



The PC11 Report Summary

An evaluation of consumer involvement in the
London Primary Care Studies Programme

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Introduction

This document summarises the contents of The PC11 Report. It is not intended to be a detailed account, but to present the essence of the research and its findings. For a copy of the full report there are details of how to contact us on the last page of this document.

The full title of this project is *An Evaluation of Consumer Involvement in the London Primary Care Studies Programme*. For ease of use, we have called it *The PC11 Project*. Commissioned by INVOLVE*, this evaluation ran from March 2004 to March 2005.

Background

The 11 projects

This is an evaluation of the **impact*** of consumer (service user/carer) involvement in 11 research projects known collectively as the London Primary Care Studies Programme. The Programme was commissioned by the London Research and Development Directorate in 2001 and was part of a capacity development programme to increase service user/carer involvement in primary care research. All 11 studies were required to include service users/carers and the Directorate also commissioned training and support for everyone involved. This evaluation also considered the **impact*** of this and any other training that took place among the 11 studies.

* INVOLVE is a national advisory Group, funded by the Department of Health, which aims to promote and support active public involvement in NHS, public health and social care research.

* This is not an evaluation of the studies themselves, nor of the training.

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Based in locations across Greater London, the Studies covered a wide range of subjects. These included:

Orthodontics.	Learning disabilities.
Child health surveillance.	Communication difficulties.
Mental health.	(Screening for) tuberculosis.
Falling.	Self management.
Unmet health needs.	

Service users/carers of different ages and backgrounds were involved in a variety of ways, and the Studies lasted for different lengths of time, from 12 months to 3 years.

The evaluation team

The evaluation team is a group of academics, researchers, representatives from Folk.us* and a service user, all based at the Peninsula Medical School. This group formed the Project Management Group, which met every month throughout the project. There was also a Project Advisory Group, which met every three months and included representatives from INVOLVE, an academic, a member of Folk.us and a service user.

* Folk.us is a Department of Health funded initiative, which was established to facilitate and promote meaningful and effective service user, patient and carer involvement, in all types of research relating to health and social care in North and East Devon.

What we set out to do

We had three main research questions:

- To gain an in depth understanding of the experience of consumer involvement and the effect of this on the quality of individual projects. We considered this both in terms of the research process and the research outcomes.
- To assess the impact of the training on consumer involvement.
- To dovetail our previous experience with lessons learnt from this project, in considering methods and criteria for evaluating the impact of user involvement.

How we carried out the research

We collected information (data) from the following sources:

- Commissioning documents, project applications and other background documents
- Project progress reports, minutes of meetings and other relevant documents
- Interviews with commissioners (2)
- Questionnaires to everyone involved in the projects and the trainers (163 sent out, 61 completed)
- One-to-one interviews (44)
- Focus groups (2 groups, 16 people in total)
- Feedback day (30 people came)

We collected information – data - from researchers, service users, carers and other people involved in the Studies. The data was both quantitative (consisting of numbers) and qualitative (consisting of people's words). We analysed the quantitative data to find out, for example, how many people attended training or the percentage of people who thought user involvement was useful. We then analysed the qualitative data to look for important issues to help us understand these numbers better, for example to find out about people's experiences of involvement.

What we found

How people described themselves

On our questionnaire we asked people to describe their role in the Studies. There were four choices of description (label); Researcher, Service user, Carer and Other. 40 people ticked 1 label, 20 people ticked 2 labels and 1 person ticked 3 labels. Ten of the 20 people who ticked 2 labels described themselves as Service User and Researcher. It is important to allow people to choose their own labels and so we have put the people who ticked more than one label in a group called Mixed. The way people saw their own role and the way other people saw them was not always the same. This can lead to problems and misunderstandings, but it can also show that peoples' roles in research are changing and people with different experiences are becoming involved. We found that this was an important matter within the Studies.

What different people did in the Studies

Although all the 11 Studies involved service users and carers, they did so in different ways and at different stages. We found that most of the involvement was in research activities, such as designing questionnaires and carrying out interviews. By contrast we found that most of the design of the Studies had been carried out by researchers with just a few people with Mixed and Other labels involved at this stage. We also found that some service users and carers were involved in interpreting data (analysis), report writing and giving presentations about their findings.

