Briefing Guide
Effective Patient and Public Involvement

August 2011
RCGP Centre for Commissioning
Introduction
The Royal College of General Practitioners (RCGP), launched the RCGP Centre for Commissioning in October 2010 in response to the government’s healthcare reforms, set out in its White Paper, Equity and Excellence: Liberating the NHS. DH 2010.

Set up in partnership with the NHS Institute for Innovation and Improvement (NHS Institute), the Centre aims to equip GPs and GP practices with the skills, competencies and expertise required to deliver effective healthcare commissioning which ensures patient-focused and high quality healthcare, leading to improved health outcomes.

Our Mission
We support those involved in clinically-led commissioning to continually improve health outcomes by developing the required skills and knowledge.

Our Vision
Through effective collaboration between clinicians and other professionals, we will contribute to improving commissioning that will ensure local communities receive the healthcare they need.

Our Values
- Achieving excellence
- Improving outcomes
- Effective collaboration
- Empowering communities
- Commitment to caring.

The Centre provides a range of learning resources on clinically-led commissioning. This Briefing Guide outlines how to involve local people efficiently and effectively in the process of commissioning.

Patient and Public Involvement (PPI) is an essential business requirement and without deep roots in the community and a responsive commissioning process, plans are more likely to unravel and difficult decisions will become more difficult to take.

Listening and responding
Commissioners and providers need to be good at both listening and responding. In general, the NHS is good at listening to both patients and the public. Most PCTs know what their cardiology patients think about local services. But, in general, the NHS remains poor at responding to the needs and wants of individuals and communities.

The basis for effective PPI is in being a responsive organisation: having systems and a culture that reach out to the populations you serve and allow you to alter commissioning plans to meet their expressed needs.
The business case for PPI

Safety
Users of the service and their carers are most likely to identify safety failings in services and systems. Responding to these issues is essential. Commissioners must ensure that providers develop effective processes for identifying and responding to safety issues raised by patients and carers.

Decommissioning
CCGs will on occasions find themselves faced with difficult decisions around decommissioning specific services. By adopting an approach that involves patients and the public from the outset, is more likely to lead to an acceptable outcome, with the reasons for the decision both recognised and understood.

Pathway redesign
Patient involvement is crucial in fully understanding the best way to redesign pathways of care which meet the needs of patients.

Involving users in redesigning services will help to ensure a more effective outcome. Seeing these experiences “in the patient’s shoes” transforms redesign.

Once new pathways are in place, users’ experience is also essential to ensure the redesign is effective. Questionnaires and ‘mystery shopping’ are useful tools to gather such information from users.

Dialogue with communities
There is increasing evidence that proactively working with communities using Community Development (CD) and co-production can result in more effective PPI as well as leading to improved health protection and financial savings. Undertaking such an initiative with your local authority will ensure a wider range of views are taken into account.

Users as problem-solvers
Lay representatives or groups can be very helpful in working through tough ethical choices facing commissioners.

PPI and Clinical Commissioning Groups – new responsibilities following the listening exercise
Clinical Commissioning Groups will have duties to involve the public in:
- Planning all commissioning arrangements
- Developing and considering all proposals for changes in commissioning arrangements
- All decisions affecting the operation of commissioning arrangements.

This obligation to involve patients and the public has been strengthened following the listening exercise. It includes patients’ representatives, as well as patients and carers.

The local population includes not only those registered with a GP practice, but also those who are not registered.
Working with others for effective PPI

Health and Wellbeing Boards after the Listening Exercise
Clinical Commissioning Groups will be expected to work with the Health and Wellbeing Boards (HWBs) in developing a Joint Strategic Needs Assessment (JSNA) which describes the health and care needs of the local population. This should be followed by a Joint Health and Wellbeing Strategy (JHWS) which describes how those needs will be met in the longer term. This is an ideal opportunity to involve local people in planning for the future.

Health and Wellbeing Boards must involve Local HealthWatch and the people who live or work in the local authority’s area when preparing the JSNA and JHWS.

Clinical Commissioning Groups must involve Health and Wellbeing Boards in preparing or revising their plans and, in particular, to share drafts with the Board and consult it on whether the drafts take proper account of the Joint Health and Wellbeing Strategy.

HWBs can object to the NHS Commissioning Board (NHSCB) if they feel that commissioning plans do not match the agreed strategy.

