

# Practice Based Commissioning & Patient & Public Involvement - The New Frontier

This document draws on “Healthy Democracy – the future of involvement in health and social care” Ed Andersson E, Tritter J and Wilson R. Involve/The National Centre for Involvement.2006.

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# ISSUES FOR DEBATE

## Practice Based Commissioning & PPI

### – the current situation on the ground

PBC offers an opportunity for GP practices, Primary Care Trusts and local people to work together developing more appropriate pathway-based care and more efficient services.

However despite a general feeling that users should be involved, views of local communities are rarely taken on board with PBC.

Surveys carried out by NHS Alliance and Developing Patient Pathways suggest that some practices are experiencing barriers to involving patients in the early phases of PBC, despite adequate mechanisms:

- 299 responses were received to a survey of primary care trusts. Of these, 172 reported active PBC.
- Seven out of ten PCTs said that PPI can have a positive impact on PBC and that they have good mechanisms for engagement.
- Yet just 29% of those who already have active PBC in their areas said they have moderately or well functioning PPI in PBC <sup>1</sup>

Although there is an increasing amount of involvement and a positive approach by professionals, the actual experience of patients seems to be poor:

- Most (93%) health professionals say that ordinary people should have a say in how their local health service is run and feel that involving patients would improve services.
- 74% of the public want to have a say in how their surgery is run. However, 50% think that ordinary people can't influence their local health service.
- 76% have never been asked for their views.
- 68% of people do not know how to feed in their views. <sup>2</sup>

There remains no formal mechanism for influence over the general development of services in PBC. Commissioning practices may decide that most diabetics should be cared for outside hospitals; or that the local A+E send back to their GPs patients who attend inappropriately. These may be sound decisions, but they may have had no discussion with local people at

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<sup>1</sup> Effective practice-based commissioning: engaging with local people  
Mar 2006 NHS Alliance, DPP and NAPP

<sup>2</sup> Effective practice-based commissioning: engaging with local people  
Mar 2006 NHS Alliance, DPP and NAPP

all. The same is true of non-Foundation Trust hospitals – they can make investment (or dis-investment) decisions with little recourse to local people. While PBC and PPI are often mentioned together they are distinct.

Foundation Hospitals have a mechanism by which patients and staff can influence decisions. The model, based on the Co-operative movement, includes a large members' group, with a central committee having some powers over decision-making. There is debate over its effectiveness, but it is an important and interesting model which could be exported, with improvements, to PCTs.

## Benefits of Involvement

Measuring benefit is immensely difficult. This is partly because benefits vary widely and because many are unpredictable. What follows is based on experience over the years, extrapolated to the new situation with PBC.

**Effective demand management:** when users are involved in discussions about demand management or rationing, and when they have received clear information about the issues, they may become better able to offer helpful and supportive solutions.

**Improved care pathways:** experience suggests that involvement in defining and designing care pathways improves flow and appropriateness of care. Again, where care pathways are going to involve volunteers and community activity in parts, this is a good way of getting buy in and recruitment by involving the public in early commissioning decisions. The Clinical Governance Support Team is a good source of evidence and experience.

**An involved public is an informed public,** enabling people to make decisions about their health and well-being.

**Cost-neutral improvements are often recommended,** contrary to the fears of NHS staff. Usually lay people do not ask for expensive changes, but mainly for culture/attitudinal shifts from professionals. The National PALS programme has evidence of this.

**Prevention of social exclusion** together with the reintegration of those who have become excluded back into society. 1

**Partnership working** between local services with a better fit between "top down" and "bottom up planning". 2

**Improved services:** experience shows that involving local people at an early stage can lead to improved design, the saving of time and the development of new services. 3,4

**Involvement in planning may enhance Choice.** If a group of patients have been involved in commissioning a service then they may be more likely to have ownership and spread the message. This would be helpful not only for the use of the service but also in terms of public perception

about how services are commissioned and the credibility of the commissioner.

**Involvement in planning can help users and carers understand regulatory and self-regulatory systems** and access these, especially BME groups.

**It is likely that, by working with communities, PCTs will find solutions to problems that might otherwise be seen as intractable.** Engaging with the public needs to be seen as a solution to a problem rather than a problem to be solved. This is most obviously the case with the issue of mental health where a community's understanding of a problem that is pressurising it, for example safety and crime, may help to explain what has only otherwise been seen as an individual problem of mental health.

## The difference between PPI and Choice

As currently construed, "Choice" and PPI are different. Choice is seen by the DH as an individual's ability to get what they want from the system, mainly in referral, but in future, over management of their care.

PPI, is a more holistic, collective approach, where the local population, as well as individuals, the public as well as patients, offer recommendations for good practice that affects and influences the delivery of care for all. Choice is subsumed within PPI.

There remains an urgent need to ensure that, in the new NHS, PPI is integrated into decision-making in such a way that:

- local recommendations are heard
- local recommendations are debated
- local recommendations are responded to
- transparency about how decisions are made and who makes them

## The Issue of Representativeness

The argument is often made that those involved in a PPI initiative are not representative, and therefore their views can be ignored.

Finding a cross section of local representatives is well nigh impossible. There is a similar problem with the representativeness of professionals involved – often clinicians are represented by the same people who are often unrepresentative of the wider clinical body.

