King's Fund

Primary Care Programme

Public involvement in Primary Care Groups and Trusts

# Review and Learning Day 20.11.00

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# Contents

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# Presentations

1. Making sense of the diversity of patient and public involvement work in Primary Care Groups & Trusts
2. Methods of involvement and mechanisms of change

## Making sense of the diversity of patient and public involvement work in Primary Care Groups & Trusts

Across the Primary Care groups in the King's Fund study, approaches to patient and public involvement are remarkably diverse. This is an attempt to try and make sense of this diversity.

### Common features: lay members and public board meetings

There are some basic features which are common to every PCG: in particular, lay members and public board meetings.

There is no doubt that lay members have been crucial in supporting the development of public involvement work in PCGs. However, the role of the lay member was never made clear in national guidance and has been interpreted quite differently in different places. Within the six PCGs, lay members have been variously thought of as:

- a lay/community voice in themselves
- a conduit for community voices
- an advocate for public involvement
- responsible for the development of public involvement
- responsible for undertaking public involvement

None of the PCGs put much effort into bringing the public into board meetings. This is not surprising: PCG board meetings are not much fun and are not easy places to get effective public input. However, this does mean that – whether they like it or not – the lay member voice is important at board meetings as a check and balance to professional views.

Gaining acceptance at board level was a real struggle for some and fairly straightforward for others, depending on the attitudes of other members. In general, the contradictions involved in having a formal non-professional role (an expert non-expert) did mean that it could be difficult to demonstrate credibility. Although their own personal experience was usually important, lay members often sought to bolster their credibility either through their existing community contacts or through direct engagement in public involvement work.

> *One of the reasons I had applied for the job was that I had worked with families and young people all from this area so I felt that I really knew what was happening in a lot of people's homes and what their cares and worries were and a lot of the things are not health but they are all inter-related like poor housing, family problems and things like that that are all linked in the end.*
>
> *I would like to feel that I can become more conversant with what the people in the area want so that I am then able to have a stronger voice on the board, you know, a more convinced voice possibly rather than just my own personal thoughts and feelings.*
>
> lay member

## Approaches to public involvement in the King's Fund study

Beyond the lay member and public meetings, the different PCGs in the study are all doing different things. The following is a brief summary of the key things which characterise each of the six PCGs.

*Central Croydon PCG*

- Link patient scheme
- Community Network meetings
- Local CVS worker contracted to run the process

In Croydon, the local Council for Voluntary Services, Croydon Voluntary Action, runs regular community meetings for the PCG which bring together local stakeholders and members of the public. Croydon is also recruiting patients from local practices to form a link between the PCG and patient experience at practice level.

*City and Hackney PCG*

- Community Participation Steering Group
- Outreach to community organisations
- Community intelligence of front-line workers

In City & Hackney, a Community Participation Steering Group functions both as a place for the PCG to hear from local community stakeholders and as a forum for planning public involvement work. However there is also a strong emphasis on going out to hear the voices of local community groups, rather than assuming that they will come to the PCG – an approach which has been particularly evident in their recent PCT consultation. There is also interest in tapping in to the community knowledge of workers who live as well as work in the area.

*Dagenham PCG*

- Important history of patient participation
- Promotion of patient participation throughout Dagenham
- Hearing the voices of those who have high needs but little power to express their views

In Dagenham, there is an important history of patient participation, albeit isolated to one practice. This has lead to a desire to promote local participation and clinician-patient partnership across the PCG. They also have a project underway to hear from local people who have high health needs but who do not usually get the opportunity to express their views to public authorities.

*Harrow East and Kingsbury PCG*

- Diabetic focus groups
- Citizen's panel questionnaire
- Linking outcomes for public to outcomes for PCG (demand management)

In Harrow East, the patient and public involvement subgroup has sought to identify how the PCG can buy in to existing local activity. So, for example, it is supporting a series of local diabetic focus groups for people from ethnic minorities, initiated by the health authority, and is also developing a questionnaire for Harrow borough's citizen's panel. One of the concerns in the PCG is to ensure that public involvement serves the interests of the professionals as well as those of the public themselves – such as in demand management.

*Hillingdon PCT (Hayes and Harlington Directorate)*

- Lay members and non-executive directors
- Outreach to community organisations
- Public panel run by CHC

Hillingdon PCT has three executive boards mirroring the three old PCGs, one of which is Hayes and Harlington. The Hayes & Harlington boards has retained its two lay members, and also has representation from the Trust board non-executive directors, as well as from the CHC. The lay members have an important role, distinct from the NEDs, in engaging in local public involvement. This includes local community outreach and communicating to the board the views of the standing public panel which, run by the CHC.

*North Lewisham*

- Practice-based needs assessments and participation development work
- Community development and partnership
- Listening/consultation days for specific communities/client groups

There is a long history in Lewisham of practice-based needs assessment and community development work and getting change at practice level is an important local value. There is considerable local investment in community development, which is seen both as an end in itself and as a means of increasing the capacity of local organisations to engage with the PCG in its public involvement work. Specific PCG initiatives have included health events for local communities.

## No easy answers

It's obvious from these thumbnail sketches that public involvement encompasses a great diversity of ideas, methods and (less obviously) objectives.

If we are going to learn from each others' experiences, we have to begin by recognising that the differences between these approaches to public involvement go deep. They don't just reflect different technical choices. They are shaped by differences in values, experience and commitments as much as by different local circumstances and the perceived pros and cons of particular methods.

This means that there is no simple answer to the question 'what should we be doing?' We cannot avoid the messiness of public involvement. After all, public involvement is about trying to engage with ideas and views which do not conform to institutional priorities and expectations. Public views are unbounded, messy, irritating, surprising, inappropriate, difficult – different. We need to be a bit messy and creative if we are going to engage with local people on anything other than our own terms.