Some facts & figures

We found that, among the eight people in charge of the projects (Principal Investigators) who completed questionnaires, only three had previously worked with service users/carers. 41% of all the people who completed the questionnaire (respondents) felt that they were aware of the issues around service user or carer involvement, with 51% saying that they had thought about the practical considerations of service user or carer involvement before taking part in their project.

A majority of all respondents (89%) said that they believed in the need for service user/carers involvement from the beginning of their project. Various reasons were given for getting involved, including an interest in user involvement generally, a particular interest in the research question, and a desire to influence health care and clinicians.

In 9 of the 11 grant applications, at least one service user was named as a co-applicant. Service user involvement in this development stage varied from “*consultation*” with existing user groups to “*(user group) originated the project and contributed to its design through a series of steering group meetings, feasibility studies and pilot work.*” Some respondents (28%) agreed that service user or carer involvement should have taken place at an earlier stage in their projects.

A large majority of respondents (82%) agreed or strongly agreed that service user or carer involvement in their project had been useful, with the same percentage of respondents saying they believed that service user/carers involvement in their project had had or would have a positive effect on the outcome.

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A majority of respondents (56%) had been clear about their role in their project from the beginning, with the same percentage agreeing with the statement “I felt able to influence the project”. 46% of respondents agreed that their project had changed their views about service user/carer involvement, and a majority (51%) plan to use service users or carers in future research.

A mix of Researchers, Mixed and Service Users/Carers (32 people) had received training. More Service Users/Carers and Mixed (41%) than Researchers (6%) found the training useful. A majority of Service Users/Carers, Other or Mixed had received training with others from their own project, whereas more Researcher respondents had received training with people from other projects.

How the Studies were grouped

Service users/carers were involved in different ways and in different numbers across the 11 studies, but it was possible to identify two distinct groups (of studies), which related to the quality of peoples’ experiences. These were:

- i) Mainly positive experiences
- ii) A mixture of positive and negative experiences

These are general patterns within the two groups of studies and do not suggest that everyone in each of the groups shared the same experiences.

The Projects in group i) tended to treat service users/carers like partners, but among the projects in group ii) some of the service users/carers felt remote from senior researchers and clinicians and did not always feel able to contribute.

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Some characteristics among the projects which achieved a partnership style were: varied and effective methods of communication (eg regular one-to-one telephone contact, use of easy-to-understand language); respect for the knowledge and insights of service users/carers; and a strong personal commitment from everybody to use involvement to improve both research and service delivery.

Among the projects that did not achieve this type of partnership, people experienced the following: the continued use of 'jargon' by researchers and clinicians, and a small number (one or two) of 'representatives' on steering/advisory committees.

These messages were very strong and can be recognized in the common subjects (themes) we identified from the data we collected.

What people experienced

In the answers to the questionnaires, in the write ups (transcripts) from interviews and in the focus groups we identified some common themes. These were as follows:

- Empowerment

People described this in terms of mutual respect, valuing different kinds of knowledge and experience, development, learning, growth, expressing potential and having a recognisable impact.

- Support

This was described as empathy, sensitivity and individual contact.

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- Communication

This related to the need for clarity of roles, responsibilities, expectations and the use of appropriate language.

- Resources

These were described as time, money and skills.

- Motivation

This included enthusiasm, commitment and inspiration.

Peoples' experiences of these themes varied, but the fact that so many people mentioned them, shows how important they are, either as positive or negative influences.

We have put all the elements of peoples' experiences together in the form of two stories or composites in order to illustrate the positive and negative experiences of service user/carer involvement in research.

ALI'S STORY

Ali belonged to a local support group for people with heart diseases. At one of their monthly meetings a researcher from the local hospital came along and asked the group for ideas for a project she was planning. She asked if anyone would like to meet again to develop the ideas into a proposal. Ali went along and was introduced to a team of researchers, doctors, other people with heart disease and a research co-ordinator. After a long discussion about several ideas the group agreed on two that would be really useful for people with heart disease and the doctors who treat them.