A study of users involved in social services work showed different approaches to the issue of representation; most said they did not see themselves as representative. All said they brought a user perspective to the role. Some stressed that they were more than a user.<sup>3</sup>

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<sup>3</sup> USER PARTICIPATION IN THE GOVERNANCE AND OPERATIONS OF SOCIAL CARE REGULATORY BODIES : Frances Hasler (formerly SCIE, now CSCI) Edited: October 05

Despite the intractability of this problem, there are ways of mitigating it:

- Consider users not as representatives but as “patient involvement advisors” asking key questions and ensuring appropriate responses to local people.
- Working with an existing local voluntary group and encouraging them to consult with a wider population.
- Looking at the literature on the field in question:
- Harnessing PCTs’ existing mechanisms for engagement

## About what issues should we consult?

In this section, we look again at the different stages of commissioning, this time focusing on how patients and the public can best be involved.

### 1. What pathways or issues are the PBC group going to start with?

Information such as the savings that could be made by intervening in different ways for different pathways, will enable a debate with local people about which pathways to begin with.

### 2. The convenience and problems of existing services

The aim is to identify the main problems experienced by patients that need to be corrected as part of the commissioning process.

Problems experienced by patients are important, but they also need to be set next to those experienced by clinicians and administrative staff.

### 3. Commenting on the design of new approaches and developing new approaches that the group has not thought of before

This may be difficult for lay people if the pathways involve technical discussions. However, it is often possible to obtain a useful dialogue if local people are specifically asked about pathways from their experience.

### 4. How to spend the savings

Involvement in this decision is very important. If there are net savings these will be owned by the practice/practices and their patients. However, a decision may need to be made as to where the funds are applied. This might be a choice between, say, orthopaedic issues and diabetes. These are essentially ethical choices that need to be underpinned by data of effectiveness and equity. There is no reason to suggest that lay people cannot make a valuable contribution to these decisions.

### 5. Organising around governance issues: how will quality be guaranteed and measured?

Patients can be involved in developing standards for practices and others  
4. Also monitoring some of these standards in the PCT clinical governance programme

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<sup>4</sup> [http://www.modern.nhs.uk/improvementguides/patients/3\\_8.html](http://www.modern.nhs.uk/improvementguides/patients/3_8.html)

## General Principles of engagement 5

1. Involving patients should be easy and safe for practices and the public – for instance confidentiality should be maintained at all time.
2. Patients' time is paid for.<sup>6</sup>
4. The recommendations of patients are seen as a discussion point.
5. A monitoring process can be carried out in different ways, including visits, questionnaires, panels, focus groups or "mystery shopper" contacts.
6. Feedback is handled in a non-threatening and facilitative manner.

## Tensions in commissioning and ppi

This section tries to describe the tensions within the concept and practice of PPI. both in general and in relation to PBC. It then examines whether the new system of LINKs addresses these difficulties.

Tensions in general.

1. The NHS has become much better at listening to local people but remains poor at responding.<sup>7</sup> The main task for PPI structures and processes is now to ensure that the NHS seeks out and responds to local need, defined both by professionals and local people.
2. NHS management and clinicians are frightened of PPI. A common fear is that "the floodgates will open" – once local people's opinion is sought, a torrent of expensive demands will be impossible to fulfil. Experience shows the opposite: most requests are modest and usually focused on change of attitude rather than increasing costly services or facilities.
3. There is also a fear that local people will demand ineffective and inappropriate things. This certainly is one interpretation of local demands for ineffective therapies or institutions to be kept going when they are no longer needed. There can be a clash of different cultures of evidence.
4. PPI and the new structures shift the risk towards the NHS, away from the patient. Payment by Results, Choice and PBC mean that NHS organisations feel a whiff of market forces. A rebalance here is long overdue.
5. The NHS has relatively inflexible management with little experience nor inclination for the shifts in focus and approach demanded by effective PPI.

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<sup>5</sup> Lewisham PCG Clinical Governance Programme 2003

<sup>6</sup> "Reward and Recognition: The principles and practice of service user payment and reimbursement in health and social care" (DoH, 2006)

<sup>7</sup> Commission for Health Improvement. Sharing the learning on patient and public involvement from CHI's work. i2i - Involvement to Improvement. CHI report 2004

6. When the toe is dipped in the water and feedback is received, the vast majority of responses show high satisfaction with services.
7. In essence, however, no-one wants to share power. So, to make PPI work, policy has inclined towards formal structures and processes that often act as a brake on developments. These can include scrutiny functions held by Community Health Councils, Overview and Scrutiny Committees and Patient and Public Involvement Forums, all of which need to be consulted about significant changes in the system.

### **Tensions at PBC level**

1. Clinicians in general and perhaps GPs in particular have not had a culture of involving patients in non-clinical decisions. In some respects, PPI is analogous to involving patients in consultations, but writ larger. Practices, like the rest of the NHS are learning fast, but there is still a long way to go.
2. GP practices which are small profit-making concerns have become more engaged with Choice and feedback from patients in the last couple of years. Practices earn money for carrying out standard surveys of their patients and responding to its results. Referrals are increasingly through Choose and Book, where Choice is a key aspect.
3. Responsiveness may be stimulated by competition by the private sector which will be taking on primary care responsibilities over the next few years.