Clinical Commissioning Groups’ annual reports must also describe to what extent they have contributed to delivering the Joint Health and Wellbeing Strategy.

Local Authorities
The local authority can offer the group a range of benefits including:
- Democratic input and involvement
- A long-term investment in combating the social and economic determinants of health
- Extensive experience of commissioning a range of health-related programmes
- Expertise in processes of consultation and engagement
- Many councils have engagement processes in small areas that the CCGs and practices could use. For instance, participatory budgeting or Local Assemblies.

The local authority will have a significant impact on the thinking of CCGs and development. We recommend that Clinical Commissioning Groups explore with their local councils how to maximise collaborative work, saving time and sharing expertise.

HealthWatch/LINks
The structure and function of HealthWatch is under discussion, but the aim is that it should build on LINks.

HealthWatch will give local communities a bigger say in how health and social care services are planned, commissioned, delivered and monitored, to meet the health and wellbeing needs of local people and groups, and address health inequalities.

From April 2013, HealthWatch roles will include:
- Influencing – help shape the planning of health and social care services
- Signposting – help people access and make choices about care
- Advisory – advocacy for individuals making complaints about healthcare.
Patient Participation Groups (PPGs)

PPGs offer a well-known and effective way for practices to listen to their patients. The National Association for Patient Participation (NAPP) offers detailed guidance.

The PPG can offer a patient perspective by:
- Conducting patient surveys or collecting feedback in waiting rooms
- Advising practices and patients of new systems and treatments
- Sharing good practice by networking with other PPGs
- Sitting on recruitment panels for new staff, including GPs
- Lobbying to improve a range of health services.

PPGs can promote health matters by:
- Organising presentations on important health needs
- Producing a directory of self-care support groups
- Running courses within surgeries on health topics
- Raising awareness of key public health messages
- Running volunteer support services.

In addition, a number of areas are bringing representatives from PPGs together into a “Super-PPG” to offer advice to commissioners.

Cluster/Locality Group

Difficulties that can arise with PPGs include:
- They can be easy to start but difficult to continue
- They can involve mainly white middle-class retired people
- They can lose impetus.

The third sector

The third sector, i.e. voluntary and charitable groups, offer services to a wide variety of people in every part of every CCG. They add value to every CCG’s local area. But it can be difficult to find out how and where they are and what they do. In addition, often due to their dependence on grants for funding, their services and approaches may change without notice.

Most areas have an umbrella organisation that is in touch with the majority of local third sector groups and this offers a simple way into collaborative arrangements. Work between commissioners and the third sector could include:
- Commissioning local organisations to do relevant work
- Listening to their expert views on problems and solutions in the pathways
- Working with relevant groups to redesign pathways and monitor the changes.
What you should ‘listen’ to

Literature
Start with what is already known. For instance, we know that almost all patients value:
• Fast access to reliable health advice
• Effective treatment delivered by trusted professionals
• Involvement in decisions and respect for preferences
• Clear, comprehensible information and support for self-care
• Attention to physical and environmental needs
• Emotional support, empathy and respect
• Involvement of, and support for, families and carers
• Continuity of care and smooth transitions.

There is also literature on the needs and wants of particular groups, such as people with cancer. Literature can include other media such as videos, for example those on HealthTalkOnline. However, only the users of local services will be expert on the details of the services you commission.

Complaints
You need to know what the common problems are and how they are changing over time. The simplest way of aggregating complaints is to ensure that Patient Advice and Liaison Services (PALS) feeds its data to your CCG regularly.

Serious and untoward Incidents
These need to be brought to the attention of the CCG rapidly, so that any patterns or trends can be identified and dealt with. Every Trust keeps a record of these and systems need to be developed in primary care to do the same. Naturally they need rapid investigation and response.

HealthWatch database
A number of LINKs are developing a database into which all patient views from a wide range of sources can be deposited. The data can be searched and becomes an invaluable resource on which to base commissioning decisions to improve patient experience and quality of service.

Electronic noticeboards
NHS Choices and Patient Opinion both enable users to place their opinions of a service online. Responsive Trusts and CCGs will encourage patients to use these services which also allow practices and Trusts to engage in online discussions to explain and debate. CCGs can arrange to receive opinions automatically.