### A working model

To make sense of all of this, I now want to try and describe everything that's going on in all the PCGs all at once.

I want to present a model which illustrates all the different things which contribute to the shape and impact of public involvement work within the six PCGs and PCTs in the study.

Figure 1 illustrates the model as a whole. There are five basic component:

- the context of public involvement work
- the approach which is adopted
- the mechanisms (methods) of involvement used
- the mechanisms of change within the organisation
- outcomes

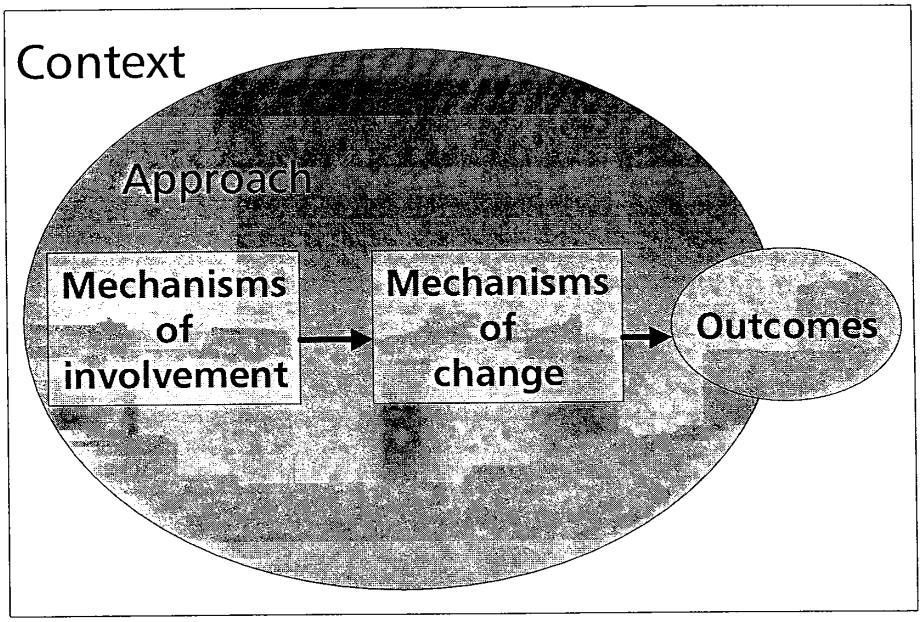


Figure 1: a model of public involvement

## Context

What are the things you start off with, which you have little or no choice about, but which may be important in shaping the way you go about doing public involvement work?

There are some things which everyone shares:

- national policy and guidance:
- constitution of PCGs and PCTs (including lay members and non-executives)
- National Service Frameworks
- NHS Plan (PALs, patient forums, ILAFs)
- national targets

We all know how influential all these are in defining local policy. This has always been a key tension for public involvement work which arguably is getting worse – how can we expect to involve the public in local decision-making when the centre makes more and more demands?

There are lots of other local contextual factors which together are crucial in defining what happens:

- demography and needs of local population
- board commitment to public involvement
- officer commitment to public involvement
- professional/worker commitment to public involvement
- values and viewpoints of all stakeholders
- board cohesion
- resources
- personnel time
- leadership
- infrastructure
- experience and expertise
- demands of local management agenda
- interpretation of the role of the lay member
- local history of patient participation and public involvement work
- relationship with CHC
- relationships with community/voluntary sector
- history and current practice of partnership working

Some of these factors are similar across all six PCGs. In particular, no-one is flush with resources for public involvement and officer time is very limited. Even in those PCGs which do have dedicated personnel time for public involvement, this is always one part of a larger job description.

However, most of these factors varied a lot across the six PCGs, not least commitment at board level, local expertise, local histories and individual values.

## Approaches

Given these different contexts, it is not surprising that public involvement looks so different across the six PCGs. However, this diversity is not merely a reflection of different circumstances – it is also a reflection of the choices people make locally about what they want to achieve. This is what I have called approaches. An approach here means

- the general terms of local engagement in public involvement – why, how and for whom public involvement is pursued – but not the specification of individual methods.

We can think of local approaches as the ways in which the following questions are answered:

- Who should set the agenda?
- What do we want to achieve?
- Are we interested in outcomes for the PCG, for its constituent practices or for local people?
- Should we pursue this in partnership? If so, who should our partners be?
- Should we set up new initiatives or buy into existing ones?
- Which professional stakeholders need to be involved?
- Do we want a standing mechanism or not?
- Who do we want to involve?
- Whose involvement should we prioritise?
- How do we link this work with the broader interests of the organisation?
- Do we need a strategy?
- Do we need a subgroup?
- Who should lead the work?

These questions are not asked once and answered once. In fact, they are always being asked in different ways by people within PCGs. Approaches shift and change depending on the changing context, and particularly on who is involved at any one time and what their values and interests are.

### Mechanisms

Having explored context and approaches, we can now get on to the mechanisms – the bits of kit intended to turn ideas into reality. In the six case studies, these include:

- public board meetings
- standing patient/community meetings (open or closed)
- patient participation groups
- practice-PCG link patients
- community health events
- patient-/public-focussed research
- focus groups
- community/voluntary sector networking & capacity building
- lay member direct input
- communication resources: newsletters, notice boards, leaflets

It's important to remember that perceptions of what these methods are for will vary depending on the local context and approaches. Two PCGs which appear to be doing similar things may actually have very different ideas about what they are trying to achieve. A community meeting could be a means of getting support for PCG policy, for finding out about local needs, for educating people about how to use services properly, or for encouraging local networking and partnership. Of course, such differences of interpretation can exist within PCGs as well as between them.