## STATUTORY GUIDANCE AND ISSUES

### Accountability to patients and the wider public in PBC – DH advice

Here is the current DH advice on PPI and PBC. It is summarized in Practice Based Commissioning: Practical Implementation (DH Nov 06) It says:

2.34 Practice based commissioners now have the ability to redesign services, and with that comes a responsibility to ensure they involve their patients in developing their plans. Practices should make their plans available for public scrutiny by their practice population and should be included in the annual PCT prospectus.

2.35 PCTs need to ensure that the collective plans for all the practice based commissioners are available for scrutiny by the Overview and Scrutiny Committee of the local authority and also by the general public. PCTs also need to ensure practices have engaged their patients in service redesign.

2.36 All NHS organisations are required to ensure they have effective complaints procedures in line with national regulations. PCTs are required to ensure that any new arrangements for services meet national guidelines on complaints and patient advice and liaison services (PALS). <http://www.dh.gov.uk/assetRoot/04/14/15/64/04141564.pdf>

So, the advice is clear, but there is little emphasis on PPI and no real incentives for practices and clusters to actually carry out realistic and useful PPI.

### Section 11 and its implications

The NHS is not accountable to its users or to the public. There is no formal democratic process for the whole of the Health Service that ensures a say in its development or its management. The current evidence suggests that recommendations by local people can improve the nature, style and quality of health services.<sup>8</sup>

Section 11 of the Health and Social Care Act 2001<sup>9</sup> declares that NHS organisations seek out the views of local people, though there is no

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<sup>8</sup> Farrell C, Patient & Public Involvement in Health. The evidence for policy implementation. DH May 04. Gateway Ref 2880

[http://www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh\\_4008005](http://www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_4008005)

<sup>10</sup>Commission for Health Improvement. Sharing the learning on patient and public involvement from CHI's work. I2i – Involvement to Improvement. CHI report 2004

guarantee that those views will be acted on. Although Foundation Trusts offer an important approach to accountability through their members, there are no similar structures in the primary care world nor in the ordinary, non-Foundation trusts. Most NHS organisations have developed mechanisms for hearing the views of local people in specific aspects of care, but it is not systematised, nor very effective.

## LINKs may offer a new approach to PPI in general and PBC in particular. Perhaps.

LINKs are the new approach to PPI across the UK, following the demise of the PPI Forums.

They are designed to be a more open, less structured approach to PPI, with strong links to the Local Authority (LA) and the Overview and Scrutiny Committee (OSC)

However, it seems likely that they will be underfunded and it is also of concern that the link with the LA might mean that they become less independent than would be useful.

Here is the DH advice:

### ***What will LINKs do?***

Their functions will be:

- **promoting and supporting the involvement of local groups and individuals** from across the community to influence the commissioning, provision and scrutiny of health and social care services;
- **obtaining the views of local groups and individuals** about their health and social care needs;
- **gathering the views of local groups and individuals** about their experience of health and social care services;
- **conveying those views to organisations responsible for commissioning, providing, managing and scrutinising health and social care services;**
- **enabling local groups and individuals to share their skills and experience** in order to influence the development and improvement of local health services;
- **supporting people within the community to make their voices heard**, including people who find it hard to participate in traditional ways or do not choose to;
- **supporting the commissioners and providers of health and social care services to engage with the local community**, and in particular those groups and individuals who find the services they need difficult to access;
- **act as a hub within a network of user-led and community based groups** in the area covered by the host local authority, providing a channel for views and information between these groups and the local health and social care organisations;

- **LINKs will set their own agenda and focus on issues of concern to local people** and seek to influence change; and,
- **LINKs will be required to report on their activities and expenditure to the public**, to health and social care bodies, the relevant local authority, the Secretary of State for Health, and other interested organisations.

**Although the functions will be set out in legislation, and whilst guidance will be provided, we will not prescribe how they will be carried out.** They will also be able to carry out additional work commissioned and funded by the NHS and/or OSC if they decide that this is appropriate and within their remit. It must be remembered that the primary responsibility is to approach and hear from **all** groups and people within the area.

**The host organisation will enable and support the LINK members to undertake its work.** It is therefore vital that the establishment of the LINK takes into account the breadth of remit and the skills and knowledge that will be required,

**Learning for the host organisation will include:** understanding equality issues and legislation; experience and understanding of community development approaches; experience of engaging with and involving individuals and groups from diverse communities; experience of using a variety of forms of communication both formal and informal, for example using interpreters or sign language; experience of research methods, e.g. questionnaires, focus groups, participatory appraisal, and community panels; data collection and management; and, administrative support. The methods that the host applies to establishing the LINK are likely to influence how successful the LINK is in effectively fulfilling its role.

### **How will the LINK carry out its role?**

Each local authority with social services responsibilities will be appropriately funded by the Department of Health to carry out a new statutory duty to make arrangements providing for the establishment of a LINK in its area. Each LINK will have a wide membership which is inclusive, diverse and made up of both individuals and organisations. To reflect this diversity, it will need to make use different methods of involvement and communication amongst members as well as with their local communities. This means that LINKs will not solely base their communication and involvement with members through meetings.

