King's Fund

Patient and public involvement in Primary Care Groups and Trusts

Central Croydon case study

September 2001

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Acknowledgements

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Contents

Introduction

This report presents the findings of a study of public and patient involvement in Croydon from February 2000 to April 2001. Central Croydon Primary Care Group (PCG) was one of six case studies participating in a King's Fund study of public and patient involvement in primary care groups and trusts, funded by the Health in Partnership initiative of the Department of Health. In each of the six case studies a slightly different focus was taken. The focus of the work in Croydon was on public and patient involvement at a primary health care team (PHCT) level.

Overview

Background

- Central Croydon PCG is one of three PCGs covering Croydon, the other two are North and South Croydon. It covers a population of 141000.
- The borough of Croydon is relatively prosperous as a whole but this prosperity is concentrated in the South, with significant areas of deprivation in the North. Central Croydon PCG exhibits this contrast, encompassing the business centre, leafy suburbs and pockets of deprivation, particularly in New Addington.
- Central Croydon PCG began life as a commissioning pilot in 1997 and became a shadow PCG in 1998.
- The current approach to public and patient involvement was established during the period as a commissioning pilot, before Central Croydon PCG was formed. The process was copied in the other two Croydon PCGs.
- Central Croydon PCG has a history of working with Croydon Voluntary Action (CVA) and Croydon Community Health Council (CHC). The CVA has played a crucial role in developing and sustaining the PCG's public involvement work.
- The PCG has set up a community involvement subgroup of the PCG board but there is no written strategy for public involvement in the PCG.

The Primary Health Care Community Networks and Link Person Scheme

- The three Croydon PCGs employ a structured approach to public and patient involvement in terms of Primary Health Care Community Networks and a Link Person Scheme. In principle, each primary health care team (PHCT) should have a 'link person', a patient registered at the practice, whose role is to provide a link between patient interests at practice level and the interests of the PCG and the wider health economy.
- The main forum for communication is the Community Network meetings which bring together link people and other local stakeholders including PCG board members and officers, the CHC and representatives from local voluntary organisations. Each of the PCGs has its own Community Network.
- The link people have their own support meetings which are organised on a Croydon-wide basis.
- Lucy Darlow from CVA ran the Community Network and Link Person meetings until she left the post. Ann Ball has now taken over this role.

Mary Bond, the lay member of Central Croydon PCG Board, attends the Central Croydon Community Network and Link Person meetings. She brings views and information from these meetings to the attention of the PCG Board. PCG officers also support this communication role. However, this reliance on individuals 'feeding back' to the board limits the impact of the complex and varied discussions in the Network meetings.

Practice-level initiatives

- Three Croydon practices had Patient Participation Groups and one of them had organised educational meetings which were open to the public and patients from other nearby practices.
- One Croydon practice is doing innovative work involving a patient group helping to develop patient held records for older people.
- Leaflets and notice boards are the main ways in which information is given to patients outside consultations and approaches to information provision which involve more patient participation such as educational meetings or self-help groups are not common.
- Most primary health care teams do not gather feedback from patients other than through complaints or via individual patient-professional relationships but some do and the ways in which they do it include suggestion boxes and patient satisfaction surveys.

Board meetings

- Central Croydon PCG holds public meetings every three months with closed seminars in the intervening months.
- The PCG has tried to make the PCG board meetings more accessible to the public by re-organising the seating arrangements, having a slot for questions after each item on the agenda and removing the requirement to submit questions in advance.

Outcomes

- A clear and accessible structure in place for patient and public involvement
- Enthusiasm amongst link people to attend meetings and express their views
- Recruitment of link people to 35 practices across Croydon
- Information sharing with link people on how the PCG functions and makes decisions
- Some influence on PCG policy development
- Improved links with local community and voluntary sector

Methods

The focus of the work in Croydon was on public and patient involvement at a primary health care team (PHCT) level. We wanted to find out:

- how PHCTs inform patients
- how they get feedback from patients
- the extent of and interest in patient participation groups
- professional attitudes to patient and public involvement
- about the Primary Health Care Community Networks and Link Person Scheme
- how public and patient involvement works within the PCG

The following methods were used to study the patient and public involvement in Croydon:

- in-depth interviews with key stakeholders in Central Croydon PCG
- observation of relevant meetings
- case studies of three PHCTs in Central Croydon
- a survey of patient involvement practice in all Croydon PHCTs

In-depth interviews

Interviews were conducted with:

- Service Development Manager, Central Croydon PCG
- Lay member, Central Croydon PCG
- Health Authority non-executive, Central Croydon PCG
- Chief Officer, Croydon Community Health Council
- Community Projects Officer, Croydon Voluntary Action

Observation of meetings

Meetings of the Croydon Link Person Scheme, Central Croydon Community Network and a Central Croydon PCG board meeting were observed. Notes were taken during meetings and agendas and papers were collected. The PCG also provided papers from clinical governance and prescribing committee meetings.

