



## **Patient and public involvement in Primary Care Groups and Trusts**

---

### **City & Hackney case study**

Draft report, July 2001

Will Anderson & Dominique Florin, King's Fund Primary Care Programme



- ◆ Patient and public involvement in Primary Care Groups and Trusts: City & Hackney case study

## Acknowledgements

Undertaking six concurrent case studies across London has been challenging. Happily, in every locality I have met people with enthusiasm, interest and good humour. Thank you to everyone for supporting the research, giving up your time to talk to me and welcoming me as a participant and observer in your many events and activities.

In particular, I would like to thank:

- Elizabeth Bayliss
- Laura Sharpe
- Errol Franklin, Mary Cannon, Cathy Pelikan (.....) and the members of the City & Hackney Community Participation Steering Group
- Gaby Tobias, Clare Highton, Mary Clarke and all the members of the City & Hackney PCG board
- Hilary Scarnell, Barbara Landey, Maureen ? and all the officers of the PCG
- Janet Richardson, Jane Leaver and the City & Hackney CHC
- The six respondents in the substudy on frontline community intelligence

Will Anderson, July 2001

# Contents

Introduction .....	4
Description .....	5
The model.....	5
Context.....	6
Approach.....	6
Mechanisms of involvement and mechanisms of change.....	7
Outcomes .....	8
Analysis.....	9
Structure.....	9
Why bother?.....	10
What counts as public involvement? .....	10
What do you want to achieve? .....	11
Working out an approach.....	12
Making a difference .....	13
Getting the details right .....	14
Dangers and obstacles.....	15
Doing it better.....	16
Special focus .....	17
Valuing the knowledge of workers in primary and community care.....	17

- ◆ Patient and public involvement in Primary Care Groups and Trusts: City & Hackney case study

# Introduction

This report has been written for the members and officers of City & Hackney Primary Care Trust (formerly City & Hackney Primary Care Group) and their partners in the local health economy. It presents the results of a study of the PCG's patient and public involvement (PPI) work between February 2000 and April 2001.

City & Hackney was one of six case studies participating in a King's Fund study of PPI in primary care groups and trusts, funded by the Health in Partnership initiative of the Department of Health. This report is one of six case study reports from each of the six sites. The sites were:

- Central Croydon PCG
- City & Hackney PCG (became City & Hackney PCT in April 2001)
- Dagenham PCG (became part of Barking & Dagenham PCT in April 2001)
- Harrow East & Kingsbury PCG
- Hayes & Harlington Directorate, Hillingdon PCT (formerly Hayes and Harlington PCG)
- North Lewisham PCG

All but one of these case study reports are presented in the same way in order to enable comparison between them. This report is divided into two main sections: a descriptive overview and a more detailed analysis. Although the headings used are not ideal for every case study, and may not always seem intuitive, they provide a guiding framework both for comparison of the individual case reports and for the development of the final output from the study.

A full 'cross-case analysis' will be published early in 2002, designed as an accessible guide for practitioners rather than as a pure research report.

A number of secondary pieces of research were conducted in the participating sites, defined by the interests of the participants within each site. In the City & Hackney case study a particular interest was taken in the community intelligence of frontline workers in primary and community care. The report from this substudy is included in this report.