Contributions may range from responding to a comment card that the LINK has provided to all service providers and commissioners asking for general views on health and social care services, to joining a focus group discussing the experience of people receiving a newly implemented service, or participating in a discussion with LINK members that have visited an existing community group. Contributions may be specific to an issue that the LINK is researching, or not. It is therefore important that LINKs have

mechanisms in place to ensure that there is regular communication with commissioners and providers of services about people's experience on all types of services available.

LINKs will be an important part of the new arrangements to strengthen the public voice, and will have statutory powers enabling them to require NHS and social care bodies to provide information about their services and priorities and to respond to recommendations. LINKs will be able to set their own priorities and agenda driven by the priorities for local communities. They will do this taking into account the plans developed by other organisations, networks and partnerships, including Local Delivery Plans, Local Area Agreements, Community Plans, and Children and Young People's plans. This freedom will require LINKs to develop strong, credible networks and relationships across their communities, enabling them to involve seldom heard groups and individuals, and ensure that they are not only heard but are also influential. This will need to be demonstrated in their annual report to the Secretary of State for Health.

As LINKs will provide an authentic and inclusive local voice, commissioners and service providers should recognise the value that LINKs can provide to help them shape and develop the services, and should therefore be proactive in developing relationships with their local LINK

### ***How will LINKs undertake their role?***

There is no prescribed view about how LINKs will undertake their role, although they will be required to demonstrate that they are fulfilling their statutory role, and in particular that they are maintaining their inclusivity, independence, and accountability. LINKs will need to act both proactively, in identifying local priorities through contact with the wider communities, and reactively in response to imposed change. Members will also need to be able to identify the different views of groups within the community, recognising that if an area has been through an extensive consultation around changes to a service and gains local approval, there will still be some people who disagree with the final decision.

The following example suggests how a LINK might choose to work.

#### Setting the annual LINK priorities

- a) At the beginning of the year the LINK might hold an open meeting with local people to discuss what priorities it might have for the forthcoming year. Those members and interested parties that are unable to participate in a meeting could be asked to provide information through a number of ways, for example by letter, telephone call or through the use of computer based questionnaires. Members of the LINK might also visit local groups and community settings to find out the important issues for local people.
- b) In order to set the context for the discussion and create opportunities for complementing existing work, the process might

include information about existing local and national health and social care priorities, building on the existing formal process for identifying priorities.

- c) Using a number of different methods to assess the issues raised, the outcome of the information gathering process would be to identify and agree the main priorities for the LINK to look at, taking into account the likelihood that issues would arise during the year.

This arrangement attempts to find a balance between a proactive approach building on current energy and experience and a formal approach that can sometimes tie groups down and encourage a defensive attitude by the NHS.

It may be that this arrangement will be found to be too informal to have teeth, but it is being linked with a change in the law that is likely to mean that responsiveness will be enhanced.

It remains unclear how LINKs will link with PCTs' current PPI arrangements.

## The Local Gov + NHS Bill and possible implications for PPI

There is a new bill going through Parliament. Part of it is designed to strengthen arrangements for PPI. It will impose some requirement on PCTs to respond to local recommendations that have been derived from the work of the LINKs. However, this requirement seems very weak and may not actually be much of an inducement to better practice.

In addition, it has nothing specifically to say about PBC and its responsibilities for PPI.

"Section 11 of the Health and Social Care Act 2001 places a general duty on NHS organisations to do three things:

- involve and consult people in the planning of the provision of health services;
- to involve and consult people on the development of proposals for changes to services;
- to involve and consult people in decisions that affect the operation of services.

But at no point in the legislation does it say to what level that applies, so it literally can be from the biggest reconfiguration to the smallest issue; indeed, it could even relate to something that has no impact on service delivery from the point of view of the patient. The change might be made and people would not be aware of the difference.

What we have done (in the Bill – my addition) to simplify it is introduce the notion of significance.

**The duty kicks in when it is above a certain level.** That is not to say that it must be a huge reconfiguration; it just needs to be significant in terms of the range of services or the manner in which they are provided. We are simplifying it to enable the NHS to say of a particular matter that it is clearly something on which it needs to consult and involve people and now it knows where it is.

**The Act will include a requirement on NHS organisations to have regard to statutory guidance.** Currently, section 11 does not have that requirement. We believe that statutory guidance is absolutely fundamental to enable the NHS to be better at what it is supposed to do.

**There will be a new duty for PCTs to report back on what they have done.** They will now be required to say how they will engage people, say what they have heard and say what they are going to do about it.”<sup>11</sup>

The following is the section of the Bill that relates to PPI. Essentially, it means that the PCT must make a report on how it has responded to local views. That’s it – there is no further responsibility. In our view, this does not amount to a significant increase in accountability

#### **155 Duties of services-providers to respond to local involvement networks**

(1) The Secretary of State may by regulations impose, on a services-provider, duties—

- (a) as respects responding to requests for information made to the services provider by a local involvement network;
- (b) as respects dealing with reports or recommendations made to the services-provider by a local involvement network; or
- (c) as respects dealing with reports or recommendations which, in accordance with any requirement imposed in regulations under paragraph (b), have been referred to the services-provider by another services-provider.