The case studies

Three practices in Central Croydon PCG were selected to be case studies:

- the first had a link person and PPG
- the second had a link person but had not found it successful
- the third actively pursued the idea of public involvement but not through either the link person scheme or a PPG.

At each practice the practice manager, practice nurse and one or two GPs were interviewed. At the practice with a PPG two members who were patients were also interviewed. The issues covered during the interviews were:

- how the practice went about public or patient involvement
- what they felt had been achieved in their practice through public or patient involvement
- any difficulties associated with achieving it
- plans for future initiatives

The survey

The questionnaire for the survey was developed using information from the case studies and from discussion at the link person meetings and Central Croydon PCG board meeting.

The questionnaire was piloted on staff (GP, practice nurse and practice manager) from three primary health care teams. They were asked to consider the content of the questionnaire and whether all relevant topics were covered, whether the questions were easy to understand, the format of the questionnaire, instructions for completion and time to complete and whether it was acceptable. The questionnaire was modified in light of their comments.

The questionnaire was sent out to all 69 PHCTs in Croydon. The questionnaire was sent to one GP, the practice manager and the practice nurse at each primary health care team. A total of 203 questionnaires were distributed. A reminder letter was sent three weeks after the initial mailing and a second copy of the questionnaire and a further reminder letter four weeks later.

Response rate

A total of 113 usable questionnaires were returned, a response rate of 56%. Response rates by PCG and staff group are shown below.

Response rate by PCG

PCG	Response rate
Central Croydon	49%
North Croydon	60%
South Croydon	62%

Response rate by staff group

Staff group	Response rate
GPs	55%
Practice managers	65%
Practice nurses	48%

Data presentation

The survey included different PHCTs and different professional groups. Consequently, the results are reported by professional group (GP/practice nurse/practice manager) or PHCT as appropriate. Some results are also presented out of all the respondents, regardless of professional group or PHCT.

Where the data is presented by PHCT there is scope for different respondents in the same PHCT to have answered the question differently. If there was disagreement between respondents from the same PHCT over the answer to a question, their answers were excluded from the analysis of that question.

Results

Information for patients

Providing information is the most basic form of relationship between professionals and patients. Although this primarily takes place in the consulting room, there is great scope for supporting verbal information with other resources. We asked respondents to identify both what other resources they used and what kind of information these resources covered.

The three PHCTs acting as case studies used notice boards and leaflets as the main ways to give out information to patients. Leaflets were available on a wide range of topics and were given out by all the staff – doctors, nurses and receptionists. Notice boards were used both for general information and seasonal campaigns. Two of the three practices also produced quarterly newsletters.

Across all Croydon practices, leaflets and notice boards were by far the most common means of distributing information. Approaches to information provision which involve more patient participation such as educational meetings or self-help groups were not common.

Table 1 describes the information resources which PHCTs across Croydon made available for patients. The types of information provided by these resources are described in Table 2.

In one of the case studies, leaflets were made available in a variety of languages and staff were trying to get their practice leaflet translated. Across Croydon, resources were available in languages other than English in two thirds (66%) of practices.

Table 1 Sources of information available to patients

Source of information	Proportion of PHCTs with this information source
Leaflets	100%
Noticeboards	97%
Educational books to loan out	53%
Newsletter	25%
Video in waiting room	20%
Educational meetings	9%
Self-help groups	6%

Table 2 Topics covered by information sources

Information topic	Proportion of PHCTs which reported information sources covering topic
Services at practice	100%
Health promotion/clinical issues	94%
Voluntary organisations	90%
Changes in the NHS	90%
Primary Care Group	79%
Community Health Council	68%

Key points

- Leaflets and notice boards are the main ways in which information is given to patients outside consultations
- Approaches to information provision which involve more patient participation such as educational meetings or self-help groups are not common
- Resources were available in languages other than English in 66% of practices

Getting feedback from patients

Information going in the other direction, from patient to professional, also happens predominantly in the consulting room. However, if patients want to give feedback about the service rather than discuss their own needs, the consulting room is far from ideal. Although every PHCT must have a complaints procedure, this is not always an appropriate method for giving feedback. We asked respondents to identify any other ways in which they received feedback from their patients.