# Description

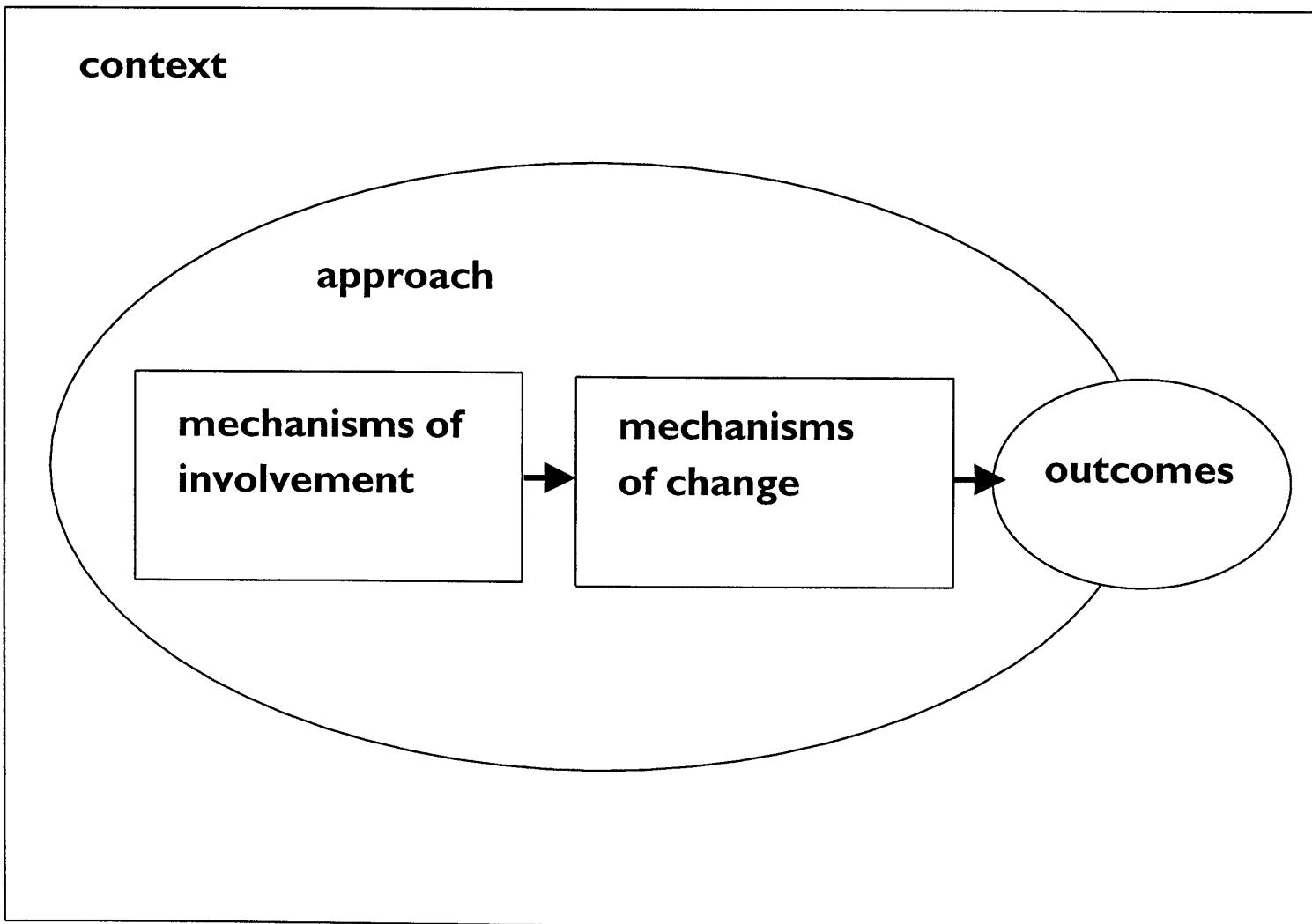
## The model

This section describes both the detail of the PPI work that was undertaken and the broader context which shaped this work, including local history, organisational priorities and professional values.

The model, based on that of Pawson and Tilley (*Realistic Evaluation*, Sage, 1997), has five different elements: context, approach, mechanisms of involvement, mechanisms of change and outcomes. Together, these offer a comparative description of each locality. In summary:

- The context is the givens: the things you do not have much choice about.
- The approach is the choices that have been made (recently or otherwise) to shape the form of local PPI.
- The mechanisms of involvement are the specific PPI initiatives undertaken.
- The mechanisms of change are the processes by which PPI has an impact.
- Outcomes are the results (which may include changes in processes).

The main point of the model is this: if something works in one place, it may not work in another. To get PPI right, you have to make it work for your circumstances and your values. Similarly, in order to make sense of PPI initiatives, we have to attend to local history and local priorities as well as to the detail of how they are actually implemented.



- ◆ Patient and public involvement in Primary Care Groups and Trusts: City & Hackney case study

