

The impact of consumer involvement in research: an evaluation of consumer involvement in the London Primary Care Studies Programme

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Background. The value of consumer involvement in health services research is widely recognized. While there is a growing body of evidence about the principles of good consumer involvement, there is little research about the effect that involvement can have on the research. This evaluation assessed the level and impact of consumer involvement in the London Primary Care Studies Programme (LPCSP), all of whose individual projects had to demonstrate substantial involvement as a condition of funding.

Objective. To evaluate consumer involvement in the LPCSP and understand what impact consumers had on the research process and outcomes.

Methods. A multi-method case study approach was undertaken, using survey techniques, interviews, focus groups, observation and scrutiny of written documents. The overall data set comprised 61 questionnaires, 44 semi-structured interviews, 2 focus groups and 15 hours of observation of meetings. Eleven primary care-based research projects which together made up the LPCSP.

Results. An in-depth description of consumer involvement in the Programme was produced. Nine projects had consumers as co-applicants, four projects had been completed before the evaluation began and one was still ongoing at the time of the evaluation. Of the eight projects which have produced final reports, all met their aims and objectives. Consumers had had an additional impact in the research, in the initial design of the study, in recruitment of the research subjects, in developing data collection tools, in collecting the data, in analysis and disseminating the findings.

Conclusions. Consumer involvement in National Health Service research is a relatively recent policy development and while there is an increasing amount of literature about how and why consumers should be involved in research, there is less evidence about the impact of such involvement. This evaluation provides evidence about the impact that consumers have not only on the research process but also on the outcomes of the research.

Keywords. Consumer involvement, evaluation, primary care.

Background

Over the last decade in the UK, a number of policy initiatives have called for public involvement in health and social care research.^{1–3} Current National Health

Service (NHS) guidance on research governance states that ‘consumer involvement should exist at every stage of research where appropriate’.⁴ The term ‘consumer’ refers to patients, service users, parents and guardians as well as carers of people who use services and is

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distinct from being a 'participant' or 'subject' in the research. The importance and value of involving consumers in the research process has been given a clear political mandate with the establishment of INVOLVE (formerly Consumers in NHS Research) as a Support Unit to provide guidance for both consumers and researchers.⁵

In 2001, 11 primary care research projects were commissioned by the London Research and Development Directorate creating the London Primary Care Studies Programme (LPCSP). Foremost among the funding criteria was the stipulation that the projects must involve consumers in the research. These projects were part of the Capacity Development Programme aimed at establishing a pan-London consumer involvement network. The overall aims of the LPCSP were to: 'Equip consumers, carers and their authorized representatives with the knowledge, skills and confidence to participate in research according to their wishes', and 'Ensure that health professionals also involved in commissioning, managing and conducting research understand and embrace consumer involvement so that they are able to work in effective partnership with consumers' (Original Commissioning Document). Overall, the projects within the Programme were expected to 'provide answers to important, original questions in ways which enable people working in primary care to provide high quality, consumer-centred services'. Although the original intention had been to have a formative evaluation running parallel to the projects, changes in the structure of the Directorate meant that it was not until 2003 that INVOLVE commissioned an evaluation of the LPCSP, one of the aims of which was to 'evaluate the impact of consumer involvement on the quality of those 11 primary care projects'.

There is an increasing number of articles exploring the nature of consumer involvement and providing suggestions as to what constitutes 'good practice' around involvement,^{5,6} although very few studies have examined the impact of involving consumers on the research process. In 2001, a survey of consumer involvement in clinical trials in the UK found that one-third of the trial centres were involving consumers and that for the majority of respondents, involvement was perceived to have led to positive changes.⁷ A recent study identified a range of collaborative and consultative projects within a Mental Health Trust and looked at the impact of consumer involvement on the project. While the consumers and service providers identified benefits that had arisen from these partnerships, most were at a personal level, such as gaining knowledge, understanding different perspectives; few tangible impacts on the outcomes of the research were cited.⁸ A further study which looked at the challenges of consumer involvement in research, in particular cancer research, felt that there was a lack of

overarching infrastructure to foster and support involvement despite the Department of Health policy initiatives, which meant that involvement tended to be piecemeal rather than an integral part of research.⁹

These and other papers call for the need to build the evidence base on consumer involvement in research, particularly how consumers can impact on setting research priorities and selecting appropriate methods for the research.^{7,8,10}

This present study, which itself was a collaboration between lay and academic researchers, aimed to evaluate the consumer involvement and the impact of this involvement on the LPCSP.