Only 32% of respondents to the questionnaire said that feedback was gathered from patients in ways other than through individual professional-patient relationships and complaints. Feedback was obtained in informal ways through letters to the practice, telephone calls and verbal remarks to staff. Receptionists in particular were seen as a useful source of feedback. Some practices had more formal mechanisms such as suggestion boxes and detachable slips on newsletters for feedback. One of the case study practices had a suggestion box for two years and in that time three suggestions and between 10 and 20 requests for repeat prescriptions were put into it. Patients had been invited to attend meetings at the practice by 22% of PHCTs.

Those practices which had patient participation groups (see below) had a regular means of listening to patient views. Some practices had also carried out surveys or audits which included patient feedback. However patient satisfaction surveys can be difficult to carry out. In one of the case studies, the receptionists had handed out a survey to patients to measure satisfaction but selected patients who they thought would not mind filling it in – thereby potentially causing bias in the results.

Of the respondents who got feedback other than through complaints or their professional-patient relationships, two-thirds (67%) said that their practice or procedures had changed as a result of the feedback they received. This compares to 44% of all respondents who had changed practice or policy as a result of complaints.

The results were similar for PHCTs: in 29% feedback was received other than through complaints and ordinary professional-patient relationships; of these, 45% did something with their feedback. In 38% of PHCTs complaints had led to change.

Key points

- Most primary health care teams do not gather feedback from patients other than through complaints or via individual patient-professional relationships
- Sources of feedback mentioned included both informal methods such as letters to the practice, telephone calls and verbal remarks to staff and more formal methods such as patient satisfaction surveys
- Receptionists have a potentially important role in receiving feedback from patients; suggestion boxes do not work
- Informal feedback was more likely than complaints to lead to changes in practice

Patient participation groups

Patient participation groups (PPGs) are typically practice-based groups of patients who meet regularly to support the development of the practice, promote patient education and improve communication between the professionals and their patients. They have a long history in the NHS and have the support of a national network, the National Association of Patient Participation. We asked respondents whether they had a PPG and whether they saw any value in setting them up.

One of the three case study practices had a thriving patient participation group. Their PPG was run by a committee which consisted of the practice manager, a doctor and eight patients from the practice. The enthusiasm of the senior partner was seen as the key factor in both setting up and maintaining the group.

The committee met regularly to update patient members on things which were happening within the practice, consult on planned changes to the services provided and plan quarterly talks on health issues, which attracted up to 100 people at a time. They also produced a newsletter.

Committee members felt that they were kept well informed through the meetings and that most things were discussed with them. Members could bring issues to the meetings which they saw as important and also drew upon the experiences of family and friends. The patient representatives on the PPG felt that they were listened to and that their ideas could influence the decisions taken within the practice. They said that their suggestions were put on to the agenda for staff meetings. A patient representative said:

> *There have been occasions when they've said we're thinking of doing this or that…what do you think…I must admit they do ask the group which is nice.*

The main area where patient representatives felt they could have influence was in how the appointment system is run. They felt they had influenced the decision for each doctor to have some appointments reserved for emergencies each day. At one point a letter was drafted to be sent to people who abused the emergency appointment system and the members were not happy with it. A patient recalled:

> *We said, 'no you can't do that' and they didn't… so they do listen, definitely*

One of the other case study practices did not have a formal PPG but had formed a patient group to support a specific project about patient held records for older people.

From the survey, three PHCTs in Croydon said that they had a PPG. A further three practices had had a PPG in the past but had discontinued it.

What can PPGs offer?

Some respondents were positive about what PPGs could offer. The suggestions they made about the value of PPGs included:

- better identification of patient needs
- allowing services to be improved in line with patient needs
- an opportunity for empowerment of patients
- encouraging patients to be more involved in their treatment
- liaison between professionals and patients
- promoting greater understanding between patients and professionals of each other's problems and needs
- raising awareness of services in the practice or community
- fundraising
- facilitating transport
- providing support for other clients
- heightening the practice profile
- making a PHCT more popular

What are the barriers?