## Context

---

- City & Hackney PCG was established in April 1999 and subsequently merged with the local community trust to become a PCT in April 2001. The PCT covers a large population (220,000) in one of the most deprived parts of the country. Of the London boroughs, Hackney has one of the highest scores on the Department of the Environment Index of Local Conditions (only Newham and Southwark have marginally higher scores). The population includes an estimated 37.5% from ethnic minorities. The City of London has a tiny, prosperous population.
- The PCG board members were committed to working in partnership with local people and stakeholders in the health economy. Openness and trust were identified at the outset as important organisational values. This was partly because of the failures of trust that characterised the local history of public consultation – there have been several poorly executed and counter-productive public involvement initiatives in the area.
- The demands on the PCG were enormous, principally because of the extent of local deprivation and the low provision and standards of primary care services. On top of this, the decision to become a PCT at a relatively early date put considerable organisational development demands on the officers.
- There is a wealth of community and voluntary activity in the area, but the sector suffers from chronic under investment. Many organisations have been struggling to survive as the effects of a bankrupt council are felt across the sector. The CHC has a high profile and a strong relationship with the PCT.
- The creation of the PCT and merger with the community trust involved the development of a new Health and Social Care Partnership Board with representation from the PCT, local authority and voluntary sector.
- The lay member brought a wealth of experience in the local voluntary and community sector to the PCG board (not least as Director of a local community research organisation). Although the board took a corporate view on PPI, the lay member was expected to provide leadership on this issue. She has now become a non-executive director of the PCT. Other members and officers, not least the chief officer, also had experience of public communication and involvement work.
- A Community Participation Steering Group was created to provide a focus for the development of PPI, chaired by the lay member. The group has a wide membership, including representatives from the voluntary sector, local authority and tenants' associations as well as PCG and primary care staff and professionals. A separate group was established to manage the PCT consultation process.
- Resources and support for the PCG's PPI work were very limited beyond the specific funding identified for the PCT consultation. Officer support has been a particular difficulty – the key officer with responsibility for PPI was consistently unable to make time for it because of the extent of her workload.

## Approach

---

- The most significant choice made by the PCG was to 'break with the past', i.e. to try to create an organisational culture built on openness, trust and partnership, rather than defensiveness and secrecy. This has meant being much more responsive to the questions and interests of other stakeholders in the local health economy.
- Within the PCG there have been different interpretations of the radicalism of these values. In particular, the lay member has been committed to creating an 'open system' in the local health economy in which everyone's views are respected and valued. This has meant putting a lot of time in to sharing ideas across the sectors rather than imposing a particular model of PPI. However there have been real difficulties moving beyond this stage to the design of appropriate PPI work. There is no written strategy for PPI.

- Nonetheless, the PCG's commitment to working in partnership has been evident across its operational activity and is now more clearly formalised in the Health and Social Care Partnership Board.
- As well as working with the voluntary and community organisations closest to the PCG (near voices), effort was also put into reaching the far voices – the communities which have little or no contact with the PCG or even with local health services. The importance of 'going to the community rather than expecting the community to come to you' has been widely articulated and was a strong theme of the PCT consultation.
- Alongside this tension between the near and far has been a more radical understanding of the local community which deconstructs the distinction between professionals and lay people, organisation and community. A real interest has been expressed in exploring how the people who work for the organisation can be channels of community intelligence, both through their interactions with local people as providers and through their own identities as patients, carers and citizens.
- The key people within the PCG understood the importance of working with the pluralism of the local community, including the need to understand health issues on terms other than their own. However the demands of the PCG development agenda and the lack of resources for PPI made it very difficult for the organisation to be genuinely challenged by alternative, non-professional perspectives on the health of the community.

## Mechanisms of involvement and mechanisms of change

---

- The lay member. The lay member was respected as a lay voice on the PCG board. Her input was characterised by her professional knowledge of community issues such as regeneration and community development programmes and funding streams. She consistently encouraged the board to think about their responsibilities to the health of the local community in the broadest terms.
- Board meetings. The PCG board meetings attracted few members of the public, but were well-run to ensure that anyone who did attend was welcomed, knew who the members were and had opportunities to speak.
- The Community Participation Steering Group. This group suffered from a lack of clarity about its own role. The lay member wanted it to be principally a place for discussion and overview, bringing together a variety of local stakeholders to build a shared understanding of PPI priorities and activity in the area. The officers, including the officer with responsibility for PPI and the chief officer, wanted it to be more of an executive group which actually planned and implemented the PCG's PPI work. However, the lay member's wariness of imposing a programme and the lack of officer support in practice meant that the group remained largely a discussion forum. The lay member took issues raised by the group to board meetings and to other forums where appropriate, but there remained a lack of capacity to deliver on them.
- PCT consultation. The PCT consultation, planned with the local CHC and voluntary sector, involved outreach to a large number of local community groups. These meetings were designed as opportunities for members of the groups to identify their priorities for the new organisation. The outreach was very successful, but the implementation of the identified priorities has been stalled because of the difficulties faced by the Community Participation Steering Group in performing an executive role.
- Patch meetings. The local area is divided into four patches, each with a patch manager. Patch meetings are intended to bring together all the professional and community stakeholders in each area to discuss common concerns. The participation of community and voluntary organisations in these meetings has been variable.
- Newsletter. The PCG/T newsletter is distributed to a very wide community audience, exploiting a detailed local database of voluntary and community sector activity. The newsletter is an opportunity for two-way communication as recipient organisations are invited to submit news and articles.