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Several weeks later Ali received a letter saying that there was a grant for the project and inviting him to join the project team. At the next meeting they agreed dates, times and venues for monthly meetings, and different members of the group volunteered to take turns to act as Chair. Ali was given an information pack, his fares and the telephone number of the research co-ordinator so that he could contact him if any questions came up before the next meeting.

He was surprised to find so much in his pack. He found small print difficult to read and was pleased that everything was in large print. There was confirmation of his reading and dietary needs and a form for him to sign so that he could be paid for his time. The rate was £20 an hour and, as Ali received state benefits, he rang the number on the form and spoke to someone for advice about this new income. The pack also contained a booklet about research, explaining some of the technical terms that he might hear at meetings and an invitation to attend training events for people who hadn't been involved in research before, along with maps of where they were taking place and information about how to get there.

Before the next meeting Ali received a copy of what the researchers had written so far, notes of what had been decided at the last meeting and a list of the things they would discuss at the next meeting. The co-ordinator rang him to find out if he was still able to come and if there was anything he wanted to ask about. At the meeting he was able to talk about what difference the research could make to his life and was asked if there were other groups or individuals that he thought could help ensure the project made a difference.

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Ali offered to give a talk at his local mosque to encourage people to take part in the research. The research team was really pleased and the co-ordinator helped him produce information sheets and tapes in Urdu that he could give out. Two of the people at the talk offered to give out more sheets and tapes in their communities and soon there were enough people willing to take part in the research.

Over the coming months Ali was fully involved in all the project planning and decision making. He was learning new skills, understanding more about research and about services for people with heart disease. He sometimes went to the hospital between meetings to work on writing questionnaires or to carry out interviews. He chaired two of the meetings and wrote some of the final report. He was also one of a smaller team who had volunteered to give talks about the project and write articles, especially for local Asian communities. He was particularly pleased to be asked to speak to doctors from three other hospitals who had agreed to carry out pilot studies based on the project's findings.

Ali had been telling his local group all about his involvement in the project and they decided to think of some research subjects themselves. They worked with some of the doctors and researchers from the hospitals doing the pilot studies and were given a grant to take their work onto the next step.

JULIA'S STORY

Julia saw a notice in her local doctor's waiting room asking for people with diabetes to attend a meeting about a research project based in the local medical school. As she had been diagnosed with diabetes a year ago, and felt she had very relevant first-hand experience, she decided to go to the meeting to see what the project was all about. When she got there, she was told about the research topic and what questions the researchers wanted their research to answer. Julia was also told about the ways in which the research would be conducted. At the end of the meeting, she was asked to comment on what she had heard, and was also asked whether or not she had any questions about it. She said that she felt a bit overwhelmed by all the information, but promised to come to the following meeting, which was to be held a month later. She was asked to bring a receipt for her fares so that she could reclaim her travel costs when she came to meetings. As she didn't know this beforehand, she hadn't kept her bus ticket that day, so she could not be repaid.

Julia had no contact with the research team between the first and the second meetings. At the second meeting, she was told some more about the research, and felt that she was beginning to understand it a bit better. Although Julia knew a lot about the problems faced by people with diabetes, she found some of the medical and research terminology a bit difficult to follow. She knew that she could interrupt, when necessary, to ask the research team to explain anything she didn't understand, but couldn't always pluck up the courage. She also felt that some of the people she knew in the local community and at the doctors' surgery would be interested in the research, but was not sure whether or not they would be welcome to participate.

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At the end of the second meeting, Julia was told about a large training event taking place to which many service users and carers from a variety of research projects were invited. She was keen to go, even though it was going to entail an awkward journey. She hoped that the training event would fill some knowledge gaps for her. She met some interesting people from other research projects at the training event, and learnt some important things about research in general. Some of this new knowledge, however, was not particularly relevant to the diabetes research project, and Julia wished she had some more specific information to help her with this, or someone she could ask.