#### **164 Primary Care Trusts: reports on consultation**

In Chapter 2 of Part 2 of the National Health Service Act 2006 (c. 41) (Primary Care Trusts), after section 24 insert—

##### **“24A Report on consultation**

(1) Each Primary Care Trust must, at such times as the Secretary of State may direct, prepare a report—

- (a) on the consultation it has carried out, or proposes to carry out, before making commissioning decisions, and

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<sup>11</sup> Meredith Vivian, Head of Patient and Public Involvement at the Dept of Health giving evidence to the Health Select Committee Feb 07

(b) on the influence that the results of consultation have on its commissioning decisions.

(2) In subsection (1) "commissioning decisions", in relation to a Primary Care Trust, means (subject to any directions under subsection (3)(e)) decisions as to the carrying out of its functions under Parts 4 to 7.

(3) The Secretary of State may give directions as to—

(a) the periods to be covered by reports under this section;

(b) the matters to be dealt with by reports under this section;

(c) the form and content of reports under this section;

(d) the publication of reports under this section;

(e) decisions that are to be treated as being, or that are to be treated as not being, commissioning decisions for the purposes of subsection (1)."

## A PRACTICAL GUIDE

What are appropriate mechanisms to deliver PPI at PBC level, at the level of practices or clusters?

- PPGs clustering together
- Community development at a locality level
- Questionnaires, including QOF
- Literature searches
- Think pathways

## WHAT STRUCTURES AND PROCESSES COULD SUPPORT PPI IN THE WORK WITH PBC?

The key challenge is to provide engagement without exhaustion, developing effective PPI without interfering excessively in the daily life of practices who continue functioning under an increasingly workload.

It is also essential that whatever structures do emerge, that the PBC groups design them themselves – bottom up, not top down.

This section offers suggestions that build on current PCT experience as seen in the Alliance Acorn awards<sup>12</sup>.

### Taking advice from your PCT's PPI leads

They have much experience both of the theory and the practice of PPI. They will have handles both large and small consultations.

A dialogue in the context of PBC may lead to interesting new collaborations that could be quite fruitful.

### Patient Participation Groups/Critical Friends.<sup>13</sup>

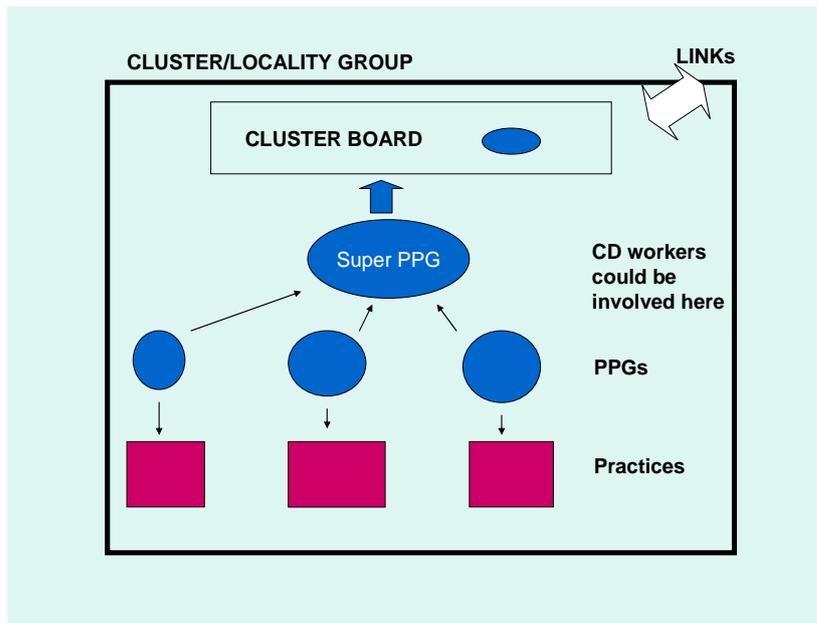
Patient participation/patient critical friends groups could be attached to each practice. For clusters, there could be a democratic forum composed of representatives from all the individual practice groups.

There is a long tradition and interest in PPGs for many years. The movement is ably led by NAPP which can support any practice wanting to set up a PPG. <http://www.napp.org.uk/>

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<sup>12</sup> [www.nhsalliance.org](http://www.nhsalliance.org)

<sup>13</sup> Greco, M. and Carter, M. 2001. *Establishing Critical Friends Groups in General Practice*. Report to the North and East Devon Health Authority. Exeter and North Devon NHS Research and Development Support Unit, United Kingdom.



### Working with community development workers (CDWs)

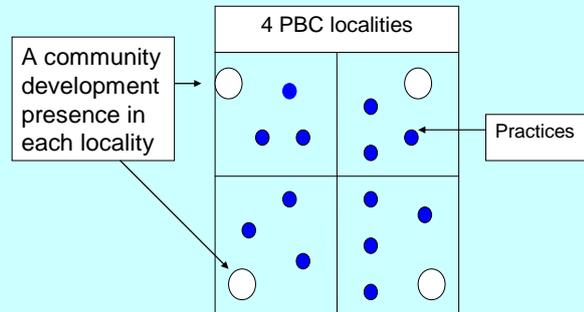
One approach is to work with existing CDWs or Health Trainers to gather local views on behalf of cluster or practice. The PCT and the local authority may already have funded such workers.