◆ Patient and public involvement in Primary Care Groups and Trusts: City & Hackney case study

- Citizens' panel. The health authority and three local authorities in east London fund a citizens' panel survey. The PCG is able to contribute questions to this survey, but problems of communication and administration have so far inhibited effective use of this resource.
- Working relationships with the voluntary sector. The Health and Social Care Partnership Board represents the formal realisation of the PCG's commitment to partnership working in the local health economy. However, there are a range of less formal relationships which come into play on a regular basis, particularly with the CHC, and the local Carer's Association.
- The HlMP. The HlMP is perceived to be a key mechanism for driving the PCT's commitment to PPI, particularly by the lay member. However, the development of the HlMP remains bureaucratic and far from her 'bottom-up' ideal.

## Outcomes achieved

---

- an organisational culture which is respected by community organisations for its openness and honesty
- greatly improved relationships with local community and voluntary organisations
- identification of community priorities for the new PCT
- increased understanding across the health economy of the activities and interests of its constituent parts

# Analysis

## Structure

---

The structure of the analysis reflects the structure of the main output of the study – a practitioners' guide to PPI in primary care. Although this structure suits some of the case studies better than others, it has been consistently used for all of them in order to enable comparison. It aims to be an accessible framework which covers all the key issues which people involved in PPI work are likely to be concerned about – as well as providing plenty of hooks on which the research themes from the study can be hung.

The gist of the structure of the guide is this:

### **Why bother?**

The case for PPI always has to be made. If people pursue PPI only because it has to be done, not because they see any value in it, little is achieved and lots of people get annoyed. This chapter will encourage a critical attitude to all PPI work.

### **What counts as public involvement?**

PPI means different things to different people. This chapter will map out the scope of what PPI can encompass, stressing the value of a broad and plural vision.

### **What do you want to achieve?**

This chapter will look specifically at the aims which people identify for PPI, and the outcomes which actually emerge in practice. It will stress the importance of being open to unexpected outcomes and to changing your ideas of what success might mean as methods get put into practice.

### **Working out an approach**

This chapter explores the many choices which people make, explicitly or implicitly, in developing PPI work, and the constraints upon these choices.

### **Making a difference**

The question of making an impact (mechanisms of change) gets a chapter to itself, principally because it is so widely neglected.

### **Getting the details right**

The detail of doing PPI is widely discussed in existing 'toolboxes'. This chapter will not repeat these, but draw attention to the detail of what has helped and hindered initiatives in the study.

### **Dangers and obstacles**

This will be a critical discussion of how all the above can go wrong or be obstructed. The emphasis of the chapter will be on seizing the opportunities of PPI and not being put off by the range of common but narrowly conceived criticisms.

### **Doing it better**

The final chapter will explore how people can learn from their experience of PPI, stressing the value of all types of evaluation and learning, however informal.

- ◆ Patient and public involvement in Primary Care Groups and Trusts: City & Hackney case study

## Why bother?

---

### **Why is any PPI happening at all? How critical are local stakeholders of why they are doing PPI?**

The PCG began life with a corporate commitment to building a new culture of openness and partnership in Hackney. This was driven by a recognition of the troubles which had beset the health economy of east London and a determination to use the new structure as an opportunity to break new ground. The PCG's commitment to community participation is therefore part of a broader commitment to working in partnership with all the stakeholders in the local health economy.

Despite the acceptance of stakeholder involvement as a core value, the work of community participation remained a low priority, pushed out by the many demands of the development agenda. Only those with a clear vision of the long term gains from community participation went on making the case for it.

The lay member was the key person making such a case in the PCG. For her, the PCG's commitment to working in partnership with other local stakeholders was a radical vision: transforming the health economy through the creation of an 'open system' in which everyone's voice is valued. However, she also recognised that greater commitment to (and investment in) community participation may only happen if other members and officers recognise the potential gains for the organisation's core business, requiring the case for community participation to be made less in terms of the process of delivery (working in partnership) and more in terms of the realisation of outcomes – the health and well-being of local people. However, there has rarely been any opportunity for critical debate among members about the value of community participation, not least because in principle everyone is signed up to it.

