Community participation in health: How does it work?

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Introduction

Reducing health inequalities and improving local people's quality of life requires public services to take a more holistic and innovative approach in health development activities and to listen to and act upon local people's voices and concerns. This research case study is based in a deprived and disadvantaged area of Liverpool covering two Census Wards, Breckfield and Everton, where the health and development problems have been exacerbated by large population losses since 1971. It describes how local people, through participatory research, were able to influence management decisions on their local health services to prevent a community health clinic being closed by the NHS Community Health Trust. Whilst the study area has a long history of activism in urban development, there had been little involvement of communities in influencing health care services. This article consists of accounts by two local women and the facilitator who worked with the community campaign group, describes the benefits and the challenges faced, and highlights some factors which influence the process and outcomes of participation.

Community profile in brief

The two census wards have a total population of 20,511. Key demographic data below indicates the scale of problems faced in the area.

Percentage	Breckfield	Everton	Liverpool	National
Residents with limiting long-term illness	18.6	23.5	17.3	12.4
Unemployment	32.3	45.1	21.6	6
Lone adult families	10.4	8.5	7.0	19
Households with no car	75.5	86.6	56.9	32

(From: Key Statistics Liverpool Wards 1991 Census: General Household Survey 1991; 1991 National Census).

How it all began

Lyn (Local resident – Breckfield and Everton Community Health Advisory Group [BECHAG] member)

In 1994, we started a community campaign group, made up of 2 different communities, to keep our local community health clinic open where management decisions to close it down were being made behind closed doors.

Many local people thought the clinic was already closed so stopped going there. Those who went found that clinics had been moved to different days and times. Many local people do not have phones and only by walking there could they find out, so attendance numbers dropped, which the Trust used as an excuse to close it down. Local people felt that this was about saving money instead of providing a better health service for the area, which already had less GPs than other communities and some of the worst health problems in the city.

Our campaign group had open meetings with the Liverpool Health Authority, the Community Health Trust and local people to discuss what should happen. The group pushed for research to be done on the clinic and primary care services in the area before the final decision

Map I Clusters
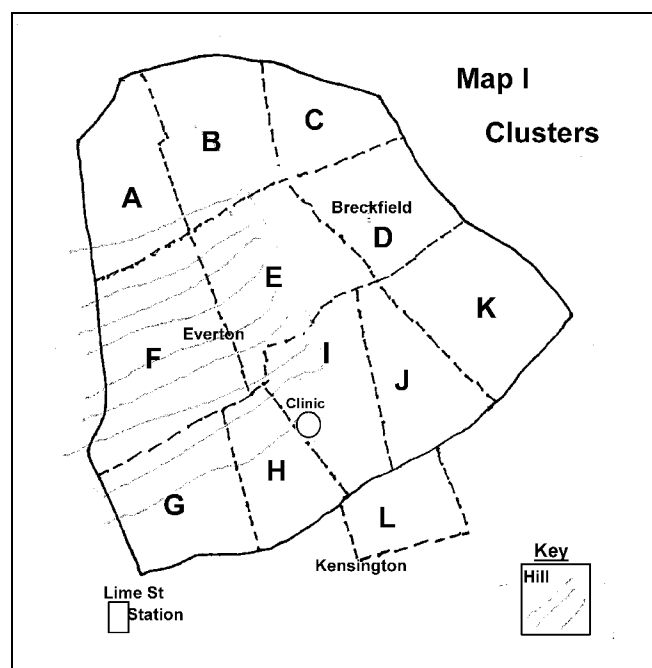
was made. The Health Authority agreed to let us do the research ourselves and provided some funding with the Liverpool Community Voluntary Services. We then found and appointed an independent and sympathetic researcher to help us.

The research
Training for the research gave us a lot of confidence and time to get to know and trust each other, so we could work together. The research had to be done properly, so we practised the questionnaire interviews in our training sessions before we went out into the community.

Over three weeks, our survey team walked around the whole area, sometimes in strong winds and rain. We discovered a lot about our own community we didn't know before. We found many local people had no one to talk to or care for them, and many of them wanted us to stay and talk. We also kept telling people to go and use the clinic to help stop it closing.

I joined the campaign group because it made me angry that managers were making decisions on my behalf without discussing it. They were deciding for me what services I could have and who would provide them. It's easier for health professionals to reach the hierarchy in their system than it is for us local people, but it is also hard for professionals to meet and understand us at our level.

