King's Fund

Patient and public involvement in Primary Care Groups and Trusts

Harrow East & Kingsbury case study

Draft report, July 2001

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

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.

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Will Anderson, July 2001

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Introduction

This report has been written for the members and officers of Harrow East & Kingsbury PCG 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.

Harrow East & Kingsbury 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.

Description

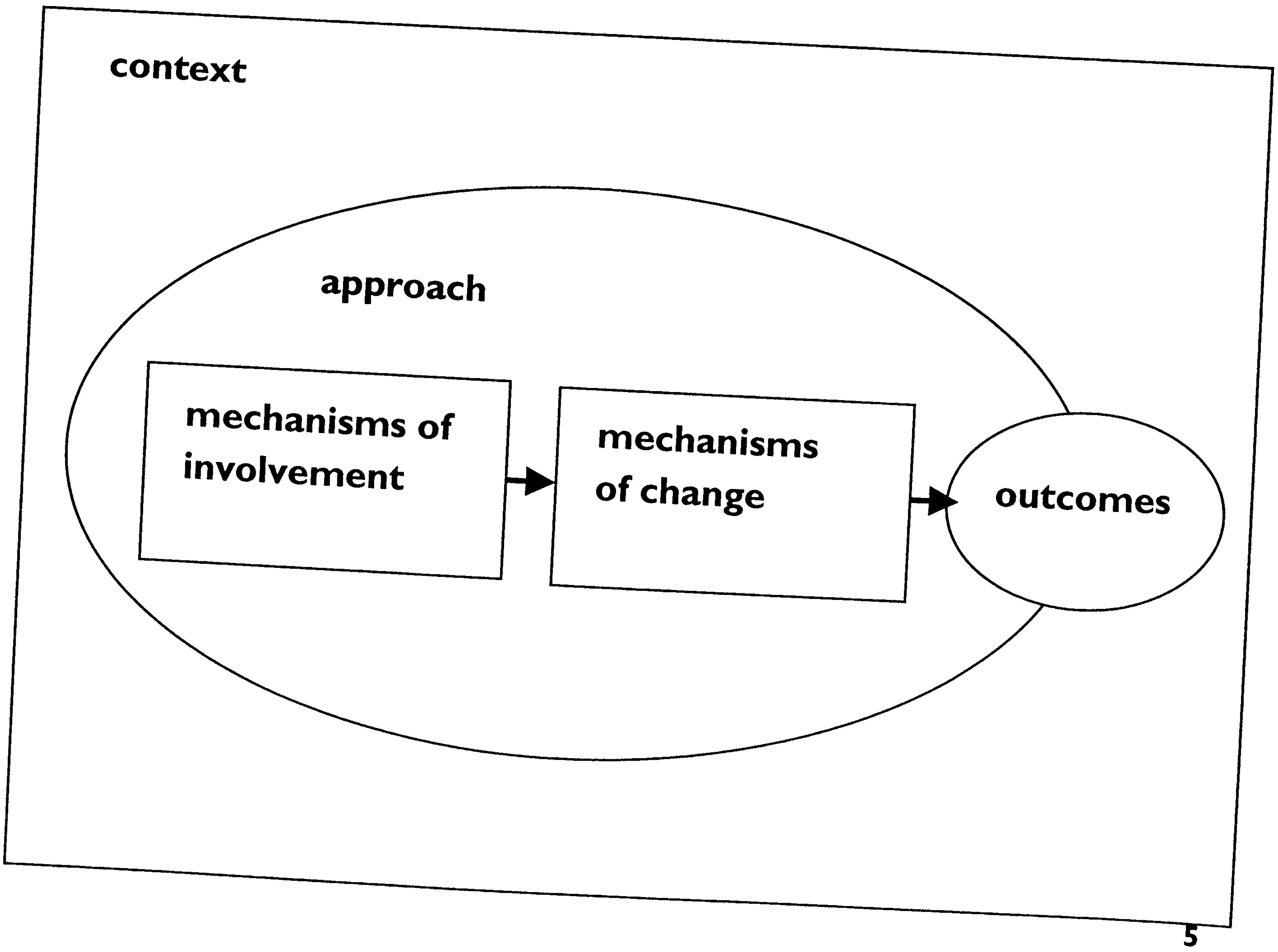
The model

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.