Some respondents felt that PPGs could offer nothing to their practice or just extra work. The barriers to setting up PPGs identified included:

- resources
- space
- time, particularly for doctors
- lack of patient interest
- finding the right people to be involved
- over demanding patients
- agreeing objectives
- other GP partners

Most respondents were not interested in setting up a PPG. Only two thirds (66%) of respondents answered the question; of these 60 (80%) said they were not interested in setting up a PPG and 15 (20%) said that they were. Analysed by PHCT, 88% were not interested in setting up a PPG.

Key points

- Only three practices in Croydon have a PPG
- One Croydon practice has a thriving PPG which attracts up to 100 people to its educational meetings and another practice is doing innovative work involving a patient group helping to develop patient held records for older people.
- Most primary health care teams are not interested in setting up PPGs
- Benefits of PPGs include needs-based services, patient empowerment, improved understanding between professionals and patients and practical support
- The main barriers to setting up PPGs are that staff do not think patients would be very enthusiastic and that doctors do not have time

Professional attitudes to patient involvement

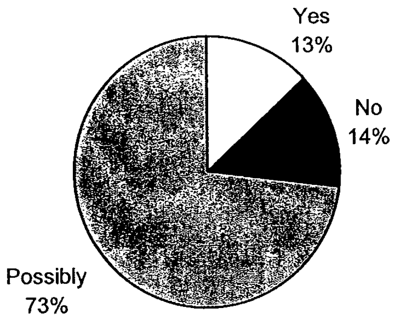
Professional attitudes to patient involvement vary. A GP interviewed for the case study commented that in an ideal world it would be 'lovely to involve patients more' but in reality it was unlikely as time and competing priorities left little enthusiasm or capacity for taking on extra workload. He commented:

> *You're not going to go fishing for more work when you're already giving your all... I wouldn't do it unless there was a government edict and even then I would say so what are you going to do about it*

At the practice with an active PPG the GP commented that public involvement and PPGs were seen to be 'trendy' and were a good way to raise the practice profile. However, he did not believe that the group really changed the way things were done in the practice and said that more confidence was required within the group to come up with suggestions for change.

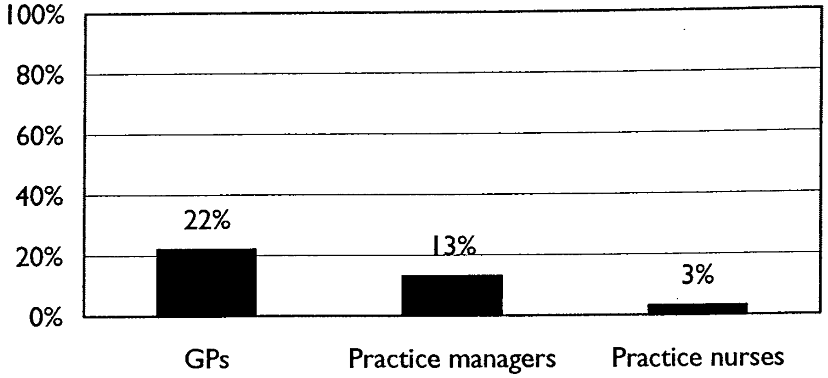
Respondents to the questionnaire were asked whether they thought patient participation in general practice, beyond individual professional-patient relationships, was worth the time and energy involved. Responses are shown in figure 1.

Figure1. Is patient participation in general practice worth the time and energy?



Overall, there was little enthusiasm for patient participation. Of the three staff groups, GPs were most likely to state that patient participation was worth the time and energy involved and practice nurses were least likely to. The differences between the three staff groups are illustrated in figure 2.

Figure 2 Proportion of staff who said that patient participation was worth the time and energy involved.



Respondents to the survey nonetheless suggested a variety of potential benefits of patient participation. These included:

- informing patients about the management of particular illnesses, about the NHS in general and about decision making processes
- empowering patients
- gathering information on what patients want and measuring patient satisfaction
- contributing new ideas
- fostering a sense of community
- improving relationships and helping patients to understand the working environment of GPs
- contribution to needs assessment
- improving services
- increasing the accountability of staff

What are the barriers to patient participation in general practice?

A few respondents said that very little or nothing substantial could be achieved through patient participation. Respondents identified many barriers to patient participation in general practice, including time, space, venues and materials.

Lack of motivation for patient participation from both GPs and patients was also highlighted as a problem. A GP commented:

> *I have spent a lot of time, often for little result*

Unrealistic patient expectations and the potential for raising expectations further were also professional anxieties. One person said:

> *Too often, the more one offers the more is expected*

Several respondents felt that it was difficult to get 'appropriate' people involved in patient participation and suggested that they need to be unbiased and should also reflect a cross section of the practice.