There are two mechanisms in Figure 1: the front-end mechanisms of involvement and – crucially – the back end mechanisms of change. How do changes in policy, practice, services and communities actually happen?. Unfortunately, these mechanisms of change do not get much attention. Turning processes of involvement into processes of change is both the hardest and the most neglected task.

These mechanisms are not so easy to specify. Here are some possibilities:

- lay members contributing directly to board discussion and decision-making
- board members and subgroup members considering reports from PCG involvement initiatives
- members and officers participating directly in involvement initiatives
- officers discussing PCG issues directly with community stakeholders
- professionals attending and engaging with patient participation groups
- direct officer support in the development of community networks

The crucial question is: does any of it work? And, if it does work, what are the outcomes?

Although I have already discussed outcomes as a key issue in defining approaches, we need to bear in mind that the actual outcomes are often very different from the intended outcomes. This is not necessarily a bad thing: specific initiatives set up with a very narrow purpose in mind can often have much wider effects on the relationships between organisations and their community stakeholders.

However, there are outcomes and outcomes. A well-attended public board meeting may be perceived as outcome enough for someone who has been struggling to bring in the punters. But the punters themselves may think that being listened to, or seeing an impact on decisions, or seeing a change in services, or seeing an improvement in the health of their community is the appropriate outcomes.

Any of the following may be considered outcomes of public involvement at different times and for different reasons:

- changes in the attitudes of members, officers and workers
- changes in PCG decisions
- changes in working practice of officers and workers
- changes in working partnerships of the PCG
- changes in service specification
- changes in service quality
- changes in demand for services
- changes in satisfaction with services
- changes in community and voluntary sector capacity
- changes in knowledge, attitudes and behaviour of patients and public

### Rational and pragmatic models

Different approaches to public involvement are about doing different things, in different ways, with different people, in different circumstances for different outcomes. Getting public involvement to work means attending to all of these things – above all to what you are trying to achieve. However, that's easier said than done.

There is a nice, tidy model of how to public involvement which appears in many places which looks something like this:

- decide what your aims are
- define achievable objectives
- design appropriate methods and provide appropriate resources
- implement
- monitor and improve

I am happy to report that absolutely no-one is doing this. Here's a view from someone caught up in the heat of public involvement work:

> *I don't know that anybody is completely sure what it is they are expecting to achieve because, you know, you're not going to suddenly get the community setting up primary care centres or something. We've got the link person's scheme and we get the community, the voluntary sector and the residents associations in – really bringing them into the fold and running information sessions for them. Well, you know, it's better than a kick in the teeth isn't it? And I've had so little time to concentrate and devote on that, 'cause really you need to go out and do visits to each of the practices. It's starting to trickle in and all the board members have made sure that they've got one now and it's starting to trickle in.*
>
> public meeting facilitator

This quote illustrates a key feature of any public involvement work: it is always exploratory, changing, developmental. There is never a clear beginning and end. A more realistic plan of action for some-one taking responsibility for public involvement in a PCG might look like this:

- find out what's going on already and identify organisational strengths and weaknesses
- find out what different people want and expect from public involvement work
- find out what resources are available
- facilitate a process which helps people to share their values and interests
- identify ways of building on these shared understandings, making the most of existing practice and partnerships
- identify what is being achieved and plan collaboratively to increase impact.

Although we must always try to be clear about what we are trying to achieve through public involvement, it is really important to remember that in practice we do not move from aims to objectives to implementation to change (Figure 2).

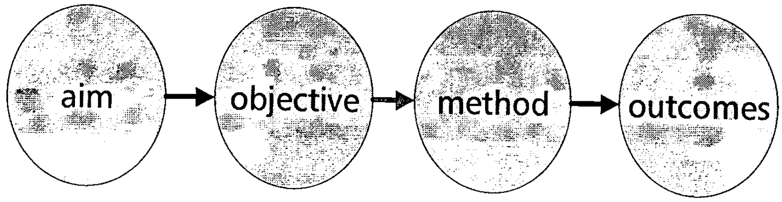


Figure 2: the rational ideal

The development of public involvement work involves a negotiation across all these things at once: fine-tuning methods while redefining aims, while finding new resources, while valuing the contribution of new players to the game. It's about keeping all these balls in the air at once (Figure 3).

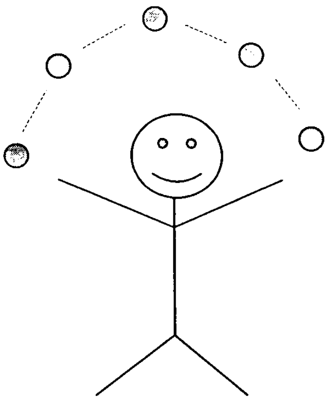


Figure 3: the reality

Unfortunately, it's easy for some of these balls to get dropped and forgotten. The goal of public involvement work is often one of them, which is why it is important to keep revisiting the strategic questions when the practical issues of implementation threaten to overwhelm. It does not matter if the answer to the following question changes over time, what matters is that the question is always asked:

- What are you trying to achieve through public involvement?

## Methods of involvement and mechanisms of change

In recent years there has been a lot of emphasis in national guidance on integrating patient and public involvement into the work of NHS organisations. The following is typical:

> Patient and public involvement should not be a discrete 'add-on' task, but a part of the way all NHS organisations work, permeating all areas of the NHS and health. This means looking at involvement not as an end in itself but as a way of thinking and working, so that the NHS can deliver services that are high quality, appropriate and responsive to users.
>
> Action: NHS and health organisations should strategically and systematically build patient and public involvement into the way they operate.
>
> (*Patient and public involvement in the new NHS*, NHSE, 1999)

These are fine-sounding ideas, but what do they mean in practice? The policy document itself did not spell this out and the NHS plan has not been much help.