Context

- Harrow East & Kingsbury PCG was established in April 1999, building on a history as a total purchasing pilot. It straddles two local authorities: Harrow and Brent. Kingsbury, the area in Brent, is thought to form a 'natural community' with the east of Harrow. The PCG has a population of 101000 in a relatively prosperous area of London – though not without its areas of localised deprivation. It has a large ethnic minority population, predominantly South Asian.
- There is no history of direct PPI work within the PCG. A survey of the constituent practices undertaken by the PCG also revealed no experience of practice-level patient participation in any meaningful form.
- The lay member has considerable personal experience of the health service as a user and carer, and in providing pastoral care to people with health needs. He also has experience as a school governor. He does not have experience of wider public involvement work, but is charged by the board to lead the PCG's work this area.
- A Patient and Public Involvement Subgroup is chaired by the lay member. Other members of this group include: two PCG officers, a GP member, a nurse member, officers from both local CHCs, a social services officer and the minority ethnic communities officer from the health authority's community involvement directorate. The two PCG officers provide what support they can to the subgroup, though they have many other responsibilities.
- There is considerable local experience of partnership working, particularly through the Harrow Partnership: a collaboration initiated by the borough which brings together local statutory and community organisations in four policy streams, one of which is health and social care. The chief executive is both very committed to, and very involved in, this process.
- None of the board members have significant experience of PPI; however the work is supported in principle and there is no opposition to the lay voices: the views of the lay members and CHC officers are respected.

Approach

- The lack of experience and expertise in PPI within the PCG is reflected in a fairly *ad hoc* approach. There is commitment to the work, recognition of the policy requirement to deliver on PPI, but a lack of strategic thinking about what ought to be done and why.
- There is however a general consensus that PPI should inform the provision and development of primary care services – shaping services to needs. This includes a strong interest in demand management, a particular priority of the chair which is also pursued by the officers.
- The tension between outcomes for patients and outcomes for professionals and the organisation is characteristic of PCG debate about PPI. There is some anxiety among members and officers that if PPI does not deliver on both fronts, it will be unsustainable.
- The focus on the experience of service use has kept patient interests to the fore rather than broader public or community interests.
- The subgroup provides a good focus for discussion, but there is no clear leadership to turn these discussions into anything more systematic. The group proceeds fairly opportunistically,

particularly by exploiting group members' knowledge of existing PPI initiatives in the local health economy.

- The PCG's approach is therefore to build on current practice and local enthusiasms, rather than to set out a strategy of its own. Although a PPI strategy was agreed by the board, this was put together very rapidly and served only to demonstrate the PCG's commitment to the work rather than to define what it was going to do.
- As the PCG has not had the capacity to develop a detailed approach to PPI, much of the emphasis in small initiatives has been on public information and education.
- The lay member does not sit on any other board subgroups and there is no other lay representation within the working of the organisation. The subgroup is principally focussed on the development of discrete pieces of PPI work, rather than the institutional forms of lay representation.
- Considerable officer time is put into partnership work, not least by the chief officer. However this tends not to be recognised as an integral part of the PCG's PPI work.

Mechanisms of involvement and mechanisms of change

- The lay member. The lay member's direct contribution at board level is valued, but relatively minor. He seeks to be the 'conscience of the board' by providing a patient-focussed view on items under discussion. Although he is consistent in this approach, his position as a member limits his ability to take an alternative critical approach.
- Board meetings. The board meetings are held bimonthly in public. Although there are only ever a handful of members of the public present, they are given plenty of opportunity to speak (at the end of every item). This occasionally helps to remind the members of the particularity of their professional perspectives.
- Diabetic groups. In collaboration with the health authority, and inspired by a HImP priority, focus groups were facilitated by a diabetic specialist nurse with patients from a range of local ethnic groups. The specialist nurse developed further educational seminars with diabetics patients. Their success resulted in the creation of evening self-help support groups.
- Citizen's panel. With the support of the King's Fund, a questionnaire was designed for Harrow Council's citizens' panel. As this is a sample of local citizens rather than patients, the focus of the questionnaire was on knowledge, use and attitudes to local health services. Results were presented to the PCG board.
- Education/information outreach. The PCG promotes its services through local community events (such as fairs organised by the two boroughs). It has also undertaken educational outreach in local schools.
- Newsletter. A patient newsletter has been developed, distributed through local primary care practices.
- Each of the PPI initiatives is designed to have a direct impact on the patients and local people who participate in them. The mechanisms of change for the organisation and professionals are not thought through in any detail: there is a hope that any specific initiative will have outputs which will be received by members and officers and so influence PCG practice.