CDWs do outreach work identifying key health issues as seen by local people, and work with health organisations to discuss implementing their recommendations.<sup>14</sup>

One arrangement, as in Lewisham, could be a CDW is attached to each GP commissioning cluster, brokering a dialogue between local people, community groups and practices.

<sup>14</sup> Fisher B Community Development. In: New Beginnings, King's Fund London. 2001

## CD workers in each locality



Such arrangements can foster improvements in provision of care without exhausting either practices or the public.

The CDWs, with voluntary agencies, are represented on PBC groups as advisors and participants, helping to draw users into relevant sub-groups where needed. An excellent example of community development in action can be seen in the Lewisham Community Development Partnership.<sup>15</sup>

There is now a lot of interest in community development as a route to PPI. The LINKs trial sites have been described as “community development projects” by the DH. There has been an important recent paper, The Commissioning framework for health and well-being (DH Mar 07)

<http://www.dh.gov.uk/assetRoot/04/14/38/54/04143854.pdf>

This examines the crossovers between Health and Social Care. This in turn builds on the “Community Development Challenge” from the Home Office [http://www.communities.gov.uk/pub/971/TheCommunityDevelopmentChallenge\\_id1504971.pdf](http://www.communities.gov.uk/pub/971/TheCommunityDevelopmentChallenge_id1504971.pdf) which shows how CD can offer practical and health-protective approaches to PPI.

### Citizens' Juries

When specific questions need answering (what policy on classified drug use should we follow?), a Citizens' Jury can be employed. Here, a small group of people are picked to represent, so far as possible, the local community. They are given background information about the topic and then call witnesses to discuss the issue with them. Their conclusions are frequently accepted by the organisation that paid the considerable cost of organising the process.<sup>10</sup>

They are a gauge of public opinion, and are best used “to assess public opinion on high profile or contentious issues”. They can be expensive if

<sup>15</sup><http://www.soc.surrey.ac.uk/sru/SRU37.html>

peoples time has to be paid, Further information  
[http://www.cabinetoffice.gov.uk/REGULATION/consultation/consultation\\_guidance/methods\\_of\\_consultation/citizens\\_juries\\_forums.asp](http://www.cabinetoffice.gov.uk/REGULATION/consultation/consultation_guidance/methods_of_consultation/citizens_juries_forums.asp)

### **A not-for-profit organisation.**

Social Enterprises are third sector organisations which also includes charities and voluntary organisations. Characteristics include

- Shared ownership, which can include employees, users, and people in the wider community
- Restrictions on how profits are distributed –may be re-invested or shared between 'co-owners'
- Stated social aim
- Restriction on use and disposal of assets.

They are outside the Public Sector and are not subject to the same obligations on pay, pensions and conditions of employment.

Further information <http://www.socialenterprise.org.uk/>

Practices can band together in a formal structure similar to a company with a Board including patient representatives. This can then have an outer shell of members to offer a more representative approach, along the lines of a hospital Foundation Trust.

## **ABOUT WHAT ISSUES SHOULD WE CONSULT?**

In this section, we look again at the different stages of commissioning, this time focusing on how patients and the public can best be involved.

### **1. What pathways or issues are the PBC group going to start with?**

Information such as the savings that could be made by intervening in different ways for different pathways, will enable a debate with local people about which pathways to begin with.

### **2. The convenience and problems of existing services**

The aim is to identify the main problems experienced by patients that need to be corrected as part of the commissioning process.

Problems experienced by patients are important, but they also need to be set next to those experienced by clinicians and administrative staff.

### **3. Commenting on the design of new approaches and developing new approaches that the group has not thought of before.**

This may be difficult for lay people if the pathways involve technical discussions. However, it is often possible to obtain a useful dialogue if local people are specifically asked about pathways from their experience.

### **4. How to spend the savings**

Involvement in this decision is very important. If there are net savings these will be owned by the practice/practices and their patients. However, a decision may need to be made as to where the funds are applied. This might be a choice between, say, orthopaedic issues and diabetes. These are essentially ethical choices that need to be underpinned by data of effectiveness and equity. There is no reason to suggest that lay people cannot make a valuable contribution to these decisions.

### **5. Organising around governance issues: how will quality be guaranteed and measured?**

Patients can be involved in developing standards for practices and others<sup>16</sup> Also monitoring some of these standards in the PCT clinical governance programme

### **General Principles of engagement<sup>17</sup>**

1. Involving patients should be easy and safe for practices and the public – for instance confidentiality should be maintained at all time.
2. Patients' time is paid for.<sup>11</sup>
4. The recommendations of patients are seen as a discussion point.
5. A monitoring process can be carried out in different ways, including visits, questionnaires, panels, focus groups or "mystery shopper" contacts.
6. Feedback is handled in a non-threatening and facilitative manner.