Here are some ideas from the study of what integration of patient and public involvement might mean:

- setting up standing mechanisms (such as patient forums for every trust)
- always asking about the impact of decisions on patients and public
- working in partnership with community organisations in all service developments
- involving users at the beginning of any planning process
- operating in way which is transparent and always open to public views

All of these seem to be good ideas, but their diversity demonstrates the difficulty of the concept of 'integration'.

Perhaps this is not such a useful concept. After all, it is possible for something to be entirely integrated into an organisation and yet also be completely ignored or powerless. If integration ends up meaning institutionalisation, it may not be such a good thing.

Furthermore, integration sounds like a tall order: it suggests that change is needed in the way everything is done in the PCG. Although this might well be true, it is also very unrealistic, and as a result risks putting people off doing anything at all.

Here's a definition of my own:

- *integration* means making sure that your methods of public involvement connect with the mechanisms of change in the PCG, in its constituent practices and in the local community.

It may be that you only have the capacity to do a relatively small amount of public involvement work. According to this definition, what matters is not how much you do, but whether what you do makes a difference.

This is, of course, the hard part. It is too easy to assume that there are inherent processes of change within the NHS and that the outputs of public involvement initiatives will 'trickle down' to changes in policy and services. But this is almost always not the case.

So can we increase the impact of public involvement on the work of the organisation, its providers and patients/public themselves?

This is not about a whole set of different mechanisms from the actual methods of involvement. There is a lot of overlap between the two. Also, I think this is often about small changes in the ways in which members, boards, officers and professionals work – small, but crucial.

Change is always dependent on people. So I want to look at the range of people involved in PCGs and map out in brief the possible ways in which public involvement work can bring about change for them:

- members
- officers
- front-line workers
- local people
- local community and voluntary sector organisations

### Members

The most obvious locus of change for members is the board and its subgroups. How do patient and public views bring about change here?

- lay member input
- public input
- reports to board from public involvement initiatives
- CHC input

Lay members have clearly been crucial in making sure that PCG boards respond to lay views, either their own or those that they present from other activity. This quote illustrates both of these:

> *I think everything that we have dealt with has been dealt with by board meetings. I think we're well respected. Our written report from the public meetings is enclosed with the board papers every month. But if there was something pressing I would be quite happy to ask for it to go on the agenda and would kick up merry hell if it wasn't, if I felt it was important and should be raised.*
>
> lay member

The emphasis on the board reflects its strategic authority. But how much difference does the board really make? Are board members really in the 'driving seat' or are they more of a check and balance on the work of the officers? Furthermore, given the pressures on PCG boards, do they have the capacity to learn from their communities:

> *There are a number of projects that have been around that have been making recommendations, community projects or particularly self-help groups, that never actually influence policies because there's no mechanism for that to happen and it's actually a question of the PCG making itself aware of all those things and utilising that information and the intelligence that's out there around what are their needs, and then that informs us.*
>
> officer

### Officers

In practice, it is much more likely to be the officers who deal with this kind of community intelligence. It is the officers who actually write the plans and make recommendations. They are the ones who have to really grapple with the Chinese puzzle of improving local services to meet local needs with very limited budgets.

So how is the work of officers influenced by patient and public views?

- meetings and daily contact with community organisations
- intelligence fed through local workers and other local stakeholders about community needs
- participation in involvement initiatives
- reading reports from involvement initiatives
- dealing with complaints

Much of this assumes that officers will simply listen, learn and then act. That is not always so easy:

> *The most important part is the us going out and listening, but you then have to do something with what you've heard, you can't just take it in and hold onto it. The point of doing the listening is to actually feedback through to somewhere and at the moment, the mechanisms for that aren't clearly established.*
>
> officer

Nonetheless, when senior officers participate directly in public involvement initiatives, this reassures participants that they have got a hook into the centre of power:

> *The Chief Exec very often comes to the meetings and that's a definite factor, if members of the public can actually see that the Chief Exec is there they'll come, which is something we hope to keep going.*
>
> officer

### Frontline workers

What about the frontline workers, the professionals actually providing the services? Is this the point where change is going to make the most difference?

> *I think the PCGs are the practices. Because if you've got a small team of like 7 or 8 people then that isn't anything and the resources are so limited. But the practices, they're the ones that will make the changes to health and services.*
>
> chief officer

Yet having an affect at practice level is perceived by some to be hardest task, not least because of the history of GP isolation.

Frontline workers may change their practice through:

- direct contact with local people as patients
- direct contact through patient participation groups and other practice-based involvement/ community development initiatives
- reading reports from involvement initiatives
- engaging with PCG development mechanisms which include elements of user involvement (e.g. clinical governance)

Yet the distance of PCG boards from practices remains a real problem.

> *In trying to formulate our overall strategy part of it would be saying 'well, if we find out such and such information what do we do with it?' Then I guess it has to come to the board, which would hopefully, where possible, make changes in service provision. However, if it's down to individual practices there's a limit to what you can do to individual practices. You can encourage them, but the amount to which the board can control what practice X does is limited.*
>
> lay member

This quote illustrates the difficulty of getting public involvement to bring about change when the organisation as a whole has inherently weak development mechanisms.

### Local people and communities

Many public involvement initiative are designed to have a direct impact on the people who are involved:

- patient participation groups
- health education events
- newsletters and other forms of communication

Even when methods are established which are supposed to be mainly geared to influencing the PCG, there is almost always an element of public education involved.