Outcomes achieved

- Professional acceptance of the value of non-professional views in decision-making.
- Clearer understanding within the PCG of the knowledge and attitudes of local people about their local health services.
- Better knowledge of local health services among some local people.
- Greater confidence in health self-management among some local patients, particularly in diabetic population.

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 ensure that the guide is strongly rooted in the results of the research.

The structure 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. It comes before discussion of approaches and involvement methods in order to emphasise the importance of addressing this issue at the outset.

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.

Why bother?

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

The public involvement subgroup was first convened at the end of 1999 in response to the health service circular *Patient and public involvement in the new NHS*. The PCG is therefore undertaking PPI in part as a direct response to government policy. The board, the chair and the officers understand that this is no longer optional, but something which they have to deliver on.

The degree to which this response to a policy imperative is backed up by personal commitment among members and officers is very variable. There is considerable anxiety among the professionals in the PCG, particularly the GPs, that PPI will only make their life more difficult, particularly through increasing demand. The people who are actually involved in the PPI development work – the lay member, key officers, nurse member etc – understand this anxiety but have a stronger positive vision of the value of the patient perspective in the development and provision of services. They have sustained the work because they accept the limitations of professional views in the management and development of the health service. The chair seeks to balance both perspectives: recognising the fears of professionals but assuaging them with assurances that PPI can actually make their lives easier.

Although the people who have promoted the PCG's PPI work have a general view of the value of user voices in service development, this is not translated into a clear understanding of what this might look like in practice – they are motivated to do the work, but are unsure of what the work involves. Consequently, it is not easy for them to make judgements between different bits of work or to assess the value of what they have implemented beyond immediate process outcomes.

What counts as public involvement?

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

With little or no local history to build on, the PCG's PPI work was shaped largely by the particular interests of the people involved in the public involvement subgroup (and by the enthusiasm of the diabetic specialist nurse). Although this group included a member of Harrow CHC and representatives from the health authority and local social services, most members were PCG members and officers. Their interests reflected the main concern of the PCG itself: primary care development. The subgroup's discussions were therefore largely about the quality of local services and the experience and knowledge of patients and other users.

The patient and public involvement strategy approved by the board defined objectives of accountability, user-focussed services, health improvement and education. In practice, accountability has not been an active concern and the other three objectives have all been interpreted in terms of professional and PCG relationships with patients. In particular, the role of PPI in health improvement was described as 'encouraging patients and the public to play an active part in the management of their health through health promotion and effective self-care'. This demonstrates the lack of interest in the community dimension to PPI within the PCG. The dominant interest in service delivery keeps patients and the patient experience to the fore.

The priority given to patient involvement is not exclusive. For example, health education outreach in schools was considered to be an appropriate subject for the public involvement subgroup to discuss. However, the emphasis here remains on individual health and individual choices and behaviour, rather than on community responses to health and illness. Similarly, although the PCG has made use of the borough's citizens' panel, the questionnaire was designed to explore panel members' knowledge and experience as patients.

In this context, attitudes to working with local community groups are ambivalent. The chief executive is the strongest advocate of working in partnership across the local health economy and puts considerable time into the main strategic body, the Harrow Partnership. However he acknowledges that the rewards from this work are only achieved in the long-term. Furthermore, this work is not seen as integral to the PCG's PPI work and is not discussed by the subgroup, which tends to concern itself only with direct methods of corporate PPI. The lack of strategic vision about the value of community partnerships to PPI work contributes to the perception within the PCG that they are doing very little of this work. A narrow understanding of what public involvement means – direct engagement with patients – leads to a failure to recognise the broader existing potential in local community resources. However, it takes internal resources to engage with community resources. The lay member does recognise that there is a potential community networking task to public involvement, but he feels that he does not have adequate time to take this on himself.