Conversations
NHS staff receive comments from patients about the service they have received. These conversations can be captured by staff adding them to the HealthWatch database, or somewhere else where they can be accumulated and searched.
Who should you listen to and how?

Unheard voices
In each CCG area, there are populations that struggle to have a voice, for example, people whose first language is not English, migrants, travellers, refugees and prisoners. These populations generally have the greatest health and healthcare challenges, and commissioners will have to work hard to understand their needs.

This is an ideal situation to be working with partners in the field. The local authority may well already have workers in touch with these groups and there may be a range of third sector groups who know a great deal about them. Other agencies such as the police or ambulance service may also have a lot of relevant information, experience and advice.

Another effective approach would be to use outreach services such as community development to contact people where they are and begin the process of engagement.

Relevant voices – key parts of your population
Local Public Health departments may be able to identify key populations for whom care could be improved. They will also be able to identify those whose voices you are going to find most difficult to hear.

Governance arrangements that help you be responsive

Commissioning for Quality: transforming patient experience information into commissioning action
CCGs need to ensure that there is a central group or committee that receives patient experience information from a variety of sources, including conversations, JSNA, PALS, Significant Untoward Incidents, audits and NHS Choices. This could all be processed by LINk or HealthWatch.

With lay representation on this committee, the group is mandated to decide on priorities for action in response to this information.

Representatives on Committees
This is a basic approach that should be seen as good practice. Having lay people on committees can profoundly change the nature of conversations.

Obtaining a representative group of people for commissioning purposes is almost impossible. Working with some people is better than working with none. It needs to be made clear to the lay delegates on the committees that they are a gateway to other groups and individuals outside. They should be communicating with them and bringing their views to the table. You are not expecting them to represent all people in your borough.

Most CCGs will have arrangements for paying lay representatives. An example contract can be obtained from brianfisher36@btinternet.com. A Clinical Commissioning Group with a good track record of doing this is Principia www.nottinghamprincipia.nhs.uk14.

For a discussion about Non-Executive Directors, see NedNet15.


**Elected members**

There is increasing interest in either having councillors on key committees and/or holding elections for non-professional members of the Board. Elections are being tried for Health Boards in Scotland and it may be useful to see how those develop before making commitments in England.

**Staff**

It is important for staff to see patient and public involvement an integral part of their role. This could be written into job descriptions and contracts. For instance, they may need to have an obligation to add patient comments into a database; or an obligation to explore, in their own departments, how to listen and respond to the voices of lay people.

**Governance and pathway redesign**

Working with patients who use the pathways is essential to their redesign:

- Every redesign group must have users involved
- Users can identify blockages and problems
- The same users can suggest solutions with clinicians for those problems. Although some solutions will be clinical, many will not. Users may already have worked out how to meet specific challenges
- Using national patient data can save an enormous amount of time and energy. Much of the existing national or international evidence is available through organisations such as Picker Institute Europe\(^{16}\) or The Kings Fund\(^{17}\).

**Governance and LINk or HealthWatch – representation**

Every PCT area has a Local Involvement Network. They will become HealthWatch groups from 2013 and will sit on the Health and Wellbeing Board. It is recommended that each CCG has a LINk or HealthWatch representative on every key committee in the group.

The LINk should be in touch with a wide range of local groups; they may have funding for volunteer expenses; they are able to support practices in setting up PPGs; they can find skilled people to sit on committees; they can run limited training programmes; they can get in touch with patients with particular conditions (such as diabetes) to help with pathway redesign.

In Lewisham, the LINk has produced a database, described above\(^{18}\).
Co-production and community development

Co-production defined
Co-production is about individuals, communities and organisations having the skills, knowledge and ability to work together, create opportunities and solve problems. The central idea in co-production is that people who use services are hidden resources, not drains on the system, and that no service that ignores this resource can be efficient.

Key ideas within the concept are:
- People as assets, not problems to be solved
- Neither the government nor the public have access to all the necessary resources to tackle problems on their own
- Individuals, organisations and statutory services working together to improve civil life
- Both local people and statutory services have skills that should be combined for maximum effectiveness.

Edgar Cahn, who defined the concept of Time Banking said: “The only way the world is going to address social problems is by enlisting the very people who are now classified as ‘clients’ and ‘consumers’ and converting them into co-workers, partners and rebuilders of the core economy.”