Similarly, initiatives which involve local community organisations, such as local networks and consultation events, ought to have direct positive outputs for them as well as for the PCG, even if this is only in information sharing and networking.

Community development really works the other way round: it is focussed on increasing the capacity of local community organisations and identifying community needs and resources. However this clearly contributes to how PCGs learn from their communities.

There are many direct mechanisms of change for local people and organisations:

- direct participation in involvement initiatives
- education and communication resources
- community group meetings with officers and members
- community development

This overview demonstrates that there is no simple answer to the question 'how do you make public involvement work bring about change'? There are all sorts of points of influence, but much relies on changes taking place inside people's heads. It's relatively straightforward to set up a focus group to find out what people think about local services, for example. But it is not so easy to get the messages from such a group fed into policy, decision-making and professional practice. This will only ever happen if the members, officers and professionals concerned are willing to listen and learn in the first place.

It is crucial that PCGs consider how they can improve all these processes – the board meetings and subgroup meetings, the involvement initiatives themselves, the daily working practice of officers and workers, the process of organisational development – in order that messages from patient and public to get through to where they really make a difference.

## Three principles

Let me finish with three general principles to help get this process of change to work. The first is:

- work where change is already accepted

There is little point in doing public involvement work for a service where those responsible are averse to change. If they are already engaged in a process of change, you have a much greater chance of making a difference.

> *There is something about being very focused about an issue that you feel the public should be involved with in contributing to, rather than saying 'There is a Board Meeting' because that's a turnoff to some people. So I think one can focus on an issue or an initiative that the PCG is doing, maybe a health improvement initiative, and involve the public to help that initiative, not just in the implementation but in the actual development.*
>
> Chair

Second principle:

- be honest about how much change is achievable

> *It's about recognising what the limits are of what you are doing and being honest about that, not pretending that you are doing otherwise, so if you are disseminating information, be clear that that is actually what you are doing, you're not actually getting people's views, you're actually just giving them information. Where you're consulting with people you're being clear with them whether they can influence policy. I suppose it's about PCGs not setting themselves up as something that they're not, and being clear on which issues they have provided information; then on another issue they have talked to a few people but it's no way it's the whole range of people; on another issue they've actually reacted to it very locally.*
>
> officer

And finally:

- small changes in process can make big differences in impact

Here is a final quote which illustrates how the frustration of one member of the public was compounded by a whole series of simple but fundamental obstacles at a board meeting.

> *I took a couple of members and went down to a PCG meeting. Well it was the wrong place to hold it in the first instance, because the acoustics were non existent, there was traffic noise all round, and obviously you've got to have the windows open, there were doors banging up the corridor. The group was sitting round the tables in a square and we were some 20 yards away sitting in a row of chairs and we couldn't hear a thing. They went on for a little while and I thought 'Well, this is nonsense', so I stood up and attracted the Chairman's attention. And I said 'Excuse me', and he said 'Is there a problem?' I said 'Yes, we can't hear a damn thing over here, so we don't know what's going on', 'Oh, I'm sorry about that', he said, so he opened the end side of the square and we moved our chairs in. So we more or less took up the business half-way through and we sat and listened, but of course since it was only open to the public, we had no part in this discussion whatsoever. They sat there and they made decisions, and they made decisions, and they made decisions, and we had no say whatsoever. When I queried this I was told 'Oh, well, write it down on a piece of paper and give it to the Chief Officer or the Chairman at the end of the meeting'. Too late, the decisions had already been made then. So the chances of them reversing that decision because of our objections are very slim, because they were not going to discuss the objections were they?*
>
> PPG chair

Attention to detail in the day-to-day processes of management and professional practice is crucial to getting the lifeblood of community views into the arteries of PCG decision-making and service delivery. However much investment a PCG makes in public involvement, its members and officers must still reflect on their daily working practice if the investment is going to pay off for everyone concerned.

# Workshops

This section contains a summary of the comments on flip charts from the two workshops. As flip chart comments can be difficult to make sense of at the best of times, they have been grouped into themes.

1. What can patient and public involvement achieve for PCGs, primary care and local people?
2. What can be done to increase the impact of patient and public involvement work?

## What can patient and public involvement achieve for PCGs, primary care and local people?

### accountability and transparency

Supporting executive team (non-exec role) Critical friend

Accountability – distinguish between management/ business process and developing responsive services (latter requires patient/public involvement)

Paying more than lip-service to accountability

Local accountability – transparency

### needs-driven services

Enables PCG to hear what local needs are

More sensitive/response services – needs-based

Makes services more responsive to people's needs

Shapes priorities based on local need

### patient-centred services

User friendly services

Improved services

Putting the patient at the centre

### linking with communities

Linking practices with patients and wider communities

Making wider/better use of local community resources

### two-way communication

Change the culture: not consultation but two-way dialogue

Communication PCG – community; two-way feedback

Listen to patients *and* respond

Get the public's views heard on the PCG board

Increased communication pathways between professionals ands users.

Listening and responding

Interaction between what people want and PCG board

### the clinician-patient relationship

Got to tackle clinician-patient relationship

Training GPs to listen (a question of power)

Changing attitudes of GPs and other health professionals

Gives primary care staff opportunity to know more about local people's views

**integrating services**

Integrated services – NHS/ local government/ voluntary sector

Combine HImP and social care priorities

**empowering local people**

Mechanism for empowering people

Empower support local people.