What do you want to achieve?

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

Although aims and outcomes are not often discussed, there is a strong underlying consensus among the members and officers involved in the PCG's PPI work that it should serve the PCG's main aim of improving primary care by making services more patient-focussed. The following was minuted from the first meeting of the public involvement subgroup:

> *The group agreed that to develop patient-focussed services it was important to find out about the patient's healthcare experience and see how services could be developed more sensitively. It was acknowledged that this had to be balanced with patient education – explaining how services work within limited resources, managing patient expectation and encouraging patients to take a level of responsibility for their own health.*

This statement not only describes the specific focus on patients and services, it also expresses a tension between outcomes for the service and outcomes for individual patients which was characteristic of the how the PCG dealt with the internal anxieties that PPI would simply lead to more demand and more work for the frontline professionals. The following pairs of outcomes illustrate how every outcome which might bring greater pressure to bear on the service could be matched by an outcome which ought to reduce pressure on the service:

- better knowledge about availability of local services – more appropriate use of local services
- greater sensitivity of professionals to patients' needs – greater sensitivity of patients to the constraints placed upon health professionals
- greater public participation in decision-making – greater public appreciation of the collective responsibility to manage finite resources
- greater patient awareness of the health issues which might affect them – greater patient ability to self-care

In practice, these tensions were normally expressed in the public involvement subgroup as an on-going concern for demand management through improving patient knowledge, attitudes and behaviour. Although the language in the quote above is of a 'balance' between patient input and patient education, there is a real tension here between a view of patients as a valuable resource for the development of services and an alternative view of patients as a drain on resources. It is difficult to sustain both of these understandings at the same time and the latter tends to dominate.

The patient and public involvement subgroup found it difficult to sustain a clear focus on what it was trying to achieve. Although the group enjoyed an unusual degree of consensus about what PPI is for, this was easily lost in the difficulties of implementation. The subgroup began work in a highly ordered way: responding to a policy imperative, it articulated its aims clearly and developed a strategy. But this disguised a fundamental lack of confidence and knowledge about how to do the work. The strategy was soon forgotten and the subgroup proceeded in a fairly opportunistic way, largely through buying into existing local initiatives (such as the borough's citizens' panel and the health authority's diabetic focus groups). However, aims and outcomes were not forgotten: members of the subgroup did continue to question, every now and then, what the methods under discussion would achieve.

Although links between aims and methods were rather hazy, this left plenty of flexibility in the implementation of methods to maximise the value of all the emergent outcomes, expected or otherwise. This was most evident in the diabetic focus groups which were so valued by participants as opportunities for peer support that they became regular events.

Working out an approach

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

The PCG began life with little local PPI history to build on and a distinct lack of PPI experience or skills among its officers and members. However, there was no strong resistance to the work – a basic level of corporate commitment was evident in the respect shown to the lay member and the considerate and open way in which the bimonthly board meetings were run.

The lay member sought to be 'the conscience of the board' by bringing a patient perspective to its deliberations. However this proved difficult, both because he lacked the confidence to consistently present a challenging view to a board of which he was a member and because the board's discussions were dominated by technical, service-side issues which were hard to engage with at the level of patient experience. Although there were other members of the board, particularly the nurse members, who also had an interest in the patient perspective and public involvement, corporate interest in PPI was relatively weak. Consequently, the lay member was charged with the responsibility of leading on the issue even though, as he made clear, he had little idea about how to pursue this responsibility.

The public involvement subgroup was originally created as a short-life group to develop a strategy. It was sustained following the completion of the strategy with an ongoing task orientation: planning and implementing the PCG's PPI work. The strategy itself made explicit the aims of the subgroup, but did not articulate a clear approach – just a range of possible interventions. It therefore proved of little use after it had gained the board's seal of approval on the work.