## What counts as public involvement?

---

### **What are local stakeholders talking about when they discuss PPI? How narrow or broad are their conceptions?**

The PCG expressed a remarkably broad understanding of what patient and public involvement – or rather community participation – encompasses, particularly through the meetings of the community participation subgroup. Items which appeared on the agenda of the community participation subgroup included:

- lay and community representation in the formal structures of the organisation
- specific initiatives to consult with local people
- relationships with community and voluntary organisations
- the work and participation initiatives of other local organisations
- information and networking across the health economy
- local investment in the community and community-based initiatives
- the capability of the PCG to assess community needs
- the systemic problems which disempower local communities
- the role of workers and professionals in the health economy as members of the community and conduits of community intelligence

This agenda describes a vision of community participation which includes both traditional mechanisms of patient and public involvement and a longer-term interest in community development and empowerment. The subgroup was concerned not simply with the process of dialogue itself, but on the sizeable dual contexts of

dialogue – the needs and resources of the community and the understanding and resources of the PCG and its partners in the health economy.

The interest the subgroup took in ethnic monitoring illustrates its breadth of concern. Ethnic monitoring is not an issue which obviously falls under the participation brief, yet it was not out of place in the group's discussions. The local failure to fully implement ethnic monitoring meant that at a basic systems level the organisation was failing to understand its users. Thus although community participation can be conceived narrowly as one of many ways in which an organisation learns about its users and community, it was conceived here as the entire process of communication and learning between organisation and community.

The unique focus in this case on the ways in which frontline staff could be conduits of intelligence about the local community, as workers or local people, also demonstrated the subgroup's imagination in thinking about the relationship between organisation and community. However, this focus on the needs of the local community relegated patient and carer participation: the group was not interested in practice-level involvement and never sought the involvement of any GPs in its work. Progress in community participation was perceived to be more readily gained at a corporate level, given the existing pressures upon local primary care services.

## What do you want to achieve?

---

### **What are local stakeholders trying to achieve? How explicit are their aims? And what are the potential outcomes?**

Community participation was integral to the PCG's commitment to openness and to working in partnership with all local stakeholders in the health economy. The principle aim of community participation work was therefore to promote a way of working based on trust and respect. This is a process outcome, but not 'just' a process outcome. The organisation upheld these values because it believed that only by working in this way could it strengthen and develop local services and their health-improving potential. Thus the process of working in partnership served the greater process of improving the health of local people. It may not be easy to demonstrate such a link, but this is why openness and partnership are values rather than technical choices. In the view of other local stakeholders – notably the CHC – the PCG has been very successful in achieving these aims, changing a long established culture of defensiveness and isolated practice.

The broad vision is complemented by the more focussed aims of particular initiatives. The PCT consultation process, for example, set out to inquire into what local people wanted from their health services, with the aim of taking these views into account in the development of the new organisation – designing services to respond to community needs. However the consultation process was judged by the board to be a success on process terms: groups attended, quality of debate, issues raised. There has yet to be any impact on the organisation.

Within the subgroup, the chair's broad vision of community participation as a process of opening the health economy to enable all its stakeholders to have a voice represented a radical interpretation of the organisation's corporate values. Other members of the subgroup, particularly the key officer with responsibility for community participation, wanted a greater focus on more immediate outcomes for the organisation and the community. However, because there was always ambiguity about the role of the subgroup itself (see below), these more fundamental questions about the role of community participation tended to get sublimated.

In practice, because the subgroup's agenda was so broad, most of its members were able to participate without feeling that their own sense of the purpose of community participation was being excluded. Early on, the group spent some time mapping the range of local community participation activity. At no point in this process did anyone challenge whether something should be part of the map or not, or even question the boundaries of the map. The inclusiveness of the group meant that all the possible outcomes of community participation were effectively acknowledged, even if they were not made explicit.

However, this made it hard for the group to decide where it should focus its energies and act. In the event, this decision was imposed by the board, which charged the group with the task of implementing the outcomes of the PCT consultation. The board's action and the group's passive acceptance illustrate the dangers of pursuing a

- ◆ Patient and public involvement in Primary Care Groups and Trusts: City & Hackney case study

broad vision without clear priorities – by not defining their own objectives, it was easier for others to impose their own.

There was, then, a lack of clarity about aims, but a consensus that community participation is essential to a healthy public organisation and so, in time, to a healthy community.