Greater say and influence for local people

**informing and educating patients and local people**

More knowledge among local people

Educating local people about appropriate use of primary care

Greater self-management, patient knowledge (different patient expectations)

Raises expectations and knowledge about health and primary care (strengthens support for primary care)

Create awareness of PCG in the community

Information and access to services

**better health**

Improved health

Meeting basic health demands

Increased community involvement improves the health of the local population

To achieve something for local people e.g. improved health care

**problem-solving**

Finding answers to development questions

Helping GPs to cope with demand problems

## What can be done to increase the impact of patient and public involvement work?

**focus on results**

Make sure you can deliver something at the end of it

Let staff, public and patients see some results

Encourage the process through demonstration of improvements and impact

**communication and honesty**

Openness and honesty. Explain if no action.

Sharing information

Mutual understanding and respect

Make sure you feed back

Feedback – people always told that they will get response

**everyone's business**

Embed processes in the organisation.

Listening has to happen at all levels: on-to-one, practices, PCG, PPGs, public forums

Make it everyone's business

**clarity about expectations**

Set out short term targets as part of long term plan – people can see achievements

Be clear from the start – what you are expecting from them and what you can offer

**timeliness**

Ensure that reports etc are timely; that insights from involvement are on the agenda when the board has to make decisions.

Strategy/systems to keep reminding people about views expressed

**resources**

Identify necessary resources

Resources!!

**HImPs**

Use the Himp

How to make HImP real?

**professional development**

Need to get GPs committed to advocacy for people

Encourage GPs to set up PPGs

Work with public professionals

Investment needed in professional education.

Staff empowerment

Ownership by the professionals

**investment in community groups**

Supporting community groups to take the lead in consultation

Use existing groups

Use community development approaches

**stamina**

DON'T GIVE UP!

Not quick fix – long term

**new opportunities**

Pro-active encouragement of people from local community to become non-execs on PCT

Take opportunity of setting up new Boards to establish new, more open ways of working

More influence when PCT

**other comments and ideas**

Review and evaluate

Developing positive relationship with the press

Increasing opportunities to influence services – ensure human contact and someone available regularly

Open questions to the public – not pre-defined

Select key local issues to involve people on

Use clinical governance

Exploiting existing mechanism

Commitment of lay member is essential

# Posters

Everyone was a bit too busy to pay much attention to the posters, so there were very few comments added to them. They may be more useful here.

1. The community rubber stamp
2. What counts as public involvement?
3. Are your values shared?
4. What is essential to success?
5. Partnerships: hard work but worth the effort?
6. Organisational change: threat or opportunity?
7. Jo Bloggs vs. special interests
8. Standing processes or one-offs?
9. Selling public involvement

## The community rubber stamp

*The whole of the PCG needs to look at how it's going to be more 'public orientated' if you like, for want for another word. I can't do that as an individual – that has got to come from the whole of the Board. There needs to be commitment from the Board about how they're going to make themselves accountable to the local community. It is not just saying 'well, we will put this particular thing in place and that's it, that's our public involvement'.* (Lay member)

Any method of public involvement can produce very different results depending on the approach and priorities of the PCG. Methods which are supposed to enable PCGs to hear public voices and improve their decision-making can easily become the means of legitimating those decisions instead. Rather than challenging the PCG, public involvement becomes a 'community rubber stamp'.

This does not necessarily happen because people deliberately manipulate processes of public involvement. If public involvement is marginal to institutional concerns, everything else just takes over.

- Can public involvement be used both to sell PCG decisions and to inform them?
- How can PCGs learn from local people without letting their own agendas take over?

## What counts as public involvement?

*I'm trying to get people to think in a different way, less about community participation being about 'the other', about 'being out there', and more about saying that community participation is about ownership of our public services, and that ownership includes the people who clean the offices as well as the people who run the hospital, and that many of the people who work in our local public services live here, locally, and that edge between working in an environment and being a recipient of it is something that has been artificially divided. I actually think that there's something really important about people feeling trust in their services and feeling that they belong to their local area, and that they include the local services in that belonging.* (PCG lay member)

Because public involvement is now one of the many 'tasks' which PCGs must deliver on, it is often described within PCGs as a certain set of initiatives or methods. There is often an assumption that public involvement work has to be built from scratch.

This may disguise a lot of less obvious activity or resources which offer ways of learning from local people, such as informal officer contact with community organisations; daily worker contact with people in need; and the community knowledge of all the officers, members and front-line workers who live locally.

- Are there things which you would not normally think of as public involvement which still involve interacting and learning from local people?
- Are there activities and resources in your PCG which are undervalued as ways of learning from local people?

## Are your values shared?

*I think our board is quite participative from what I've seen of some PCG boards. I think there is a tone of honesty, starting at board level and chair level and at my level, which means that you don't have to try and cover everything up and make it seem alright all the time. You can actually acknowledge all of it and it takes a lot of heat out of the system. So for me that's critical.* (PCG chief officer)

*People have got opinions and need to be listened to, but I think until we change that cultural idea of what the patient is and what their role is in health care, we may not succeed. I think there needs to be a bit of work done at board level.* (PCG nurse member)

Public involvement is rarely pursued simply as a means to an end. Choices about what kind of public involvement to engage in (or whether to engage in it at all) are shaped by personal and organisational values. For example, pursuit of public involvement may reflect the value of patient experience against professional expertise, of local accountability against bureaucratic control, of working in partnership against going it alone, or of honesty and openness against secrecy.

In developing public involvement work, there is rarely a clear consensus about what values are shared. Similarly, differences in values may be left unexamined. This may mean that different people have different ideas about what public involvement is for, even when they agree about the methods. This can result in on-going tension or unexpected conflict.

- Do you think there are differences in the values of the people involved in public involvement work in your PCG? If so, is this a problem?
- What values do you think are most important in advocating for public involvement?