One of the first things the subgroup did was to assess what was already going on in the area. This was an early indication of their general approach to the work: given their lack of skills, leadership and resources, it made more sense to buy into or support existing work than to try and develop their own. Unfortunately, the subgroup discovered that next to nothing was going on in local practices, a result which lead to an abandonment of any attempt to encourage or develop work at this level. This decision meant that the subgroup effectively decided to pursue PPI at the corporate level only.

Given the limitations of the subgroup's capacity and expertise, members sought to exploit any opportunities which came their way. Although this approach was rather arbitrary, the emphasis on methods did mean that they maintained a focus on implementation. However the subgroup's lack of clear direction left it vulnerable to distraction as well as open to possibilities. For example, the emerging PCT development process came to the subgroup's attention. It was perceived to be something they should concern themselves with, but there was little feeling that this could be a new opportunity for some potentially high impact PPI work. The subgroup assumed that the health authority would run a bureaucratic process and sought only to ensure a minimum of lay representation in this process.

Although the PCG was very focussed on improving services, it was far from oblivious to the complexity of local community needs. The ethnic diversity of the population was a particular concern which was effectively addressed in the development of the work with diabetics. The initial decision not to undertake a survey was made precisely because of the language problems that this would present. The diabetic focus groups which emerged as the solution were run in a number of different local languages, a practice sustained for the ongoing seminars and support groups. By choosing to prioritise one patient group – diabetics – the PCG was able to address more effectively the complexity of the needs of the audience it was dealing with.

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 idea that PPI should 'shape services' or generally contribute to their improvement is straightforward and relatively uncontroversial – which is why it proved to be a good focus for building a consensus within the PCG about what PPI is for. For all the members of the subgroup at least, the user view provided a self-evidently valid contribution to service development. However, the simplicity of the idea of user influence belies the difficulties in practice. When the lay member was challenged within the subgroup to describe how a piece of work about user views would bring about change, he could only describe the weak organisational process of a report going to the board for consideration and action. There was no other obvious internal process for learning.

The subgroup has been very focussed on the methods of involvement with very little consideration of how any of this work may have an impact on the organisation and professional practice. Furthermore, having given up on promoting PPI at practice level, they have little buy-in from the local professionals, other than the nurse and GP who are members of the subgroup. As the lay member acknowledged, it is not an easy task getting GPs to read any kind of report, let alone one about a subject which they may be wary of.

Despite this lack of any clear process, the subgroup does have a strength: its aims are highly convergent with those of the PCG as a whole. By keeping a focus on patients and service delivery, the subgroup is working in the same locus of change as the rest of the organisation, thereby making the links between its own work and the interests of other members and officers much more powerful. The diabetic seminars and support groups played an important role in raising the profile of diabetes across local professional practice at precisely the time when new treatment protocols were being introduced. The citizens' panel survey provided data on local patients' knowledge, attitudes and use of services which were particularly relevant to the PCG's programme to improve access to primary care. The presentation of the results from the survey to the board coincided perfectly with a heated professional debate about the relative priority of promoting access to primary care services. Consequently, what could have been an easily ignored report proved to be a critical intervention in supporting investment in better access. Thus, by developing PPI interventions with PCG priorities in mind, the subgroup produced outcomes which had an immediate value for the PCG and its professionals stakeholders.

This strength is not, however, fully exploited. Although the members of the public involvement subgroup pick up on the concerns of the organisation, there is no comparable effort by the organisation to identify the areas of its work which might be amenable to PPI input. Nothing gets directed to the PPI subgroup from the clinical governance group, for example. In the PCIP, a substantial section on patient involvement was presented at the very end and failed to make explicit links with the rest of the document. Hence although PPI is conceived in the PCG as being instrumental to the needs of the organisation, the instrument tends to get left on the side.

As much of the subgroup's work was been focussed on education and information, its biggest impact was probably directly on patients. The fact that participants in the first diabetic focus groups pressed for their continuation certainly suggested that real outcomes were being achieved. The impact of other interventions, such as outreach to schools, presentations at community events and the practice newsletter is harder to assess.