Attitudes and language or professional words keep us out of the system. Doors can be opened or closed by the language people use. Luckily we had two sympathetic senior managers in the Health Authority (HA) who supported us and came to our steering group meetings, where they also shared some of their problems which made us realise we were not the only ones with problems. We built up a good relationship with these managers, which remains true today.

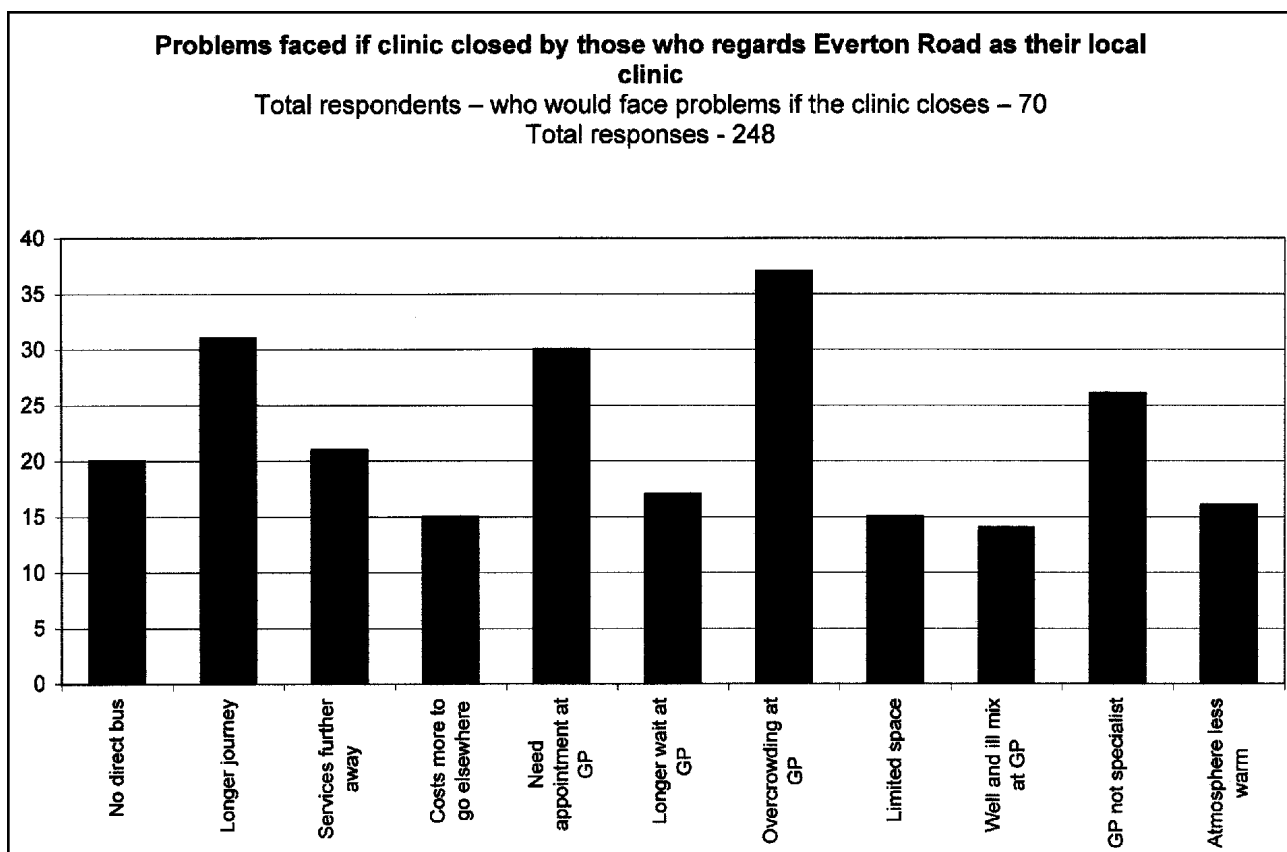## What did I think was good about this project?
The open, honest approach in the training and the survey helped us to build up trust, and as a team, we