Methods

A multi-method case study approach using surveys, face to face interviews and focus groups, observation (attending individual project steering group meetings) and scrutiny of relevant documentation was used to understand the context, processes and any impact of consumer involvement in the 11 studies.¹¹ As the aim was to look at the Programme as a whole, data were examined both within and across cases to evaluate the involvement and its impact within projects and to look for any overarching approaches which led to, or hindered, involvement in the research.

In this paper, the term 'participants' refers to consumers, researchers, service providers and academics involved in the design and conduct of the 11 projects. The term 'subjects' refer to people who were the actual respondents taking part in the research, the research sample. This paper is mostly concerned with the participants rather than the subjects.

Scrutiny and collation of written information

All documents relevant to the 11 projects, including original applications, ethics forms, minutes from project meetings and any interim or final reports from the projects were scrutinized. All relevant data were extracted from the written documents and anonymized.

Sampling strategy

In order to comply with Data Protection legislation, those involved in the design and process of each of the projects were approached through its principal investigator (PI). PIs were sent sufficient questionnaires for all the project applicants and were invited to request further questionnaires for other people (not named as applicants) who were involved in the design or delivery of the project. Participants for the interviews and focus groups were self-selecting as we could not contact people directly; the questionnaire included a form for completion by those who were willing to give their contact details so that they could take part

in interviews/focus groups. All PIs were sent a reminder 6–8 weeks after the initial mailing. Table 1 shows the responses for each project for questionnaires, interviews and focus groups.

Questionnaires

A questionnaire was developed by the co-applicants to gain an understanding of how and why participants (academics and service users) came to be involved in the project, what their role was, whether consumer involvement was what they expected, what participants felt was working well and anything which was not working so well. The questionnaire was a mixture of open questions and attitudinal statements which people were asked to score on a scale from strongly disagree to strongly agree. The questionnaire was piloted for face validity through Folk.us (a DH-funded research Programme which seeks to promote and support meaningful consumer involvement in research in Devon) and amended in light of comments received from consumers and service provider/academics. Although the questionnaires were anonymous at an individual level, people were asked to identify which of the 11 projects they had worked on.

Interviews and focus groups

Data were obtained from open-ended interviews and focus groups with the consumers, service providers and academics involved in the design and delivery of the research. Interviews and focus groups were held between June 2004 and January 2005. All those who provided their contact details in response to the questionnaire were invited to be interviewed and/or attend a focus group. Interviews were conducted to gain an individual perspective of the project; people were also invited to attend a focus group (separate focus groups for service users/carers and academics/service providers were held) as it was felt that focus groups would be likely to yield different and complementary responses. Two people who had been involved in the commissioning of the LPCSP were also interviewed to provide contextual, background information relating to the Programme. All interviews were tape-recorded and transcribed verbatim; detailed notes were taken during the focus groups, a summary of which was then fed back to the participants at the end of the session.

Analysis

A within and across case study approach to analysing the projects was undertaken. An overview of the Programme was made by analysing within cases and across cases, taking each project as a case. The case studies used multiple sources of evidence: interviews, focus groups, surveys and written documents. A synthesis of the cases was then undertaken in order to analyse the overall Programme to identify any patterns of the process of involvement and the impacts of such

involvement where they occurred.¹² To assess the validity of the research, two approaches were used:¹³ respondent validation in the form of negotiated feedback as well as eliciting written feedback. The feedback was to check whether the data analysis and interpretation represented the participants' views, and because the research design explicitly sought to incorporate a wide range of perspectives, including those of the commissioners, consumers, academics and service providers.¹⁴

The studies were anonymized to avoid identification of individuals and services. The study received Multi-centre Research Ethics Committee approval in March 2004 and research governance approval from the relevant host organizations by April 2004.

Results

In total, 61 of 163 questionnaires sent to the 11 PIs of the projects were completed and returned (a response rate cannot be calculated as we do not know how many questionnaires were sent out by the PIs to the participants), 44 face to face interviews were conducted and 2 focus groups were held. In two of the projects, the PIs requested further questionnaires. One of the projects remained ongoing (at the end of the evaluation) and final reports were available for eight of the projects. Interim and progress reports were available for all projects, thus we had some information for all 11 projects.

Of the 11 projects that were funded, 9 had service users or carers as co-applicants; none had a consumer as the lead applicant. One of the projects altered its research question in response to consumers' comments, although most projects did not involve consumers in establishing the research question or the design. Four of the projects had been completed by the start of this evaluation. The majority of the projects were largely qualitative in design, with some using a mixture of quantitative and qualitative designs. The studies covered a variety of issues with most being directly related to service provision.