Mobile populations, religious and cultural differences and language barriers were identified as specific challenges to getting people involved.

The distinction between the patient role in the consulting room and the patient role in participation initiatives was also a concern; i.e. the problems of confidentiality and preventing meetings from becoming opportunities for people to air their personal grievances.

Key points

- Only 13% of survey respondents thought that patient participation was definitely worth the time and energy involved; most were uncertain
- GPs were most likely to feel that patient participation was worth the time and energy involved
- Benefits of patient participation include informing and empowering patients, improving relationships, fostering a sense of community and improving services
- Barriers included time, resources, getting the right people involved and fears of raising false expectations

Croydon Link Person Scheme

The Link Person Scheme is an integral part of the mechanism in Croydon for enabling communication between practices and the PCG and for supporting the development of practice-based information and participation work. Unfortunately, data from all the methods used in the study indicated substantial problems with the scheme. This is partly because there is no shared understanding of the aims of the scheme and no agreed process for the Link Person Scheme to feed into the PCG.

Case studies

In one of the case study practices the chair of the PPG committee was also the practice link person. He felt that the support of a PPG was essential if the link person was to be effective and said:

> *I can't honestly see what a link person without the support of a group like ours is going to achieve*

However, he did not feel clear about what the Link Person Scheme was trying to achieve and was considering handing over the job to another committee member. He found the link person meetings frustrating as some members used them as an opportunity to discuss their own personal experiences rather than concentrating on where the opportunities for influence lie.

In another of the case study practices, staff had asked someone to be a link person and they had agreed, but as far as the staff were aware this person had never attended any meetings and nothing had been achieved within the practice. Whether or not the Link Person Scheme could work was thought to depend upon the individual link person recruited. Staff felt that the link person would need to be very keen, proactive and be a good communicator. They had not been able to find a suitable person for their practice. Staff at this practice were not clear what the purpose of the scheme was or what the link person was supposed to do.

The third case study practice did not have a link person involved in the scheme. Staff were uncertain as to what the Link Person Scheme was for. They were concerned that if patients were given a forum for putting forward ideas which were likely to be constantly turned down then false expectations would be raised.

Link person meetings

The link person support meetings were held every two months and brought together link people from across the whole of Croydon. They were well attended and those who attend were enthusiastic.

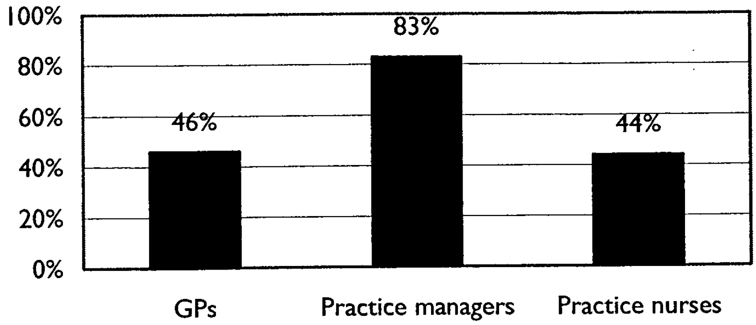
At the meetings, link people highlighted the lack of clarity about what they should be doing within their practices and their difficulty in getting practice staff to involve them. The PCG chief executives wrote to practices asking them to invite their link people to practice meetings to get to know the staff but this has proved difficult.

Much discussion at the meetings focussed on getting notice boards for link people in GP practices.

Had people heard of it?

In the survey of practice staff across Croydon, 59% of respondents had heard of the Link Person Scheme, 26% had not heard of it and 15% were not sure. Knowledge of the Link Person Scheme by different staff groups is shown in the figure 3.

Figure 3 Knowledge of the Link Person Scheme by staff group



No one indicated that they were interested in getting a link person.

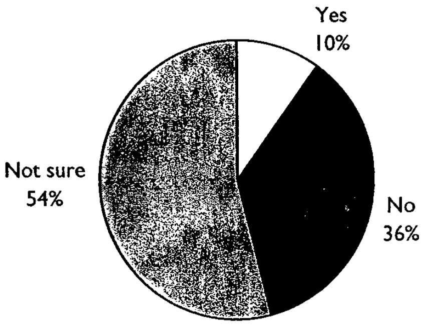
Notice boards for link persons

Of the PHCTs who answered this question 62% said that the link person had a notice board, 31% that they did not and 7% were not sure.