Community Development
This approach involves outreach work, usually with trained community development workers, who listen to issues brought up by the community in which they work. By seeing the community as an opportunity, as an asset, as a collaborator, change can happen rapidly. Community development has been shown to enable the NHS to:
- Enhance PPI
- Tackle health inequalities
- Offer significant health protection to individuals and communities
- Enhance behaviour change.

General information and evidence for effectiveness and cost-effectiveness can be found at http://www.healthempowermentgroup.org.uk.
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The Power of Social Networks
There is evidence that strong social networks protect people against the impact of stressors (mental or physical). The effect is significant, comparable to traditional medical interventions\(^1\).

Harnessing Community Development in a Clinical Commissioning Group
This could be done in a variety of ways, for instance:

- Identifying geographical areas where community cohesion and health are poor
- Jointly funding a community development intervention with the local authority
- Supporting the resident-led partnerships that developed
- Supporting the resulting joint working with the relevant agencies, such as police, education, health
- Responding to resident-led partnerships with shifts in commissioning services.

One example of this process can be found in Solihull\(^2\). In Bradford, community development has been used in geographical areas, but also with communities of interest, such as people with diabetes.

Procurement, providers and PPI
There are a number of ways that you can increase the chances of the patient voice becoming integral to the process:

- Ensure that lay people are involved in procurement processes
- Ensure that every contract includes the requirement that the provider needs to audit key criteria that we know are vital to patients. If the provider does not keep up or increase standards against these criteria, their income would be reduced. Examples of standards:
  - Fast access to reliable health advice
  - Effective treatment delivered by trusted professionals
  - Involvement in decisions and respect for preferences
  - Clear, comprehensible information and support for self-care
  - Attention to physical and environmental needs
  - Emotional support, empathy and respect
  - Involvement of, and support for, family and carers
  - Continuity of care and smooth transitions\(^3\)
- Use the Commissioning for Quality and Innovation payment framework (CQUIN\(^2\)) and Patient Reported Outcome Measures (PROMs\(^3\)) systems to ensure patient voice is involved.
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Analyse and Plan (Listen):
This is the first step in a JSNA process in co-operation with the local authority, the third sector and public health and building strongly on patient need. Work with your LINk and include patient experience data such as complaints, PALS data, SUIs and so on. It is important to involve not only users of the NHS, but also people who may have not used the NHS at all, or not for a long time. Agree strategic objectives and priorities, incorporating local communities. Involving your communities from the start in this process means that you are more likely to arrive at a realistic, supported and effective plan. Third sector organisations can be immensely helpful.

Design Pathways (Respond):
Outline your CCG’s commissioning plan, incorporating local communities. This is where the tough choices are put into sharp detail. The precise details of pathway design must be completed with patients and/or using patient experience techniques.

Specify and Procure (Respond):
Patients and the public can be involved in this aspect both directly and indirectly.

For individual outcomes, patient-derived outcome measures need to be incorporated into all contracts. We know what key user issues are for virtually all pathways. They include issues such as shared decision-making, confidentiality, respect and cleanliness. These criteria need to be part of every contract.

Reach out to third sector providers who may be able to help define and describe patient-sensitive pathways of care.

Deliver and Improve: CCGs need to monitor all contracts. Patients can be extremely important in this process, particularly in monitoring the patient-derived outcomes outlined above. Complaints and experience-based design principles are all useful at this stage.

The reality of this is not always as straightforward. However, clinical commissioners have an opportunity to take this process by the horns and make it useful, efficient and effective.24
References and Other Reading

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18. www.lewishamlink.org.uk
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20 http://www.healthempowermentgroup.org.uk/locations_solihull.php


About the author
Dr Brian Fisher has been a GP in South East London for 25 years. He is a member of the Professional Executive Committee (PEC) in Lewisham PCT with a particular responsibility for liaising with the local authority. He is also chair of the Patient and Public Involvement (PPI) steering group. He was awarded an MBE for his work in the area of community development. Dr Fisher is a co-opted member of the commissioning consortium in Lewisham and has helped to support PPI in the process. He is PPI Lead for the NHS Alliance and co-director of PAERS Ltd, a company that, with EMIS, has made possible patient record access for 60% of the UK population. He leads on the HELP project, a DH-funded community-development programme.
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