were successful in saving the clinic and getting more GPs into the area too. We felt we owned the project and that we were all equals, but this took time and commitment to achieve! Through being involved in the research, we have had the confidence to do things which we would not have done before, like speaking at national and international conferences and teaching international Masters students at the Tropical School of Medicine.
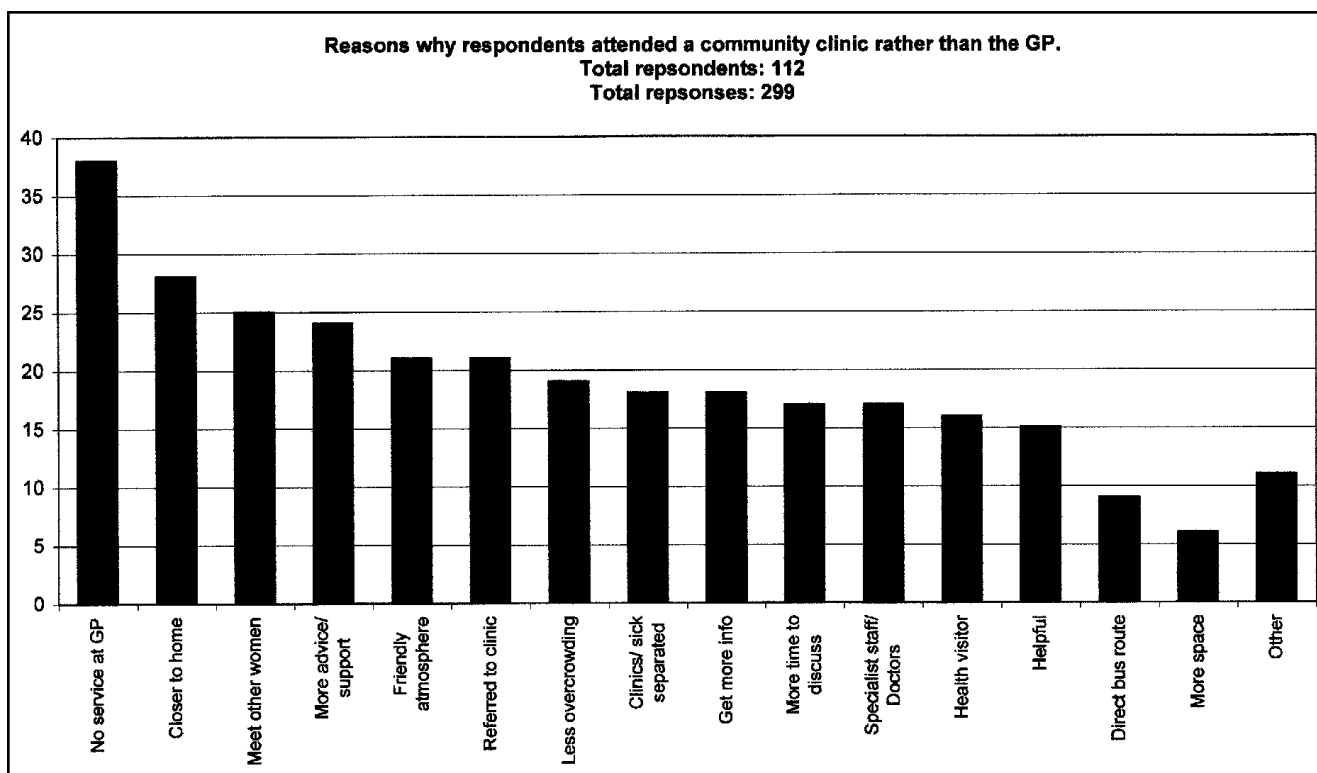
Instead of quiet whispers in the community, we built up our voices to loud-hailer levels, as together we weren't going to be moved from achieving our goals and we did it!