## Working out an approach

---

### **Why have the particular local methods of PPI been adopted? What choices have been made?**

The PCG's corporate commitment to stakeholder involvement did not ensure that community participation was taken seriously across the organisation. There was a degree of marginalisation in practice: the lack of resources made available for community participation, including officer time, inhibited anyone other than members of the community participation subgroup giving it much attention.

The subgroup itself faced an institutional catch 22: the group's chair wanted it to have an oversight role, monitoring all the organisation's work and making sure community participation is taken seriously within it. But the very existence of a 'community participation subgroup' allowed other members and officers to identify this group (and not theirs) as the locus of community participation activity. The board's decision to give responsibility for implementation of all of the key points of feedback from the PCT consultation to the subgroup may have been based on an understanding that the subgroup had a corporate responsibility, but the effect was marginalizing: there has been a failure to take the consultation findings to heart in all the areas of the PCG's work.

Within the subgroup, this corporate/marginal problem was one of the elements of a greater tension – between talk and action. The subgroup's chair argued for a sustained strategic discussion of community participation and resisted the pressure to lose this discussion for the sake of the business of implementation, although she did also want to develop an 'action plan'. The principal concern which defined her approach was the complexity and diversity of the local community and the range of stakeholders in the local health economy. The challenge, and the main point of spending time talking rather than doing, was to enable people to come together from across the health economy to share values, ideas and practice. Building a shared vision of local practice, albeit out of a range of different commitments and understandings, was perceived by the chair to be the only way to address the plurality of local needs. Going it alone was not an option. This approach was reflected in the representation on the subgroup of people from all sectors of the health service, the council, the CHC and the voluntary sector.

Although the membership of the subgroup suggested a priority for networking and communication rather than executive action, the pressure to act was always present in the group's discussion. However, as well as the strategic investment to talking rather than doing, there was also a critical lack of officer capacity to realise any commitment to action. The chair of the subgroup was always wary of asking the officer with the brief to take anything on and the officer always made clear the extent of the demands upon her time. Hence although it was the key officer who urged the subgroup towards action, she was unable to offer much time to implement any action and the chair was unwilling to press her for more.

As the subgroup has never been clear about the balance it should strike between talking and doing, it has lacked the confidence, as well as the resources, to choose where and when to act. Making such choices inevitably means narrowing the focus of the discussion; something the subgroup has been unwilling to do. When the subgroup was given the results of the PCT consultation to act on, it struggled, eventually choosing to create further subgroups to tackle each of the four key points of feedback. However, this move coincided with the creation of the PCT and the closer involvement of officers from the health promotion department (previously part of the community trust).

The context of Hackney's diverse population defines another key choice of the PCG: a commitment to reaching out beyond the more familiar community voices to individuals and communities whose voices are not usually heard in health service decision-making. This commitment is, inevitably, difficult to realise in practice.

The PCT consultation was informed by this principle – reflected in the explicit attempt to go out to communities and engage with them on their own turf rather than expecting the community to come to the PCG. However, meeting people on their own turf does not necessarily mean meeting people on their own terms. Although the consultation was designed to be accessible and to give people a chance to talk about their own concerns for health services (rather than simply asking them what they thought of the PCT proposals), the agenda was still set by the PCG and the feedback reflected a focus on health service delivery. This was necessary – this was, after all, a formal consultation about changes in delivery – but it illustrates the difficulty for the institution of giving communities the opportunity to identify their own health priorities. It is one thing for the PCG to make its agenda simpler and more accessible, another for it to work with the complexity of someone else's health agenda, which may have little to do with what the PCG can influence.

However imaginative the PCT consultation may have been, it was a one-off process, albeit providing a range of contacts for on-going dialogue. Within the community participation subgroup, there is an understanding that engagement with the whole community is a long term goal, dependent on the development of a range of relationships with intermediary organisations as well as enterprise outreach. Despite the diversity of the subgroup's membership, it has struggled to build such relationships. A protracted engagement with a local tenants' convention held great promise but suffered from a lack of sustained input from the PCG. Working in partnership and tapping into existing mechanisms of communication and participation is demonstrably not a cheap option.

Despite such problems, the PCG has demonstrated that it values the role of the community and voluntary sector and has not been side-tracked by arguments about representation – in a population as diverse as Hackney's, it is self-evident that engagement with the voluntary sector can never achieve this elusive ideal. The voluntary sector is formally involved in the reference groups of the new Health and Social Care Partnership Board, but there are also a range of informal contacts, not least through the community participation subgroup, which sustain, to some extent, the voice of local organisations in the PCG's work.