Impact of involvement on the participants

Participants discussed the effect that involvement had had on them personally. Academic researchers commented on the value of having the consumer perspective and how much they had learnt from having consumers involved. Consumers commented on enjoying 'feeling useful' and being able to offer an 'unexpected contribution'. Finally, several researchers commented on the difficulty in measuring any impact on outcomes as there was no comparison group without involvement to allow associations between outcome and involvement to be made.

Impact of consumer involvement on quality of projects

Of the eight completed projects for which we have final reports, all appeared to have met their original

TABLE 1 Responses for each project for questionnaires, interviews and focus groups

Project	Number of applicants	Number of service user/carer applicants	Number of questionnaires completed	Number of interviews completed	Number who took part in a focus group
A	6	1 (three service users recruited after start of project to form a consumer panel)	9	6	2 service users/carers 1 academic/service provider
B	8	3	2	0	1 service user/carer
C	4	0	2	1	0
D	9	2	6	2	1 service user/carer
E	3	1 (two additional service users recruited after start of project)	6	2	1 academic/service provider
F	8	1	5	5	1 service user/carer
G	14	2	1	0	0
H	5	1	2	2	0
I	9	1	8	3	1 service user/carer 1 academic/service provider
J	11	3	17	14	1 service user/carer 3 academics/service provider
K	5	0	3	0	0

aims and objectives. There were additional impacts within the research process for these projects which the participants (researchers and consumers) directly attributed to consumer involvement. These impacts were in the initial design of the study, recruitment of the research subjects, developing data collection tools, collecting the data, analysis and dissemination of the findings, as detailed in Table 2.

How the impacts occurred and how they were viewed

For the most part, the projects were intentionally structured in such a way as to encourage input from consumers which could affect the delivery of the project. For example, several projects formed a consumer panel which met frequently and worked alongside the project. These panels devised the interview/focus group schedules and assisted in the analysis of the resultant data. Consumers in several of the projects received training in the appropriate research methods to facilitate their active participation in the delivery and analysis of the research (see Table 3). Given the flexible way the projects had been designed, it is perhaps not surprising therefore that the interviews and questionnaires found recurring, positive comments about the effect of this involvement. Fifty of the 59 respondents who answered the question as to whether they considered the project outcome to be better because of the involvement, either agreed ($n = 17$) or strongly agreed ($n = 33$) with the statement; seven people were not sure and two people strongly disagreed. The interviews and focus groups showed how people felt the involvement had affected the overall outcome (Table 4).

The majority of participants (researchers and consumers) interviewed felt that consumer involvement had improved the quality of the research citing 'enhanced credibility', 'improvement' and believing that

it had made the project a 'different' one. Looking across the projects, participants identified factors which enabled meaningful involvement. These characteristics were varied and effective methods of communication, respect for the knowledge and insights of service users and carers and a strong personal commitment from all the participants to realize the fullest potential of involvement as a means of improving both research and service delivery. Similarly, participants (researchers and consumers) involved in other LPCSP projects identified barriers that they had experienced either with involving consumers or with allowing the involvement to directly affect the project. Characteristics from these projects were the continued use of jargon by researchers and clinicians, a small number (one or two) consumer 'representatives' on steering/advisory committees, a physical remoteness of senior researchers and a consumerist attitude to involvement which saw service users and carers as 'products' with limited 'shelf lives'.

Discussion

The Department of Health developed and funded the LPCSP, consisting of 11 primary care projects which all included the active collaboration of consumers in the conduct of the research. Almost all the projects had consumers as co-applicants for the funding and the majority continued to have extensive ongoing involvement in the delivery and dissemination of the research. This would appear to be the first commissioned Programme of research which was aimed specifically at establishing a pan-London consumer involvement network. The evaluation was based on a wider range of experiences of consumer