Methodology
Grindl (Research Facilitator and BECHAG Member)

Conventional research is based on values, assumptions and methodologies, which generate an imbalance of

Problems faced if clinic closed by those who regards Everton Road as their local clinic
Total respondents – who would face problems if the clinic closes – 70
Total responses - 248

Reasons why respondents attended a community clinic rather than the GP.
Total repsondents: 112
Total repsonses: 299

power between the researcher and the researched. Participatory approaches may be seen as political, when based on a commitment to align oneself with disadvantaged or marginalised communities. Facilitators must address the way community participation challenges the *status quo.* Developing a participatory process is not simply to collect useful research data, but further to enable the individual and collective empowerment of those participating.

The first challenge is not to take over, but to share and enable all participants to participate in the planning, conduct and outputs of the research. Participants expect the facilitator to bring greater independence and needed skills to the process, and a commitment to ensure local people's voices are heard. However, these expectations can sometimes be exploited by outsiders fulfilling their own agendas.

Local people need to ask specific questions of the facilitator/trainer before activities begin: Who will be making the decisions? What experience/skills does the researcher have? How will they ensure that local people are able to participate in the process? Who will own/control the process and its outcome e.g. reports and academic/professional papers?

Not all communities have the confidence or informed experience to identify the type of skills and commitments they require from professional researchers. The key factor in participatory approaches is that no one person has

ownership or control of the research process. Rather, it is a shared experience based on mutual respect for each other's different skills, experiences and knowledge. The campaign group approached the research with a firm commitment to quality – aware that this would be necessary to convince the Health Authority – but they were also concerned about retaining ownership of the process and its outcomes for the whole community.

The process
A very practical planning framework was applied using flip charts pinned up on the wall (see Fig.1) to facilitate everyone's participation. This enabled people to see and contribute to the progress of the research planning and share their knowledge and experience in developing the focus, the important issues to be addressed and the conduct of the research. Specific tasks were delegated between participants i.e. collecting further secondary data to better inform the final research objectives.

I conducted the qualitative semi-structured interviews after the initial planning was completed and research questions agreed. The local research steering group organised and found initial interviewees and others were identified through them. The preliminary report was edited by the whole team, who used this to develop, field test and edit a quantitative questionnaire. The survey purposely identified those who most used primary care services – those over 60 years, the main carers of children, those with disability/chronic illness – in randomly chosen streets (50) and households (6/street).

Because of limited time, I analysed and prepared a written report on the questionnaire data (300 questionnaires – 73.3% response rate). The final report was edited and commented on by the whole campaign group and included the qualitative and quantitative findings, together with a series of broad recommendations identified by all participants in the research. The team made presentations of the findings to the wider community in public meetings. They later planned, then presented the report's findings and recommendations to the Health Authority Board, which is unusual as communities rarely have such access at this level. Both directly and indirectly, nearly 400 people locally were involved in this research project.

Interim events

During the research, several GPs retired leaving even fewer practitioners in the research area. The HA initiated the appointment of new GPs, but this time, consulted community members via the campaign group. Now better informed and with increased confidence, the research team members prepared and gave presentations, over a lunch of butties at their own centre, to a group of potential GP candidates on the type of attributes they wanted from a new practitioner in their community. Asked if the team would like to appoint a member to sit in on the GP interviews, they decided that the Community Health Council (CHC) representative would attend so as to avoid wider community criticism of the campaign group if the new practitioner turned out to be unacceptable or did not meet their expectations.

Often managers and practitioners see the appointment or invitation of individual community members to sit on various committees as an appropriate approach to community involvement. This is often not a positive experience. Unless the community member is confident, well informed and able to communicate in a language that has other committee members listening, decisions are often rubber stamped and made without that individual's full participation, leading to criticism and resistance from within their own community. There is also the fear that the local representative may be promoting their own agenda and ignoring the wishes of the wider community. In this type of situation, health professionals are often naïve, and lack the experience and skills required enabling local people to participate. Thus, unintentionally, it exacerbates divisions within communities, and excludes local people from exercising power to influence decisions that affect their health and quality of life.

Sustainability in community participation

The greater challenge in health is sustaining local involvement in the longer term. Recent government policy has placed great emphasis on **partnerships** between local communities and government, but this often fails to acknowledge the main factors that enable or disable people from making the concept a reality. In this study, there was some degree of partnership achieved, but

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Figure 1: Planning framework for research and development projects

Policy ➡
Aims ➡
Secondary data ➡
Themes/ categories ➡
Objectives ➡
Sub-issues/ challenges ➡
Informants ➡
Methods ➡
Notes/organisation

Using this framework provides a reminder of the essential steps that need to be taken in the planning process, assists in developing a record of the information being used, enables and stimulates ongoing discussion on the various activities or information being acted on until there is a consensus in the team that the final plan is acceptable. Each step or category aids planners to identify information for the next step, moving from the top of the column (Policy – if that is the starting point or focus for the research) working towards the end of the column (Notes/organisation). Movement between Secondary Data and Objectives usually takes a *to and fro* process before refinement of final research objectives are agreed.