Julia attended monthly research project meetings, and heard from the team about how the project was progressing, how they were interviewing people with diabetes, and then analysing responses. She was sometimes a little surprised about the sorts of questions they were asking, and felt that people with diabetes may not feel comfortable answering them. She also sometimes thought of other questions that could have been asked, but was frustrated that it was too late to suggest these. At the end of each meeting, Julia was asked to comment on what had happened in the project, and sometimes felt that she had something interesting to contribute, but at other times it was difficult to know what to say.

Towards the end of the project, the research team got quite anxious about the lack of time and money, and some people had to work on the project without getting paid. At the end of the project, Julia was sent a project report, which she found difficult to understand, as it included a lot of technical terms. She was keen to know what was going to happen as a result of the research, but the report did not include explicit plans for changes.

What were the effects of service user/carer involvement on the Studies?

We found that service user/carer involvement had the following effects:

- Changes to research questions were made because service users/carers were able to say what the important questions were for improving services
- New or revised questionnaires, interview designs etc. (research tools) were created by service users/carers
- Service users/carers found new ways of collecting data and were able to include many more people to provide data
- Service users'/carers' explanations of data related directly to how people experience the delivery of services
- Service users/carers used their own networks to tell other people about their findings
- Service users/carers were successful in finding ways to change services, based on the research findings, and in measuring those changes
- Their involvement increased the number of service users/carers in research

Conclusions

How people benefited

Most people said that the involvement of service users/carers in the Studies had been beneficial. The service users/carers described many personal benefits and positive experiences. Researchers also described how they had benefited from and learned from service users/carers.

How the projects benefited

Most people agreed that the Studies themselves had been carried out more successfully and had better outcomes because of the service users/carers involved.

What effects the training had

Many people said that they found the training that had been commissioned was useful. Many more people said that the training and learning that went on in the individual Studies was more useful to them than the commissioned training.

How can these effects be measured?

Ways of measuring (criteria) the effects of user involvement both in research projects, and of the research projects themselves, can be general (the same set of criteria applied to all projects), or they can be specific (criteria that relate directly to each project). We conclude that while general criteria may be useful, it is better to develop criteria which match each project, and which allow for the differences between groups of people, the experiences they have, the ways in which they are involved and the services they are trying to improve.

Recommendations

Policies

We make a range of recommendations, some of which are for changes in policy and some are what we call ‘good practice’, which people could do without any policy change.

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They are arranged in tables, with a column for each of the following groups:

- Researchers & academics
- Commissioners/funders
- Ethics & governance bodies
- Potential collaborators (service users, carers, community groups, etc)

In some cases, although a recommendation may be beyond the influence of a particular group, we still consider it useful to bring it to that group's attention.

Many of our findings and recommendations are similar to those of other projects in related areas of service user/carer involvement in research. Despite the emphasis on user /carer involvement in policy since 1999, research on this topic is still new to many and there is much more work to do. Our recommendations address the groups who might become involved in research and include some things that are set by national policy. We believe that there is much that commissioners/funders, researchers and academics can do to increase the amount and improve the quality of service user/carer and other potential collaborators' involvement in research.

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Policy Recommendations	Researchers & academics	Commissioners /funders	Ethics & governance bodies	Potential collaborators
Clear evidence of service user and carer involvement at all stages of a project, including adequate funds and other resources, should be a requirement of applications for research funding.	✓	✓	✓	
Existing barriers to payments for individuals, voluntary sector and community partners in research should be removed and such payments should be offered as a matter of course.	✓	✓		
The provision of timely, relevant and specific training, should be available to all those involved in collaborative research.	✓	✓		
Evaluation of processes, quality and outcomes needs to be conducted in parallel with collaborative research in order to contribute effectively to shared learning and the existing evidence base.	✓	✓	✓	
A far greater flexibility in all approval systems is required in order to achieve effective collaboration in research, particularly in the early stages of a project (ie application for funding and ethical approval)		✓	✓	
Funding should be made available to projects to facilitate the involvement of all collaborators in the development of appropriate research tools.		✓	✓	
Projects should appoint coordinators to act as a bridge between groups not used to working together, ensuring effective communication and acting as agents of outreach between projects and the wider communities in which they take place.	✓	✓		✓