## What is essential to success?

*I think it is really important to have fun and I'm not very good at hierarchy and stuff anyway and if I want to talk to somebody, the Chief Exec or whoever, then I'll talk to them, and maybe people don't always take that terribly the right way but I feel that's their problem and not mine. The atmosphere we have is light-hearted, there's a bit of micky taking, there's a bit of in-house jokes, and I just think people enjoy something light. They get something out of it, they get something out of it in more ways than one. It's not just about getting someone out and sitting down and thinking right they're going to challenge us. It's also what you get out of it personally, you know. I enjoy that.* (public meeting facilitator)

In some PCGs there has been a struggle to gain even the bare necessities of organisational support for patient and public involvement. However, board commitment is only ever a starting point – it is never enough to ensure that the work takes hold and delivers change.

There are many other things which arguably are necessities, such as leadership, resources, personnel time, expertise, local partnerships, professional buy-in, community sector capacity – and good humour. However, what matters to success varies across different PCGs and their different approaches. There is no magic formula.

- What do you think is crucial to the success of public involvement in primary care?
- Why is this important in the context of your work?

## Partnerships: hard work but worth the effort?

*I think there's lots of potential for us not just using other processes but being part of other processes. I think it's quite hard for the public to identify with the PCG and we know that there are existing mechanisms and existing efforts to increase public involvement in the borough. The obstacles are time and resources, because if you do become part of the partnership then you are actually committing to quite a significant amount of time and effort when there isn't often any immediate or obvious benefit to partnership working really. It doesn't happen in that way, so I think convincing board members that it's is an effective use of time and resources is a barrier.* (PCG chief officer)

Much public involvement work is enabled by the relationships a PCG has with the other players in the local health economy including CHCs, local councils, the community and voluntary sector, health authorities and community trusts.

Although partnerships can reduce short-term costs if mechanisms of public involvement are shared, on-going partnership requires an investment of time and resources which is not easy to achieve. It is not always possible to demonstrate the benefits of partnership working when there is so much core work to get on with.

- How can the benefits of partnership-working be maximised and demonstrated?
- How has your PCG benefited from local partnerships?

## Organisational change: threat or opportunity?

*The health service is a bit like Sainsbury's, every time you get used to the way everything is laid out they change it again – that's the view from local community organisations.* (PCG officer)

*I want to define what we expect the PCT to do in community consultation. Can we use the consultation period to identify this and develop it, and therefore be in quite a strong position of stipulating what local people want from a PCT, how it should behave and how it should engage with them? We're very clear that this is not a consultation about people saying 'no thank you, we don't want one of those' and then PCTs won't happen. Let's be honest about it. Let's talk about when we are one, what do we want to be and what can we start to work together on.* (PCG chief officer)

The hard task of bedding down public involvement initiatives into the practice and development of PCGs is easily undermined by the bigger processes of organisational change imposed from above – particularly the change to Primary Care Trust. Such changes may force PCGs to rebuild infrastructure, renegotiate community partnerships and rethink their terms of reference for public involvement. However, if they are approached creatively from the outset, such changes can be opportunities to set new standards and establish new working practice.

- How can we ensure that organisational change does not undermine what has already been gained?
- What are the opportunities of the change to Primary Care Trust?

## Jo Bloggs vs. special interests

*I suppose there is a fair bit of interest in focus groups, but you inevitably get people involved who have some kind of interest relating to their personal patient situation or to some issue which goes to their heart. There are interest groups who often get involved in these things, and that might be good in some way, but does it mean we are consulting Jo Bloggs on the street? That's the main difficulty, to actually find Jo Bloggs on the street to say something about what they want.* (PCG chair)

There is a common anxiety that public involvement initiatives fail to be representative and that they disproportionately attract people with 'special' interests. However, anybody who is willing to get involved in health policy will inevitably have some kind of interest, 'special' or otherwise. The most disinterested person (Jo Bloggs?) may have the least to say.

Some PCGs are unsure whether to value (and make the most of) the special interests of local groups and individuals or to try and get past them in order to achieve better representation. However the same principle is not applied to professional representation on PCGs, which is acknowledged to involve advocacy of special interests.

- How important is it for public involvement work to be 'representative'?
- Are there particular contexts when this is important and others when it is not?

## Standing processes or one-offs?

*I found the focus groups to be the best method for really getting to know what people think, but different things require different methods don't they? I wanted the panel to be a very informal place where people could really feel free about talking about their experiences and those of other people they knew, but at the same time we could train them up to an extent so that they could receive the information and actually comment on it in a slightly knowledgeable way.* (CHC chief officer)

There has long been criticism of approaches to public involvement in which it is treated as an 'add-on' to organisational business. However, if a PCG wants an 'integrated' approach to public involvement, does this mean that it should set up a standing process, such as a regular community meeting or panel? Such methods allow participants to learn more about the organisation and be more 'deliberative' in their comments.

But even standing processes can be treated as add-ons by those in power. If they become institutionalised, their impact may be limited. Although one-off initiatives, such as focus groups, only have an impact for a short period of time, their specific focus can produce a more targetted impact on policy and practice.

- What are the pros and cons of standing processes of public involvement?
- What is the best balance between standing processes and short-life initiatives?

## Selling public involvement

*For health professionals and the staff involved in providing care, you will not get them involved by giving them the impression that this exercise is about increasing demands. I think the approach is one of demand management, that's one spin-off that would be good for health professionals, and the other is about making their jobs a bit more rewarding because they can actually provide a better service. Part of it is giving professionals a real opportunity to make their jobs more responsive to the needs of those they provide care for, and thereby making them feel better about themselves and their jobs.* (PCG chair)

There are still many fears within primary care that public involvement is too risky, and may lead to increases in demand, conflict with local organisations and lots more work for everyone without any obvious benefits. Those who are committed to public involvement do not always make their case in a way which addresses these fears directly. This is usually because their own commitment is based on their values rather than the power of a 'business case'.