Has anything been achieved by the Link Person Scheme so far?

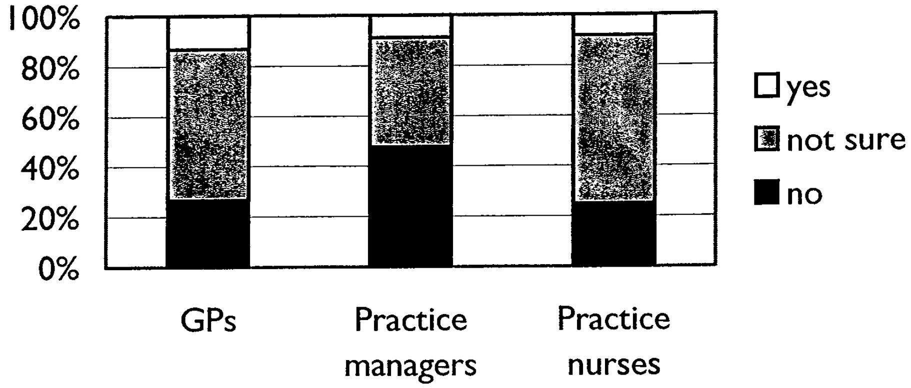
Respondents to the survey were asked 'is there anything you think the Link Person Scheme has achieved so far?'. Only 44% of respondents answered the question. Of these, only 10% were confident that the scheme had achieved anything, two GPs, two practice managers and one practice nurse (see figure 4).

Figure 4 'Is there anything you think the Link Person Scheme has achieved so far?'



The responses by staff group are shown in figure 5. Practice managers were more likely to answer that they did not think the Link Person Scheme had achieved anything and the other staff groups were more likely to be unsure.

Figure 5 Responses of staff to whether the Link Person Scheme had achieved something so far



What could the Link Person Scheme achieve?

Respondents to the survey did have ideas about what the Link Person Scheme could achieve. Several respondents suggested communication and advocacy roles, including liaison between patients and practice staff, informing patients of changes and acting as a negotiator where the patient feels unable to approach practice staff. Other potential benefits mentioned included trying to improve services to patients and influencing decisions made about service provision at the PCG level.

Several respondents said that they did not think that the Link Person Scheme could achieve a lot that was not already offered; or could not achieve anything more than a PPG. Others simply did not know what the scheme could achieve.

Key points

- Only 59% of staff responding to the questionnaire had heard of the Croydon Link Person Scheme
- There was lack of understanding amongst the people interviewed about what the Link Person Scheme was for
- Only five people responding to the survey were clear that the Link Person Scheme had achieved something

PCG Community Networks

The Central Croydon Community Network meets every three months. The meetings bring together local lay stakeholders including link people from local practices, PCG board members, particularly the lay member and PCG officers, the Community Health Council, representatives from local voluntary organisations and a few members of the general public. The aims and objectives of the Community Network are:

- To promote and support community and voluntary sector involvement in the development of health and social care services through Central Croydon PCG
- To act as a channel for ongoing communication and dialogue
- To increase and encourage community involvement
- To ensure that good ideas are shared with GPs, health care providers and local communities

Central Croydon Community Network meetings

The meetings were organised and supported by the officer from Croydon Voluntary Action, acting in her role as PCG community development officer. She shared the role of chair with the lay member of the PCG board. The meetings were well attended. In principle, the lay members and any officers attending acted as channels of communication to and from the PCG board.

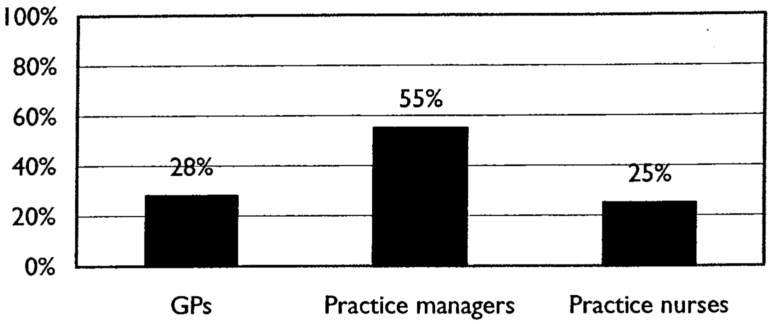
The Community Network is a broad interest group with a potentially wide range of topics to discuss. The meetings have very full agendas which means that important items such as discussion of the use of new money from the 'Modernisation Fund' get short slots on it. No background information on the topics to be discussed is circulated to participants beforehand. People attending the Community Network have very different levels of understanding of the issues and very different viewpoints on the items being discussed. It can be difficult for many of those attending to contribute in an informed way.