## Making a difference

---

### **Do PPI initiatives bring about change? What are the mechanisms of change, both for the organisation and for patients and local people?**

The PCG's commitment to working openly in partnership with other local stakeholders has had a great impact upon the culture of the local health economy. Although circumstances have been difficult, the PCG has built trust by being open about these difficulties rather than trying to present a false corporate profile to its many local partners. Community participation has been, and continues to be, part of the long term process of building effective partnerships and through them a healthier economy.

This broad vision has not, however, been matched by attention to the detail of change. Community participation has been perceived as an organisational value which contributes to a range of potential outcomes, but it is not intimately linked to the business of the organisation, i.e. the range of organisational objectives which members and officers are involved with on a daily basis.

The community participation subgroup developed its own agenda, but in doing so failed to make strong connections with the existing agenda of change in the PCG. This is partly because the subgroup's chair did not see community participation principally as something instrumental to other goals, but as a necessary part of organisational culture; and partly because she did not have close daily contact with the business of the organisation. There was plenty on the PCG's development agenda that could have been open to community participation, but there was no-one with a clear role to identify and exploit these opportunities (to 'find the hooks'). For the chief officer, the value of community participation was always linked to other organisational goals, but her priorities were inevitably focused on the achievement of those goals, usually without any community participation input.

The PCT consultation was a partial example of the effective use of existing processes of change – the formal duty to consult was treated as an opportunity to explore what local people might really want from the new organisation. However, the PCT emerged quite happily without any progress in acting on the feedback from

◆ Patient and public involvement in Primary Care Groups and Trusts: City & Hackney case study

the consultation. Although implementation of the consultation feedback has begun, the key process of change – and so the key opportunity for influence – is over. The design of the consultation focussed on an imaginative approach to consultation, but failed to address the process which would be needed to turn the learning from the consultation into changes for the organisation. A considerable investment in the front-end process was undermined by a singular lack of capacity to deal with the less visible but more critical process of corporate change.

Without the connections being made to organisational needs, and without people in place to make such connections work, the intelligence which the PCG gains through community participation loses its power. The protracted discussion about the local citizen's panel is an example – no-one was ever very clear about the value of its outputs because the questions were created at a distance from the pressing concerns of the organisation.

Latterly, the community participation subgroup has begun to make some connections more explicit. In particular, the Hlmp is perceived by some to be a critical locus for community participation because it is the defining document which should inform the SAFF and the PCIP. It remains to be seen whether there is enough leverage in the Hlmp to make it an effective vehicle for community input.

Although the subgroup had problems with officer support, when the lay member took issues to the board, they were taken seriously by the chair and other members and acted on. This appeared to be the main mechanism through which the group could tap into officer support and bring about change.

This discussion has focussed on the difficulty of connecting community concerns with organisational interests. However, community participation is also about the organisation showing concern for community interests, rather than its own. Inasmuch as this happens at all, the mechanism of change is much harder to realise as there may be no institutional interest in the changes proposed. The creation after many years lobbying of a local sickle cell centre reflected, in the view of the director of the CHC, nothing less than the determination, perseverance and political will of the local people who had fought for it.

## Getting the details right

---

Board meetings. Public board meetings were held every month, and were usually attended by a few members of the public. They were run well:

- papers were sent out ahead of the meeting to anyone who wished to receive them
- the venue was small enough to ensure that everyone could be heard
- the fourth 'side' of the table was open to the public
- the chair welcomed everyone, including members of the public at the beginning
- every board member introduced themselves, in turn, to the audience

However, public input was limited to an open discussion at the end; members of the public were not invited for their input after each item on the agenda.

The lay member. The lay member was accepted and respected by other members of the board. As the director of a community-based research and development organisation in the neighbouring borough, she was able to bring to the board a detailed knowledge of the wider agenda of health – regeneration, housing, neighbourhood renewal – and pressed other members to try and make the connections with this agenda. She did not try to represent the community, but made representations to the board about community needs and opportunities. In doing so, she was challenging the other board members not to think of her as a community voice, but rather to think more strategically in their decision-making about the needs of the community.

PCT consultation. During the development of the PCT consultation, officers were keen to find a way of talking about the process which did not use the word 'consultation', thereby distancing themselves from the disastrous history of consultations in the area. In the event, what they came up with was not a new name, but a new approach. Critically, the PCG treated their obligation to undertake a consultation as an opportunity for the new

organisation rather than one more bureaucratic hoop to get through. The question of whether or not the PCT should be established was marginal to a broader discussion with local groups about what they would like from the PCT. The consultation was also treated as a 'trial run' for how the new PCT should engage with the local community on an on-going basis. Although the follow-up to the consultation has been weak, the front-end was a creative response to a statutory requirement, avoiding the risk of wasting lots of community energy to gain a rubber stamp for decisions already made.