This difference is also seen in attitudes to local people and local communities, who may be perceived as a resource for a PCG (if their ideas, experience and knowledge are taken seriously) or as a problem (if the focus is on their needs, demands and lack of knowledge).

- Can the case for public involvement be made in cost-benefit terms, or should it be based on values?
- How can professionals be persuaded that patient and public involvement is worth their time and commitment?

# Feedback

### Something gained from the day

Finding out what is being done in other areas.

Very enjoyable day.

Thank you for such an insight into lay involvement

Professional presentation.

Thanks Will, very informative when are you visiting subgroups ?

Helpful to hear your overviews.

Very useful to share experiences/working.

Non-committal – uphill struggle but hopeful.

Useful networking opportunity to bounce ideas off colleagues.

Very useful to meet other PCG/PCT representative to share ideas. A positive day.

Very good to hear what the others are up to!

Useful reinforcement of my perception of some of the key issues.

Yes Will, but it will be hard work for some.

Useful, informative and supportive.

Will, wider context very tough.

Thanks Will. Not your fault but would have been pleased to have seen and had more discussion with other lay members.

Some useful ideas leaving somewhat bemused, questioning.

Perhaps some user involvement.

Good to consolidate views and hear what other are up to.

### Something to leave for Will

Better pay for lay members and non-executive directors.

Propagation of PPG's a priority.

Make sure public involvement becomes mainstream and real not tokenistic consult real people and act upon that consultation.

Find a safe place for public involvement in the new PCT arrangements.

A great many positive ideas which could lead to real steps forward.

Identify issues in practices that are preventing involvement.

Tell us good practice –what's really working!

PCT Status – why do lay members see their role as needing to be retained and the executives not so sure of the value.

PCT non-executive members should be more representative of communities they serve.

Lobby NHSE to review appointment process for Non-executive directors.

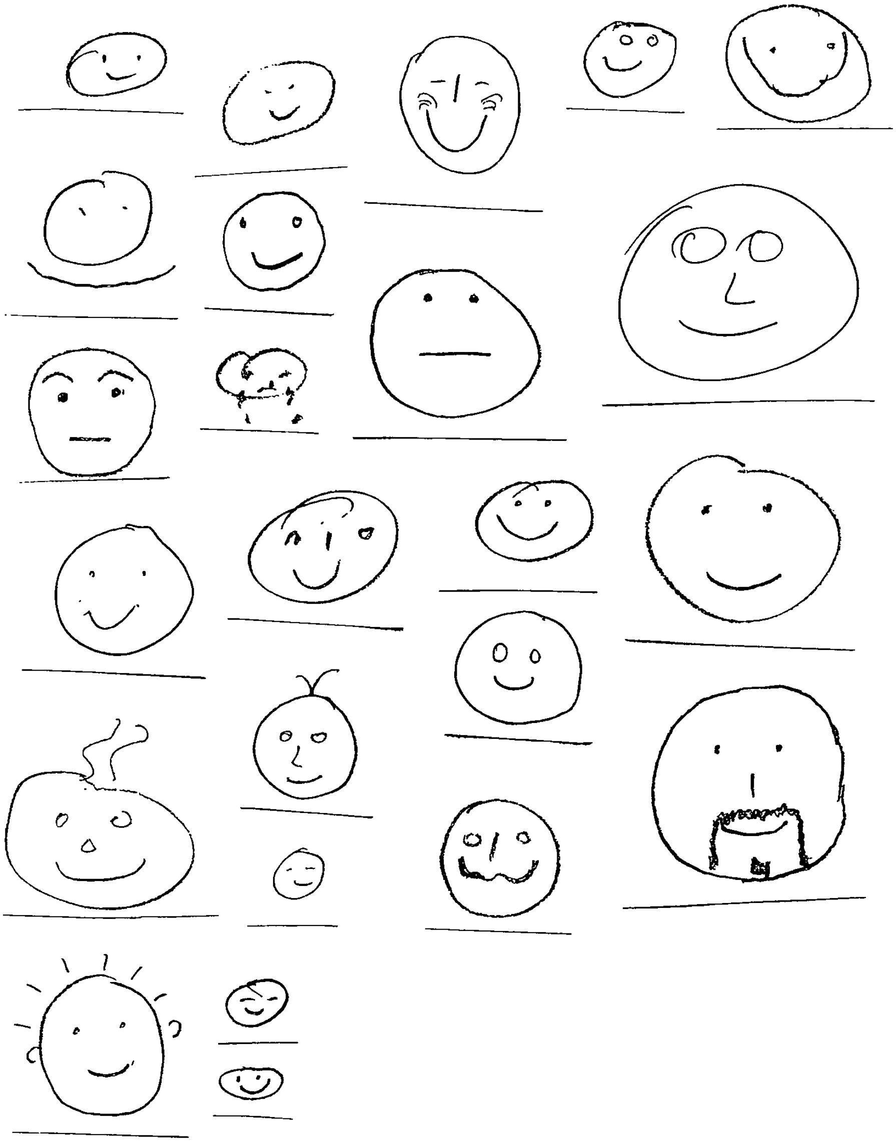
Will – can the King's Fund work to ensure that PCT non-execs are drawn from a wide range of experience within the community and do not lose the specific public links and expertise of lay members?

Will – what are benefits for using additional resources i.e. dedicated worker for public participation.

Work on how best to support frontline staff in their role in taking forward the community participation agenda.

Please help by diagrammatically showing the range of issues/ the number of levels involved.

Faces on departure:



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