Different people attend each meeting, some of whom have never been before. This means that at each meeting some issues which have arisen before have to be explained to newcomers. Some participants use the Community Network meetings to relay personal experiences in great detail. All of these factors combine to make chairing the meetings very difficult. Although they provide good opportunities for patients and local people to find out about what the PCG and other local health services are doing, they are not well-suited to consultation on PCG business and priorities.

The survey

Overall, 37% of the survey respondents had heard of the Croydon Community Networks, 42% had not heard of it and 21% were not sure. The proportion of staff who had heard of the Community Networks are shown in figure 6.

Figure 6 Proportion of staff who have heard of the Croydon Primary Care Community Networks



Key points

- Central Croydon Community Network meetings were a good mechanism for informing and communicating with patients and local people but were not ideally suited to consultation
- 37% of survey respondents had heard of the Croydon Community Networks
- Practice managers are most likely to have heard of the Croydon Community Networks

Central Croydon PCG's role in patient participation

Central Croydon PCG holds public meetings every three months with closed seminars in the intervening months. Very few members of the public attend. The PCG has tried to make the meetings more accessible to the public by reorganising the seating arrangements, having a slot for questions after each item on the agenda and removing the requirement to submit questions in advance.

The PCG board's lay member, Mary Bond, attended the Central Croydon Community Network meetings and the link person meetings. She saw these as opportunities for her to engage more closely with patient and public views on behalf of the organisation but wanted more members and officers to have direct experience of this.

The lay member found it difficult to establish a clear role for herself within the organisation. This was partly because the Community Network and Link Person Scheme were set up before the PCG and so she had to fit into a structure which already existed and try to use this as a way to inform her contributions to the PCG board. Overall, the PCG did not establish a clear mechanism for the Community Networks and Link Person meetings to feed into PCG decision-making, but relied on the intermittent roles of the lay member and PCG officers who also attended.

Respondents to the survey suggested several ways in which they thought the Croydon PCGs could support patient participation. These included:

- financial incentives to staff and patients for taking part
- finance to help with running expenses of newsletters
- paying travel expenses for attending meetings
- sharing venues, resources and speakers
- a workshop on best practice
- someone from the PCG to co-ordinate groups
- holding public meetings regularly
- link people or leaders of PPGs to attend monthly PCG meetings
- a Croydon wide PPG
- a PCG magazine for patients

The PCG has recently set up a community involvement subgroup of the PCG board to inform future development of patient and public involvement work in the locality.

Key points

- Few members of the public attend Central Croydon PCG Board meetings but the PCG has tried to make the meetings more accessible to the public
- Reliance on individuals 'feeding back' to the board limits the impact of the complex and varied discussions in the Network meetings
- The PCG has set up a community involvement subgroup of the PCG board to inform future development of patient and public involvement work in the locality

Discussion

Central Croydon PCG has a structured approach to public and patient involvement in terms of the Community Network and Link Person Scheme. In principle, each primary health care team (PHCT) should have a 'link person' whose role is to provide a link between patient interests at practice level and the interests of the PCG and the wider health economy.

The main forum for communication is the Community Network meetings which bring together link people and other local stakeholders including PCG board members and officers, the CHC and representatives from local voluntary organisations.

Central Croydon Community Network meetings are well attended, a wide range of topics are discussed at them and the agenda is usually very full. No background information on the topics to be discussed is circulated to participants beforehand. People attending the Community Network have very different levels of understanding of the issues and very different viewpoints on the items being discussed. It can be difficult for many of those attending to contribute in an informed way, but there is a commitment to educating all participants about the PCG and local primary care services.

The Central Croydon PCG lay member attends the Central Croydon Community Network and Link Person meetings. She brings views and information from these meetings to the attention of the PCG Board. PCG officers also support this communication role. However, this reliance on individuals 'feeding back' to the board limits the impact of the complex and varied discussions in the Network meetings.

The Community Network meetings therefore provide good opportunities for patients and local people to find out about what the PCG and other local health services are doing but they are not ideal mechanisms for consultation on PCG business and priorities. Background information in advance, a smaller agenda orientated to where opportunities for influence lie and more involvement of PCG members and officers in the Network meetings may improve their effectiveness.

