured the attention of policy makers in the UK with its promise of improvements in public health. However, the strategy, which was initially thought to be common sense and straightforward, is increasingly recognized as being quite complex. This study uncovers issues of misunderstanding and conflict in one participation project. However, further systematic approaches are required to evaluate the policy in situ and demonstrate accountability for scarce health service resources.
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References