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<sup>16</sup> Lewisham PCG Clinical Governance Programme 2003

<sup>17</sup> "Reward and Recognition: The principles and practice of service user payment and reimbursement in health and social care" (DoH, 2006)

## **PRACTICAL EXAMPLES OF GOOD PRACTICE IN PPI AND PBC**

### **Ashton Leigh and Wigan PCT**

We have set up a PCT patient Panel drawn from the 7 areas where we have practice based commissioning clusters. The panel was set up in Oct 06 and currently has just over 200 members - this can be used as a whole or as a cluster group so that practices can contact members of the public from within their practice area to ask them their opinion on service developments or quality standards. We have used the panel members so far to ask questions on what they would require from an urgent care centre development, we have invited them to open evenings about our fair access project to recruit more primary care services into under doctored areas and we have used the panel members to assess patient information leaflets.

### **Lewisham PCT**

Every meeting of both clusters and central, Federation, meetings has a community development representative present. This ensures the meetings are open and transparent and has resulted in feedback on the design of diabetic services which is one of the key initiatives for PBC in our patch.

### **Walsall Teaching PCT**

This PCT has set up a number of Health Commissioning Consultation Groups (HCCGs) to ensure that local residents, local workers and communities are able to feed their views into the four Practice Based Commissioning Groups.

The remit of the Health Commissioning Consultation Groups will be: -

- To facilitate debate amongst local residents and workers concerning health needs, health priorities and current service provision. This will need to be focussed on a specified geographical area, but also be aware of the Walsall-wide agenda and issues that affect other commissioning groups.
- To provide a framework for the input of information relating to health commissioning priorities.
- To collect feedback from the community about current health service provision and suggestions concerning gaps and how services could be improved.
- To raise awareness of voluntary sector service providers and their potential in terms of capacity and competence to deliver local health services.

## WHAT COULD A DEMOCRATICALLY ACCOUNTABLE PRIMARY CARE SYSTEM LOOK LIKE?

In this section, we want to examine possible models that would offer a more democratic approach. To our knowledge, these have not been applied anywhere in the NHS in the UK – we are speculating on what might be possible and useful. The Alliance is not advocating any of these approaches. What we feel is that the NHS needs to explore engagement and involvement in more depth and with more honesty – these approaches may give food for thought.

Accountability is the process whereby individuals or groups who are responsible for a set of activities explain or answer for their actions.

Accountability can be:

1. **Professional:** the clinician is accountable to their professional peers and to the patient. Competence and legal and professional conduct are the most important elements.
2. **Economic or consumerist:** the accountability of the marketplace is applied to healthcare. PBC and PbR are the current model. If the provider is inadequate, the consumer “exits” and the provider fails.
3. **Political:** the goal of healthcare remains the patient’s well-being, but the mechanisms for fine-tuning are subject to interpretation by the community.

Currently all NHS organisations are accountable upwards, to the DH who sets targets and measures performance. The Alliance is exploring accountability here in the opposite direction – downwards, to the people whose NHS it is.

Local people’s needs and wants are recognised and understood better now than ever before. However, the current gap in the process is the responsiveness of NHS organisations. The government’s main focus in this regard is the concept of choice – NHS organisations will respond to individual patients’ choices as consumers of health care. Organisations will respond to the pressure of demand – it will become in their interests to understand what their populations want and need and to respond to it in an ever increasingly sensitive way. The quasi-market may respond in that way, but it may not. It may be that the organisations will be more driven by financial constraints and offer cheaper cost-cutting measures that will be dressed up to seem a response to the needs of the local population. One could argue that this is what is happening already in some of the big reconfigurations up and down the country.

However, there is an important proactive aspect of involvement that offers a parallel and vital link in the planning and commissioning process. Local people have a legal right to be part of the planning of local services from the outset. The NHS needs to harness those views.

*“People’s voices – their opinions, preferences and views – need to be heard at a local level as that is where the vast majority of spending decisions are taken and where key priorities are set. They need to be heard in a variety of different ways. And they have to count – at present, people do not feel that health and social care organisations listen enough to their views. It is important that these arrangements offer scope to groups – such as children and young people – who do not always have a choice to participate.”* Our Health, Our Care, Our Say

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4127453](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4127453)

Currently, there is little incentive for NHS organisations to change in response to this sort of local demand. There is no real accountability, despite the fact that PCTs are spending local people’s money.

No-one is suggesting, however, that the will of local people (whatever that is) should be applied, without reservation, to health. For instance, no-one wants to see clinically ineffective interventions merely because they are popular.

#### **What level of accountability do clusters and practices want?**

- a list of recommendations that can safely be ignored?
- recommendations that clusters must respond to?
- patients or patients’ reps sitting in most of the clusters’ meetings, integral to decision-making?
- patients having voting rights?

### **1. Accountable Commissioning – reporting and discussion**

Through their management of indicative budgets, practice based commissioners will be responsible for major amounts of public expenditure. They are formally accountable to Primary Care Trusts who in turn are overseen by Strategic Health Authorities. But practice based commissioners should also *feel* accountable to local communities. Not only will this increase the perceived legitimacy of their decision-making, it will also contribute to the critical process of getting our society more involved in health and health care. How might this local accountability operate in practice?

It is still early days for practice based commissioning but it has to be acknowledged that, to date, most decisions have been taken by professionals in smoke-free rooms. So the first stage in accountability must be to report on the current position. This should be the first in what will become a series of annual reports produced by each commissioning cluster. The reports should come in two variants. First, a straightforward, highly readable version and, second, a more detailed account produced with the more interested individuals and groups in mind.