TABLE 2 *Details of the 11 projects, research design and involvement process*

Project	Consumers as applicants	Study design	Recruitment of service users	Type of involvement
A	Co-applicant	An exploration of information needs for a potentially vulnerable group—literature review and qualitative design.	From local consumer support groups and community groups.	Consumer panel formed to act as steering group and work alongside the project. Assisted with interview schedules, analysis and dissemination. Consumers were offered payment for their involvement.
B	Co-applicant	Evaluation of a consumer led health promotion programme—quantitative and qualitative design.	Relevant local community group.	Consumers recruited to lead and evaluate programme, conduct interviews, analyse data and disseminate findings. Consumers were offered travel expenses.
C	No consumer applicants	Cross-sectional study to look at whether perceived and actual needs of a specific population vary by ethnic background—questionnaire design.	Relevant group of consumers from one of the participating sites.	Consumers recruited to comment on questionnaire design and delivery of the project. Indirect payments were made to organizations where consumers were recruited from.
D	Co-applicants	To assess the needs of an age-specific group in a particular area of health to develop quality standards for use in primary care.	National relevant consumer group. Formation of an 'expert panel' from initial focus groups.	Consumer led project with consumer researcher. Expert panel conducted interviews, data analysis and development of standards. Consumers were offered payment for their involvement; one of the employed researchers was a consumer.
E	Co-applicant	An exploration of issues regarding health promotion programmes—qualitative.	Through national and local relevant community groups.	Research led by service users who conducted research alongside academic researchers. It is not clear whether consumers were offered payment for their involvement.
Project	Service users as applicants	Study design	Recruitment of service users	Type of involvement
F	Co-applicant	Development of a tool to assist with identification and management of unmet needs in a potentially vulnerable group—qualitative study.	Locally and nationally relevant support and community groups.	Consumers worked alongside the researchers, developing interview schedules, running focus groups, analysis and interpretation of data. Consumers were offered a token payment for their involvement.
G	Co-applicants	Evaluation of effectiveness of a screening programme—insufficient detail regarding study design.	Local community group.	Insufficient information regarding involvement and payment.
H	Co-applicant	Identification of main features of communication between service users, carers and GPs—qualitative study.	Local relevant support groups (who are part of national support groups).	Working group and Steering Committee created to develop topic guide and assist with analysis. Consumers were offered a token payment for each session they attended.
I	Co-applicants	Identification of factors relating to a good outcome for people with a specific condition—qualitative study.	Relevant consumer group.	Consumers as researchers. Consumers conducted and analysed the research. Some consumers employed by project.
J	Co-applicants	Development and evaluation of a tool to reduce access inequalities for a potentially vulnerable group in primary care.	Relevant local and national consumer group.	Consumers as researchers. Consumers developed and piloted the research tool and analysed and disseminated the resulting findings. Consumers were employed by the project.
K	None	Development and evaluation of an education programme for a potentially vulnerable group—insufficient detail regarding study design.	Insufficient detail regarding how people were recruited.	A consumer was employed part time on the project.

involvement than would be possible with the evaluation of a single study; it was able to examine the different processes of involvement and the impact of involvement on the research projects.

This research suggests that the overall impact of consumer involvement on this Programme was

positive, both in terms of the research process and the project outcomes, achieving one of its main objectives of ensuring that the projects were collaborations between consumers and academics. The nature of the involvement varied between the projects, with some projects being delivered as partnerships (or consumer

TABLE 3 Impact of consumer involvement on the research process in the projects

Design of study ^a	Recruitment of research subjects	Development of data collection tool	Data collection process	Analysis	Dissemination
Three of the projects involved consumers in designing the original proposal. Another project commented that they would have liked to involve consumers at an earlier stage, in the design. Another project deliberately did not involve consumers at this stage as they felt it was 'unethical' to involve people in a project that may not be funded.	Five of the projects altered their recruitment processes in response to consumer's comments. Consumers in one project highlighted the need for a more ethnically diverse, appropriate population. Difficulties with recruitment, how and where people were invited to participate in the research, were resolved due to a more direct approach from consumers in the project. Another project was able to enhance recruitment of research subjects by promoting the project through the consumer groups which some of the participants were part of.	In six of the projects, consumers alongside the academic researchers. For example, consumers ensured that questions being asked as part of a questionnaire or semi-structured interview or focus group were sensitive to the subjects of the research members, written in lay language and were culturally appropriate.	Six of the qualitative projects it was agreed that consumers should run or observe interviews or focus groups and provide comments, the focus groups or conduct the interviews. This process was agreed by the research teams in these projects in the belief that such involvement would enable the projects to collect 'richer data'.	Five of the projects had consumers analysing the data from the transcripts. This involved consumers undertaking the coding and development of the themes and in the interpretation of the data. Although this process was time consuming and involved additional support for the consumers, it was felt by the research teams to have 'enhanced the credibility of the findings'. Another project involved consumers in the interpretation of the analysis, although the initial themes were generated by the academic researchers.	Three of the projects involved consumers in the dissemination of the research findings. Two of the consumers co-wrote the reports from the research and co-presented the findings at a conference. Two of the projects also involved consumers in disseminating the findings back to relevant community and consumer groups.