Adapted by G Dockery & K deKoning1994

ultimately much still needs to be changed if the term is to be meaningful and credible. Listed below are the main factors or concepts that, in our experience, are most influential in building partnerships.

Partnership implies and suggests equality between partners through:
- shared visions
- joint decision-making
- negotiated priorities
- shared duties/responsibilities
- mutual respect/trust of – different knowledges,
- skills/abilities, needs, constraints
- **real power sharing – this is the tricky one!**

Reflections on the outcome
Erica (Local resident – BECHAG member)

Six years after the formation of BECHAG, our experiences indicate some of the serious problems that community projects face in developing partnerships and achieving sustainability. Because of it's past history of success, BECHAG is seen as a model of good practice in community involvement. We get asked to do a number of presentations in Liverpool, across the country and abroad. This is hard work, though the results can be rewarding. However, good practice is being allowed to die because of feelings of defeat, disillusionment, demoralisation and exhaustion.

The loss of the Save the Children Fund community development worker, after the formation of BECHAG,

who had provided most of the administrative support throughout the whole process, meant that the time consuming occupation of trying to access extra resources for the long term development of local health initiatives fell to a few volunteers. With less demand for 'hands on' community work, members began to leave the group.

The result is that fewer people are doing more of the work. The reality is that an experienced skilled worker takes a fraction of the time it takes a volunteer who lacks skills in typewriting, computing, written English, bookkeeping or accounting. We need to get local residents involved using the skills they have, like networking in, and finding the real needs of the community, training them to be community advocates and empowering them with confidence to fight for a quality service. With very few professional volunteers in the community, we need paid trained people to do the administrative work that includes researching and applying for funding, servicing meetings and so on, giving local people the time and support to recruit others to campaign for local needs and issues. At present there is neither time nor energy for this. **If local and central government want to take the local voice seriously, they need to seriously support that voice.**

Positive outcomes

We cannot relate all the successes and events that have occurred in this study, but important developments took place at both individual and collective levels. For the participants it was at times challenging and frightening. Their success gave a huge boost to participants' self-esteem and confidence, captured people's interest in health matters and inspired them to continue, leading to the formation of BECHAG, with ongoing links and activities in the local community health clinic, and continued involvement in other community development initiatives.

We have won regional and national awards for health development initiatives and community-led activities. Many participants have gone on to further personal development paths including access education courses, employment and the development of crucial skills that have enabled them to become important assets within their own communities in the daily struggle for a better quality of life. Outsiders played an important supporting role, but crucially everyone worked together in developing relationships that were built on trust. The challenge now is to achieve greater equality in decision-making on issues that most affect community health and quality of life.

Concluding comments

Many of the points raised here about sustainability, support from the statutory sector and community volunteering in health, reflect the experience of many communities from different contexts. The political or professional rhetoric on partnerships usually ignores the inequality that exists between the different parties and their ability to equally access resources and exercise power. It is often left to local people to initiate meaningful working relationships with the statutory sector or funding agencies and this dramatically increases the workload and pressure on communities who are already stressed by poverty. Those most affected by this are usually women, who are the main carers in families and volunteers in health and social movements, but are least able to exercise power in wider society and at policy and planning levels within government.

Innovative approaches that enable communities to have meaningful participation in health and that bring professional health workers closer to the community will generate inevitable tensions between professional duties or demands and those of the community. These can be limited by all parties being realistic in their expectations and building relationships that are based on mutual respect. There is also a need for professional workers to be re-trained or develop further those skills that enable them to work with communities in a participatory way. Despite positive outcomes in this case study, the longer-term process of sustainable development continues to raise important questions for all those committed to reducing health inequalities.

There is no magic toolkit in participatory approaches, but we believe that anything is possible when positive relationships are based on equality and when both visions and power are shared!

Acknowledgements

Abbreviations

HA -   Health Authority
NHS -   National Health Service
CHC -   Community Health Council
GP -   General Practitioner (Dr)
CAB -   Citizens Advice Bureau

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For further information, and for discussion on participatory approaches in health research in the UK, from a theoretical and practical perspective, see listed references below:

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