The community participation subgroup. The breadth of this subgroup's agenda and the diversity of its membership have been both strengths and weaknesses. Members of the group had real opportunities to share ideas, reflect on local practice and develop an understanding of community participation which extended well beyond the PCG. The group survived because it was valued as a place to talk about community needs and participation away from the 'coalface'. However, its disconnection from implementation (for both strategic and practical reasons) was a source of disillusion for many members, some of whom left. Now, with increased officer support and a stronger focus on implementation, the subgroup will once again face the challenge of getting the balance between reflection and action right.

The Health & Social Care Partnership Board. This board only came into being with the PCT. However, there was much discussion prior to its creation of how it would operate and how community and voluntary sector interests would be represented. Early in this discussion, the lay member noted that attention to the formal structure needed to be matched by attention to the informal dynamics which make the critical difference in practice. She was proved right: the very first meeting of the board was a bitter experience for the voluntary sector representatives attending, who felt that the meeting had been a 'stitch-up', lacking precisely the qualities of openness and partnership which the structure had been designed to facilitate.

The newsletter. The PCG's newsletter was widely valued because it gave a consistently high level of detail not only about PCG policy but about the range of activity in the local health economy. The simple procedure of encouraging readers to submit articles about their own services helped to ensure that it presented more to its audience than a PCG perspective on the world.

The art of building trust. The Director of the CHC expressed most concisely why the PCG's relationships with its local stakeholders had prospered. The PCG had been honest about its capabilities and not sought to change the world overnight. Consequently, it had not ended up playing a game of defensiveness and spin. This meant that local people could see and accept that the PCG was, in fact, trying to do something, and so gained confidence that their own voices would be heard rather than ignored.

## Dangers and obstacles

---

Lack of officer support. Although the PCG's approach to community participation was sophisticated, it suffered from a very simple problem: the lack of any clear, sustained officer support. The only specific ongoing support was for the newsletter. Numerous opportunities rose within the community participation subgroup only to fall away because of the lack of capacity to pursue them. Crucially, these were not typically suggestions for specific bits of participation work, but opportunities for engagement with existing networks or ideas for improving practice across the PCG.

Embracing diversity and providing direction. The development of community participation work in a place like Hackney requires attention both to the diversity of local community interests and needs, and to the diversity of local institutional and professional values and interests. The lay member recognised this and set up a process in the community participation subgroup which, to some extent, brought together a range of these different institutional interests to consider how to engage with the range of local community needs. The difficulty with the process, as with any process of working with both mutual and disparate interests, has been direction. The lay member was unwilling to impose an agenda, because she is committed to working from 'the bottom up', i.e. giving other member an equal role in defining the way forward. In practice, this proved difficult because of the ambiguities about the subgroup's role and the turn-over of its membership. It may be that the agenda defined by the community, through the PCT consultation, will resolve this perennial problem.

- ◆ Patient and public involvement in Primary Care Groups and Trusts: City & Hackney case study

## Doing it better

---

In the community participation subgroup, the PCG had an ideal forum in which to reflect on practice and learn from experience across the health economy. The discussions within the group often touched on members' knowledge and experience of existing and past practice. However, because the PCG did not actually do very much beyond the PCT consultation, there was little within the PCG to learn from. The PCT consultation itself was judged to have been successful (in process terms) and helped to ground the organisation's commitment to 'going out' to the community as well as bringing the community in.

The value of the community participation subgroup as a locus of learning rested in the breadth and the depth of its experience, i.e. in the diversity of the membership, drawn from across the health economy, and in the long histories of local experience in participation which some members brought to the group. Different professional perspectives were also important; for example, one member of the subgroup who worked in mental health services consistently offered the critical insight into professional values of mental health service users.

Even in this favourable context, opportunities for learning were easily lost because of the size of the subgroup's agenda. For example, a representative from the local tenants' associations brought to the group's attention the new tenants' compact which had been developed locally. Although the group expressed keen interest in this process and acknowledged that they would probably learn a lot from it, the opportunity was lost.

Patient and public involvement in Primary Care Groups and Trusts: City & Hackney case study ◆

King's Fund



54001001329658