Many primary health care team members had not heard of the Community Network or the Link Person Scheme. There was lack of understanding amongst the people interviewed about what the Link Person Scheme was for. Link people themselves highlighted the lack of clarity about what they should be doing within their practices and their difficulty in getting practice staff to involve them. Developing a clear idea of what the Link Person Scheme is for in collaboration with primary health care teams may help to raise the profile of the link people within their practices.

Some interviewees felt that little could be achieved within a practice by a link person without the support of a PPG. Three Croydon practices had PPGs but there was little interest from other practices in setting them up. The main barriers to setting up PPGs are that staff do not think patients would be very enthusiastic and that doctors do not have time due to other priorities such as clinical governance.

One Croydon practice, which does not have a PPG, is doing innovative work involving a patient group helping to develop patient held records for older people. This type of approach could be useful for practices who are interested in involving patients but do not have the time for or doubt the effectiveness of a formal PPG. PPGs do not need to be 'representative' or have large memberships. A small group of enthusiastic patients working in partnership with a PHCT can have a large impact.

Some practices had mechanisms other than PPGs for gathering feedback from patients, such as suggestion boxes and detachable slips on newsletters. In other practices feedback was obtained in informal ways through letters to the practice, telephone calls and verbal remarks to staff. Receptionists in particular were seen as a useful source of feedback. Ensuring that this feedback, whether formal or informal is fully utilised within practices is important. PHCTs need to make explicit opportunities to share the feedback and insight they get informally from patients and carers.

Central Croydon PCG holds meetings in public every three months with closed seminars in the intervening months. The PCG has tried to make the meetings more accessible to the public by reorganising the seating arrangements, having a slot for questions after each item on the agenda and removing the requirement to submit questions in advance. But very few members of the public attend. The PCG could work to increase attendance at these public meetings through existing channels such as the Link Person Scheme.

The PCG has set up a community involvement subgroup of the PCG board to inform future development of patient and public involvement work in the locality. We hope that this report proves to be useful in informing their work.

Summary of key points

Information and feedback

- Leaflets and notice boards are the main ways in which information is given to patients outside consultations
- Approaches to information provision which involve more patient participation such as educational meetings or self-help groups are not common
- Resources were available in languages other than English in 66% of practices
- Most primary health care teams do not gather feedback from patients other than through complaints or via individual patient-professional relationships
- Sources of feedback mentioned included both informal methods such as letters to the practice, telephone calls and verbal remarks to staff and more formal methods such as patient satisfaction surveys
- Receptionists have a potentially important role in receiving feedback from patients; suggestion boxes do not work
- Informal feedback was more likely than complaints to lead to changes in practice

Patient participation groups

- Only three practices in Croydon have a PPG
- One Croydon practice has a thriving PPG which attracts up to 100 people to its educational meetings and another practice is doing innovative work involving a patient group helping to develop patient held records for older people
- Most primary health care teams are not interested in setting up PPGs
- Benefits of PPGs include needs-based services, patient empowerment, improved understanding between professionals and patients and practical support
- The main barriers to setting up PPGs are that staff do not think patients would be very enthusiastic and that doctors do not have time

Professional attitudes to patient involvement

- Only 13% of survey respondents thought that patient participation was definitely worth the time and energy involved; most were uncertain
- GPs were most likely to feel that patient participation was worth the time and energy involved

- Benefits of patient participation include informing and empowering patients, improving relationships, fostering a sense of community and improving services
- Barriers included time, resources, getting the right people involved and fears of raising false expectations

Croydon Link Person Scheme and Croydon Primary Care Community Networks

- Only 59% of staff responding to the questionnaire had heard of the Croydon Link Person Scheme
- There was lack of understanding amongst the people interviewed about what the Link Person Scheme was for
- Only five people responding to the survey were clear that the Link Person Scheme had achieved something
- Central Croydon Community Network meetings were a good mechanism for informing and communicating with patients and local people but were not ideally suited to consultation
- 37% of survey respondents had heard of the Croydon Community Networks
- Practice managers are most likely to have heard of the Croydon Community Networks

Central Croydon PCGs role in patient participation

- Few members of the public attend Central Croydon PCG Board meetings but the PCG has tried to make the meetings more accessible to the public
- Reliance on individuals 'feeding back' to the board limits the impact of the complex and varied discussions in the Network meetings
- The PCG has set up a community involvement subgroup of the PCG board to inform future development of patient and public involvement work in the locality