^aAlthough more projects involved consumers as applicants, they were not necessarily involved in the planning and design of the study.

led) while others involved consumers in perhaps more traditional ways of involvement, such as being part of an advisory group. Participants in all the projects reported that the processes of development and delivery of the research benefited directly from the involvement of consumers. Researchers, service providers and consumers also described the effect that this involvement had had on them personally.

A limitation of the research was the retrospective nature of the evaluation: a formative evaluative process could have captured how the research projects evolved and likewise whether the participants' roles had changed over time. It was the initial intention of the Programme to conduct such an evaluation but the changing structures within the DH and its associated regions meant the evaluation was, for the most part, retrospective. A further potential limitation was the need (in line with the Data Protection Act) to access participants through the PIs. This raises the possibility that only people who had a good relationship with the PI were included; however, as some people discussed difficulties in the relationship between the PI and other partners, this would not appear to be the case. Furthermore, the information accompanying the questionnaires clearly stated that the questionnaires were anonymous and were to be returned directly to the evaluation researchers. Similarly, while people self-selected for interviews and focus groups, the data show there was a variety of responses to the issues raised in the interviews and focus groups. Although all 11 studies were qualitative in nature and it could be argued that these methods provide a wider scope for involvement, this Programme of studies is the largest funded Programme to date of projects which had active consumer involvement throughout the research process. As is the case with any evaluation, the lack of a comparison group makes any attributable causation subjective. Similarly, a more general lack of objective measures of research quality mean that the 'success' of the research can only be judged in terms of whether the research was finished and met its aims and objectives and subjectively, by the people involved, as to whether the project was deemed to be successful.

There was a strong consensus from the participants across the Programme that the involvement of service users and carers had brought tangible benefits to the research, on both the processes and outcomes of the studies. Most participants also cited personal benefits especially the learning that had taken place as a result of the involvement. However, the presence of service users and carers as co-applicants is not itself a sufficient condition to ensure active and meaningful involvement. Within the Programme, there were projects which strived hard to create this environment and where service users and carers clearly felt that they were active partners throughout the process. Similarly, there were other projects where this partnership style

TABLE 4 Illustrative quotes concerning the impact of involvement on the projects

Certainly from the point when I came into the project which was when the users and carers were employed, I think it's really helpful, they've had lots of input, in terms of the development of the questionnaire. They've picked up on things that professionals wouldn't have thought about. [academic researcher]

We questioned each other and then anything that we thought didn't work, we ... said something about it. So, one of the questions was about any problems we had with the questionnaire, as carers. [consumer]

there would be notices put up in surgeries and those kinds of things. And that got a very kind of bitty response. And the consumers were then kind of wonderful about getting up the response ... the lead [consumer] said, 'well why don't we just go and ask them?' ... And [it] was a combination of all of those sorts of things, and they went to the groups and the clinic groups and all of those sorts of things, and recruited and recruited very well for it. [reflections from an academic researcher on the difference consumers made]

As researchers, the consumers brought to the groups a specialised knowledge and credibility, enabling participants [the subjects in the research process] to openly discuss their thoughts and experiences. [lead researcher]

I have a negative view of it because, because I feel that in this project people did bring their own agendas to it and I really think that's a bad thing in research, to bring your agenda to the research strategy and proposal. [academic researcher]

We could have done the project with a professional researcher and with interviewing individuals and with having focus groups of users, and you know, we have probably all done that kind of thing lots of times, so its hard to say its essential, but its better, you know. [academic researcher]

of working was not achieved and where the involvement felt 'tokenistic' for the service users and carers. It is perhaps not surprising that the greatest impacts of involvement were in the projects which strove to ensure service users and carers were partners throughout the research. These new ways of conducting research did have resource implications, particularly additional time for meetings, which also affected the monies required to fund the additional time.

In commissioning the 11 projects, the Research and Development Directorate hoped to achieve two objectives, namely to 'build capacity in terms of partnership working with consumers' such that the projects shared knowledge and learning and in creating an 'evidence base' for consumer involvement. The restructuring of the NHS London Regional Office meant that for the most part there was not much dialogue between the projects, although what is clear from this evaluation is that consumers can bring about changes in the research process which can benefit the outcomes of the research. In agreement with other researchers,^{7,8,10,15} we would suggest that unless more research is commissioned which has consumers as research partners or as PIs, or comparative studies which contribute to the evidence base of the impact that involvement can bring on the outcomes of research, involvement will remain the preserve of the committed few, rather than an accepted way of conducting research.

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