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Policy Recommendations	Researchers & academics	Commissioners /funders	Ethics & governance bodies	Potential collaborators
Those working collaboratively should have access to mentors who are not involved in their projects and who can act both as facilitators in the case of problems/disputes, and as critical friends.	✓	✓		✓
Plans for the implementation of research findings should be clarified and agreed among participants and, where possible, these should dovetail with other community/local developments and work plans.	✓	✓	✓	

Recommendations for <i>best practice</i>	Researchers & academics	Commissioners /funders	Ethics & governance bodies	Potential collaborators
Those responsible for management and supervision of projects should ensure that individuals' backgrounds and skills are used as fully as possible within their projects.	✓			
Those responsible for the supervision and management of projects should encourage and foster an ethos in which it considered healthy for questions and challenges to be aired by those involved.	✓			
Mutual ownership of research should be ensured by including all stakeholder groups in the design of projects which affect them and/or in which they may be involved.	✓	✓		
Those in positions of authority within research projects need to release power in order to achieve greater diversity. If research is to reflect a new ethos of	✓	✓		

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Recommendations for <i>best practice</i>	Researchers & academics	Commissioners /funders	Ethics & governance bodies	Potential collaborators
partnership, and to be truly collaborative, power cannot remain solely with those who have traditionally held it.				
Those responsible for supervising or managing collaborative groups should ensure that the individuals/groups concerned have the opportunity to articulate their particular interest (aims, intended outcomes, motivators, etc) in order to establish a commonality of purpose within projects.	✓			
Those planning research should seek partners who will enrich that research, thus avoiding token representatives and the ‘usual suspects’. (Ref. Section 4.6.1)	✓	✓		
Empathy between individuals with shared experiences should be recognised as a positive contribution to the quality of research, particularly in terms of data collection.	✓	✓	✓	
Practical help (eg transport, crèche), sensitivity to individual needs and circumstances and a range of other support mechanisms encourage greater participation, and should be integral to collaborative projects.	✓	✓		
Great care should be taken in the use of labels, and individuals should be allowed to define themselves and their own role wherever possible.	✓	✓	✓	✓
Training should be organised with sensitivity as to when it is helpful and when it may be divisive to bring different groups within a project together.	✓	✓		
There is no fixed formula for how and when individuals and groups can become involved in research and this should be reflected in a diversity of involvement in research.	✓	✓	✓	✓

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Recommendations for <i>best practice</i>	Researchers & academics	Commissioners /funders	Ethics & governance bodies	Potential collaborators
Those working collaboratively need to show mutual respect for the knowledge base, backgrounds and values of all those involved, either as participants or ‘subjects’.	✓			✓
Provision should be made to accommodate the different lifestyles, cultures and abilities within projects.	✓			✓
Individuals involved in collaborative research are urged to avoid imposing pre-conceived limits upon the knowledge, understanding and values of those with whom they are working.	✓			✓
Training should not overshadow the valuable learning (much of it shared) which takes place within projects. Such learning should be encouraged and, where possible, captured and recorded.	✓	✓		✓
All individuals engaged in research should be clear about their roles within a project and how they relate to those of other participants and to the project as a whole.	✓			✓

The PC11 Team

Project Management Group

Nicky Britten (lead applicant)	Professor of Applied Health Care Research, Peninsula Medical School
Angela Barnard (co-applicant)	Service user and Research Fellow, PC11 Project
Mary Carter	Research Fellow, PC11 Project
Annie Ellis (co-applicant)	Research Fellow, Centre for Evidence Based Social Services
Rachel Purtell (co-applicant)	Co-ordinator of *Folk.us
Katrina Wyatt (co-applicant)	Principal Investigator of Folk.us & Lecturer North and East Devon RDSU

Project Advisory Group

Project Management Group plus:

Sylvia Downs	Folk.us member
Annie Mitchell	Clinical Director, Doctorate in Clinical and Community Psychology, University of Exeter
Carey Ostrer	User involved in the London Primary Care Studies Programme
John Sitzia	Member of INVOLVE, Head of R&D Worthing and Southlands Hospitals

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