Getting the details right

Board meetings. Public board meetings were held bimonthly, usually with a few members of the public attending. The chair was welcoming and took care to ensure that members of the public could have their say at the end of each item on the agenda. The chair understood that members of the public were not always likely to behave as good committee members and address precisely the issue under consideration – he was willing to let people have their say and took their comments seriously.

The citizen's panel. A key feature of the citizen's panel project was the timing of the presentation of the results to coincide with board discussion of exactly the issues which the survey addressed. This was, to a degree, serendipity, but it also reflected the consistency with which the officers concerned had kept the issues which they knew were important to the PCG – access in particular – to the fore in the design of the survey (which took the better part of a year). They were not tempted to make the survey about 'everything they wanted to know', but kept a clear focus on their own organisational priorities.

Diabetic seminars and support groups.

One of the key professional anxieties raised by patient involvement work is the prospect of individuals wanting to address personal concerns, either about their condition or the service they are getting, in contexts where these cannot be adequately or appropriately addressed. However, there is a flip-side to this: the risk that patients will be unable to contribute to such initiatives (or their contributions will be ignored) precisely because their perspective is so governed by their own individual experience. The diabetic specialist nurse who ran the diabetic seminars and support groups managed these tensions very well.

The support groups followed a regular schedule: a 10 minute introduction including basic education; a 45 minute presentation; then a further 45 minutes of group peer support. It was made clear to participants that individual issues should be kept to the last part of the meeting, in order that the presentations were not side-tracked by matters which would not be useful for the whole group. Participants were free to leave after the presentation if they were not interested in the peer support and discussion. However, the diabetic specialist nurse also played a critical role in picking up on personal concerns within these discussions and, if appropriate, going back to the relevant professionals at practice level. By maintaining good relationships with the practice nurses and, to a lesser extent, the GPs across the PCG, she was able to resolve individual problems and improve practice (assisted by the implementation of a practice incentive scheme relating to new diabetic treatment protocols). Consequently she was able to sustain a group process of learning while also addressing individual needs. This approach of actively making the links between informal discussion and ongoing professional practice is unusual, but it made perfect sense within the diabetic specialist nurse's role and helped her both to keep track of new referrals and to promote the development of service standards across the PCG.

The groups demonstrated the value of professional communication with patients outside the expectations of the typical one-to-one professional-patient relationship. In particular, patient confidence in asking questions was greatly enhanced in a group context where other people were also asking questions. However, this relies on the 'ice being broken', i.e. on a professional facilitator who encourages questions and feedback – again, an important skill of the diabetic specialist nurse.

Dangers and obstacles

Professional defensiveness. The idea of listening to patient experience, accepting criticism and doing something about it is still a threat to many professionals. There is a failure to understand that any disagreement is not simply a dispute over facts, but a meeting of different world-views. Rather than recognise the limits of their own world-view, it is always easier for professionals to retreat into their own. However this can be difficult. At one board meeting a visiting consultant was able to deflect criticisms from the GP members about problems with outpatient appointments by playing their own game and criticising the administration in primary care. But when two women in the audience pressed home the same criticism against him, using the language of everyday experience, he was lost for words.

Lack of leadership. There was no-one in the PCG who was able to really promote the organisation's patient and public involvement work. The lay member felt he had neither the skills nor the time and the officers involved, including the chief officer, were enthusiastic but unsure of themselves and anyway very busy.

The elephant sandwich. All the key officers and members involved felt that the PPI agenda was massive, leaving them wondering where they should take the first bite. This left them with a sense of the limitations of what they were doing rather than the value of what they were doing. Furthermore, by thinking of PPI as a special set of methods, rather than (for example) a special set of relationships, they undervalued the extent of their current practice.

Anxieties about representation. Although the PCG's diabetic focus groups were an excellent example of targeted educational work, the public involvement subgroup was very wary of setting up forums or groups for consultation because of the difficulty of deciding who to invite and who not to invite. On at least one occasion this delayed the development of the work significantly.

Institutional change. Although the PCG was very focussed on service development in its PPI work, the force of institutional change tended to get in the way. Just when the PCG had got to a position of some stability, the pressures of PCT development took over.

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