These annual reports should cover the following ground and should be hosted on the PCT website and displayed in every practice:

- Summary of decisions made by the practice based commissioning group
- The process by which those decisions were made, together with the mechanisms by which they will be evaluated
- The reasoning behind those decisions, including anticipated health and financial gains
- The decisions taken on reinvesting any savings, together with the process by which those decisions were taken
- A statement on how members of the public can contribute to the decision-making process in future
- A statement that explains any financial implications for the commissioning practices of the decisions that have been made

This report could then be presented at a specially called annual meeting for the commissioning cluster and those present would have the opportunity to raise issues and put forward their own proposals for future action. The meeting should be widely publicised and specific invitations should be sent to, at the very least, the following:

- the Local Involvement Network (subject to legislation currently going through Parliament)
- the Overview and Scrutiny Committee membership
- the Patient Participation Groups within the practices concerned
- the local MP
- all local health Trusts and social care providers
- the overarching body for the voluntary sector in the area
- local public health and health promotion specialists

The annual meeting would also be an opportunity for those present to highlight their priorities and to discuss how patients and members of the public will be able to contribute to decisions over the coming year. Naturally, over time, the meeting will serve to assess whether the changes have brought about the desired outcomes.

This process will help to deliver both “upwards” and “downwards” facing accountability, building accountability to communities into a system that currently only stresses formal accountability to the NHS hierarchy. It will give commissioners greater confidence that they are effectively working to meet local needs and improve local health. It will also allow patients and the public influence over a key area of public spending, holding directly to account those who are making decisions on their behalf. This will have the further benefit of addressing the democratic deficit that currently prevails in health care decision-making.

*Graham Box, NAPP  
March 2007*

## 2. A Representative Democratic Approach

Another approach is to offer local people the ability to truly hold their local health service to account. The right to remove the head of the organisation would surely concentrate minds. The annual report would then become a base on which performance could be monitored. In addition, it would be possible, with the amount of available data on health process and outcomes, to obtain a fair grasp of how the local NHS was performing. The Healthcare Commission could, and does, produce a national dataset on outcomes.

**Elections:** it is perhaps unlikely that local people would get fired up about electing local health officials – though you never know. However, a good turn-out and a meaningful result might be more likely if elections were held as part of voting for the local authority. <http://www.unison-scotland.org.uk/revitalise/accountability.html#top>

**An elected PCT Board.** It would perhaps be too demanding to vote for all NEDs. But it would be feasible to vote for the Chair.

**Democracy at practice level.** Currently, the practice is effectively owned by the partners. However, there are examples in other countries of practices having a local Board composed of members of the practice population who have a say over the style and priorities of the practice.

**Democracy at PBC cluster level.** One representative of each cluster could be elected at the same time as the PCT Chair. Again, there would need to be information for local people on which to base their decision. This could include performance and redesign programmes as well as the extent to which the cluster had been responsive to local views.

**A Foundation Trust PCT.** There is no reason why the engagement process in hospital trusts could not be transferred to PCTs. The details might differ, but the principle could remain the same. NHS Foundation Trusts are democratic.

Local

people and staff directly elect representatives to serve on the Board of Governors. The Board of Governors works with the Board of Directors – responsible for day-to-day running of the Trust. In this way, the Board of Governors plays a role in helping to set the overall direction of the organisation.

There is controversy about how effective this approach is. Although on paper there may be hundreds of local people and staff involved, their actual influence on the organisation may be too small to be useful. These issues may need to be redesigned if transferred to a PCT in order to make the process more effective.

**Giving local people information about their practice.** It may be helpful for every practice to have a duty to provide their population with details of practice performance. QOF data is available on: <http://www.qof.ic.nhs.uk/search.asp>

Farrell C. Patient and Public Involvement in Health. The evidence for policy implementation. DH May 04. Gateway Ref 2880

**Give local people data about their PCT.** The HealthCare Commission collects important data on performance and this can be matched with PCTs with similar populations to take into account economic and social issues which affect health status and outcomes.

### 3. Participatory budgeting

Participatory Budgeting refers to ways of involving users, community, other employees in decisions about how a budget is spent. This can be wider involvement in how the overall budget is allocated or allocating small parts of the budget to be spent according to the priorities of the people in a local area or using a service.

Further information <http://www.participatorybudgeting.org.uk/>

Participatory budgeting (PB) is a mechanism of local government, which brings local communities closer to the decision-making process around a public budget. Internationally PB has achieved recognition by the UK's Department for International Development (DFID), the World Bank, the UN, UNESCO and others, and is widely cited as a model of good practice in local governance. It is increasingly used in the UK

<http://society.guardian.co.uk/localgovt/story/0,,2049200,00.html>

**The PB Unit was set up to raise awareness of PB** and what it can offer citizens and service providers. In the UK participatory budgeting is still a novel idea - of uniting local knowledge with public money and technical ability. <http://www.participatorybudgeting.org.uk/Brief.htm>

**So far participatory grant making has been the most common experience of PB in the UK.** A number of local authorities, local strategic partnerships and regeneration agencies are now using it to improve their engagement with residents.